

TEVA



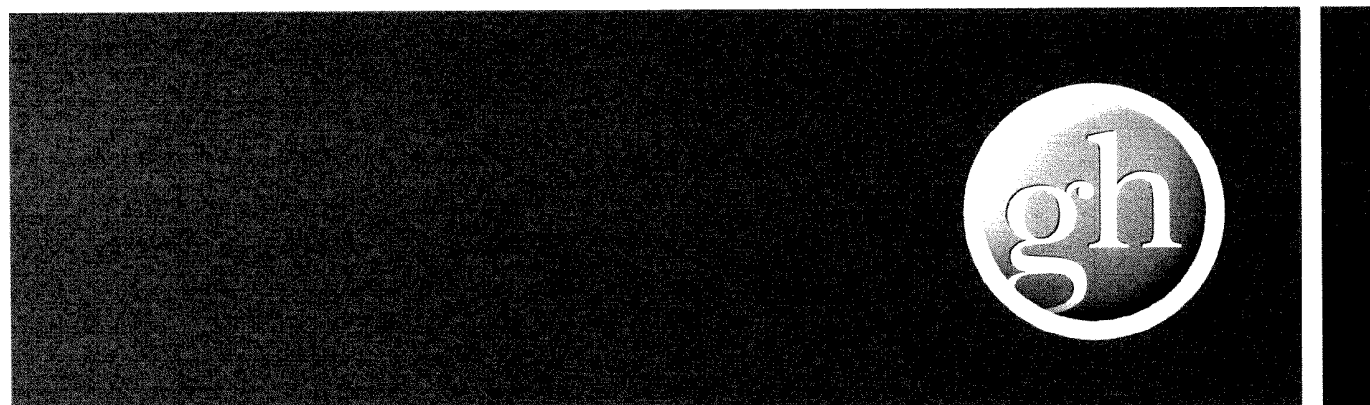
Teva Advocacy Mapping: Identifying Advocacy Partners to Enhance Patient Care

March 2013

PLAINTIFFS TRIAL
EXHIBIT
P-18154_00001

TEVA ADVOCACY MAPPING

MARCH 28, 2013



TEVA

DRAFT: FOR INTERNAL REVIEW ONLY

ADVOCACY MAPPING NEED

- Although Cephalon has a heritage within the pain space, Teva is relatively new to the pain community – specifically to those who manage chronic pain. It's critical to engage patient and professional advocacy groups to help establish positive relationships with both patients and HCPs.
- GolinHarris analyzed the pain/oncology advocacy landscape to help identify and prioritize those groups with which Teva is most aligned. This proprietary GH program is designed to help brands better understand potential allies and detractors as an important early step in developing strategies to engage and/or minimize them.
- As the priorities differ for each pain brand, GolinHarris created two reports: one that evaluated pain groups and another that looked at oncology groups.

ONC. TEAM

TEVA

DRAFT: FOR INTERNAL REVIEW ONLY

2

AGENDA

- Advocacy mapping methodology
- Advocacy group matrix
- Engagement strategies
- Key influencers
- Next steps → ADVOCACY/ADVOCACY COMMUNICATION STRATEGY (w/KATHY)
→ PATIENT COVENANT




METHODOLOGY

- **Utilized GH proprietary processes:**
 - "Engage" specialty practice
 - Advocacy mapping process
 - Independent, objective analysis
 - Provides "directional" strategies for engagement
- **Examined a variety of sources:**
 - Factiva
 - IMS data
 - Guidestar.org
 - Internet analysis
 - Social media analysis
 - Congressional and regulatory sources

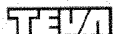


DRAFT: FOR INTERNAL REVIEW ONLY



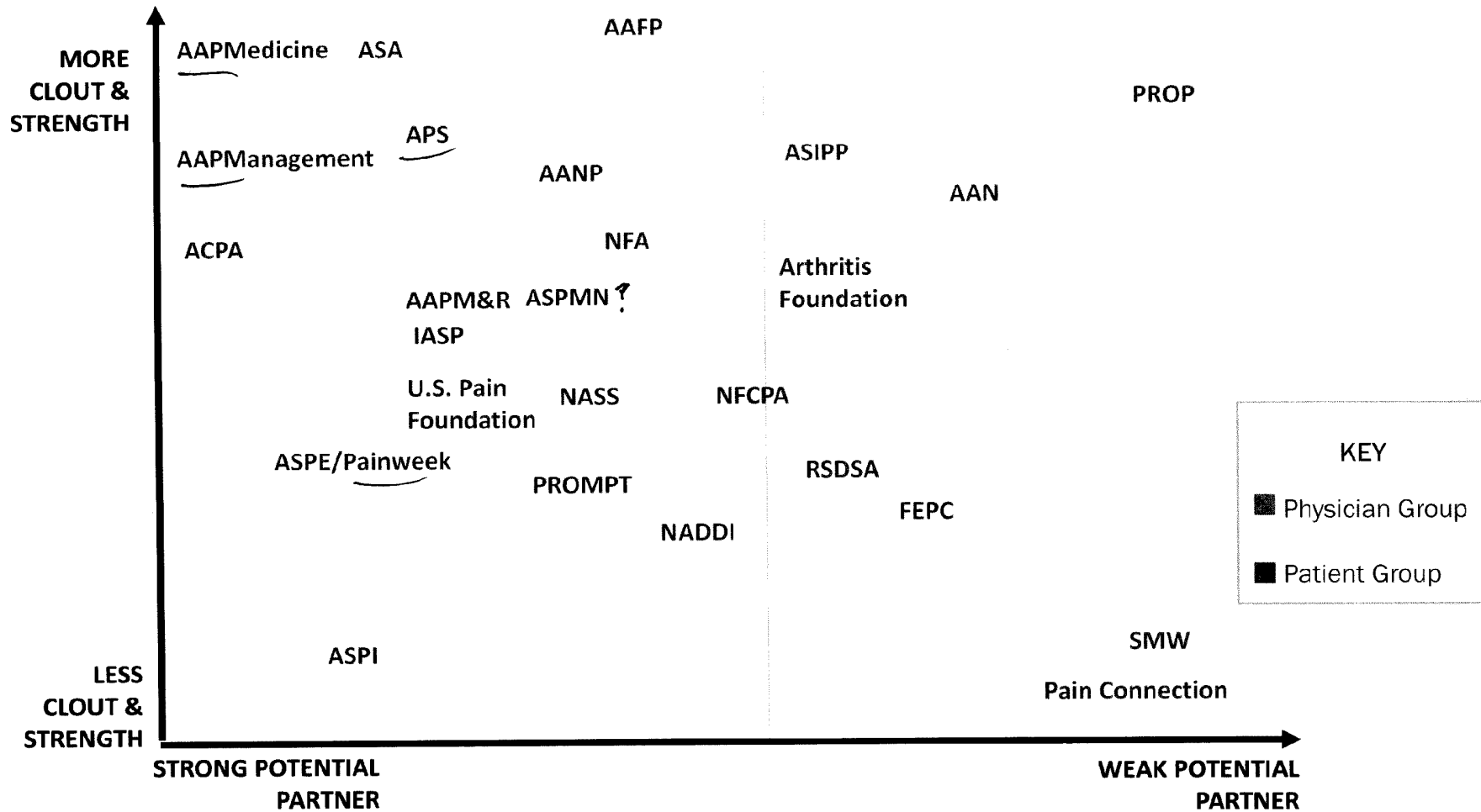
SCORING CRITERIA

- **Organizational resources:** Annual revenue, expenses, # of employees
- **Membership:** # of members, prescribing habits
- **Visibility:** Publications, congresses, social media and traditional media presence
- **Partnerships:** Corporate opportunities and sponsorship; past partnerships, particularly with pharma
- **Issues:** AD properties, label changes, rescheduling, access to pain medication, REMS, other
- **Influence:** Active on the Hill, medical guidelines, achievements
- **Focus on pain management:** Particularly relevant for oncology groups



DRAFT: FOR INTERNAL REVIEW ONLY

GRID – PAIN



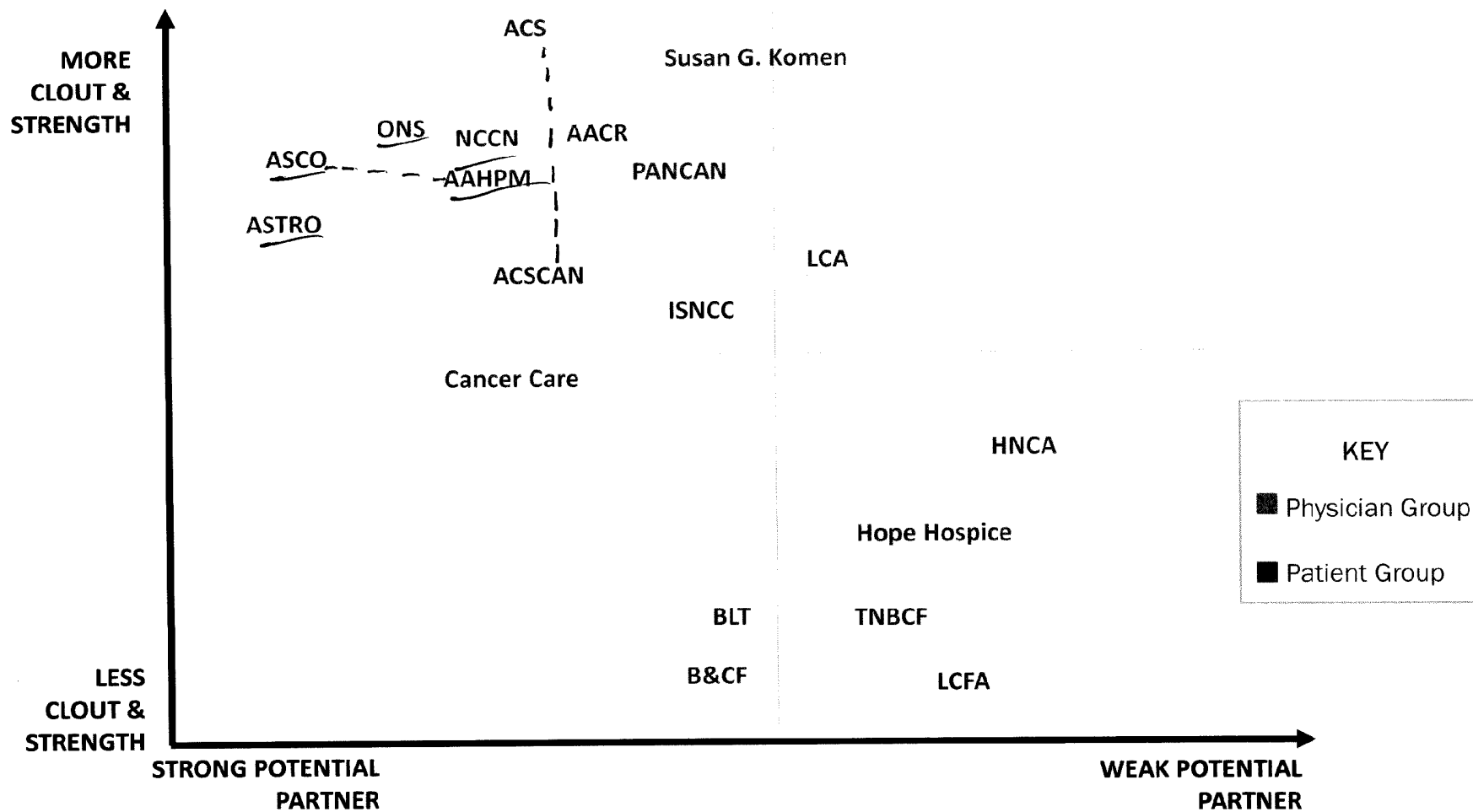
TEVA

DRAFT: FOR INTERNAL REVIEW ONLY

6

GRID - ONCOLOGY

PARTNER W/ STEPS IN ONC BU



TEVA

DRAFT: FOR INTERNAL REVIEW ONLY

7



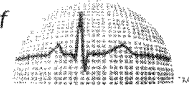
ENGAGEMENT STRATEGIES

DRAFT: FOR INTERNAL REVIEW ONLY

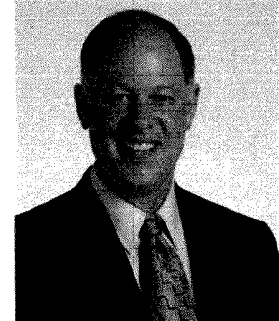
TEVA

AMERICAN SOCIETY OF ANESTHESIOLOGISTS

American Society of Anesthesiologists



- **Why:** Largest anesthesiology organization; write 23% of LAO prescriptions¹; >half of physicians board certified in pain medicine are anesthesiologists
- **Engagement Strategy:** Provide tools and resources tailored to anesthesiologists unique needs to show Teva value
- **Approach:** Participate in introductory meetings at annual meeting to understand alignment and partnership opportunities
- **Key Dates:**
 - Annual Meeting: October 12 – 16, San Francisco; 12,000+ attendees
- **Influencers:**
 - John F. Dombrowski, MD, Board of Directors
 - Richard W Rosenquist, MD, Chair, ASA Committee on Pain Medicine



1. American Society of Interventional Pain Physicians (ASIPP) Guidelines for Responsible Opioid Prescribing in Chronic Non-Cancer Pain: Part I – Evidence Assessment

DRAFT: FOR INTERNAL REVIEW ONLY

U.S. PAIN FOUNDATION



- **Why:** Newer advocacy organization with fewer resources that could be more receptive to Teva partnership
- **Engagement Strategy:** Identify overlap between Teva and the organization's future goals and strategies moving forward
- **Approach:** Current awareness run/walk only takes place in one city; become the title sponsor for the event and work with the organization to add additional events throughout the country
- **Key Dates:**
 - April 21, 2013 - Patient and Family Day to Learn About Managing Pain
 - May 4, 2013 - 5th Annual Triumph Over Pain Triumph Over Pain: Run, Walk, Roll Event
- **Influencer:**
 - ✓ Paul Gileno - Founder & President, U.S. Pain Foundation and Advisory Board Member for *PainPathways* magazine



TEVA

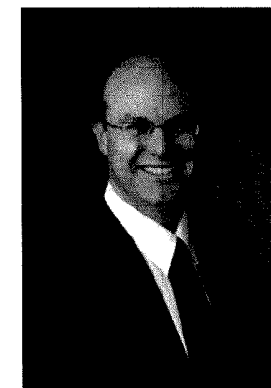
DRAFT: FOR INTERNAL REVIEW ONLY

AMERICAN CHRONIC PAIN ASSOCIATION



American Chronic Pain Association

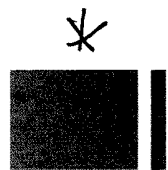
- **Why:** ACPA is the most visible patient advocacy group in the pain space. As a current top-tier corporate sponsor, there is room for Teva to lead more focused initiatives
- **Engagement Strategy:** Work with ACPA to fulfill unmet needs among pain patients to improve quality of care and empower them to become pain advocates
- **Approach:** Assess success of chronic pain survey/TaskRabbit campaign in Q4 2013 and discuss extension opportunities
- **Key Dates:**
 - Pain Awareness Month: September
- **Influencers:**
 - ✓ – Penney Cowan, ACPA Founder and CEO
 - Sean Mackey, M.D., Ph.D., ACPA Advisory Board Member, AAPMed VP of Scientific Affairs, Chief, Pain Management Division, Stanford University School of Medicine



TEVA

DRAFT: FOR INTERNAL REVIEW ONLY

11



AMERICAN SOCIETY FOR PAIN MANAGEMENT NURSING

AMERICAN SOCIETY FOR
Pain Management
Nursing

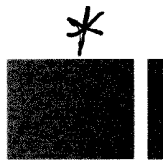
- **Why:** Nurses and NPs are often frontline practitioners and key in managing patients' pain; audience is often underserved and under-recognized
- **Engagement Strategy:** Hold on programming until FDA decision on hydrocodone rescheduling
- **Approach:** Expand website to include patient/HCP tools regarding pain; host roundtable to discuss challenges in pain care at annual meeting
- **Key Dates:**
 - Annual Meeting: October 9-12, 2013, Indianapolis
- **Influencers:**
 - Patricia M. Bruckenthal, PhD, RN, ANP, President Elect, Communications Committee Liaison; Clinical Associate Professor, Stony Brook University School of Nursing (COE)



TEVA

DRAFT: FOR INTERNAL REVIEW ONLY

12



AMERICAN ACADEMY FOR HOSPICE AND PALLIATIVE MEDICINE

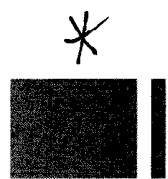


- **Why:** Palliative care practitioners play an important role in pain management among patients with serious illness, but are often overlooked among oncologists
- **Engagement Strategy:** Hold introductory meeting with leadership during 2013 Assembly and identify strategically aligned opportunities (completed)
- **Approach:** Provide tools to elevate the importance of palliative care among oncologists to help improve pain care
 - ✓ Pursue opportunities for AAHPM/ASCO partnership; collaborate on public policy issues; engage with AAHPM bloggers/Twitter influencers
- **Key Date:**
 - Annual Assembly: March 2014, San Diego
- **Influencer example:**
 - Dr. Amy Abernethy, AAHPM President-elect



DRAFT: FOR INTERNAL REVIEW ONLY

13



ONCOLOGY NURSING SOCIETY

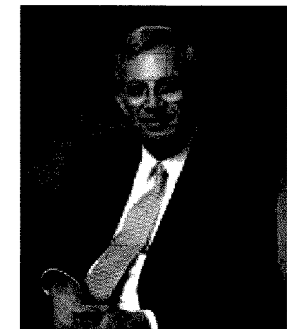


- **Why:** Nurses are frontline caregivers for cancer patients; ONS is a highly reputable organization with a well-attended annual congress
- **Engagement Strategy:** Highlight the important role nurses play in pain care to elevate Teva's reputation among oncology nurses
- **Approach:** Introduce Teva to the ONS community through symposium on BTP highlighting FENTORA's new sublingual administration; create awards program recognizing practitioners who have provided exceptional pain care
- **Key Dates:**
 - Annual Congress – April 25-28, Washington, DC
- **Influencers:**
 - Georgia Decker, APRN, ANP-BC, CN, AOCN, ONS:Edge Director
 - MaryGullatte, PhD, RN, ANP, BC, AOCN, FAAN, ONS President (2012– 2014)



DRAFT: FOR INTERNAL REVIEW ONLY

AMERICAN CANCER SOCIETY





- **Why:** ACS/ACSCAN increasingly is prioritizing palliative care and pain management. There is a history to capitalize on, as Cephalon was involved in ACS/ACSCAN initiatives in the past
- **Engagement Strategy:** Participate in introductory meetings to understand alignment and partnership opportunities
- **Approach:** As an active public policy organization, engage Teva government affairs to work with ACS to secure pain on policy agenda
- **Key Dates:**
 - Celebration on the Hill National Advocacy Day: September 2013; 700+ advocates attend
- **Influencers:**
 - Rebecca Kirch, JD, Director of Quality of Life and Survivorship
 - Vincent T. DeVita Jr., MD, President, ACS Board of Directors, Advisory Board Chair, Yale Cancer Center

TEVA

DRAFT: FOR INTERNAL REVIEW ONLY

15



KEY INFLUENCER ENGAGEMENT

DRAFT: FOR INTERNAL REVIEW ONLY

TEVA



INFLUENCERS – ORGANIZATIONAL

- Work with organizational influencers to understand organizations' agenda, create partnership opportunities and advocate for pain
 - **Keysha Brooks Coley**, Director of Federal Relations, American Cancer Society Cancer Action Network
 - **Scott Fishman**, MD, Chief, Division of Pain Medicine, University of California; Senior Editor, *Pain Medicine*, American Academy of Pain Medicine; Board of Directors, American Pain Society
 - **Jeffrey Fudin**, PharmD, FCCP, Adjunct Associate Professor of Pharmacy Practice, Albany College of Pharmacy; Founder and Chair, PROMPT
 - **Bob Twillman**, PhD, FAPM, Clinical Associate Professor of Psychiatry, University of Kansas School of Medicine; Director of Policy and Advocacy, American Academy of Pain Management
 - **Amy P. Abernethy**, MD, FACP, FAAHPM, President Elect, American Academy of Hospice and Palliative Medicine



DRAFT: FOR INTERNAL REVIEW ONLY

17

INFLUENCERS - COES

- Extend invitations to COE influencers to ad boards, symposia, speakers' bureaus and other Teva events to build relationships and identify opportunities to provide educational content to COE practitioners
 - **John T. Farrar**, MD PhD, Associate Professor of Anesthesia and Critical Care, Associate Professor of Neurology, University of Pennsylvania; Director at Large, American Pain Society
 - **David Craig**, PharmD, BCPS, Director, Pain and Palliative Care Specialty Residency, H Lee Moffitt Cancer Center; Chair, *E-News* Editorial Board, American Pain Society
 - **John D. Loeser**, MD, Professor of Neurological Surgery and Anesthesiology, University of Washington School of Medicine; Editorial Advisory Board of *Pain Physicians*, American Society of Interventional Pain Physicians
 - **Steve Feinberg**, MD, Adjunct Clinical Professor, Stanford University Pain Service; Board of Directors, American Chronic Pain Association

TEVA

DRAFT: FOR INTERNAL REVIEW ONLY

18



SUMMARY

- There is opportunity to be more **focused** ✓
- Meet with organizational influencers to determine group priorities and develop **mutually-beneficial initiatives**
- Expand advocacy relations to **peripheral groups** as the Teva pipeline continues to expand
- **Maximize current** corporate membership and funding **opportunities**
- Building advocacy relationships may also provide opportunities to **provide COE education**




TEVA

DRAFT: FOR INTERNAL REVIEW ONLY



NEXT STEPS

- Teva alignment on priority groups
- GH/Kathy to develop individual group engagement plans
- Assess success of ACPA/AAPM partnership and identify potential extension opportunities



TEVA

DRAFT: FOR INTERNAL REVIEW ONLY

20

QUESTIONS?

DRAFT: FOR INTERNAL REVIEW ONLY

TEVA



Pain Advocacy Organizations Index

Acronym	Organization Name	Page Number
ASPI	Alliance of State Pain Initiatives	1
AAFP	American Academy of Family Physicians	3
AAN	American Academy of Neurology	6
AAPManagement	American Academy of Pain Management	9
AAPMedicine	American Academy of Pain Medicine	11
AAPM&R	American Academy of Physical Medicine and Rehabilitation	14
AANP	American Association of Nurse Practitioners	17
ACPA	American Chronic Pain Association	19
APS	American Pain Society	21
ASA	American Society of Anesthesiologists	25
ASPMN	American Society for Pain Management Nursing	29
ASIPP	American Society of Interventional Pain Physicians	32
ASPE/PAINWeek	American Society of Pain Educators	34
	Arthritis Foundation	36
FEPC	Foundation for Ethics in Pain Care	39
IASP	International Association for the Study of Pain	41
NADDI	National Association of Drug Diversion Investigators	43
NASS	North American Spine Society	45
NFA	National Fibromyalgia Association	47
NFCPA	National Fibromyalgia and Chronic Pain Association	51
	Pain Connection	54
ASPE/PAINWeek	PAINWeek	56
PROP	Physicians for Responsible Opioid Prescribing	58
PROMPT	Professionals for Rational Opioid Monitoring and Pharmacotherapy	60
RSDSA	Reflex Sympathetic Dystrophy Syndrome Association	62
SMW	Save the Michaels of the World	64
	U.S. Pain Foundation	66



ALLIANCE OF STATE PAIN INITIATIVES (ASPI) OVERVIEW

The ASPI appears largely inactive. Although it maintains an online Resource Center for individual State Pain Initiatives (SPIs), most of the links are defunct; a description of the organization is not even accessible. Individual SPIs' activity varies, but none appear to be doing anything significant. However, in the past ASPI worked with groups like RWJF, Lance Armstrong Foundation, Medtronic and Purdue. Its main partner in some states has been, and appears to continue to be, the American Cancer Society. It seems like the program should be linked to the University of Wisconsin's Pain & Policy Studies Group, but no evidence online supports that conclusion.

Address

<http://trc.wisc.edu/>

University of Wisconsin School of Medicine and Public Health
1300 University Ave, Suite 3795
Madison, WI 53706

ORGANIZATIONAL RESOURCES

- The Alliance of State Pain Initiatives (ASPI) is a program housed by the Carbone Comprehensive Cancer Center at the University of Wisconsin School of Medicine and Public Health.
- Wisconsin started the first SPI in the 1980s, which focused on cancer pain and became a model for other states. Most SPIs now focus on all types of pain, but some have continued with cancer pain focus.
- It appears that most states have had SPIs, but many now appear to be inactive. In many states the SPI is funded by the American Cancer Society (ACS), and the ACS often dedicates staff to it. Other states appear to work through various hospice and palliative care programs.
- Neither the ASPI nor individual SPIs are available on GuideStar.org.

MEMBERSHIP

- Among volunteer members of SPIs are physicians, nurses, pharmacists, lawyers and clergy, as well as many patients. However, the number and activity of volunteers varies significantly by state as well as by year depending on funding.
- The American Cancer Society has allocated staff in some states to serve the SPIs.

VISIBILITY

- The ASPI was not mentioned in any media in the last year, nor does it have any social media channels.
- Leadership varies by state; no information on national leadership can be found.

PARTNERSHIPS

- Some SPIs have partnered with the American Cancer Society to providing some funding and resources support.
- The Massachusetts SPI has partnered with the Senior Centers and Councils on Aging to educate its constituents.
- In 2005, Purdue gave \$300,000 grant to provide 11 SPIs with grants of up to \$10,000 for projects that were designed to:
 - Remove one or more of the barriers to effective care for pain.
 - Build the capacity of Cancer Pain Initiatives to become self-sustaining b: designing fund-raising initiatives and creating comprehensive strategic plans or promotional materials.
- Purdue looks to be somewhat involved, as some SPIs list Partners Against Pain on its website as a resource.
- The Robert Wood Johnson Foundation (RWJF) provided has provided four grants including:
 - Two unsolicited grants totaling approximately \$1.85 million. However, those grants only last through 2005. The first grant was for developing the Resource Center for State Pain Initiatives, which is still available but not robust or functioning well. It is hosted by the University of Wisconsin Extension. The second grant sought to improve program communications and provide technical support to the SPIs.



- Grant to the University of Wisconsin-Madison Medical School and the American Cancer Society to improve pain management policies in four states through the collaboration of clinicians, regulators, and law enforcement.
- Grant from 1999 – 2003 to the University of Wisconsin-Madison Medical School to create the Achieving Balance in Federal and State Pain Policy: A Guide to Evaluation and the Progress Report Card on state pain policies.
- Among other funders have been Medtronic and the Lance Armstrong Foundation.

ISSUES

- SPIs work to improve pain management by reducing educational, regulatory, and economic barriers within the state. Those organization's goals are usually:
 - Improve the pain management knowledge of professionals.
 - Increase public awareness and health literacy regarding pain issues across the states.
 - Support legislation and regulatory change which promotes consumer protection and excellence in pain management.
 - Educate state legislators and government agencies on pain issues.
- SPIs promote a balanced approach to pain management.

INFLUENCE

- SPIs' main audiences are legislators, dentists, nursing homes and home health agencies (both of which have high staff turnover).
- It appears the ASPI was more visible in the 90s and early 00s. Looking at both the ASPI and some individual SPIs, it appears most are now inactive. Perhaps the organizations may be more influential with the upcoming March 2013 release of the Wisconsin state report.
- In its 2012 investigation on the ties between pharmaceutical companies and third party organizations, the Senate Finance Committee asked Purdue to provide a detailed account of all payments from 1997 to the present to the ASPI, among 10 other organizations.
- The last annual meeting found occurred in 2009, but there is no website for it.

FOCUS ON PAIN MANAGEMENT

- The ASPI's entire focus is on pain management. At first it was focused on cancer pain, but it now includes all types of pain.



AMERICAN ACADEMY OF FAMILY PHYSICIANS (AAFP) OVERVIEW

While the American Academy of Family Physicians (AAFP) is a leading professional group, it is not a primary leader in the pain space. The AAFP could be a good partner for Teva because it appears open to working with pharmaceutical companies and has issued resources and policy positions on pain management. Its main pain policy focus is not mandating REMS for ER/LA opioids. The AAFP is partnering with Purdue to launch a "Chronic Pain and Safe Use of Opioids" webinar in late summer 2013, so Teva would have to differentiate as a partner.

Address

www.aafp.org

11400 Tomahawk Creek Parkway
Leawood, KS 66211-2680

ORGANIZATIONAL RESOURCES (2011)

- Total revenue: \$83 million (membership dues, followed by publications, \$7 million in courses and programs)
- Total expenses: \$77 million

MEMBERSHIP

- The AAFP is one of the largest national medical organizations, with 100,300 members in 50 states, DC, Puerto Rico, the Virgin Islands, Guam and the uniformed services.
- 25,000 AAFP members have reported CME credit for AAFP CME activities on pain. The AAFP has 179 AAFP-certified CME activities that address pain management in its educational portfolio.
- 45% of PCPs prescribe LAOs and 46% of LAO prescriptions come from PCPs.
- The AAFP has 55 constituent chapters, which are organized much like the national chapter.

VISIBILITY

- As the primary organization for family medicine doctors, the AAFP is highly visible and often included in national discussions about various U.S. healthcare topics.

Publications/Congresses

- AAFP News Now: Provides email and online/blog news and updates to members and those who register; AAFP News Now also includes email action alerts on policy issues.
- Government Update Report: Weekly summaries of legislative news.
- *American Family Physician*: Semi-monthly, peer-reviewed journal, circulation 156,000.
- *Family Practice Management*: Peer-reviewed journal published six times per year.
- *Annals of Family Medicine*: Peer-reviewed research journal sponsored by six organizations in addition to the AAFP.
 - Note: All publications have separate websites, blogs and social media presence.
- AAFP hosts several annual meetings. The Annual Scientific Assembly – the single largest gathering of family physicians each year -- is in September each year (Sept. 24-28 in 2013). It includes more than 4,300 members from across the U.S.

Social Media

- *Facebook*: 10,375 likes
 - Posts are daily and typically comprise AAFP News stories and alerts and AAFP blog posts. Posts also include media stories of note, statements on current issues and photos/videos posted from AAFP events.
 - AAFP has separate pages for AAFP President, American Family Physician and Family Practice Management journals, and the American Academy of Family Physicians Foundation, as well as events like AAFP National Conference of Family Medicine Residents and Medical Students.
- *Twitter*: 10,126 followers
 - Tweets often – anywhere from four to 20 tweets per day. Participates in conversation surrounding national events (e.g. State of the Union and ACA news), AAFP news,



including blog posts, awards, events, etc. AAFP is also conversational and retweets and/or responds to other tweets.

- *LinkedIn*: 1,292 followers (company)
 - Provides news updated from AAFP News Now blog
- *LinkedIn*: 2,238 members (group)
 - Group has significantly increased since March 2012.
 - Group is closed to family physicians who are active members of AAFP.
- *YouTube*: 167 subscribers, 41,936 video views
 - Posted are 55 videos that comprise mostly interviews with board members. Also includes informational videos about health topics, information on current AAFP ad campaigns, recaps of events and annual meetings and AAFP KOL quotes.

Media Coverage

- AAFP has been referenced in 1,056 articles in the past year. It is most often mentioned regarding a wide range of issues that affect family physicians, including medical education, healthcare access, decisions by the U.S. Preventive Services Task Force (USPSTF), Supreme Court cases, the ACA, Medicaid, etc. In addition to national coverage, it receives a great deal of coverage from Washington, DC publications.
- AAFP President Dr. Jeffrey Cain and Board Chair Glen Stream are quoted most often in media. Glen Stream was most recently quoted in AAFP statements related to pain issues, but he does not appear to be a KOL in the area.

PARTNERSHIPS

- AAFP does not readily disclose pharmaceutical relationships on its website beyond listing pharmaceutical companies as exhibitors at meetings. However, in May 2011, Sen. Chuck Grassley sent a [letter](#) to the AAFP, asking for more transparency on its website of donations from pharmaceutical and medical device companies. In its response, AAFP detailed the money it has received from pharmaceutical companies, mainly from sponsorships, exhibits and non-CME education. Cephalon was listed, along with Endo, Purdue, etc.
- The group has often partnered with pharmaceutical companies either via sponsorships, grants, etc. on a number of [programs](#). Notably, the AAFP will unveil a new "Chronic Pain and Safe Use of Opioids" webinar to members in late summer 2013 supported by an educational grant from Purdue.
- The vast majority of visible pharmaceutical partnerships have been through the AAFP Foundation. It is sponsored by most major pharmaceutical companies including Purdue, Pfizer and Abbott. Teva and Endo are also sponsors, but at a lesser tier.
- Ultimately, the AAFP and AAFP Foundation would both be good partners for Teva. However, it appears the AAFP is more conservative towards partnerships given government and media scrutiny.

ISSUES

- AAFP's position on pain management is largely aligned with Teva, as its longstanding priority is maintaining patient access to pain medications while recognizing the serious concerns of opioid misuse, as well as public health consequences of the undertreatment of pain.
- AAFP "strongly encourages" its members to enroll in ER/LA REMS. AAFP is developing a CME program by March 1, 2013 that will fulfill FDA requirements outlined in July 2012. In a [response](#) to Sen. John Rockefeller (D-WV), AAFP strongly reiterates it is against mandated ER/LA REMS.
- AAFP maintains increased evidence-based physician and patient education is best to stem drug abuse. AAFP wants to "preserve the ability of family physicians to properly take care of patients with chronic pain, including the use of opioids."
- AAFP supports prescription drug monitoring programs and the state exchange of registry information. It also advocates for the incorporation of pain management into the patient-centered medical home model, a primary advocacy issue of the organization.
- AAFP has not expressed a position on hydrocodone scheduling or relabeling.



INFLUENCE

As the primary organization for family practice doctors, the group is highly influential on the Hill and among its members and professional and patient groups. Initiatives include:

- An annual Family Medicine Congressional Conference (FMCC) to advance family medicine on Capitol Hill.
 - A grassroots network of advocates, providing an advocacy page of tools and information to reach out to elected officials.
 - Often consulted by government, advocacy organizations, etc., on healthcare issues.
- AAFP supports several advocacy related programs/initiatives; among the most relevant are:
 - Consumer-facing website FamilyDoctor.org
 - [AAFP Foundation](#), a separate entity focused on global humanitarian, educational and scientific initiatives. The Foundation has an overall two-star rating (out of four) on Charity Navigator.
 - Political Action Committee (PAC) [FamMedPAC](#) has received more than \$2.6 million in donations from more than 5,000 AAFP members, enabling the PAC to help almost 300 candidates since 2005.
 - [AAFP Connection](#), a members-only online community that allows doctors to connect virtually via discussion forums, file sharing and wikis.

FOCUS ON PAIN MANAGEMENT

- Pain is one of many focuses of the AAFP. For example, AAFP has a [Pain Management and Opioid Abuse](#) position paper, but it's one of many papers. The AAFP's main goal is to maintain the family physician's authority to prescribe opioids and manage pain treatment.
- The AAFP has a webpage devoted to pain management, which includes its position paper, a series of CME offerings, patient education materials (housed on FamilyDoctor.org) and a list of recent research published in AAFP-affiliated medical journals.
- AAFP membership can prescribe opioids and the organization advocates for its continued authority to do so. It has no position on prescribing TIRFs, but emphasizes its membership should not have to go through mandated REMS for ER/Las, while it does encourage it.



AMERICAN ACADEMY OF NEUROLOGY (AAN) OVERVIEW

The American Academy of Neurology (AAN), established in 1948, is an international professional association dedicated to promoting the highest quality patient-centered neurologic care and enhancing member career satisfaction. AAN's core values are:

- **Leadership** - Provide guidance and inspiration through education, information, policy development and advocacy for members and their patients.
- **Integrity** - Set and maintain the highest ethical and professional standards for organization, staff and programs.
- **Professionalism** - Work with expertise, commitment and diligence to provide high quality neurologic care.
- **Commitment** - Dedicated to upholding the integrity and mission of the AAN.
- **Respect** - Embrace the dignity and uniqueness of every human being and keep the interests of the patients first.
- **Compassion** - Sensitive and empathetic to the needs of others

ADDRESS

www.aan.com

201 Chicago Avenue
Minneapolis, MN 55415

ORGANIZATIONAL RESOURCES (as of 2011)

- Total revenue: \$21 million (\$9 million in "other", \$8 million in program services, \$2.5 million in contributions, \$814,000 in investments, \$332,000 in sales).
- Total expenses: \$18 million (\$17 million in program services, \$1.5 million in administration, \$510,000 in "other").

MEMBERSHIP

- AAN has more than 25,000 neurologists and neuroscience professionals from around the world as members.

VISIBILITY

Publications

- *Neurology*® is the official scientific journal of the American Academy of Neurology. As the leading clinical neurology journal worldwide, *Neurology* is directed to physicians concerned with diseases and conditions of the nervous system. <http://www.aan.com/go/elibrary/journal>
- *Neurology: Clinical Practice* brings peer-reviewed, timely updates in clinical neurology, plus helpful analyses of office-based and health policy issues. The focus is on day-to-day needs as a practicing neurologist. <http://www.aan.com/go/elibrary/clinicalpractice>
- *Continuum: Lifelong Learning in Neurology*®, the American Academy of Neurology's self-study continuing medical education publication is issued six times a year. <http://www.aan.com/go/elibrary/continuum>
- *AANnews*® is the American Academy of Neurology's (AAN) member newsletter. Published monthly, *AANnews* provides members with AAN and practice information while highlighting AAN products and services. *AANnews* is provided free of charge to all AAN members. <http://www.aan.com/go/elibrary/aannews>
- *NeuroFrontiers* radio show is produced in collaboration with the American Academy of Neurology and explores new research, diagnosis and treatment in all areas of neurological disease. This series also addresses the most relevant clinical topics, trends, news and advances pertaining to all areas of the practice of Neurology. <http://www.aan.com/go/elibrary/neuro>
- *Neurology Now*® is the AAN's bi-monthly magazine for neurology patients, their families, and caregivers <http://www.aan.com/go/elibrary/neurologynow>. *Neurology Now* seeks to:
 - Improve communication between patients and their physicians
 - Support disease awareness and self-management
 - Provide public outreach for the AAN



- AAN patient education brochures offer newly diagnosed patients and their families a quality resource developed by experts in the field. Each brochure covers topics such as causes, symptoms, diagnosis, and treatment. The brochures also include tips on healthy living with the disorder and information on other AAN resources for patients and other patient organizations.

Membership Visibility

- AAN'S 65th annual meeting is March 16-23, 2013 in San Diego.

Social Media

Facebook: 5,700+ followers

- Actively posts tips, information and profiles on neurology-related issues/topics.

Twitter: 2,000 followers

- Regular tweeting on a variety of neurology-related issues/topics.

LinkedIn Group: 4,500 members, 125 discussions this month

- Active site.

YouTube: 466 subscribers, over 290,000 video views

- 98 videos posted on a variety of neurology-related issues/topics over three years.

Media Coverage

- In the past 12 months, AAN has appeared in 31 articles linked to pain.
- The majority of the articles focused on migraines and the different treatments used to reduce the pain, such as Botox.
- *HealthDay* released an article in April 2012 explaining what treatments worked for migraines and which ones do not. Dr. Stephen D. Silberstein, co-author of new guidelines developed by the AAN and the American Headache Society, was quoted stating, "Approximately 40 percent of people with migraines need preventive treatment, and only about one-third of them are actually getting it."
- Other articles include highlights from the 64th AAN Annual Meeting in New Orleans.
- Migraines and the treatments surround them were the topic of other article(s).
- *USA Today* had an article about preventive medicine and how it can help with migraine pain. Stephen Silberstein, a neurologist at Thomas Jefferson University in Philadelphia and lead author of the guidelines from the American Academy of Neurology and the American Headache Society, was quoted stating, "Migraine is one of the most disabling conditions known to man, but patients need to know that there is hope."

PARTNERSHIPS

- AAN issued a position paper in 2011 "Principles Governing Academy Relationships with External Sources of Support," stating, in part, "Concerns that the acceptance of external support create an inappropriate conflict of interest occur in two particular situations: 1) when external support is from for-profit companies (or not-for-profit entities funded largely by for-profit companies); and 2) when the amount of external support, particularly from a single source, becomes large enough that the Academy may become dependent on external support to continue essential activities." <http://www.aan.com/globals/axon/assets/2304.pdf>
- AAN does not seem to have any corporate partners. Its website does not contain information about corporate support.

ISSUES

- AAN regularly disseminates policy statements, position statements, and position papers on various neurology-related topics. <http://www.aan.com/go/advocacy/positionstatements>
- AAN regularly issues press releases on topics of interest, including new studies, legislative issues, its own initiatives, etc. <http://www.aan.com/press/index.cfm?fuseaction=release.archive>
- AAN publications have included mention of hydrocodone in various articles. http://search.aan.com/search?entqr=0&sort=date%3AD%3AL%3Ad1&output=xml_no_dtd&client=patient_frontend&ud=1&ce=UTF-8&ie=UTF-8&site=aan-com&proxystylesheet=my_frontend&q=hydrocodone
- Abuse does not seem to be a prominent issue for AAN.



INFLUENCE

- AAN's Government Relations Committee (GRC) recommends priorities for the Academy's federal and state advocacy agendas and direct member efforts to influence health policy. Its mission is to engage AAN members in advocacy in support of the profession of neurology and patients with neurologic disease.
- The Academy advocates for neurologists on Capitol Hill, ensuring that Congress is aware of members' concerns regarding potential reforms in health care. Use the links and information on this page to find out what the Academy is doing for you, what you need to know about new reimbursement policies for your practice, what you can do to advocate for neurology, and the latest health care reform news. <http://www.aan.com/go/advocacy/reform>
- AAN is currently an active influencer in the neurology arena.

FOCUS ON PAIN MANAGEMENT

- AAN issued a position paper in 2001 on "Ethical Considerations for Neurologists in the Management of Chronic Pain" which says, in part, "Opioid treatment of CNP raises concerns about efficacy, safety, dependence, patient misuse, and regulatory oversight. Nevertheless, there is consensus among pain specialists that opioid therapy is appropriate for selected patients with CNP and can provide sustained benefit to such patients. <http://www.neurology.org/content/57/12/2166.full.pdf>
- AAN does not have a dedicated pain management section of its website.
- The opportunity seemingly exists for pain management to become a larger focus for AAN.



AMERICAN ACADEMY OF PAIN MANAGEMENT OVERVIEW

The American Academy of Pain Management serves clinicians representing a broad number of disciplines who treat people with pain. The Academy was founded in 1988, and is the largest pain management organization in the nation, as well as the “only one embracing a patient-centered integrative model of care focusing on the whole person.” The Academy is respected among pain specialists and is looked to as an important resource among general practitioners. It is an organization often quoted and referenced in top-tier media regarding a range of pain topics. The Academy was one of the few organizations not included in the recent senate investigation regarding advocacy ties to pharmaceutical companies.

ADDRESS

www.aapainmanage.org
975 Morning Star Dr., Suite A
Sonora, CA 95370

ORGANIZATIONAL RESOURCES (2011)

- 13 employees
- Total Revenue: \$2.5 million (\$897,000 in grants and contributions, \$1.4 million in program service revenue, \$229,000 in other revenue)
- Total Expenses: \$2.6 million (annual meeting, publications and continuing education)

MEMBERSHIP

- The Academy has 5,300 members. Members represent a variety of disciplines but are often general practitioners who treat pain.

VISIBILITY

- The Academy is focused almost exclusively on healthcare professionals and has few patient resources.

Publications/Congresses

- “Currents: Pain Management News and Research.” Monthly newsletter distributed to more than 65,000 clinicians that includes pain news, abstracts, clinical practice guidelines and more.
- *The Pain Practitioner*. Published once each quarter with a distribution of more than 10,000. The publication accepts articles that address practical considerations of pain management which can include condition-specific articles (headache, musculoskeletal pain, neuropathic pain, rheumatology, etc.), treatment-specific pieces (pharmacologic, non-pharmacologic, hands on, etc.), case studies, research updates, lifestyle/wellness, communications, etc.
- Annual Meeting: Occurs Sept. 26–29, 2013 in Florida. Approximately 1,500 pain management clinicians attend.

Social Media

Facebook: 528 followers

- Post news and articles of interest every couple of days. There is very little Friend engagement with the page.

Twitter: 767 followers

- Posts mirror those on its Facebook page.

LinkedIn Group: 119 followers

- Includes a brief description of the organization

YouTube: 5 subscribers; 3,000 video views

- It does not have a YouTube channel.

Media Coverage

- The Academy has been mentioned in 65 articles in the past year. Local members are sometimes quoted in articles of various topics. AAPM has recently been referenced as an organization against opioid label changes and other legislative topics in several top-tier publications. AAPM Director of Advocacy and Policy Bob Twillman is often quoted as the lead AAPM spokesperson. Only a handful of these articles were regarding data announced at the AAPM annual meeting.



PARTNERSHIPS

- Corporate members include Eno, Medtronic, Neurogesx, Pfizer, Pricara, Purdue, Horizon and Teva. Corporate members receive a logo/description on the website, participate in the annual corporate ad board, receive acknowledgement in the quarterly publication and annual meeting program book, and receive logo inclusion/advertising at the annual meeting.

ISSUES

The Academy is very active on the Hill, often issuing statements and articles in response to national and state legislation. In an effort to keep Academy members updated on pain policy developments, it maintains a list of state and national legislation and its responses. Specific issues include:

- AAPM advocates against recent opioid label changes proposed by the FDA. It does not believe there is a physiological or pharmacological basis to distinguish between “cancer pain” and “non-cancer pain”. AAPM thinking this could lead regulators and insurance companies to limit treatment by refusing to pay for “non-cancer pain.” Also notes changes could “severely impede the provision of the kind of high-quality, individualized, integrated biopsychosocial care for chronic pain called for by the 2011 Institute of Medicine report on chronic pain.”
- Advocates against “one size fits all” policies to limit access to pain meds.
- Against FDA Ad Comm recommendation to move combination hydrocodone products to schedule II.
- Believes in the value of prior authorization, but feels the current process is too limiting and time consuming for HCPs. Advocates for a more seamless model such as the one proposed by California calling for one form for all PAs, response from insurance companies within 48 hours and everything to be handled electronically.
- Created a petition to end “crack-down” on Florida pill mills.

INFLUENCE

Through its various position papers and advocacy around current pain issues, it’s clear that AAPM is active and influential on the hill. The organization is also valued as a resource on pain management among general practitioners. Pain specialists value the group, but rely on it less so, as many of them have more advanced training than what the AAPM offers.

- The Academy offers a Pain Center with CME courses that educates how to treat pain across a spectrum of diseases and patients.
- The Academy also developed the Pain Outcomes Profile (POP), a 23-item questionnaire that utilizes 11-point, 0 to 10, numerical rating scales (NRS) to assess a number of relevant dimensions in the pain patient’s experience
- The Academy also offers credentialing to pain practitioners who have demonstrated additional knowledge about pain management and show a commitment to providing optimal care. Practitioners must pass a test to assess their knowledge of pain management. Although the credential gives them additional status in the pain management field, it cannot be used as board certification.

FOCUS ON PAIN MANAGEMENT

- The group’s mission is to educate clinicians about pain and its management through and integrative interdisciplinary approach.



AMERICAN ACADEMY OF PAIN MEDICINE (AAPM) OVERVIEW

As the leading medical association that represents physicians practicing comprehensive pain medicine, the mission of the American Academy of Pain Medicine (AAPM) is to promote quality care of patients with pain through research, education and advocacy. AAPM refers to itself as the “voice of pain medicine.” AAPM’s annual meeting is a leading meeting in the space where several pain-related data announcements are made. Teva is currently partnering with the organization on a national survey that explores the individual burdens of chronic pain patients.

ADDRESS

<http://www.painmed.org/>
4700 W. Lake Avenue
Glenview, IL 60025

ORGANIZATIONAL RESOURCES (as of 2010)

- AAPM has no employees and outsources staff functions to a management company (Associate Management Center)
- Total revenue: \$3.4 million (\$888,000 in contributions, gifts or grants; \$2.1 million in membership dues, conference fees and exhibit sales and journal fees, remaining in advertising or “other”)
- Total expenses: \$3.4 million (\$15,000 in President’s salary, \$2 million in service fees, \$700,000 in “other”, \$380,000 in conferences)

MEMBERSHIP

- 2,400 AAPM members represent a variety of medical specialties that focus on the diagnosis, treatment and management of pain.
- Physician members of the AAPM are specialists from anesthesiology, internal medicine, neurology, neurosurgery, orthopedic surgery, psychiatry and psychiatry. In addition, allied members are nurse practitioners, pharmacists, physician assistants, physical therapists, occupational therapists and nurses, all of whom are actively involved with pain treatment teams headed by pain medicine physicians.
- Annual meeting attendee demographics are available and likely mirror its membership: 51% anesthesiology, 21% physical rehabilitation, 8% pain specialists, 6% neurology, >4% internal medicine, family practice, psychiatry.
- Members are highly visible, serve in pain centers and publish often.

VISIBILITY

- AAPM is primarily physician-focused, but has numerous materials for patients. The group has a portion of its website set aside for patient information as well. Patient materials include: videos on various pain topics, handouts to help prepare for HCP visits, a pain log, information to ensure safe medication use and links to ACPA and other patient resources.

Publications/Congresses

- *Pain Medicine*: Premier source of peer-reviewed research on matters relevant to the multidisciplinary clinical practice of pain medicine. It is the official journal of the AAPM, Faculty of Pain Medicine of the Australian and New Zealand College of Anesthetists (FPMANZCA) and the International Spine Intervention Society (ISIS).
- AAPM’s biannual newsletter: Available to download for members and non-members. Focuses on regional snapshots of pain medicine practice updates, liaison reports from other medical societies and the accomplishments of committees and members.
- AAPMail Alerts: E-mails notifying members about FDA alerts, advocacy updates, member information and more.
- Annual Meeting: Occurs April 11-14, 2013 in Fort Lauderdale, FL. Typically draws about 1,000 attendees.

Social Media

Facebook: 1,115 followers



- The AAPM was very active and posted many updates in 2012, but have zero posts this year. Its followers are very active and often post updates on the FB page about ongoing news in the pain space.

Twitter/YouTube: Does not have a Twitter or YouTube page

LinkedIn Group: 1,150 members

- Very basic site with no information outside of a brief description of the organization

Media Coverage

- The Academy has been mentioned in 65 articles in the past year. Local members are sometimes quoted in articles of various topics. AAPM was recently referenced as an organization against opioid label changes and several other legislative topics in several top-tier publications. Bob Twillman is often quoted as the lead AAPM spokesperson. Only a handful of these articles were regarding data announced at the annual meeting.
- Recent coverage has increased slightly as a result of the investigation of AAPM President Dr. Webster. His practice is under investigation for several deaths that occurred throughout the years, but he is still highly respected and defended among peers.

PARTNERSHIPS

- Corporate members include Endo, Medtronic, Neurogesx, Pfizer, Pricara, Purdue, Horizon and Teva. Corporate members receive a logo/description on the website, participate in the annual corporate ad board, acknowledgement in the quarterly publication and annual meeting program book, and logo inclusion/advertising at the annual meeting. Cost is \$9,500.
- A survey sponsored by the American Pain Society, American Academy of Pain Medicine, and Janssen Pharmaceutica, released in February 1999, has revealed that more than four out of 10 people with moderate to severe chronic pain have not found adequate pain relief.
- Teva is also currently working with the organization on a partnership to create awareness of the individual burden of pain.

ISSUES

The AAPM is very active on the Hill often issuing position statements and articles on national and state legislation. Recent issues and position papers include:

On suggested FDA label changes:

- AAPM affirms the position established in its response to PROP's petition that limiting ongoing opioid therapy to patients who demonstrate severe pain would be clinically meaningless and lacking in a substantive scientific foundation since there is no clinical method to differentiate moderate from severe pain other than patient report, pain constantly fluctuates in severity and moderate pain may have the same outcomes as severe pain.
- Setting a ceiling dose such as 100 mg could be dangerously misleading, implying that doses below 100 mg are inherently safer than higher doses in any given individual or population of patients. Appropriate dosing requires education and training.
- There are no comparative data presented on the risk or incidence of suicide resulting from inadequate pain control, recognizing that this risk in patients with chronic pain is double the control population rate.

On rescheduling hydrocodone:

- AAPM neither supports nor opposes rescheduling but takes the position that action is needed whether the schedule changes or remains the same.
- A change to Schedule II might cause some physicians and other providers to rethink their current prescribing practices. The quantity and duration of prescriptions may drop as providers limit prescribing for pain conditions that warrant the use of an opioid. If patients formerly treated with short-acting hydrocodone products are switched to long-acting opioids, the patients may benefit from stricter monitoring guidelines that accompany therapy with long-acting agents.
- Current patients with legitimate medical need may have problems obtaining their medication, particularly if it lives in rural or other underserved areas, and costs associated with Medicare and more frequent HCP visits may increase.

Other issues:



- Supports the AMA's Code of Medical Ethics.
- AAPM worked for many years to advance the legislation that became the pain care provisions in the ACA healthcare reform bill.

INFLUENCE

- AAPM is very active on the hill, both on a state and national level and frequently issue position papers. It also worked as part of a coalition with AAPM's Committee for Legislative Affairs, the Pain Care Coalition (PCC), the American Pain Foundation (APF) and other organizations to secure the inclusion of pain care in the ACA and the passage of two bills, the 2009 National Defense Authorization Act and the Veterans Pain Care Act of 2008. It provides a continuous stream of updates on national and state legislation. Finally, AAPM appoints more than 40 state representatives who monitor local issues and assist in the quest for pain medicine specialty recognition.
- AAPM and its board of directors have researched and approved evidence-based clinical practice guidelines for treating pain patients. AAPM also has notable influencers serving as editors or senior editors of its publication.
- AAPM is committed to helping meet the deliverables identified in the IOM report. Many of AAPM's current educational efforts can be viewed here.
- AAPM's education was recently resurveyed by the Accreditation Council for Continuing Medical Education (ACCME) and awarded Accreditation with Commendation for a term of six years as a provider of continuing medical education for physicians. The six-year accreditation is the highest accreditation awarded by the ACCME.
- AAPM also maintains relationships with a number of other organizations including the AMA, the American Board of Pain Medicine and the American Pain Society to further its mission and provide opportunities for member services through liaison activities with other coalitions, organizations and affiliations.

FOCUS ON PAIN MANAGEMENT

- AAPM's mission is to optimize the health of patients in pain and eliminate the major public health problem of pain by advancing the practice and the specialty of pain medicine.



AMERICAN ACADEMY OF PHYSICAL MEDICINE AND REHABILITATION (AAPM&R) OVERVIEW

The American Academy of Physical Medicine and Rehabilitation (AAPM&R) is the only national medical society exclusively serving the needs of practicing physical medicine and rehabilitation (PM&R) physicians. AAPM&R is celebrating its 75th year. Its mission is to serve its member physicians by advancing the specialty of physical medicine and rehabilitation, promoting excellence in psychiatric (rehabilitation medicine) practice and advocating on public policy issues related to persons with disabling conditions.

ADDRESS

<http://www.aapmr.org>
9700 West Bryn Mawr Avenue
Suite 200
Rosemont, IL 60018-5701

ORGANIZATIONAL RESOURCES (as of 2010)

- Total revenue: \$9.4 million (\$3.5 million in contributions, gifts or grants; \$5.8 million in program services, \$98,000 in investments, and \$16,000 in "other")
- Total expenses: \$8.5 million (\$7.7 million in program services, \$821,000 in administration)

MEMBERSHIP

- AAPM&R membership is comprised of more than 8,000 physicians who are specialists in the field of physical medicine and rehabilitation.
- PM&R physicians are nerve, muscle, bone and brain experts who treat injury or illness non-surgically to decrease pain and restore function.

VISIBILITY

Publications/Congresses

- *The Physiatrist*: Official membership publication of the AAPM&R published 10 times each year. Provides updates on Academy activities and programs, legislative actions, practice and socioeconomic issues, educational courses, and specialty developments.
- *AAPM&R Connection*: Bi-monthly e-newsletter with updates on events, Academy and specialty news, information on policy and legislation related to PM&R and more.
- *PM&R*: Peer-reviewed journal launched in 2009 specifically for the physical medicine and rehabilitation physician. *PM&R* was selected for MEDLINE indexing later that year. Topics include acute and chronic musculoskeletal disorders and pain, neurologic conditions involving the central and peripheral nervous systems, rehabilitation of impairments associated with disabilities in adults and children, and neurophysiology and electrodiagnosis.
- *PM&R Resident*: E-newsletter developed by residents to provide information that helps residents develop opinions on subjects that will affect their professional and personal lives.
- Annual Meeting: Occurs October 3–6, 2013 in National Harbor, MD.

Social Media

Facebook: 2,358 followers

- Posts updates on legislative activity, webinars, awards, etc., every week. Has active Career Center. Moderate amount of friend engagement with the page.

AAPM&R is not on Twitter, LinkedIn or YouTube.

Media Coverage

The American Academy of Physical Medicine and Rehabilitation has been mentioned in 74 articles in the past year.

- Dr. Alberto Esquenazi, president of AAPMR, was quoted often about new advancements in spine injury treatment and rehabilitation.
- AAPM&R received a spike in coverage in October 2012 following the U.S. Supreme Court ruling about the need for continued Medicare coverage of disabled persons whose condition does not improve. AAPMR was mentioned as a plaintiff in the case. AAPM&R's outside counsel Peter Thomas was quoted in *The New York Times* about AAPM&R's perspective.



- Some coverage (10 articles) was generated by company news releases showcasing new devices at AAPM&R's Annual Assembly.
- AAPM&R research was quoted in some articles (10 articles). For example, "eighty percent of Americans will suffer from lower back pain at some point in their lives" was a statistic mentioned in a story about how minimally-invasive surgery can help patients relieve lower back pain.
- Marcel Fraix, a Fellow of the AAPMR, was quoted in a widely distributed article (20 articles) about tips to keep athletes safe.
- AAPM&R was mentioned in 30 personnel announcements noting the subject was an AAPM&R member.

PARTNERSHIPS

- AAPM&R has 64 corporate partners, including pharmaceutical companies, rehabilitation groups, laboratories, orthopedic groups, health plans and universities. Members include Allergan, Ipsen, Horizon Pharma, Lilly, Mayo Clinic, Medtronic, Purdue, Sanofi Biosurgery, Merz, GE, Millenium Laboratories, Moss Rehab, National Rehabilitation Hospital, Pfizer, SonoSite, Spaulding Rehabilitation Hospital, Terason and XenoPort. Teva is not listed as a corporate partner.
- The Academy established the Industry Relations Council (IRC) in 2003 to expand dialogue on emerging issues of shared concern. Participation affords exclusive opportunities throughout the year to meet with AAPM&R Leadership. Most of the above partner companies are members.
- AAPM&R has not made statements or expressed opinions about pharmaceutical or advocacy financial ties.

ISSUES

AAPM&R's legislative, regulatory and grassroots advocacy activities and efforts are closely aligned with priority issues that affect the specialty of physiatry (rehabilitation medicine). The organization works to advance the specialty before Congress and the federal agencies. AAPM&R also advocates on public policy issues related to persons with disabling conditions. The Academy often issues position statements, letters and legislation updates.

- AAPM&R does not seem to have specifically addressed access to pain medications, abuse issues or the scheduling or relabeling of hydrocodone.
- The Advocacy Action Center is a Web-based congressional lobbying software program designed to assist AAPM&R members in grassroots lobbying and political advocacy by providing a simple way to contact members of Congress on key health policy issues. The center is also utilized to help mobilize Academy members to participate in legislative action alerts and offers strategic targeting capability to legislative chambers, congressional committees or individuals.
- AAPM&R has launched Physforum to help state PM&R societies connect with colleagues in addition to existing networks and remain vigilant on efforts which will have an impact on people with disabilities, chronic conditions and physiatrists. The state advocacy groups will utilize state moderators to communicate with members in states on issues that need attention or advocacy. Each state has a group in PhysForum as a vehicle for information-sharing and thoughtful health policy discussions.

INFLUENCE

- AAPM&R is very active legislatively and its website contains a detailed summary of its actions, initiatives and issues across a spectrum of policy and health topics, including health care reform, disability and rehabilitation.
- In 2011, AAPM&R collaborated with the American Association of Neuromuscular and Electro-diagnostic Medicine and the American Academy of Neurology to release new guidelines on the most effective treatments for diabetic nerve pain.

FOCUS ON PAIN MANAGEMENT

- AAPM&R offers information on pain disorders under the Patients & Family section of its website. It encompasses chronic painful conditions involving the central and peripheral nervous systems and musculoskeletal system; traumatic, non-traumatic or acquired. Examples include: spine,



- manual medicine, electrodiagnostics, neuropathy/plexopathy, chronic pain, ALS, MD, Parkinson's, MS, neuro-degenerative, hereditary sensori-motor and peripheral nerve.
- AAPM&R issued a press release about a new study published in the February 1 issue of *Spine* concluding that a consultation with a physical medicine and rehabilitation (PM&R) physician before proceeding to surgery results in more efficient treatment for low back pain, high patient satisfaction, and fewer surgeries.
 - In April, 2011 AAPM&R issued new guidelines for the best treatment of diabetic nerve pain. The guidelines show that the seizure drug pregabalin is effective in treating diabetic nerve pain and can improve quality of life. Hydrocodone is not mentioned.
 - The News Room section of the AAPM&R website contains a [brief section on back pain](#).



AMERICAN ASSOCIATION OF NURSE PRACTITIONERS (AANP) OVERVIEW

On January 1, 2013, the American Academy of Nurse Practitioners (founded in 1985) and the American College of Nurse Practitioners (founded in 1995) came together to form the American Association of Nurse Practitioners™ (AANP), the largest, full-service national professional membership organization for NPs of all specialties. As The Voice of the Nurse Practitioner®, AANP represents the interests of the approximately 155,000 NPs around the country, advocating for the active role of NPs as providers of high-quality, cost-effective, and comprehensive, patient-centered healthcare. The mission of AANP is to lead NPs in transforming patient centered health care. This year, one of the featured tracks at its annual meeting is pain management.

ADDRESS

www.aanp.org
PO Box 12846
Austin, TX 78711

ORGANIZATIONAL RESOURCES (2011)

- Total Revenue: \$10.5 million
- Total Expenses: \$10.2 million
- 67 employees; 15 voting members

MEMBERS

- 40,000 members
- All members are NPs and may be practicing in any specialty:
 - 63% in family practice; 22% in adult; 7% in acute; 8% in gerontology, neonatal, pediatrics, mental health and women's health.

VISIBILITY

Membership Visibility

AANP markets and advocates for NPs extensively through multiple activities such as print and broadcast media interviews, legislative testimony, and numerous partnerships, alliances and coalitions. AANP is active in supporting collaborative agreements with government agencies, organizations within nursing and other disciplines, and with health care industry members.

- Journal of the American Association of Nurse Practitioners (peer-reviewed journal)
- Journal for Nurse Practitioners (peer-reviewed journal)
- AANP SmartBrief (electronic newsletter delivered daily)
- NP Professional Practice Compendium (quarterly online peer-reviewed continuing education publication)
- Your Partner in Health, the Nurse Practitioner (brochure to provide an overview of the NP)
- Continuing education monographs: 1 focused explicitly on pain management ("[Achieving Optimal Therapeutic Outcomes with Oral Over-the-Counter Analgesics: Assessing Benefit Versus Risk](#)")
- Various position statements and papers: none focused explicitly on pain management
- Annual Meeting: Occurs June 19-23, 2013 in Las Vegas, NV. This is the largest national conference for NPs of all specialties. One of the featured tracks includes pain management.
- Hosts the National Nurse Practitioner Health Policy Conference, which focuses on current policy information of vital importance to nurse practitioners. This year's conference, held February 24-26, 2013, included speakers from the Federal Trade Commission (FTC) and the Centers for Medicare and Medicaid Services (CMS), among others.

Social Media

Facebook: 9,211 likes

- Posts news of interest every couple of days.
- Followers engage with AANP through Facebook primarily by reacting to AANP posts.
- Zero mentions "pain in February."

Twitter: 3,319 followers

- Tweets daily by linking to news articles of interest and engaging with followers.
- Zero explicit mentions of "pain."



LinkedIn Group: 1,132 followers

- Very basic site with no information outside of a brief description of the organization.

YouTube: 16 subscribers; 7,703 video views

- 6 videos have been uploaded since its creation in April 2011.
- Most recent post is a video excerpt from last year's AANP National Conference.

Media Coverage

- AANP has been referenced in approximately 76 articles in the past year. Most mentions refer to the merger, AANP's response to legislative decisions and AANP's stance on the role of NPs in healthcare delivery.
- AANP communicates with media outlets, journalists and others to build awareness of NPs and the NP profession. The Press Room provides news articles, broadcasts, press releases and media tools to keep NPs in the news.
- Penny Kaye Jensen (immediate past president) and Angela Golden (current president) are occasionally quoted.

PARTNERSHIPS

- AANP joins with other healthcare organizations through multiple alliances to advance the role and visibility of the nurse practitioner as a provider of high-quality, personalized and patient-centered health care including the American Cancer Society, American Chronic Pain Association, Partnership to Fight Chronic Disease and SOS Rx.
- The 2012 Corporate Council members include (contributions of more than \$10,000): Abbott Nutrition, Boehringer Ingelheim, Dey, Janssen, Merck, Pharmavite, Purdue, Sanofi Aventis, Takeda, Truvia, Vivus, Amgen, AstraZeneca, Egg Nutrition Center, Endo Pharmaceuticals, Forest Laboratories, Lilly, Medic Alert Foundation, CVS Minute Clinic, Nexa Family of Vitamins, Novartis, Novo Nordisk, Pfizer, Take Care Health Systems.
- Partners with Generation NP (an online community for NPs) and is a part of the eNP Network (an "evolving" NP online community).
- AANP has partnered with Boehringer Ingelheim and other companies to create the passport to good health program.

ISSUES

- Top AANP priorities include modernizing state practice laws and removing barriers that prevent patients from accessing the full services of NPs. Over the past two years, with AANP's assistance, more than 30 state laws were passed in support of NPs and their patients. These included laws for admitting privileges, signature recognition, advanced directives and prescriptive authority.
- No explicit mention of issues relevant to Teva, pain or pain management.

INFLUENCE

- AANP works at the national and state levels to shape health policy that ensures NPs play a lead role in the healthcare system.
- AANP's federal staff work with members of Congress, CMS, regulators and national policy stakeholders on implementation of provisions in the Patient Protection Affordable Care Act, Medicare and Medicaid regulations, medical homes for NPs and appropriations.

FOCUS ON PAIN MANAGEMENT

- Pain management is not a priority for the AANP. However, members are able to prescribe opioids, its annual meeting will feature a pain track and AANP offers some continuing education credits for pain management.



AMERICAN CHRONIC PAIN ASSOCIATION (ACPA) OVERVIEW

ACPA is the most visible patient advocacy group in the chronic pain space. It appears that most of its agenda is set by the funding it receives from third party organizations, specifically pharmaceuticals and medical device companies. Teva is already a top-tier corporate sponsor of the organization, but it has little presence on the website compared to other pharmaceutical companies, who instead sponsor specific programs rather than giving blanket funding. Teva and GolinHarris are also working with ACPA to develop a survey bringing to light the individual burdens of chronic pain.

Address:

www.theacpa.org/
PO Box 850
Rocklin, CA 95677

ORGANIZATIONAL RESOURCES (2011)

- Total Revenue: \$691,000 (\$657,000 from contributions and grants)
- Total Expenses: \$742,000 (the ACPA was \$51k in the red in its last fiscal year)
- 1 employee (Penney Cowan)

MEMBERSHIP

- The ACPA estimates it has 276 volunteers.
- There are "several hundred" ACPA support groups across the United States, Canada, Great Britain and other countries.
- The ACPA's 21-person advisory board includes several notable doctors and nurses in the pain space, representing institutions like Brigham and Women's Hospital, University of Washington, Stanford University School of Medicine, Northwestern University Feinberg School of Medicine and Johns Hopkins University School of Medicine. The advisory board also includes Jennifer Bolen, JD, the founder of The Legal Side of Pain. She spoke at the 2012 Fentora Speaker Trainings and was well received by the HCPs.
- The ACPA's 15-person Board of Directors includes ACPA founder Penney Cowan, who is the primary authority of the group.

VISIBILITY

Publications/Congresses

- *The Chronicle*: quarterly newsletter distributed to its online subscribers as well as hard copies to support groups.
- ACPA has no annual meeting.

Social Media

Facebook: 5,667 likes

- Frequently posts daily inspiration ideas, patient stories and event information. High level of engagement with numerous comments and likes on every post.

Pinterest

- Page has 39 followers and 41 pins, which include tools for dealing with chronic pain, inspirational messages, awareness messages and links to its programs.

Twitter: ACPA does not have a Twitter page.

Media Coverage

- The ACPA has been mentioned in 116 articles in the past year. Most stories have been about the need for chronic pain treatment in reference to the IOM report, "Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education and Research," how to manage chronic pain and general information on the condition and mobile apps and tips for managing chronic pain.
- ACPA founder Penney Cowan is most often quoted in media coverage (14 articles in the past year). Board member Edward Covington, M.D. has been quoted in four articles, notably saying, "Overprescribing of opioids is harming many chronic pain patients," in response to the PROP petition to limit opioid use. Board member Donna Kalauokalani, MD, MPH, was quoted in a widely



syndicated article about chronic pain that emphasized the importance of access to pain care, which can be improved by patient and caregiver advocacy.

PARTNERSHIPS

- ACPA lists Endo, Janssen, Millennium Laboratories and Teva as “ambassador” corporate sponsors, which appear to give the highest sponsorship levels. The next tier includes Allergan, Lilly, Forest Laboratories, Medtronic and Purdue. The final tier includes Pfizer, Abbott, Horizon Pharma and Zogenix.
- ACPA’s advisory board includes two pharmaceutical company representatives: Purdue’s Vice President of Risk Management and Health Policy and the Chief Medical Officer and Vice President of Archimedes Pharma.
- ACPA is funded extensively by pharmaceutical and medical device companies for many of its programs. Although Teva is in the top tier of corporate funding, other pharmaceutical companies appear to fund specific projects, gaining more visibility with the ACPA. Examples include:
 - ACPA website development was funded via an unrestricted educational grant from Medtronic Foundation and Purdue Pharma. The ACPA notes on its website that neither organization has editorial influence on the content.
 - Purdue funded the ACPA’s Pain Log tool, which allows patients to track their pain
 - Purdue funded the printing of ACPA’s wallet MedCard, Pharmacist CARE card, and ACPA workbooks: From Patient to Person: First Steps
 - Janssen and Medtronic funded GrowingPains.org, a website for young adults with pain
 - Pfizer funded the ACPA’s Fibro Log tool, which allows fibromyalgia patients to track their pain, as well as the Diabetic Peripheral Neuropathy Pain Map
 - Endo funded VeteransInPain.org, which includes resources for veterans in pain
 - Purdue, Pfizer and Horizon funded the Maze of Pain, online tools to help patients navigate CP, as well as a hotline to call for help
 - Horizon Pharma gave a 2012 grant to ACPA to develop the Living with Arthritis Ability Chart
 - Forest Laboratories funded a 2011 survey on fibromyalgia chronic pain
 - Several videos have been developed with pharmaceutical funding: Endo (Veterans in Pain), Forest Laboratories (Fibromyalgia 101), Medtronic (Implantable Medical Devices), King Pharmaceuticals (Using Opioids Safely) and Medtronic (AgrAbility video and program for farmers with chronic pain)
- ACPA has worked with several professional organizations and patient advocacy groups for the Partners in Understanding Pain program to raise awareness of chronic pain. No activity is evident since 2006.

ISSUES

- ACPA’s top issues are: chronic pain general, fibromyalgia pain, veterans in pain, young adults in pain and diabetic peripheral neuropathy pain.
- ACPA issued a PSA on the Dangers of Opioid Abuse. It is not clear who funded the PSA.
- ACPA does not issue press releases or issue statements on policy topics.

INFLUENCE

- ACPA is the leading patient group in the chronic pain space. However, most of its influence is derived from the tools and resources it provides to patients and caregivers. It rarely makes statements on policy issues and has not spoken at any recent FDA advisory committee meetings.
- ACPA was not named in the 2012 Senate Finance Committee investigation, but some media questioned the presence of pharmaceutical representatives on its advisory board.

FOCUS ON PAIN MANAGEMENT

- ACPA is entirely focused on chronic pain, as well as chronic pain associated with multiple conditions. It appears as though its agenda is largely set by the funding it receives from third parties, as its primary source of funding is through grants.

**AMERICAN PAIN SOCIETY (APS) OVERVIEW**

The American Pain Society is a prominent pain organization focused on pain care professionals. While the group has overcome some scrutiny for conflicts of interest and lack of evidence in some of its published guidelines, it remains an opinion leader in the space. The group has several pharmaceutical sponsors including Teva, but no specific pharmaceutical-sponsored programs are apparent.

Address:

www.americanpainsociety.org
4700 W Lake Ave
Glenview, IL 60025

ORGANIZATIONAL RESOURCES (2011)

- Total Revenue: \$3,412,643 (\$1.7 million in grants and contributions, \$992,000 in program service revenue).
- Total Expenses: \$3,235,399 (\$35,000 in lobbying efforts).
- No employees.
- It lists 15 voting members of its Board of Directors and 315 volunteers. None of its board members are paid.

MEMBERSHIP

- APS comprises more than 2,500 members from a variety of disciplines and work settings and are involved in basic research, clinical research and treatment, advocacy and public policy. APS calls itself "the country's leading interdisciplinary scientific society in the field of pain and the only such organization to establish a multidisciplinary, evidence-based approach to both research and clinical treatment."
- Physicians by medical specialty:
 - 41% anesthesiology; 11% PM&R; 9% neurology; 9% internal medicine and family medicine; 3% oncology
 - Half of members are from the medical field; others include psychology, basic science, nursing, pharmacy and dentistry (order of importance)
- Its membership can and do prescribe opioids. APS does distinguish LAOs and SAOs and references the organization in policy positions and education resources. APS mentions TIRF products only once – in an educational presentation about REMS.
- APS has five regional societies (Southern, Eastern, Greater Philadelphia, Midwest, Western). The Western Pain Society is the largest. Each has its own website, events, position papers and some additional state chapters within the regional chapter.
 - Each society appears somewhat autonomous from the national APS. For example, the Western Pain Society is a founding member of the Alliance for the Safe Use of NSAIDs; no other chapter, nor the national group, is a member.
- APS is a chapter of the International Association for the Study of Pain (IASP), which has 6,943 individual members from 95 countries.
- APS includes numerous committees and special interest groups on various topics that are open to all members to participate in.
- Two members of the 15-member Board of Directors/Directors at Large are from NIH COEs in Pain Education.

VISIBILITY**Publications and Congresses**

- *Journal of Pain*: Peer-reviewed monthly journal distributed to APS members. The *Journal of Pain* is cited in Index Medicus and has an impact factor of 4.851 in the 2011 Journal Citation Reports, published by Thomson Reuters.
- *SmartBrief*: Includes updates on pain and APS news. Distribution numbers are not available.
- APS offers an e-News email for its members. Distribution is 2,500. Its content is not publically accessible.



- Annual Meeting: Occurs May 8 – 11, 2013. It generates a comparatively great deal of media coverage in the space. More than 1,000 attendees from 17 countries participated.

Social Media

Facebook: 1,219 likes

- APS posts about once per week to its page regarding news about its annual meeting and studies from the *Journal of Pain*, as well as live coverage from PAINWeek. Posts are most appropriate for pain professionals.

Twitter: 1,179 followers

- APS tweeted daily until October 2012; it has only published one tweet since then, which was about registering for its upcoming Annual Meeting. It used to be fairly conversational with other pain groups and KOLs and would post pain-related news and studies. It's unclear why it has taken a hiatus.

YouTube: 12 subscribers, 3 videos, 1,041 video views

- APS' YouTube channel is fairly inactive – the group has not posted for one year. Past videos were of its Annual Meeting and Clinical Center of Excellence Award recipients.

Media Coverage

- APS has been mentioned in 158 media articles in the past year.
 - APS' guidelines on chronic and cancer pain treatment are often referenced in top-tier media articles. In some of these articles, Roger Chou, head of APS' Clinical Practice Guidelines Committee and an associate professor of medicine at Oregon Health and Science University, is most often quoted.
 - However, APS has been criticized with other organizations in the media that its guidelines lack sufficient evidence and clinician involvement and the panels who write the guidelines have many conflicts of interest.
 - APS research from its *Journal of Pain* also generates significant coverage. For example, an APS study linking chronic pain in teens and suicide was the subject of an Oct. 2012 *USA Today* article.
 - Board Member Edward Michna, who serves as head of the Advocacy Committee and head of the Pain Care Coalition and REMS Activities subcommittees, testified at the February 2013 FDA advisory committee. He was quoted in the *WSJ* about the APS' position that relabeling opioids would have "unintended negative consequences for patients."
 - APS' annual meeting comprises about one-fourth of its annual media coverage.

PARTNERSHIPS

- APS' Corporate Council "connects" corporate members with multidisciplinary leaders in the science of pain. Endo is in the top-tier of sponsorship; Activis, Lilly, Pfizer, Abbott, Covidien, Forest Laboratories, Horizon Pharma, Janssen, Purdue and Teva are in the second tier.
- APS also offers corporations the ability to sponsor various sections of the annual meeting, its e-News membership publication and the Clinical Centers of Excellence in Pain Management Awards for HCPs who provide exemplary pain care.
- APS is currently one of seven medical groups under Senate Finance Committee investigation for its ties to pharmaceutical companies. APS was mentioned in several of the top-tier media reports on the investigation. Other potential points of contention include:
 - Dr. Russell Portenoy's work in the late 1990s as APS president to make pain the "fifth vital sign" was cited in a highly influential December 2012 *WSJ* article about Dr. Portenoy's reconsideration of the appropriate role of opioids in treating non-cancer chronic pain.
 - A December 2012 *MedPage Today* and *Milwaukee Journal Sentinel* article about doctors with financial ties to pharmaceutical that have influenced treatment guidelines. The article cites a 2009 APS and American Academy of Pain Medicine guideline endorsing opioids to treat chronic pain because 14 of 21 members had ties to pharmaceutical companies.
 - Najib Babul, PharmD, President and Chief Scientific Officer of Relmada, is chair of APS' Clinical Trials Special Interest Group



ISSUES

- Access to Pain Medications: Since APS represents a multidisciplinary group of HCPs, it advocates for all trained allied HCPs to be able to prescribe, as long as they are properly educated on risks, benefits and addiction. APS does not agree with mandatory education because it could lead to fewer prescribers and therefore restrict access. Instead, it contends education should be in medical school and part of routine licensing.
- Opioid relabeling: In a statement in response to the PROMPT Citizens Petition, APS believes limiting the indication of opioids for non-cancer chronic pain lacks evidence and will not effectively address misuse and abuse issues, but rather obstruct access for legitimate pain patients. However, many APS-published articles have acknowledged that long-term opioid treatment for chronic pain may not always be appropriate.
- APS currently has six position statements. Many of its positions emphasize its interdisciplinary membership and call for integrated pain management that may not always include opioids. APS advocates for class-wide REMS, increased HCP education on addiction and abuse issues, improved and expanded monitoring programs and a public awareness campaign that emphasizes the importance of opioids for some patients when used properly and safely.
- Abuse deterrent requirements: APS has no position on abuse deterrent requirements. It has not said anything formally in social media or traditional media.
- Hydrocodone rescheduling: APS has no position Hydrocodone rescheduling. It has not said anything formally in social media or traditional media.

INFLUENCE

- APS, AAPM and the American Association for the Study of Headache organized the Pain Care Coalition (PCC) in June 1998 in an effort to influence federal healthcare policy via legislative, regulatory and research means to address quality-of-care and access-to-care issues. PCC employs a DC lobbying firm. PCC offers Washington Wire on Health Care Issues, an e-mail and web-published newsletter reporting highlights of important federal developments in health law and public policy. PCC has taken active positions on a number of legislative and regulatory activities:
 - Declaration of the Decade of Pain Control and Research,
 - Enactment of the Veterans Pain Care Act, the
 - Congressional directive for a Military Pain Care Initiative
 - Incorporating the Pain Care Policy Act into the Affordable Care Act
- APS' Clinical Practice Guidelines Program has published three current clinical guidelines: one on opioids for chronic, non-cancer pain and two on low back pain treatment. It has four archived guidelines. The guidelines are often cited in media as well as pharmaceutical, patient group and even clinical materials. However, the guidelines have been criticized in the past year for lacking sufficient evidence and having panelists with conflicts of interest.
 - The Clinical Practice Guidelines Program Committee is chaired by Christine Miaskowski, PhD RN, Professor and Chair, Department of Physiological Nursing, University of California, San Francisco. The committee identifies topics for guideline development, oversees and ensures the validity of the guideline development process and advises on dissemination issues.
 - The guidelines program is led by Roger Chou, MD of the Oregon Health & Science University's Evidence-Based Practice Center. Dr. Chou leads the multidisciplinary expert panels that issue the guidelines.
- APS has been a key player in advocating for and recognizing novel research in the field, through programs like its Clinical Centers of Excellence Program. APS has been a leading advocate for more NIH funding for pain research and sponsors University of Utah studies that track NIH pain-related funding. APS also strongly advocated for the Pain Care Policy Act, which became law in 2010 as part of the Accountable Care Act.
- APS' once-prominent "Pain: the 5th Vital Sign" campaign has since received much criticism for its role in increasing opioid use.
- Three APS member researchers serve on HHS' Interagency Pain Research Coordinating Committee (IPRCC). The group was created by the Affordable Care Act to enhance and promote interdisciplinary pain research in the federal government.



FOCUS ON PAIN MANAGEMENT

- APS is solely focused on pain management. In addition to what was already mentioned, APS offers CME on pain treatment and pain related research, education materials and programs specifically for PCPs and onsite events and courses hosted by sponsors throughout the U.S. to educate HCPs on pain management. Some prominent sponsors include Cleveland Clinic, Memorial Sloan Kettering Cancer Center, Harvard Medical School and the American Society of Addiction Medicine

**AMERICAN SOCIETY OF ANESTHESIOLOGISTS (ASA) OVERVIEW**

The American Society of Anesthesiologists appears to be the premier organization for anesthesiologists with nearly 50,000 members. The organization is an educational, research and scientific association of physicians organized to raise and maintain the standards of the medical practice of anesthesiology and to improve the care of patients. Though focused on anesthesiology, the ASA also has an entire committee and section of its member site regarding pain medicine. Its consumer website also has a large focus on the role of anesthesiologists in pain care. As it says on its website, ASA considers pain medicine a top priority of the organization.

ADDRESS

<http://www.asahq.org/>
520 N Northwest Hwy
Park Ridge, IL 60068

ORGANIZATIONAL RESOURCES (2011)

- Total Revenue: \$40 million (\$17.5 million membership dues; \$7 million annual meeting)
- Total Expenditures: \$35.7 million (\$4.5 million grants; \$2 million employee compensation; \$9 million other salaries and benefits; \$644,000 lobbying; \$1.5 million advertising; \$4.7 million conferences; \$2.2 million other)
- 145 employees
- 65 voting members of governing body; 62 independent voting members of the governing body; 708 volunteers

MEMBERSHIP

- 48,000 members
- Anesthesiologists frequently relieve pain for patients before, during and after surgery. However, in addition to performing anesthesia, many anesthesiologists are experts in pain medicine. They help patients with chronic disease live better lives through pain management treatments. These anesthesiologists have the education and training to accurately diagnose, evaluate and treat chronic pain patients through a comprehensive approach including medication and pain procedures.
- Anesthesiologists prescribe a significant amount of opioids. A 2009 survey showed 23% of long-acting opioid prescriptions and 6% of short-acting opioid prescriptions came from anesthesiologists (American Society of Interventional Pain Physicians (ASIPP) Guidelines for Responsible Opioid Prescribing in Chronic Non-Cancer Pain: Part I – Evidence Assessment)
- According to an ASA position paper, the majority of physicians seeking subspecialty board certification in pain medicine are anesthesiologists, and more than 95% of pain medicine training programs accredited by the Accreditation Council for Graduate Medical Education reside within U.S. academic anesthesiology departments. More than half of all physicians that were board certified in pain medicine were anesthesiologists, followed by physiatrists, psychiatrists and neurologists.

VISIBILITY**Publications/Conferences**

- ASA Newsletter: Monthly publication distributed to 44,632 members and non-members. Touted as one of the most widely read anesthesiology-related publications in the world. The ASA newsletter provides anesthesia-related news and events, the latest in advocacy and politics and scientific and technical literature.
- ASA Daily News: A daily newsletter distributed to annual meeting attendees and also posted online for members.
- Annual Meeting: October 12 – 16 in San Francisco; 12,000+ anesthesiology attendees annually (10,200 anesthesiologists; 1,800 nurse anesthetists, anesthesiologist assistants, respiratory therapists and pharmacists).

Social Media

Facebook: Two separate pages



- ASA FB page: Targeted to members and anesthesiologists; 2,500 likes; posts occur several times a week on the impact of Medicare in anesthesiology and pain management, educational resources for members, new data and studies.
- ASA Vital Health: Targeted to consumers; 120 likes; posts occur 2 – 3 times per week and are on recent news and updates in anesthesiology, anesthesiologists role in treating pain, pain awareness month and new ASA initiatives.

Twitter: Two separate pages; posts mirror FB content

- @ASALifeline: Targeted to members and anesthesiologists; 4,000 followers
- @ASAPatientLifeline: Targeted to patients; 1,300 followers

LinkedIn Group: 3,000 members

- Content can be viewed only by group members

YouTube: 196 subscribers, 180,000 video views

- Videos posted every few months featuring HCPs speaking on everything from what to expect when receiving anesthesia, to safe drug use and disposal and self-management tips for chronic pain patients.

Media Coverage

- 800 stories have mentioned the ASA in the past year. 238 of these have also mentioned pain.
 - Approximately 110 articles reference only the ASA's physical status grade which is used to evaluate patients' health for surgery (often part of parameters for clinical studies).
- Of the 238 pain stories:
 - 53 reference the ASA's physical status grade
 - 40+ articles are around the debate of the expanded role of nurses in the treatment of untrained providers to treat and prescribe opioids for chronic pain could compromise patient safety
 - Several articles on various university studies

PARTNERSHIPS

- Teleflex Inc., a corporate partner of the American Society of PeriAnesthesia Nurses (ASPAN) and the American Society of Anesthesiologists (ASA), has launched The Invisible Risk campaign designed to educate clinicians about the potential risks of waste anesthetic gas exposure and to heighten awareness for those working in the post-anesthesia care unit, or PACU.
- ASA is also a partner in the Partnership at DrugFree.org campaign.

ISSUES

On FDA Proposed Labeling Changes to Opioids:

- ASA issued a response to the PROP petition calling for revised opioid labeling stating that it advocates for an approach that is more flexible than the strict limits requested in the petition.
- ASA "support[ed] the broad concept that high dose opioids should not be used to treat chronic non-cancer pain." However, ASA argued that "placing specific limits on daily doses of opioids that a physician may prescribe is not scientifically founded nor is it practical." Daniel Carr, M.D., professor of anesthesiology, Medicine and Public Health at Tufts University School of Medicine and member of ASA's Committee on Pain Medicine, highlighted and expanded upon ASA's concerns with PROP's proposal at the FDA meeting.
 - It can be difficult to define cancer versus non-cancer pain because treatments for cancer often lead to chronic pain.
 - It is unclear what proportion of the time pain would need to be reported as "severe" in order to justify prescribing an opioid, and it is very common for pain intensity to fluctuate between moderate and severe during treatment.
 - The population-based conversion factors used to calculate "equivalent" morphine doses in patients treated with non-morphine opioids differ from patient to patient, and even in the same patient followed across time when renal or hepatic function vary.
 - Opioids for moderate pain, high dose opioids, or opioids taken for longer than 90 days appear to be effective and well-tolerated for certain patients.
 - Pain treatment physicians care for complex patients whose problems have persisted or worsened during non-specialist care, and mandating limits on opioid dosage and duration



would add difficulty to anesthesiologists' already-challenging task of caring for these patients.

- ASA commended the inclusion of key elements of the National Pain Care Policy Act in section 4305 of PPACA.
- ASA addressed key findings and recommendations from the Institute of Medicine's (IOM) report, *Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education and Research*, in an official Statement for the Record to the U.S. Senate Committee on Health, Education, Labor & Pensions (HELP). ASA agreed with the IOM report that pain is often a symptom of a disease, but chronic pain can be a disease in itself.
- To ensure patient safety and the highest quality of care, ASA has taken the position that "interventional pain management (and prescribing) is the practice of medicine provided only by qualified MDs/DOs."
- ASA opposes the Centers for Medicare & Medicaid Services' (CMS) decision to adopt a new and untested national policy that will allow Medicare funds to be used to pay untrained providers to diagnose and treat chronic pain. The policy jeopardizes patient safety, lowers the quality of health care and increases the risk for fraud and prescription drug abuse.
- ASA appears to be more in favor of medicinal treatments or therapies than shots. According to one recent article, the ASA noted that the rate of serious complications from injection procedures is impossible to estimate because of the lack of mandatory reporting. The ASA also reported in 2012 that epidural injections accounted for 40 percent of all claims involving pain management cases over a 20-year period, and forecast far more future serious injuries.

INFLUENCE

ASA is the leading organization for anesthesiologists, many of whom treat pain. It also has a significant website for patients called "Lifeline to Modern Medicine" that provides information on the role of anesthesiologists not only in surgical procedures, but also pain care. ASA has also created guidelines on the management of cancer pain and chronic pain.

The ASA advocates for its members on issues related to pain medicine out of the Office of Governmental and Legal Affairs in Washington, D.C.

- ASA provides standards, guidelines, statements and other documents to help guide the practice of anesthesiologists.
- The ASA has issued position papers around various issues in pain this year.
- ASA efforts this year are largely focused on advocating for maintaining the central role of specialists in treating chronic pain (as opposed to other allied HCPs).
- ASA advocated for adoption of the National Pain Care Policy Act, which would have required the Secretary of Health and Human Services to establish and implement a national education outreach and awareness campaign on pain management. While key elements of the National Pain Care Policy Act were included in the Patient Protection and Affordable Care Act, the mandate to establish a national education outreach and awareness campaign was not enacted into law. ASA urges the Senate Committee on Health, Education, Labor & Pensions to reconsider mandating a public education campaign on pain management, in light of the IOM report's recommendations.

ASA hosts an annual Legislative Conference in Washington, D.C. that is the specialty's largest meeting focusing on state and federal legislative, regulatory and political issues impacting ASA and anesthesiology. The purpose of the conference is to prepare ASA members to engage effectively in the legislative, regulatory and political processes on behalf of the specialty. This year, it will take place April 29 - May 1 at the J.W. Marriott Hotel in Washington, D.C.

FOCUS ON PAIN MANAGEMENT

- While the ASA is focused on educating both its members and patients on the latest in anesthesiology, it considers pain medicine a top priority of the organization and it provides a number of tools and resources for both patients and HCPs to support this.



- ASA recently initiated a campaign to create awareness of pain as a direct result of the IOM report issued in June 2011. It also provides a range of information on different types of pain, treatments to address pain and opioids, specifically, in managing pain.



AMERICAN SOCIETY FOR PAIN MANAGEMENT NURSING (ASPMN) OVERVIEW

ASPMN is focused on advocating for the nurse's role in pain management, as well as educating nurses about pain management. The organization has not been as active in the past year as it has in the past, perhaps for lack of resources. It puts most of its energy into its annual meeting. Teva, along with other pharmaceutical companies, is already a sponsor. There may be opportunity to work more closely, but it appears that most sponsorship opportunities are not program-specific. However, the group is in need of a website and materials revamp.

Address:

<http://www.aspmn.org/>
18000 W 105th Street
Olathe, KS 66061-7543

ORGANIZATIONAL RESOURCES (2011)

- Total Revenue: \$907,735 (300,000: grants/contributions; \$227,000: annual conference; \$220,000: membership dues).
- Total Expenses: \$1,006,543 (\$517,000: meetings/conferences/events; \$224,000: non-employee management).
- ASPMN cites zero employees, 11 members of its voting board and 20 volunteers

MEMBERSHIP

- ASPMN members comprise clinicians, educators and researchers with vastly different educational preparation, clinical roles and interest in practice issues who work in the following roles: staff nurse, clinical educator, clinical nurse specialist, academic educator, manager, nurse practitioner, administrator and researcher.
 - Students, LPNs and international nurses can join, but they cannot hold voting or leadership positions.
- ASPMN has 25 chapters, most of which are organized by state. However, some chapters combine states and some larger states have more than one chapter.
- ASPMN has seven committees, which carry out the Board's direction. The Board can also establish Task Forces on an as-needed basis for certain issues. No Task Forces are currently active.
- ASPMN offers pain management certification through a partnership with the American Nurses Credentialing Center (ANCC).

VISIBILITY

Publications/Congresses

- Pain Management Nursing: ASPMN's peer-reviewed journal.
- ASPMN's Pathways newsletter: Published online several times per year and focuses on job postings and upcoming events.
- ASPMN publishes E-News newsletter for members.
- ASPMN publishes many educational materials for pain management nurses that are for sale in conjunction with the American Nurses Credentialing Center.
- Annual Meeting: Occurs in October, typically drawing in about 1,000 attendees.

Social Media

Facebook: 536 likes

- Posts are intermittent (average one per month), and spike during its Annual Meeting. Most posts promote upcoming ASPMN events and webinars, its e-newsletter and awards.

Twitter: N/A

YouTube: 3 subscribers, 1,502 video views, 4 videos

- The channel is not listed on ASPMN's website.
- Most videos are policy-related ("ASPMN Response to Proposed Legislation and Recently Released Federal Actions," "ASPMN Comments on Washington State Proposed Rules on Pain," "FDA Acetaminophen Update"); the other, and by far the most watched, is on the nurse's role in



pain management. ASPMN Government Affairs Director Wade Delk is the spokesperson in the policy videos.

LinkedIn: 1,153 members

- The group is a professional group and is locked for members only.

Media Coverage

- ASPMN has been mentioned in 12 media articles in the past year. Seven of the articles were about a joint-effort with ACPA to declare September Pain Awareness Month in Wisconsin. Two of the articles cited an ASPMN study.

PARTNERSHIPS

- ASPMN corporate sponsors include Abbott, Purdue, Teva, Horizon Pharma, Millennium Labs, Bon Secours Richmond Health System, Abbott, Pfizer and Neurogesx.
 - Corporate membership includes: annual corporate spotlight in E-News, recognition on website, newsletter and national conference, subscription to publications, access to the Annual Meeting of the Board of Directors at the national conference, logo recognition throughout the Annual Meeting conference hall and full page ad in the program
- ASPMN joined several organizations including the ACPA, Purdue, American News Report, Johnson & Johnson, to publish the September 2012 USA Today special on chronic pain.
- ASPMN has worked with the ACPA to declare Pain Awareness Month in some states.

ISSUES

- In addition to nurse education, ASPMN prioritizes advocacy and policy. It has 19 position statements. Most date before 2011, however. It's most recent was in July 2012 about pain management in patients with substance abuse history. Some are in conjunction with other patient and professional groups.
- ASPMN consistently focuses on the following:
 - Access to effective pain management
 - Pain management should be individualized and have an interdisciplinary approach
 - Nurses need more education, as they're often the patient's best advocate
 - The public needs more education on the legitimate impact of pain on patients
 - The nursing shortage
- ASPMN wrote a letter to the FDA in opposition to rescheduling hydrocodone, citing the lack of evidence for rescheduling to limit abuse and that legitimate pain patients would have access issues and therefore needlessly suffer
- ASPMN has focused on ensuring that RNs and APRNs are reimbursed by Medicare for pain management services as was outlined in the Institute of Medicine (IOM) report, "Future of Nursing."
 - ASPMN put a lot of resources in 2012 to urge CMS to modify the 2013 Physician Fee Schedule to restore Medicare reimbursement for chronic pain management services provided by Certified Registered Nurse Anesthetists (CRNAs), which was achieved.
- ASPMN sent FDA its position that REMS for opioids should be class-wide and not just ER/LA. Its statement emphasizes that opioids don't cause addiction, and that opioid-related deaths and overdoses are the results of multiple factors including use of other medications and alcohol.
- In November 2012 ASPMN, along with several other patient and professional groups, joined a National Association of Chain Drug Stores (NACDS) letter to urge Congress to create a commission and advisory group that would bring together government agency stakeholders to address prescription drug diversion and abuse.
- In 2011 ASPMN advocated for DEA rule changes to allow nurses in long-term care facilities the same authority that they currently have in hospitals.
- ASPMN likes to remind policymakers that "All Nurses are Pain Management Nurses."
- The organization has not offered opinions on hydrocodone rescheduling, or abuse deterrent requirements.



INFLUENCE

- ASPMN's Annual Conference is typically held in September and early October and allows member nurses to hear new research, receive CME and network with others.
 - The 2013 Annual Conference is Oct. 9-12 in Indianapolis.
- ASPMN has an advocacy page, which shows policy is a priority for the group, but it is not comprehensive or updated often.
 - Has separate pages for legislative updates from Washington state, California and Massachusetts only
 - Offers a legislative toolkit that includes materials: Lobbying 101, Capitol Hill 101, Sample Letter to Request Meeting, Sample Talking Points (focused on nursing shortage), Sample Meeting Agenda
 - Includes news updates on FDA regulations, REMS, etc. The page used to be updated more frequently prior to 2012.

FOCUS ON PAIN MANAGEMENT

- ASPMN is almost entirely focused on pain management issues and maintaining the nurse's role in pain management. The only other issue it focuses on is the nursing shortage.
- Some, but not all, members can prescribe opioids. For example, the organization includes nurse practitioners (who can prescribe), and LPNs (who cannot prescribe). A detailed membership breakdown is not available. The organization has distinguished between chronic and acute pain, but does not mention breakthrough cancer pain. In some of its materials ASPMN has distinguished ER/LAOs, but it does not discuss TIRF products in any of its online materials.



AMERICAN SOCIETY OF INTERVENTIONAL PAIN PHYSICIANS (ASIPP) OVERVIEW

ASIPP touts itself as “a voice that matters in Washington.” The group, formed in 1998, supports the needs of physicians who practice interventional pain management through educational programs, publications, certification and political advocacy. Through the ASIPP-PAC, the organization is able to offer significant presence and influence in Washington. Despite its presence on the hill, the group is primarily focused on advocating for its members, rather than taking positions on various issues in the pain and opioid space. Additionally, interventional specialists often employ techniques like spinal shots, and, although it has not taken a stance against opioids, it has been quoted on the perils of pain management with opioids. However, ASIPP has a rather larger editorial advisory board with several potential key influencers included.

ADDRESS

<http://www.asipp.org>
81 Lakeview Drive
Paducah, KY 42001

ORGANIZATIONAL RESOURCES (2011)

- Total Revenue: \$3 million (\$1.5 million in contributions and grants; \$1 million in program services; \$66,000 in other).
- Total Expenditures: \$2.975 million (\$875,000 in employee salaries and bonuses; \$344,000 in annual meeting; \$431,000 in cadaver and education workshops; \$175,000 in a five-day CME course).
- 13 employees

MEMBERSHIP

- 4,500 members
- Interventional pain management is a recognized medical specialty with representation at the state and national level. Physicians practicing this specialty are referred to as interventional pain physicians, regardless of the primary focus of its practice. This spirit of unity amongst the various component specialties fosters an environment conducive to the communication of news and information.
- ASIPP has several state societies.
- ASIPP also has members on its editorial board that work at various pain centers of excellence.

VISIBILITY

Publications/Conferences

- *Pain Physicians*: Official journal of the ASIPP. It is a bi-monthly peer-reviewed, multi-disciplinary journal written by and directed to an audience of interventional pain physicians, clinicians and basic scientists with an interest in interventional pain management and pain medicine.
- ASIPP News is the official quarterly newsletter of the American Society of Interventional Pain Physicians (ASIPP). More than 9,000 copies of ASIPP News are circulated worldwide.
- Annual Meeting: June 8 – 11 in Washington, D.C.; typically attended by approximately 375 – 400 physicians.

Social Media

Facebook: 118 followers

- The Facebook page is technically for its fellows/residents as its title is ASIPP Fellows/Residents page.

Twitter: 18 followers

- There have been 45 tweets since it started the page in March 2012. Most tweets are around advancing the profession – from educational programs to member recognition to encouragement to add an IPM specialist to practices. However, the group’s guidelines were mentioned several times in recent Twitter conversations.

LinkedIn Group: 19 members

- There is only one recent discussion that is a rallying cry against expanding the role of CRNAs in the treatment of pain.



YouTube

- The YouTube channel has not been updated since 1998.

Media Coverage

- ASIPP has been mentioned in 45 articles over the past year. Most of this coverage was related to coverage of methylprednisolone acetate - an "injectable steroid – that is causing severe and deadly infections. ASIPP noted that "general consensus is not to use substances with preservatives, specifically, toxic ones, into the epidural space."
- Several stories were related to the IPM privileges for CRNAs, which the ASIPP is staunchly against.
- Much of the trade coverage was regarding the release of ASIPP's "Guidelines for Responsible Opioid Prescribing in Chronic Non-Cancer Pain."
- Caraway, the vice-president ASIPP, was recently quoted extensively in an article in *The Guardian* about the escalating use of opioids in the U.S. He spoke to many stories of patients who had been overprescribed or addicted to opioids.
- Regarding the use of opioids, ASIPP's Caraway was quoted in the *New York Times* saying, "alternatives to prescription medications for treating those in pain range from twice-a-year spinal injections to implantable devices that help physicians thwart diversion and control daily dosage," and, "there's very little evidence that with most patients a high dosage of opioids improve function and one's quality of life," said Dr. Caraway. He said limiting extended-release painkiller usage to everyone is an overreach, citing his own prescribing of the drugs, in lower doses, to women in their 70s or older.

PARTNERSHIPS

- The top sponsor of the organization is Medtronic. Additional sponsors include Boston Scientific, hospitals and Stryker.

ISSUES

Currently ASIPP is focused on IPM privileges, including prescribing rights, for CRNAs. It believes allowing nurses to perform IPM techniques risks patient safety and is lobbying against this with letters HCPs and patients can personalize and share with their representatives. It does not want CRNAs to have opioid prescribing rights.

ASIPP is also encouraging people to change its specialty code to one designated to IPM (interventional pain management). Currently, CMS claims there are too few IPM physicians, which negatively affects their reimbursement.

After a four-year effort, ASIPP was successful in March 2005 in getting the Centers for Medicare and Medicaid Services to mandate the inclusion of an interventional pain management physician on each state's Carrier Advisory Committee.

ASIPP recently issued updated [guidelines for the use of opioids in chronic non-cancer pain](#). Citing increased abuse rates and limited evidence on the benefits of the long-term use of opioids, ASIPP stresses caution in prescribing opioids for chronic pain.

INFLUENCE

- While the ASIPP is active in policy, it is largely focused on advancing its profession as opposed to general issues impacting patients and the category.
- ASIPP has published several books including, "Interventional Techniques in Chronic Non-Spinal Pain: For Interventional Pain Physicians," "Low Back Pain: Diagnosis and Treatment: On interventional pain management" and "Essentials of Practice Management: Billing, Coding, and Compliance in Interventional Pain Management."

FOCUS ON PAIN MANAGEMENT

- ASIPP is focused and often quoted on pain management; however, its primary focus appears to be on advancing and protecting the profession of interventional pain specialists.

**AMERICAN SOCIETY OF PAIN EDUCATORS (ASPE) OVERVIEW (see PAINWeek)**

The American Society of Pain Educators (ASPE) is a nonprofit professional organization dedicated to improving pain management through the education and training of healthcare professionals to become Certified Pain Educators (CPEs). As the only organization focusing on pain educator training, the Society teaches HCPs to serve as resources to educate their clinical peers and patients on ways to relieve pain by the safest means possible. Its goal is that every healthcare facility will one day have a Certified Pain Educator (CPE) on staff. Its primary event is PAINWeek, which is a well-known medical meeting focused on pain management education for general practitioners. PAINWeek appears to be the central and nearly only component of this organization. Refer to the PAINWeek profile for detailed information.

ADDRESS

<http://www.paineducators.org/>
6 Erie St
Montclair, NJ 07042

ORGANIZATIONAL RESOURCES (2008)

- Total Revenue: \$551,000 in 2007; \$52,000 in 2008.
- Total Expenses: \$675,000 in 2007; \$8,000 in 2008.

MEMBERSHIP

- Membership data is not available. Refer to PAINWeek for more information.
- ASPE does not offer a lot of information about its members through its website. PAINWeek does not have local chapters or members.

VISIBILITY**Publications**

- *Painview*: The official quarterly newsletter of the ASPE. ASPE permits free public access to *Painview* archives. It offers information for pain educators like new REMS programs, tips for educating patients and staff on managing pain and information about specific types of pain.

Social Media

- PAINWeek also has a blog includes a blog that is updated every couple of months, as well as a monthly newsletter that primarily promotes the event. Additional social media outlets follow:

Facebook: 25 followers

- It has not posted since September, 2012. Posts revolve around PAINWeek.

Twitter: 324 followers

- It has not posted since September, 2012.

Media Coverage

- ASPE has been mentioned in six articles in the past year. These were about data announcements made at its annual meeting, PainWeek.

PARTNERSHIPS

- Commercial support opportunities are available through PainWeek. It does not appear to have other corporate sponsors or partnerships.

ISSUES

- ASPE advocates for the role of CPEs in hospitals.

INFLUENCE

- ASPE is not active on the hill. However, in 2009 FDA meetings on REMS, the ASPE was noted to be a leader in pain education. One pain expert said that the ASPE was the "first and last word in pain education." ASPE states, "Unlike other pain organizations, we uniquely address the educational needs of the healthcare professionals and lay people." The ASPE prepares healthcare professionals to become pain educators and has a career-building process culminating with the awarding of the Certified Pain Educator (CPE) credential.



FOCUS ON PAIN MANAGEMENT

- As the only organization focusing on pain educator training, the Society teaches HCPs to serve as resources to educate their clinical peers and patients on ways to relieve pain by the safest means possible.

REPUTATION

- ASPE is most recognized for its annual meeting, PAINWeek. The meeting is valued among front-line, non-expert clinicians that treat pain. It is not as heavily attended by pain specialists and other specialists as other pain medical meetings. The seminars often provide more basic information about pain management. It's also not a data-heavy meeting; many posters are on pain management overall as opposed to specific drug announcements.



ARTHRITIS FOUNDATION OVERVIEW

The Arthritis Foundation is the largest national nonprofit organization solely dedicated to the prevention, control and cure of arthritis, the leading cause of disability in the United States. Founded in 1948, with headquarters in Atlanta, the Arthritis Foundation has multiple service points located throughout the country. The Arthritis Foundation is the largest private, not-for-profit contributor to arthritis research in the world, funding more than \$380 million in research grants since 1948. The foundation helps people take control of arthritis by providing public health education; pursuing public policy and legislation; and conducting evidence-based programs to improve the quality of life for those living with arthritis.

ADDRESS

www.arthritis.org
330 W. Peachtree Street
Suite 100
Atlanta, GA 30309

ORGANIZATIONAL RESOURCES (2011)

- Total Revenue: \$100 million (\$38 million in contributions, \$24 million in bequests, \$19 million in government grants and other income, \$19 million in special events).
- Total Expenses: \$6 million
- Net asset balance of \$157 million in Q411
- 78% of funds raised dedicated to mission activities, including research, public health education, public policy and patient and community services.

MEMBERS

- Primarily patient-focused; total number of members not available on website.

VISIBILITY

Per the annual report, 15 million patients turned to the foundation for information and support in 2011.

Publications and Congresses

- Arthritis Today Magazine: 6 issues per year, 4.16 million readers per issue
- Free brochures: 6 are dedicated to pain management
- Bi-weekly Arthritis Today eNewsletter
- Quarterly Research Update eNewsletter
- Monthly Mind, Body, Spirit eNewsletter
- It also hosts a myriad fundraising and visibility events planned including a 174 Arthritis Walk events nationwide, Jingle Bell Run/Walk nationwide, Advocacy Summit March 4-6, 2013 and dinners and galas (to date, 21 are planned in 2013).

Social Media

- Arthritis Connect, the Arthritis Foundation's online community, has 22,127 Arthritis Connect total users, 1,961 blog posts (a search for "pain" returns 925 posts), 58 groups (none are specific to pain/pain management), and 13 forums (one is called "Osteoarthritis – FightArthritisPain.org") with 79 threads with 300 posts (the last post was 2 days ago).

Facebook: 40,195 likes

- Posts news of interest every couple of days; followers commonly post comments and "like" articles.
- The most recent post (a link to an Arthritis Today magazine article on hip replacements) attracted 28 "likes", 6 comments and 11 shares in 24 hours.
- Followers engage daily with AF through Facebook by sharing stories, seeking support/validation or asking questions.
- Followers have mentioned "pain" in comments roughly 20 times in February.

Twitter: 13,493 followers

- Tweets about 5-10 times daily by linking to news articles regarding arthritis, engaging with followers, and retweeting tweets of interest.
- Zero explicit mentions of "pain" in February, but a number of tweets indirectly speaking to rheumatoid arthritis pain.



LinkedIn Group: 2,127 followers

- Somewhat inactive on LinkedIn. Latest activity was one month ago regarding an open job.

YouTube: 448 subscribers; 215,822 video views

- Videos include excerpts of patients talking about experience with arthritis, physicians talking about arthritis and information about fundraising efforts.
- Most recent video regarding pain management was posted 2 years ago.

Media Coverage

- Arthritis Foundation has been referenced in approximately 2,100 articles in the past year. Most mentions refer to fundraising events, community resources and obituaries (families solicit donations to the foundation in the name of a deceased family member).
- The foundation provides press releases, updated and credible source materials to encourage and assist journalists and has developed a media library to track media exposure.
- Spokespeople Jack Klippel (President and CEO), Patience White (Vice President of Public Health) and Amy Melnick (Vice President of Advocacy) are occasionally quoted.

PARTNERSHIPS

- Premier level sponsors (make an annual commitment to directly support the foundation's mission): AbbVie, Aleve, Instaflex/Beneflex, Janssen, Nature Made, Osteo BiFlex, Peak Life, Schiff, Zimmer
- Donations:
 - \$1 million and above: Abbott, BMS, Genentech, Patricia L. Pratt
 - \$500,000-\$999,999: Amgen, Bayer, Endo Pharmaceuticals, Independent Order of Odd Fellows and Rebekahs, Massage Envy, Novartis, Pfizer, Schiff Nutrition Group, Zimmer
 - \$300,000-\$499,999: Pharmavite, UCB Group,
 - \$100,000-\$299,999: Active Network, Alpha Omicron Pi Foundation, Apothecary Products, Clarity (a division of Plantronics), Helen C. Coverdill Trust, Fiskars America, Genentech/Biogen Idec, Genzyme, HealthSouth, Hoveround Corporation, Janssen Biotech, Joint Juice, McNeil Consumer Healthcare, Milgard Windows and Doors, Oreck Corporation, Pilot Corporation of America, Stryker Orthopaedics, Takeda Pharmaceuticals North America, Nancy Taylor Foundation for Chronic Diseases, Tempur-Pedic International, Troy Healthcare, Vons Foundation, Walmart Foundation, Wellpoint Foundation, Wells Fargo Advisors
- Arthritis Walk: Nationally presented by Amgen and Pfizer
- Jingle Bell Walk: Nationally sponsored by AbbVie
- Align with industry partners to drive a strategic research agenda that achieves major benefits for people with OA, RA, and JA. (A list of industry partners is not available on website.)
- Celebrity ambassadors include Jimmy Rollins, Seamus Mullen, Justin Morneau, Todd Peck, and Elizabeth Wertenberger

ISSUES

- Arthritis Foundation is advocating in support of:
 - H.R. 460, the Patient's Access to Treatments Act of 2013 (PATA), a measure intended to eliminate specialty tiers in commercial health insurance plans, which can cost patients hundreds of dollars per month for a single medication.
 - A pediatric subspecialty loan repayment program to address the critical shortage of pediatric rheumatologists in the U.S.
 - Including "post traumatic osteoarthritis" and "rheumatoid arthritis" in the Department of Defense research program.
- Arthritis Foundation supports the Affordable Care Act, saying it will make a difference in the lives of Americans with arthritis.

INFLUENCE

- Partners with federal and state agencies such as CDC, NIH, AHRQ, FDA, and other health policy entities, state public health departments, healthy communities efforts and industry to mobilize



support for public and private policies that support arthritis prevention, innovation and access to quality care.

- An Ambassador program facilitates meetings with members of Congress

FOCUS ON PAIN MANAGEMENT

- The Arthritis Foundation vision is to create a world free of arthritis pain.
- The website (www.arthritis.org) offers myriad resources for pain related to arthritis, including pain relief tips and treatment options (prescription, OTC, and alternative).
- Hosts a website dedicated to managing arthritis pain: www.fightarthritispain.org.



FOUNDATION FOR ETHICS IN PAIN CARE (FEPC) OVERVIEW

Launched in December 2010, the Foundation for Ethics in Pain Care is a not-for-profit organization dedicated to improving pain care in the United States through returning control of the discipline to patients and their HCPs. Recent decades have witnessed the usurpation of control by special interest groups that FEPC believes are not particularly interested in the amelioration of human suffering. FEPC refuses any type of industry funding to ensure the scientific integrity of its work. It consistently criticizes other groups and data available based on concerns regarding industry funding, which it also blames for the lack of information regarding the ethics of pain medicine. The executive director specifically notes the role of opioids in the “tainting” of patient treatment and believes that patients actually experience more pain when using opioids.

Address:

<http://www.painethics.org/>
15137 Se 66TH St
Bellevue, WA 98006

ORGANIZATIONAL RESOURCES

- As a foundation that is independent of university bureaucratic influences and expenses, FEPC is able to dedicate a maximum of 10% of grant monies received for conducting research to overhead, as opposed to the 30% to 69% commonly “wasted” in university settings.
- The revenue and experiences are not listed.

MEMBERSHIP

- The group is led by executive director Michael E. Schatman, PhD. Jennifer Bolen, J.D. of the Legal Side of Pain, founded the group. There are four other board members.

VISIBILITY

Publications and Congresses

- FEPC has no regular newsletters, publications or congresses. However, a number of studies authored by its executive director have been published recently and are listed on its website.

Social Media

- The group does not have a Facebook or Twitter page.

Media Coverage

- While the FEPC was quoted in several articles in 2011, which coincided with the groups launch, it has not been included in any articles in the past year.

PARTNERSHIPS

- Due to FEPC's concerns regarding the impact of special interest groups on the pain research that is being published, FEPC's policy is to refuse funding from industry, thereby ensuring the scientific integrity of its work.

ISSUES

- FEPC was developed as a response to the erosion of the professional integrity of the broad field of pain care over the past several decades, which has resulted in the deterioration of the quality of care that patients with pain receive. Once considered a noble “profession”, pain care has become merely a “business”, with this devolution from patient-focus to profit-focus adversely affecting patients suffering from pain. Professionals who treat pain are strongly influenced by third party payers, industry, and other special interest groups that deny a fiduciary obligation to the population that professionals are entrusted to aid. This influence is a broad one, and is axiomatic in the areas of clinician training and everyday practice.
- FEPC is currently working with the New York State Legislature in support of the recently introduced Senate Bill S2723, which “requires that all health care practitioners complete course work or training regarding pain management”.
- As a foundation that is independent of university bureaucratic influences and expenses, FEPC is able to dedicate a maximum of 10% of grant monies received for conducting research to



overhead, as opposed to the 30% to 69% commonly "wasted" in university settings. Too much research in pain care is performed simply because it is funded; FEPC conducts only research that makes a difference in the quality of life of pain sufferers.

INFLUENCE

- FEPC have been featured in recent articles discussing the deterioration of the quality of pain care in the United States over the past decade due to the retrogression has been pain medicine's devolution from a "profession" to a mere "business."

FOCUS ON PAIN MANAGEMENT

- FEPC is solely focused on pain care.



INTERNATIONAL ASSOCIATION FOR THE STUDY OF PAIN (IASP) OVERVIEW

IASP brings together scientists, clinicians, health care providers, and policy makers to stimulate and support the study of pain and to translate that knowledge into improved pain relief worldwide. Every year it announces a different focus such as headache, cancer pain or pain in women. This year, the focus is on pain in women.

ADDRESS

<http://www.iasp-pain.org>
1510 H St. NW, Suite 600
Washington, DC 20005-1020

ORGANIZATIONAL RESOURCES (as of 2011)

- Total Revenue: \$4.2 million; it has been more than \$9 million during the years of the World Congress (\$200,000 in contributions/grants; \$1M in program services; \$2.6M in other).
- Total Expenditures: \$419,000 (\$766,000 in grants; \$1.2M in salaries; \$1.8M in other).
- 15 employees; 15 voting members; 180 volunteers.

MEMBERSHIP

- IASP currently has more than 7,900 members from 133 countries and in 90 local chapters.
- IASP has several groups across the globe.
- Its executive leadership includes notable global representatives

VISIBILITY

Publications/Conferences

- *PAIN*: The official journal of IASP and the world's leading publication on pain research and treatment, *PAIN* offers state-of-the-art reviews, original research articles, and clinical notes, covering both clinical and basic sciences.
- *Pain: Clinical Updates*: IASP's clinical newsletter provides details on special aspects of pain management that are of interest to the frontline clinician.
- IASP Newsletter: A quarterly newsletter for IASP members with information about the activities of IASP and the Chapters and Special Interest Groups.
- Hosts the World Congress on Pain every two years with nearly 8,000 attendees. The next congress takes place October 7-11, 2014, in Buenos Aires, Argentina.
- IASP SIGs also host several meetings in international locations throughout the year.

Social Media

It appears it may have recently hired someone to handle its social media, which is currently fairly barebones.

Facebook: 2,900 followers

- Primarily includes updates about the organization such as its medical congress, new positions available and news from its publications. Occasionally, it posts a news item or study of interest.

Twitter: N/A

LinkedIn Group: 19 members

- There is only one recent discussion that is a rallying cry against expanding the role of CRNAs in the treatment of pain.

YouTube

- The YouTube channel has not been updated since 1998.

Media Coverage

- The IASP has been mentioned in 107 articles in the past year. Many times the group is listed as a reference for things such as the definition of chronic pain or persistent neck pain, or global incidence rates.
- In October, 2012, IASP launched The Global Year Against Visceral Pain, bringing global attention to pain that originates in or near the internal organs of the body. Visceral pain is the most frequent form of pain, felt by most people at one time or another, and the number one reason for patients to seek medical attention. As part of the Global Year Against Visceral Pain, IASP offers a series



of fact sheets for clinicians and health care professionals that cover specific topics related to visceral pain. These fact sheets are translated into multiple languages and available for free download. Its focus changes on an annual basis. Past years have focused on headache, cancer pain and pain in women.

- Several other articles mentioned IASP as a result of data presented at its world congress.

PARTNERSHIPS

- Endo and Purdue are affiliate members.
- No other partnerships could be found online.

ISSUES

- The IASP is not currently active on the hill or in other international government bodies. However, it convened the first International Pain Summit in 2010 to emphasize the importance of pain management as a human right and create guidelines for national strategies to help implement improved pain management worldwide. More than 260 pain specialists from 62 countries attended the inaugural Pain Summit in Montréal, Canada. It created the Declaration of Montreal as a result of this meeting.

INFLUENCE

- The IASP can be very influential on certain matters and are often referenced in articles. For instance, in 1993, the ASP proposed the name complex regional pain syndrome as a descriptive and general term for those syndromes that consist of pain accompanied by vasomotor (blood vessel function) and sudomotor (sweat function) changes. This is standard language today.
- It has also published a number of books on pain including "Chronic Pain: An Integrated Biobehavioral Approach," "Cancer Pain: From Molecules to Suffering" and "Pharmacology of Pain"

FOCUS ON PAIN MANAGEMENT

- IASP has a significant focus on all types of pains that impact people across the globe. Through its global year of pain topics, it often focuses on specific types of pain which have included headache, cancer and visceral pain. This organization also published books on both chronic and cancer pain.

**NATIONAL ASSOCIATION OF DRUG DIVERSION INVESTIGATORS (NADDI) OVERVIEW**

The National Association of Drug Diversion Investigators (NADDI) is a non-profit organization that facilitates cooperation between law enforcement, healthcare professionals, state regulatory agencies and pharmaceutical manufacturers in the prevention and investigation of prescription drug diversion ("any criminal act involving a prescription drug"). NADDI also sponsors and conducts specialized educational seminars and conferences.

ADDRESS

www.naddi.org

1810 York Road #435
Lutherville, MD 21093
410-321-4600

ORGANIZATIONAL RESOURCES (2011)

- Total Revenue: \$1.6 million (\$1.5 million in contributions, \$6,500 in investments)
- Total Expenses: \$1.4 million (\$1.3 million in program services, \$117,000 in administration)
- 2 employees; 8 voting members

MEMBERSHIP

- NADDI's 2,000+ members include law enforcement, healthcare professionals, state regulatory agencies, healthcare fraud investigators and pharmaceutical manufacturers. NADDI's objective is to improve the members' ability to investigate and prosecute pharmaceutical drug diversion.
- There are 24 US state and regional chapters.

VISIBILITY**Publications/Congresses**

- There are no official membership publications, e-newsletters or emails communications distributed to members.
- The Resources section of NADDI's website offers a variety of articles about subjects ranging from new oxycontin formulation to the DEA Internet Initiative. One original article, *Buprenorphine Use/Misuse in the Management of Opioid Addiction*, mentions that the misuse of hydrocodone is much higher than that of buprenorphine.
http://www.naddi.org/aws/NADDI/asset_manager/get_file/2740
- Annual Meeting: Occurs in St. Louis, MO, November 19-22, 2013. Attendee information was not available.

Social Media

Facebook: 186 followers

- NADDI has a minimally active presence.

NADDI is not on Twitter, LinkedIn or YouTube

Media Coverage

The National Association of Drug Diversion Investigators was mentioned in 120 articles in the past year.

- NADDI president John Burke was quoted in top-tier coverage following the January 2013 FDA advisory committee hearing on rescheduling hydrocodone as saying hydrocodone is "absolutely" the most abused pharmaceutical in the U.S. He has also been quoted frequently about how a rise in pain medication scripts has led to a rise in overdose deaths. He was also quoted in a WSJ article about how OxyContin's abuse deterrent characteristics have helped curb abuse.
- NADDI was most often mentioned in media about local "drop box" events (46 articles).
- While one of NADDI's focuses is to curb prescription pain medication abuse (40 articles), it is more often mentioned in reference to meth use (78 articles).

PARTNERSHIPS

- NADDI has nine corporate members, including Abbot, Appriss, Endo, Express Scripts, GW Pharmaceuticals, Pfizer, Purdue, Reckitt Benckiser and Walgreens.
- Teva is not listed as a corporate member. There is no information on the cost of a corporate membership.



- NADDI has 10 partners, including KSL, Cactus, National Family Partnership
- Center for Lawful Access & Abuse Deterrence, Opioids 911-Safety, Radars Systems, RxSafety Matters, Street Rx, Time to Act and MedGuard.
- NADDI partners are "non-profit special friends and supporters who have similar values and goals of NADDI in the ongoing pursuit of the reduction of prescription drug abuse."
- NADDI's LE (Law Enforcement) Grant is sponsored by Purdue Pharma to help address the complex problem of prescription drug abuse and diversion through the provision of resources to local law enforcement entities engaged in combating the abuse and diversion of scheduled prescription drugs.
- NADDI has not made statements or expressed opinions about pharmaceutical and advocacy financial ties.

ISSUES

- Abuse is a top priority for NADDI.
- NADDI's principle activities and issues involve:
 - Cooperative education and training in the specifics of pharmaceutical drug diversion, investigation, prosecution and prevention
 - Sharing investigative information and communicating with a wide variety of interested parties with regard to the nature, scope and impact of pharmaceutical drug diversion
 - Developing more effective measures to combat the problem.
- Pain management is an important issue for NADDI, with a section of its website devoted to it (see Focus on Pain Management, below).
- NADDI is not advocating for policy change in any area.
- There is no information on NFMCPA's website about the scheduling or relabeling of hydrocodone. Although President John Burke is on the record regarding the high potential for hydrocodone abuse.

INFLUENCE

- NADDI is not active legislatively, although the organization does follow and occasionally post legislation of interest, in a limited fashion.
- NADDI is not currently a major influencer of industry or legislation.

FOCUS ON PAIN MANAGEMENT

- NADDI has a section of its website devoted to pain management under Resources. It contains the following resources:
 - NADDI Pain Treatment Statement, which states "there has been an increase use in opiates prescription medications which can tremendously benefit patients but also have the potential of abuse and diversion."
http://www.naddi.org/aws/NADDI/asset_manager/get_file/15593
 - Guidelines for the Use of Controlled Substances in Pain Treatment from the Georgia Composite State Board of Medical Examiners
 - The US Federation of State Medical Boards' Model Policy for the Use of Controlled Substances for the Treatment of Pain
 - Opioid Prescribing Agreement for the American Academy of Pain Medicine
http://www.naddi.org/aws/NADDI/asset_manager/get_file/32898/opioidagreements.pdf
 - Two reprints of Alpha Pharmaceuticals' *Pain Reporter*
 - Article reprints from Pain-Topics.org



NORTH AMERICAN SPINE SOCIETY (NASS) OVERVIEW

The North American Spine Society (NASS) is the premier multidisciplinary medical organization representing more than 7,500 members in 72 countries. NASS is dedicated to fostering the highest quality, ethical, value-based and evidence-based spine care through education, research and advocacy. Members are from more than 32 specialties including orthopedic surgeons, neurosurgeons, neurologists, radiologists, physiatrists, pain management specialists, anesthesiologists, psychologists, chiropractors, physician assistants, nurse practitioners, nurses, physical therapists, researchers, coders, administrators, and other health care professionals invested in the advancement of spine care.

ORGANIZATIONAL RESOURCES (2011)

- Total Revenue: \$12.4 million
- Total Expenses: \$1.5 million
- 41 employees; 9 voting members

MEMBERSHIP

- NASS is comprised of more than 7,500 members worldwide from several disciplines including orthopedic surgery, neurosurgery, psychiatry, neurology, radiology, anesthesiology, research, physical therapy and other spine care professionals

VISIBILITY

Publications/Congresses

- Spine Line: Member newsletter that includes multidisciplinary medical and scientific education, review and commentary on recent research, and pearls to assist caregivers in providing high-quality, cost effective care.
- *The Spine Journal*: An international and multidisciplinary journal that publishes original, peer-reviewed articles on research and treatment related to the spine and high-quality, ethical, evidence-based spine care, including basic science and clinical investigations. *The Spine Journal (TSJ)* also publishes major reviews of specific topics, technical notes, editorials, commentary and special features.

Social Media

- NASS also has a blog that is locked behind a member login and a blog dedicated to advocacy, Spine on the Hill.

Facebook: 1204 followers

- Posts news of interest every couple of days; receives 1 – 2 likes and occasionally a comment or share on its postings.

Twitter: 1589 followers

- Tweets about association news and events.

LinkedIn Group: 1585 members

- Discussions average 1 per week.

YouTube: 1900 video view

Media Coverage

- In the past 12 months, the National American Spine Society has not appeared in any articles which link to pain.

PARTNERSHIPS

- A link to become an exhibitor and information about advertising are available on the website, but there are no listed sponsors or partners.
- In 2010, NASS was hit by a series of controversies in recent years over ties to medical-device makers and adopted the following changes:
 - Required medical-device manufacturers that do business with the group to follow a mandatory code of ethics.
 - Created a new position of board ethicist.
 - Barred its leaders from speaking at industry-sponsored events.
 - Greatly restricted the ability of corporations to blaze its logos on materials at educational events: No sponsorship of hotel keycards, registration-badge lanyards, welcome



receptions, or meals. If companies want to provide tote bags, its logos must be hidden inside.

ISSUES

- Recognizing the need to influence the debates that shape health care policy, NASS established the National Association of Spine Specialists— an IRS-designated 501(c) (6) trade organization— as its advocacy arm. The Association was founded in 1999 and continues to be administered by the North American Spine Society. The Association advocates in the legislative and regulatory arenas for public policies that protect members' ability to practice medicine and give patients access to the specialists, technologies and treatments they require for quality spine care. All members of the North American Spine Society are members of the Association (unless they opt out), with a portion of member dues allocated to advocacy efforts. The Association relies on its members to advocate on behalf of the spine care field and patients.
- SpinePAC is the political action committee fund through which the Association supports federal legislative candidates who champion policies that benefit spine care patients and the professionals who treat them. SpinePAC is funded through contributions from individuals in the spine care field, specifically Association members, and serves as an important tool to further the Association's advocacy agenda. SpinePAC raised more than \$230,000 during the 2010 Election Cycle. This included the two most successful fundraising years (2009 and 2010) and represents the largest election cycle collection for SpinePAC. This record fundraising effort allowed SpinePAC to contribute over \$128,425 to candidates who support spine care providers and their patients. These contributions went to candidates for federal office who are Congressional leaders and support sound health care policies; most served on committees with jurisdiction over health care issues, including physician reimbursement, quality improvement and medical liability reform..

INFLUENCE

- NASS provides members with tools in the legislative and regulatory arenas for public policies that protect members' abilities to practice medicine and give patients access to the specialists and technologies they need for quality spine care. Spine PAC backs candidates who support NASS's agenda.

FOCUS ON PAIN MANAGEMENT

- Treatment options discussed on the patient-facing site, KnowYourSpine.org are limited to surgical, injections, alternative medicine and hydrotherapy. It is not as focused on medicinal therapies.



NATIONAL FIBROMYALGIA ASSOCIATION (NFA) OVERVIEW

Founded in 1997 in Orange, California, by Lynne Matallana and Karen Lee Richards, the National Fibromyalgia Association (NFA) is the largest nonprofit 501(c) 3 organization working to support people with fibromyalgia and other chronic pain illnesses. Its mission is to develop and execute programs dedicated to improving the quality of life for people with fibromyalgia.

<http://fmaware.org/site/PageServer.html>

Corporate Offices
2121 S. Towne Centre Place, Suite 300
Anaheim, CA 92806

ORGANIZATIONAL RESOURCES

- Total Revenue: \$297,432 (2011), \$1,460,149 (2007) – see government investigation section under partnerships.
- Total Expenses: Advocacy: 0.23%, Awareness: 24.83%, Medical Education: 13.19%, Patient Assistance & Education: 44.61%, Research Facilitation: 2.99%, Fundraising: 5.35%, Admin: 8.80%

MEMBERSHIP

- Membership seems to be more patient-focused; however, members have access to the latest peer-reviewed scientific papers on the subject of fibromyalgia, which could be a selling point for prescribing HCPs.

VISIBILITY

Publications/Congresses

- Fibromyalgia AWARE Magazine - Published by the National Fibromyalgia Association, it is the first and only consumer magazine dedicated to the subject of fibromyalgia. Digital editions are available for no charge on its website, and you do not have to be a member to access the latest version.
- FMOnline newsletter is an educational monthly resource for patients and healthcare professionals. It offers the latest news on fibromyalgia and overlapping conditions.
- The Resources section of NFA's website also offers a glossary of research and other fibromyalgia terms and definitions and links to clinical trial information.
- The FMA does not have an annual meeting. It did host the first International Fibromyalgia Leaders Against Pain Workshop in Washington D.C. August 20-21, 2007. There is no mention of a meeting since then.

Media presence

- The NFA has been mentioned in 37 articles in the past year. The NFA provides press releases, updated and credible source materials to encourage and assist journalists, and has developed a media library to track FM media exposure, note misinformation and promote accurate information.
- Feature brief in The Sun Herald and Vancouver Province on "Painful fibromyalgia becomes much more prevalent in men."
 - Dr. Oz, featuring story on Michael Hastings
- Often times, NFA research is quoted as statistics in various news pieces.
- Karen Lee Richards, a co-founder of the NFA, has been quoted in the NYT
- John Fry, PhD, a psychologist in Newport Beach, CA and board member of the National Fibromyalgia Association, was quoted

Social Media

- Organization homepage offers an about FM section, a community portal with support groups and advocacy opportunities, AWARE Magazine, resources, research information and a members portal.
- NFA website is often touted as the go-to source for FM resources and information
- Members receive monthly e-newsletters, member-only portal



Facebook: 96,696 followers

- Lots of activity and regular posts from 2008-2011. Frequency of communication lulled in 2012 due to organization restructuring. Features event photos and upcoming event notifications along with notes to followers

Twitter: 3,237 followers and 410 tweets

- It has not been active since 2011's restructuring

YouTube: 247 subscribers and 95,292 views

- The NFA YouTube channel offers 14 videos and has 95,292 views and 247 subscribers.

PARTNERSHIPS

- The organization has partnered with other pharmaceuticals in the past, such as Pfizer, Forest Laboratories, Eli Lilly, Ortho McNeil, Wyeth Health Care Professionals & Swiss Medica. A survey was conducted by the American Pain Foundation, the National Fibromyalgia Association, and funded by Pfizer. There have been educational grants for physician CE/CME programs and a FM over the counter pain medication. Other partnerships of interest:
- The NFA also collaborates with the American Pain Foundation, the American Academy of Pain Management, PAINWeek and Allsup.
- Johns Hopkins And National Fibromyalgia Association Launch Fibromyalgia Educational Initiative To Bridge Chasm In Diagnosis And Care
- NFA Forms Partnership with Practicing Clinicians Exchange
- National Fibromyalgia Association, RemedyMD partner to build fibromyalgia research registry
- The National Fibromyalgia Association (NFA) and the American Pain Foundation (APF) are pleased to announce the winners of the "Helping Hands: Making a Difference in Fibromyalgia" Awards

ISSUES

- There is a note on website regarding NFA clinical trials: "Funding for clinical research comes from the federal government such as the National Institutes of Health, the Department of Defense, the Department of Veteran's Affairs, and private industry such as pharmaceutical and biotech companies, medical institutions, and foundations."
- While it is not included in government investigations concerning financial ties to industry, there was concern about abuse/misappropriation of funds
- NFA response to shutting down temporarily – "The NFA like all other nonprofit and for profit organizations was not prepared for our country's financial crisis, reduced foundation funding, or the impact of new restrictions and tighter transparency regulations put on companies that helped to financially support our organization. Our funding was cut by 50 percent to 80 percent and our annual \$2 million budget diminished by 60% in a matter of only a few months." "However, we were bound by legal constrictions and agreements of confidentiality to wait until we had developed a plan that would satisfy many of our issues."
- The FMA has been involved in various efforts designed to promote grassroots advocacy efforts. It has participated in rallies in Sacramento, California, and in Washington DC, geared towards increasing awareness among policy-makers to increase research funding at a federal level. Additionally, the NFA continues to collaborate with other national organizations, like the National Pain Foundation and the CFIDS Association of America, to get the word out about advocacy efforts and legislative issues impacting the FM community. It also encourages participation in letter-writing campaigns designed to influence the policy-making process at all levels of government.

INFLUENCE

The organization is active in increasing FM awareness and participating in legislative lobbying to raise research funding, FM awareness and improved patient protection under state and federal laws. The NFA provides both local and national opportunities:

- Assistance to local support groups, providing them with FM information (thousands of handouts and posters for health fairs and community events), national contacts and referrals and assistance with establishing and maintaining support groups.



- Patient information and education through international conferences, regional seminars, brochures, informational handouts, video and audio tapes, newsletters and a website. Telephone assistance and online assistance gives patients one-on-one help.
- Fibromyalgia AWARE Magazine. AWARE was the first reliable source of information about fibromyalgia and remains the only consumer magazine all about fibromyalgia that offers straightforward, insightful information and support.
- Annual Fibromyalgia Awareness Day Proclamation Program, an international program established in 1999 to promote fibromyalgia awareness. Thousands of mayors and other elected officials have declared "Fibromyalgia Awareness Day" in their jurisdiction, proclaiming May 12th as a day to recognize the needs of people with FM. Local groups have used the NFA's Awareness Day press releases to garner media coverage of local events and raise awareness of FM and local support group activities.
- Leaders Against Pain Coalition, an annual workshop for FM support group leader scholarship winners, who take part in a multi-faceted program that provides, advocacy, media and leadership techniques. To date over 100 individuals have participated in the NFA's LAP Coalition program. LAP is operated in conjunction with the National Fibromyalgia & Chronic Pain Association (NFMCPA).
- Participation in legislative lobbying to raise research funding, FM awareness and improved patient protection under state and federal laws.
- Continuing medical education programs for health care professionals, including symposia, conferences, distribution of workbooks that cover recent FM research, special CME Journal Programs inserted into Fibromyalgia AWARE magazine and mailings to help educate medical professionals on the diagnosis and treatment of FM.
- Supporting fibromyalgia research through networking, fundraising, locating patients to participate in clinical trials, information distribution and encouraging communication between researchers and the FM community.
- The FMA will continue to be a strong influence in the FM community in the future. The have influenced others and policy.
 - Senator Gloria Negrete McLeod, chair of the California Legislative Women's Caucus, and Assembly Member Sharon Runner co-sponsored a resolution advocating for improved treatments, expanded research at the National Institutes of Health, comprehensive health insurance coverage and increased awareness of fibromyalgia, especially in the U.S. Congress, and specifically, in the Congressional Caucus on Women's Issues.
 - Assembly Member Mervyn Dymally authored ACR 112 (introduced by Assembly Member Neil Soto), which establishes the Legislative Task Force on Fibromyalgia. The resolution calls on members of the State Assembly, Senate and the National Fibromyalgia Association to appoint a 15-member task force.
 - Since December 2006, the NFA has been involved in the creation and development of the California Chronic Care Coalition (CCCC), an alliance of non-profit and health-care provider organizations united to improve the health of Californians. Its mission is to improve the health care system so that all Californians with chronic conditions can access appropriate quality health care.

FOCUS ON PAIN MANAGEMENT

- Leaders Against Pain (LAP) is a NFA scholarship program, customized for support group leaders and advocates. The multi-faceted program focuses on media, advocacy and leadership training.
- The International Leaders Against Pain Coalition (ILAPC) comprises support group leaders and patient advocates from around the world that have completed the NFA's Leaders Against Pain media and advocacy training. Its goal is to promote FM as a global health issue.
- The NFA also supports the National Fibromyalgia and Chronic Pain Association (NFMCPA), which has the capacity to represent the fibromyalgia community through high profile and public-awareness events, as well as to further become involved in research opportunities. The NFMCPA also works to ensure that an interest will remain in continuing to investigate FM's relationship to overlapping conditions, such as irritable bowel syndrome (IBS), migraine headaches, interstitial



cystitis (IC), restless legs syndrome (RLS), reflex sympathetic dystrophy syndrome (RSD), chronic pelvic pain, and other comorbid chronic pain disorders.



NATIONAL FIBROMYALGIA AND CHRONIC PAIN ASSOCIATION (NFMCPA) OVERVIEW

The mission of the National Fibromyalgia & Chronic Pain Association (NFMCPA), founded in 2011, is to build a united patient and medical community to create a strong voice and organizational base to educate and execute advocacy programs regarding access to care, scientific research, diagnosis and treatment for people suffering with chronic pain from fibromyalgia and overlapping conditions.

ADDRESS

www.fmcpaware.org

31 Federal Avenue

Logan, UT 84321

801-200-3627

ORGANIZATIONAL RESOURCES (2010)

- Total Revenue: N/A
- Total Expenses: N/A
- NFMCPA relies on donations and membership funding to continue its services. "An NFMCPA staff member works diligently to win grants, endowments and other funding sources. With those additional resources NFMCPA can increase its program efforts for the duration of funding."

MEMBERSHIP

- NFMCPA's membership consists of scientific researchers, patients, health care providers, thought leaders, advocates, and CAM/IM (complementary/alternative/integrative medicine professionals).
- There are no available figures on the number of NFMCPA members.

VISIBILITY

Publications

- *Fibromyalgia & Chronic Pain LIFE TM* is the free, online, bi-monthly publication of NFMCPA. It offers research news, feature profiles on people living well with fibromyalgia, awareness events and other issues that relate to the fibromyalgia diagnostic criteria and continuing medical education for health care providers.
- NFMCPA is equipped to issue e-alerts to its membership but does not do so regularly (last was 2/2012).
- The *FM-CP Advocate Newsletter* is positioned as a monthly newsletter, but is produced a varying number of times in any given year (2011 - 9 issues, 2012 - 5 issues, 2013 - 1 issue).
- NFMCPA has two online brochures: *How Can We Help You?* and *Quick Consult Guide*.
- NFMCPA hosts webinars on fibromyalgia-related topics (neck pain, sleep, etc.) through its "Ask the Experts" series.
- Annual Meeting: NFMCPA does not seem to have an annual meeting, but lists links to other pain organization meetings.

Social Media

Facebook: 18,000+ followers

- NFMCPA is fairly active, posting links to articles of interest and statistics related to fibromyalgia, as well as its *Life* publication.

Twitter: 504 followers

- President & Founder Jan Chambers tweets sporadically.

LinkedIn Group: 230 members, 16 discussions this month

- Has a basic site under Fibromyalgia & Chronic Pain LIFE Magazine.

YouTube: 122 subscribers, over 9,000 video views

- NFMCPA has its own YouTube page with 15 videos posted, including webinars and community event coverage.

Pinterest: 544 followers

- NFMCPA has 20 boards, including basic information, resources and advocacy (information on FDA committee meetings and hearings, training, etc.).



Media Coverage

The National Fibromyalgia & Chronic Pain Association was quoted in 25 articles in the past year.

- NFMCPA president Jan Chambers is quoted most often in media. She was quoted in a prominent *Milwaukee Journal Sentinel* article about voting “no” to rescheduling hydrocodone at the January FDA advisory committee meeting on rescheduling hydrocodone “because she hears from the surviving family members of people who commit suicide because they are in so much pain.” She was also quoted in an article about the importance of self-management in chronic pain treatment. (7 articles)
- NFMCPA was mentioned for its participation in two government advocacy issues:
 - National Association of Chain Drug Stores (NACDS) letter to Congress to create an inter-agency commission to address prescription drug abuse. NFMCPA was a signee.
 - Letter to HHS Secretary Sebelius signed by 57 patient advocacy groups including the NFMCPA to establish strong prescription drug requirements as part of any regulation that will define essential health benefits under the Affordable Care Act.
- NFMCPA's National Fibromyalgia Awareness Day events resulted in 5 articles.

PARTNERSHIPS

- The NFMCPA leadership is associated with several fibromyalgia patient organizations and individual advocates across the nation through the LAPC members (Utah Fibromyalgia Association, Fibromyalgia Association of Michigan, Wisconsin Fibromyalgia Association, Wisconsin Fibromyalgia Network, Fibromyalgia Education & Support Network of Arkansas, Health and Wellness Resources of Mississippi, Colorado Fibromyalgia Network, Georgia Area FM Support Group, Fibromyalgia Association of Houston, Inland Empire Autoimmune Support Group, O.F.F.E.R. and New York Fibromyalgia Association).
- NFMCPA affiliate advocacy and education organizations are listed under a different tab (no hyperlink) and include groups like the Acetaminophen Coalition, Johns Hopkins PainCare Alive, Know Your Dose, Pain Care Forum, PAINS (Policy Action Alliance to Initiate a National Strategy), PAINWeek and SPPAN (State Pain Policy Action Network).
- NFMCPA sponsors are listed under a different tab and contain logos as well as names (no hyperlink; no information provided regarding cost of sponsorship). It includes Allsup, Goodnights, Harris, Preston & Chambers Law Firm, International Resting MethodMassage Envy Spa. Teva is not listed as a corporate partner.
- NFMCPA has not made statements or expressed opinions about pharmaceutical and advocacy financial ties.
- NFMCPA does not seem to be included in government investigations concerning financial ties to industry.

ISSUES

- The goal of NFMCPA is to educate the patients and the medical community as well as the public, government agencies and scientists regarding the importance of timely diagnosis and appropriate treatment of FM and overlapping conditions in order to gain the most positive outcome for this patient population.
- The Advocacy tab of NFMCPA's website lists a January 2013 Call To Action entitled *FDA Opioid Prescribing* but an error notice appears when trying to access <http://www.fmcpaware.org/component/acymailing/lists>.
- There is no information on NFMCPA's website about the scheduling or relabeling of hydrocodone, although President Jan Chambers is on the record as being opposed to rescheduling hydrocodone.
- Abuse is not a prominent topic on NFMCPA's website.

INFLUENCE

- NFMCPA has national representation in Washington, D.C. to work with legislators and report on national legislative activity. It also follows state-by-state DUR and P&T schedules (Medicaid Drug Use Review Boards and Pharmaceutical and Treatment Committees).
- Leaders Against Pain Coalition (LAPC) is the advocacy arm of the NFMCPA. It advocates for

change in policy towards access to care barriers. LAP is a program customized for support group leaders and advocates. The multi-faceted program focuses on media, advocacy and leadership training.

The mission of the NFMCPA's LAPC is to represent and advocate on behalf of people affected by fibromyalgia and overlapping conditions on critical issues including the right to good health and a high quality of life.

- CURE FM, acting as the research branch of the NFMCPA, provides interested persons with the opportunity to learn about what is being done to cure FM and how they can contribute to the cause.
- NFMCPA advocates with the U.S. Pain Foundation, American Pain Foundation, Pain Care Forum, P.A.N.D.O.R.A. and Coalition 4 Fibromyalgia.
- NFMCPA is not very active legislatively, although the organization does follow and occasionally post legislation of interest, in a limited fashion.
- NFMCPA has the potential to become a future influencer.

FOCUS ON PAIN MANAGEMENT

- The Pain Management section of NFMCPA's Resources section contains only the contact information for the following pain organizations:
 - American Academy of Pain Management
 - American Academy of Pain Medicine
 - American Pain Foundation
 - North American Spine Society
 - Pain Treatment Topics
- The Treatment section of the Fibromyalgia tab on NFMCPA's website addresses pharmacological treatments for pain management (<http://www.fmcpaware.org/treatment>).



PAIN CONNECTION OVERVIEW

Pain Connection is a nonprofit organization that helps people with chronic pain and their families. It is more patient-focused as it promotes and holds monthly support groups. While it offers a diverse array of support groups, its reach is limited to the Rockville, Md. and Virginia areas, with the exception of its conference call support group options.

Address

PAIN CONNECTION
Chronic Pain Outreach Center, Inc.
12320 Parklawn Drive, Rockville, MD 20852
<http://www.painconnection.org/>

ORGANIZATIONAL RESOURCES

- Total budget
 - \$22,345 (2011)
- Percentage of total budget used on related programming
 - Not available
- How organization is funded
 - 501(c)(3) not-for-profit human service agency, donation-based
 - Also receives donations through the United Way of the National Capital Area at various places of work (where offered)

MEMBERSHIP

- Gwenn Herman, a chronic pain sufferer and the founder of the Potomac-based Pain Connection group, worked previously with the now-dissolved American Pain Foundation
- Herman also spoke at the FDA advisory committee meeting regarding hydrocodone relabeling. According to a [MedPage Today report](#), she “turned away from the panel during her presentation and addressed the bereaved families directly. She acknowledged their grief and apologized for their loss, but noted that their concerns are “two separate issues” that should not be at opposition.”
- Newsletters are distributed twice a year, summer/fall and winter/spring
- Newsletters mainly highlight upcoming meetings and support groups and provide very little commentary or content

VISIBILITY

- The organization is not prominent and is only active on a local basis. The Pain Connection offers local opportunities with support groups in Maryland and Virginia, but also offers Pain Connection Live Conference Calls for national participants.
- 2008 - The Healthcare Initiative Foundation awarded Pain Connection a grant to increase the pool of trained mental health professionals to meet “the unique psychosocial needs of chronic pain sufferers and their families in Montgomery County.”

Media presence

- The only media coverage it receives is support group meeting details. It does not put itself in a position to be key opinion leaders or national advocates.

Online presence

- Organization homepage offers links to support groups, mental health services, training, resources like articles and books, newsletters, get involved, donate and membership
- Facebook page has 273 likes and very little content or interaction
- No twitter handle or YouTube page

PARTNERSHIPS

The organization has not partnered with other pharmaceuticals in the past as it is more patient-focused. This organization could possibly be a good partner for Teva. While the founder as vocal opponent of



hydrocodone relabeling (would restrict access to patient who need it), the organization provides more support services for pain patients on a local level. It would be interesting to gauge its interest in pharmaceutical partnerships.

ISSUES

- This organization is primarily patient-focused, providing support groups and educational resources. While it has not made its mark in the industry as advocates, the organization's founder was vocal at the February 7, 2013 advisory committee.
- Access to pain medications – Yes (attended and spoke at February 7, 2013 advisory committee to oppose relabeling as it would limit access to pain meds for those patients who need them)
- Abuse deterrent requirements (branded and generic) – No
- Scheduling of hydrocodone – No
- Relabeling of hydrocodone – Yes (attended/spoke at February 7, 2013 advisory committee to oppose relabeling)

INFLUENCE

The organization was created in 1999. The only advocacy news tied to the group resulted from Founder Gwenn Herman speaking at the FDA advisory committee meeting regarding hydrocodone relabeling.

FOCUS ON PAIN MANAGEMENT

The organization provides minimal information on pain management and the resources are older/outdated. The organization is more focused on emotional support through group meetings.



PAINWEEK OVERVIEW

PAINWeek is the nation's largest pain conference for frontline clinicians with an interest in pain management. More than 1,800 physicians, nursing professionals, physician assistants, dentists, pharmacists and psychologists attend annually. 100+ hours of CME are presented on various pain topics ranging from interventional management techniques to the use of opioids for pain. PAINWeek is not quoted in media and is primarily known for its educational benefits, as opposed to its policy positions, advocacy or membership.

ORGANIZATIONAL RESOURCES

- This information is not available.

MEMBERSHIP

- PAINWeek has faculty presenters that are chosen on an annual basis. 2013 faculty are still being selected. PAINWeek does not have a membership, but a breakdown of its attendees follows:
 - 70% prescribe opioids/analgesics, 50% and 30% do not attend other pain or medical conferences respectively
 - 56% physicians, 13% pharmacists, 12% NPs, 7% other nurse profession, 4% PAs, 8% other/research
 - Of physicians: 70% are GPs; 30% are specialists
 - PAINWeek does not have local chapters or members

VISIBILITY

Publications and Congresses

- PAINWeek distributes a daily publication during the annual meeting.
- PAINWeek occurs in September to coincide with National Pain Awareness Month.

Social Media

- PAINWeek also has a blog includes a blog that is updated every couple of months, as well as a monthly newsletter that primarily promotes the event. Additional social media outlets follow:

Facebook: 245 followers

- Posts videos and news of interest every couple of days; received 1 – 2 likes and occasionally a comment or share on its postings. Posts increase during PAINWeek, but not industry related posts are included.

Twitter: 761 followers

- Tweets about twice a week regarding policy issues, news articles regarding pain, PAINWeek members who are quoted or featured in other organizations.

LinkedIn Group: 331 members

- Commentary promotes its annual meeting.

YouTube: 5 subscribers; 3,000 video views

- Posted are several :30 – 1:30 videos of perspectives regarding PAINWeek from industry leaders like Dr. Argoff, KevinMD and Dr. Passik. It likely gets these videos during its annual meeting.

Media Coverage

- PAINWeek has been referenced in approximately 51 articles in the past year; most of which were referencing it as a medical meeting where data was announced.

PARTNERSHIPS

- The conference has several media partners. There are also plenty of opportunities for pharmaceuticals to establish a presence at the medical meeting through advertising, symposia, exhibit booths and market research. There is no evidence of a larger partnership with pharmaceuticals.

ISSUES

- PAINWeek agrees with congressional testimony that more education around pain management is necessary, and this aligns with its mission to prepare frontline practitioners to provide more effective pain management. It is not active on the hill and rarely issue position statements. Its



meeting strikes a balance between medicinal and interventional management techniques for chronic pain.

INFLUENCE

- This organization is influential among non-specialist clinicians that treat pain. It is not active in policy or advocacy.

FOCUS ON PAIN MANAGEMENT

- PAINWeek is dedicated to educating frontline practitioners on pain management. It is a 100% pain management focused and education includes everything from behavioral pain management, complementary and alternative medicine, interventional pain management, medical/legal, pain and chemical dependency, pain and palliative care, pharmacology, regional pain syndromes and sex and gender differences in pain management. 70% of attendees prescribe opioids.

REPUTATION

- PAINWeek is valued among front-line, non-expert clinicians that treat pain. It is not as heavily attended by pain specialists and other specialists as other pain medical meetings. The seminars often provide more basic information about pain management. It's also not a data-heavy meeting; many posters are on pain management overall as opposed to specific drug announcements.

**PHYSICIANS FOR RESPONSIBLE OPIOID PRESCRIBING (PROP) OVERVIEW**

PROP is a highly visible group within the pain space and is driving a great deal of the conversation about opioid abuse and misuse and the need to limit opioids. The group would not partner with Teva; it does not accept funding from industry. Perhaps the only issue on which the two would align is the need for abuse deterrent properties in opioids.

Address:

<http://www.supportprop.org/index.html>

N/A – no physical address available

ORGANIZATIONAL RESOURCES

- The group does not appear to have a budget or any sponsors. It is not registered on GuideStar.org. Its website is funded by contributions from its founding members.

MEMBERSHIP

- PROP was founded by Andrew Kolodny, MD, a prominent influencer in the space. Leadership comprises 14 people, including several key influencers: Dr. Jane Ballantyne and Pete Jackson (head of the Advocates for the Reform of Prescription Opioids). PROP's number of members is not available.
- PROP's website allows other HCPs and non-HCP advocates to join.

VISIBILITY**Social Media**

Twitter: 214 followers, 157 following

- The handle is led by Andrew Kolodny, MD. He only posts about pain-related policy and industry news. He interacts often with other HCP KOLs in the space. It has been particularly active during recent FDA advisory committee meetings, sometimes pointing out when speakers had ties to drug companies.

Media Coverage

- PROP has been mentioned in 82 news articles in the past year, often in top-tier outlets about highly visible and controversial subjects. Coverage spiked when it unveiled its Citizens Petition in July 2012 and the resulting FDA advisory committee meeting February 2013. However, the group has maintained regular coverage throughout the year.
- Dr. Kolodny was one of six KOLs in the pain space to author a February 2012 op-ed in the NYT's "Room for Debate" forum about the use of opioids.
- A February 2013 NYT editorial in favor of rescheduling hydrocodone cited PROP's support on the issue.
- Michael Von Korff, PROP vice president and a researcher in Seattle, is often quoted about the opioid misuse and abuse.
- PROP was quoted as criticizing Dr. Lynn Webster of AAPM in a recent Milwaukee Journal Sentinel article criticizing him and other KOLs in the space for taking money from pharmaceutical companies, which it says is a conflict of interest because these groups promote opioid prescribing.

Publications/Congresses

- PROP has no regular publications or communications with its members. However, it does post links to various studies, news articles and government publications that reflect its position in a "News and Publications" section on its website.

PARTNERSHIPS

- PROP does not accept financial support from pharmaceutical companies, medical device companies, urine toxicology laboratories or any other entities that could be perceived as a potential conflict of interest.
- PROP has criticized several professional and patient groups for receiving money from industry and therefore limits its partnerships with other groups.



- Pete Jackson, president of the Advocates for the Reform of Prescription Opioids (ARPO), is a founding member.

ISSUES

- PROP's mission is to reduce morbidity and mortality resulting from prescribing of opioids and to promote cautious, safe and responsible opioid prescribing practices.
- PROP's main advocacy issue – and goal of the organization thus far – is to advocate for limiting the use of opioids to treat non-cancer chronic pain, for which it submitted a Citizens Petition to the FDA in July 2012, which prompted the February 2013 FDA advisory committee meeting on the subject. The organization maintains there is no evidence for long-term opioid therapy for chronic pain and wants to re-label opioids, limiting opioid indication. PROP recognizes that opioids are appropriate for cancer pain and some long-term pain, but wants to limit marketing of opioids for this indication and allow HCPs to prescribe off-label. It does recognize the importance of opioids for short-term treating short-term of acute pain and in end-of-life care.
 - According to a February 2013 FDA Week article, PROP will try to pass state laws restricting opioids if FDA does not act.
- PROP favors rescheduling hydrocodone.
- PROP supports mandatory training for HCPs to prescribe opioids.
- PROP has been a vocal critic of organizations and physicians who receive funding from industry.
- PROP has expressed (via Twitter) that no new drug applications for ER hydrocodone should be approved, especially because of accompanying campaigns that “encourage prescribing.”
- PROP believes that the FDA should require all long-acting opioids on the market to have some form of abuse deterrence.
- PROP is not concerned with access to pain medications; in fact, it believes access is too easy and convenient right now and should be restricted.

INFLUENCE

- PROP's July 2012 petition to limit the use of opioids for non-cancer chronic pain not only led to an FDA advisory committee meeting, but several statements and reactions by members of Congress and other patient and professional groups.
- Dr. Kolodny and other founding members are highly visible in the space, often sharing PROP's position on various policy/opioid abuse issues in top-tier media, speaking at FDA meetings, etc.

FOCUS ON PAIN MANAGEMENT

- PROP is solely focused on pain management. The organization does not distinguish much between LAOs and SAOs because in its opinion both are used in appropriately to treat chronic non-cancer pain. It does not discuss TIRFs.
- PROP offers educational materials on its website for PCPs, all focused on cautious, evidence-based opioid prescribing for chronic pain, non-opioid pain management, and addiction/abuse.



PROFESSIONALS FOR RATIONAL OPIOID MONITORING AND PHARMACOTHERAPY (PROMPT) OVERVIEW

PROMPT was founded in August 2012 in response to PROP's FDA Citizens Petition to limit use of opioids for non-cancer chronic pain, with which it disagrees. The organization comprises some of the pain space's most prominent KOLs, but its participation is limited because PROMPT has few outputs. As of now, PROMPT only focuses on the Citizens Petition issue, but it may expand activity if other policies are proposed to limit opioid access. Teva would be an unlikely partner for the group, as it does not have any funding and likely would not want to be funded by Teva. However, Teva may find value in developing relationships with PROMPT KOLs, who are very visible in the space.

Address:

<http://paindr.com/prompt-info/>

N/A – no physical address

ORGANIZATIONAL RESOURCES

- N/A – there is no fee to be a member of PROMPT. The group is not registered on GuideStar.org. This could be either because 1) the group has been in existence for less than one year OR 2) the group has no offerings beyond its policy statements.

MEMBERSHIP

- PROMPT was founded and is led by Jeffrey Fudin, B.S., Pharm.D., FCCP. He is an American Academy of Pain Management diplomat and section editor for *Pain Medicine*, in addition to his positions as associate adjunct professor at Albany College of Pharmacy & Health Sciences and clinical pharmacy specialist and director of PGY2 Pharmacy Pain.
- Beyond Dr. Fudin, PROMPT is comprised of a multidisciplinary group of clinicians, researchers and academicians from various fields including addiction, anesthesiology, pain, pharmacy, primary care, etc.
- The group has 34 founding members, among the most notable include: Steven D. Passik, PhD (PROMPT Vice Chair), Russell Portenoy, MD (Founding Member), Paul J. Christo, MD, MBA (Founding Member and a physician/professor at Johns Hopkins, Paul Arnstein RN, PhD, FAAN (Found Member and a physician at Mass General Hospital). PROMPT also has 20 affiliate members which joined after the group's first response to the PROP Citizens Petition.

VISIBILITY

Publications and Congresses

- The organization has no publications or annual meetings.
- The organization has no website beyond a page on Dr. Fudin's blog, PainDr.com. The blog often includes posts from Bob Twillman, PhD, FAPM, Director of Policy and Advocacy for the American Academy of Pain Management. Twillman has also authored blog posts on pain for LIVESTRONG.

Social Media

Twitter: 146 followers

- PROMPT has no handle, but Dr. Fudin shares all PROMPT news through his Twitter handle. When not tweeting PROMPT news, Dr. Fudin tweets about his new blog posts, other pain-related media stories, and live tweets from recent FDA advisory committee meetings. Dr. Fudin actively engaged others in the pain space via Twitter during the February FDA advisory committee meeting.

Facebook: N/A

LinkedIn Group:

- PROMPT has no presence, but Dr. Fudin has 500+ connections.

YouTube: N/A

Media Coverage

- PROMPT has been mentioned in one media story – MedPage Today - in the past year. It was about the February 7-8 FDA advisory committee hearing on the PROP Citizens Petition. Dr. Fudin was quoted in the article.



PARTNERSHIPS

- PROMPT has no partnerships with any organization. It does not have a financial structure.

ISSUES

- PROMPT was founded in response to the Physicians for Responsible Opioid Prescribing (PROP) Citizens Petition to restrict opioids for non-cancer chronic pain. While PROMPT is concerned about the safety of chronic opioid use, it instead favors mitigating the problem with clinician education, proactive risk stratification, and appropriate therapeutic monitoring.
- So far, PROMPT is only engaged on the above issue, but it may engage in other issues in the future if it restricts patient access to pain care or HCPs' authority to prescribe opioids.

INFLUENCE

- PROMPT is well-known among HCPs and professional groups. It is highly influential in that it is the group in opposition to PROP, which has made a lot of noise in the past year. The group has several KOLs as members, but its participation is limited. PROMPT also is extremely limited in resources and its scope of issues.
- PROMPT has no annual meeting.

FOCUS ON PAIN MANAGEMENT

- PROMPT is entirely focused on pain management. Instead of restricting access to opioids, it advocates for increased HCP education and monitoring.

**REFLEX SYMPATHETIC DYSTROPHY SYNDROME ASSOCIATION (RSDSA) OVERVIEW**

Founded 1984, the Reflex Sympathetic Dystrophy Syndrome Association's (RSDSA) mission is to provide support, education and hope to everyone affected by CRPS/RSD while it drives research to develop better treatment and a cure. With a membership of over 7,000 people, RSDSA is committed to encouraging research into the cause and cure of CRPS. Since 1992, RSDSA has funded \$1,684,638 in fellowships and grants. During 2009-2012, it funded \$488,251 in grants.

ADDRESS

<http://www.rds.org/index2.html>

Reflex Sympathetic Dystrophy Syndrome Association
99 Cherry Street
Milford, CT 06460

ORGANIZATIONAL RESOURCES (2011)

- Total Revenue: \$591,540 (contributions, member dues, program fees, special events, and grant support from pharmaceutical and other companies, and private and corporate foundations).
- Total Expenses: \$541,699

MEMBERSHIP

Member communications come as quarterly newsletter James Broatch, Executive Vice President, Director, was quoted in two publications. Other than that, leader visibility is very low. While membership details are limited, the website notes "healthcare professionals" as potential members.

VISIBILITY**Publications and Congresses**

- RSDSA Review: Quarterly newsletter available for public download.
- RSDSA does not have an annual meeting.

Media presence

- The RSDSA is often cited as a credible source of information on RSDS and statistics throughout numerous media pieces reference RSDSA research. Its leaders are not vocal in the media.

Online presence

- Organization homepage offers organizational info, upcoming event details, membership opportunities, resources and publications of interest, CRPS info, clinical guidelines, access to research, treatment options, clinical articles, support group info and ways to give. The organization has an active Causes page with 20 actions dating back to 2007.

Facebook: 10,472 followers

- Page is equipped with event photos, a Survey Monkey survey for data collection, and links to Twitter/YouTube/Causes pages.

Twitter: 1,616 followers

- Frequently tweets news and updates

YouTube: 239 subscribers; 98,000 views

PARTNERSHIPS

The organization has partnered with other pharmaceuticals in the past, including Purdue Pharma L.P., Teva Pharmaceuticals, Endo Pharmaceuticals & The Celgene Corporation to:

- Created Complex Regional Pain Syndrome treatment guidelines (Purdue and Celgene)
- An annual sponsorship grant in the amount of \$7,500
- Participation upon request in giving RSDSA minimal input of appropriate professional expertise from time to time

Other partnerships of interest:

- The American Chronic Pain Association's "Partners for Understanding Pain" program
- U.S. Pain Foundation
- Opioids911.org



ISSUES

Its primary patient-centered focus is to provide support, education and hope to everyone affected by CRPS/RSD while it drives research to develop better treatment and a cure. It does not share the same key issues as Teva, but it has also never taken a different position than Teva.

INFLUENCE

U.S. Senator Kay R. Hagan (NC), a member of the Senate Health, Education, Labor and Pensions (HELP) Committee, received final passage of provisions of her Transforming the Regulatory Environment to Accelerate Access to Treatments (TREAT) Act. The TREAT Act will provide a consistent pathway to encourage the development of innovative treatments, and will send a clear message to the FDA that the accelerated approval pathway is to be used for the approval of treatments for rare diseases. The RSDSA was one of 35 organizations to push for the legislation.

FOCUS ON PAIN MANAGEMENT

The organization has information available on pain management on its website in the resources section. While pain is a focus, it's not its main focus and the organization is more interested in the disease itself.

**SAVE THE MICHAELS OF THE WORLD (SMW) OVERVIEW**

Save the Michaels of the World was created by Avi Israel after his son, Michael, tragically took his own life following a struggle with a prescription painkiller addiction. Its mission is to ask elected officials across the country to support legislation to battle the growing epidemic of prescription pain drug abuse. Israel is active at recent FDA advisory committee meetings, but does not seem to have much of an organization behind him. He has earned the interest of lawmakers in the New York area.

No known address.

ORGANIZATIONAL RESOURCES

- Total budget
 - Not available
- Percentage of total budget used on related programming
 - Not available
- How organization is funded
 - Non-profit, donation-based

MEMBERSHIP

There is no formal membership opportunity, nor is there an organization webpage available for additional resources.

- Avi Israel, founder of "Save the Michaels of the World" following his son Michael's tragic passing following a struggle with a prescription painkiller addiction
- Julie Israel, wife of Avi and mother of Michael

VISIBILITY

The organization has been extremely active, especially in the last year. It has been present at FDA advisory committee meetings and local charity walks such as the Out of the Darkness community walks for the American Foundation for Suicide Prevention.

- Week of 4.30.12 – The Save the Michaels of the World group had meetings with Senate Majority Leader Dean Skelos, Assembly Speaker Sheldon Silver and Jim Malatras, a senior policy advisor to Governor Cuomo (organized by Rep. Brian Higgins (D-NY)) in an effort to push New York State into passing legislation to prevent addiction and fight the epidemic of prescription drug abuse.
- 5.8.12 – Israel and fellow prescription drug abuse advocates joined Rep. Brian Higgins in his Washington, D.C. office for a discussion with high-ranking Department of Health and Human Services (HHS) representatives on strategies for combating the prescription drug abuse epidemic nationwide, including Senator Charles Schumer.
- 7.18.12 – Spoke at the Senate caucus on international narcotics control hearing on responding to the prescription drug abuse epidemic (Speakers: Sen. Dianne Feinstein, D-CALIF.; Sen. Charles E. Grassley, R-IOWA; Rep. Mary Bono Mack, R-CALIF.; Gil Kerlikowske, Director, Office of National Drug Control Policy; Joseph Rannazzisi, Deputy Assistant Administrator, DEA; John Eadie, Director, Prescription Monitoring Program Center of Excellence at Brandeis University; Sen. Charles E. Schumer, D-N.Y.)
- Staged formal protest on 10.29.12 with Advocates for the Reform of Prescription Opioids Inc., National Coalition Against Prescription Drug Abuse, Steve Rummier Hope Foundation, Mothers Against Prescription Drug Abuse, LICADD.org, OXYKILLSKIDS and the Heroin Action Coalition of Montgomery County, Md. of the FDA's inaction in relation to America's "prescription painkiller epidemic." – protest organizer was Avi Israel

Media presence

- Covered in recap summaries of FDA meetings and local legislative press releases

Online presence

- No organization homepage
- Facebook page was only created in September 2012 and has 15 likes



- Ongoing sign-in.org/democracy in action page dating back to 4.10.12 "to be delivered to The New York State House, The New York State Senate, and Governor Andrew Cuomo"- has 375 signatures
- Expired causes.com page calling on elected officials for a "controlled substance registry" to monitor the rate at which doctors prescribe addictive medications, and thereby reducing the number of "pill mills" and doctor shopping.

PARTNERSHIPS

The organization is anti-pharmaceutical and speaks out against companies that have opioids in their product portfolio. The Save the Michaels of the World organization would not be a good partner for Teva.

ISSUES

The organization is calling for stricter controls on all narcotic/opioid prescriptions, therefore, strengthening controls on physician prescribing. It is advocating for policy change on the following issues:

- Access to pain medications - "We are here not to restrict access to medicine that is needed; we instead want to stop the abuse and over prescription of these drugs in the health care community." – Avi Isreal
- Scheduling of hydrocodone – spoke in favor of rescheduling at FDA advisory committee.
- Relabeling of hydrocodone – spoke in favor of relabeling at FDA advisory committee.

INFLUENCE

Congressman Brian Higgins (D-NY) wrote a letter to the Food and Drug Administration (FDA) asking that the personal experiences of those testifying, including that of Western New Yorker, Avi Israel, be taken into serious consideration as hydrocodone rescheduling considerations were being made. Save the Michaels of the World has had a consistent presence at the various FDA opioid/hydrocodone advisory committees meetings



U.S. PAIN FOUNDATION OVERVIEW

It is the goal of the U.S. Pain Foundation to become the leading source of support and hope to those living with pain and its caregivers. To do this, it offers programs that empower, educate and inspire while offering its members a complete transparent view of spending and funding. An organization created by people with pain for people with pain, it recognizes and validates the 100 million Americans who courageously battle pain every day.

Address

U.S. Pain Foundation
670 Newfield Street, Suite B
Middletown, CT 06457
<http://uspainfoundation.org/index.html>

ORGANIZATIONAL RESOURCES

- Total budget
 - \$132,088 (2010)
 - Purdue Pharma: \$15,000
 - Pfizer: \$1,000
- Percentage of total budget used on related programming
 - \$123,473 (2010)
- How organization is funded
 - 501(c)(3) not-for-profit human service agency, donation and grant-based

MEMBERSHIP

Membership is free, but there does not seem to be a benefit to subscribing. All resources are available on the organization website. No e-newsletters or publications listed.

Members are visible:

- Paul Gileno - In addition to his work with U.S. Pain, Paul is on the Advisory Board for PainPathways magazine, the co-administrator of Heroes of Healing and co-director of the INvisible Project.
- Wendy Foster, an advocate for the U.S. Pain Foundation, called the Physicians for Responsible Opioid Prescribing's petition requests to relabel hydrocodone "extreme measures" that would block access for patients in legitimate pain.

VISIBILITY

The U.S. Pain Foundation is very active in the pain community. Along with local support groups and educational opportunities, the organization provides programs such as the Invisible Project, Heroes of Healing and various charity walk events. In addition to the national event opportunities listed below, the organization has pain ambassadors in 19 states who are individuals committed to creating pain awareness and generating change within the medical community.

- INvisible Project – Launched in 2010, the INvisible Project is a photojournalistic showcase of the day-to-day experiences of real people with chronic pain. The goal of the INvisible Project is to create pain awareness through photographs of pain survivors. Through visual images, the INvisible Project shows the determination and strength of those living with pain.
- Heroes of Healing blog is a non-judgmental, forum-based website for caregivers and those with pain to come together to share personal stories of struggle, perseverance and triumph. Designed for participant interaction, this online community is a safe place to connect with others enduring the same adversities and challenges.
- Triumph Over Pain: Run, Walk, Roll – The annual walk benefits a number of organizations dedicated to helping the 100 million Americans living with pain. The nonprofits who participated in last year's Triumph Over Pain: Run, Walk, Roll include NEADS, National Fibromyalgia & Chronic Pain Association, National Vulvodynia Association, Reflex Sympathetic Dystrophy Syndrome



Association, Susan G. Komen, Triumph Over Pain and the Wounded Warrior Project. [Dallas/Ft. Worth area]

- The Power Over Pain Walk benefits the pain community by raising awareness. Initiating a new dialogue between people with pain and society, the Power Over Pain Walk validates suffering while informing the public about chronic pain conditions. Teaming with the RSDSA, the proceeds raised provide funding for research and educational efforts pertaining to RSD.

Media presence

- Strong voice in issue of reduced access to pain medications for legitimate pain patients
- Recommended by the New York Pain Society as a valuable chronic pain resource
- See specific articles in "issues" section below

Online presence

- Organization homepage offers links to news and event information, ways to become involved, program opportunities and educational resources.
- Facebook page has 5,982 likes and was founded in April 2012. The content admin posts articles of interest and encourages followers to comment, specifically on hot topics such as decreased access to pain medications.
- Twitter handle @US_Pain has 508 followers and has tweeted 1,275 times. Primarily posts articles of interest.
- The organization does not have an official YouTube page, but founder, Paul Gileno, has created a U.S. Pain group where he has collated seven videos of interest.
- Frequency of member communication

PARTNERSHIPS

The organization has partnered with other pharmaceuticals in the past, such as Purdue, Pfizer and Endo. Partnerships are primarily research grants and donations. Additionally, some of the pharmaceutical funds came in the form of charitable walk sponsorships.

ISSUES

Access to pain medications, abuse deterrent requirements, scheduling of hydrocodone, and relabeling of hydrocodone are all key issues for the organization.

- MedPage Today (relabeling of hydrocodone) - Wendy Foster, an advocate for the U.S. Pain Foundation, called the Physicians for Responsible Opioid Prescribing's petition requests to relabel hydrocodone "extreme measures" that would block access for patients in legitimate pain.
- Bloomberg (access to medications) - "There's a difference between being addicted and needing pain medication to complete daily tasks just as someone with high blood pressure depends on their pills", said Paul Gileno, president of the Middletown, Connecticut-based U.S. Pain Foundation, in a phone interview. He said there's a stigma pain patients deal with even though "we know we're not addicts."
- Bloomberg (same as above) - In a letter written with AAPM to the FDA, the organization noted: "While appropriate policies must empower law enforcement officials to act aggressively against individuals and entities actually engaging in diversion or abuse, diversion/abuse control actions must be balanced against the needs of health-care providers to provide care to legitimate patients."
- The Times - The U.S. Pain Foundation supports policies that develop educational programs on the proper use of opioid products, encourage manufacturers to develop tamper-resistant opioid products and protect prescribers' decisions with respect to such products.
- Additionally, Paul Gileno is an advocate for step-therapy and "first fail" insurance restrictions on chronic pain care
 - The U.S. Pain Foundation exhibited photos at the Capitol in support of Assembly Bill 369, by Democratic Assemblyman Jared Huffman of San Rafael, which would bar health insurers from requiring a patient to try more than two pain medications before allowing him or her access to other doctor-prescribed medication.

INFLUENCE



The organization has a large share of voice in this space and has made its stance on critical legislative issues known.

- The U.S. Pain Foundation applauded New Jersey State Sen. Linda Greenstein (D-Monroe) and Assemblyman Dan Benson (D-Hamilton) for introducing legislation that ensures that the judgment of a health-care provider is paramount. When he or she finds it to be in the best interest of the patient to prescribe a tamper-resistant opioid formulation, that medication must be dispensed.
- Julian Phillips, a patient living with chronic pain and U.S. Pain Foundation rep, spoke at an FDA Arthritis Advisory Committee meeting and said research into potential pain drugs needs to continue on a longer basis than what the FDA allowed in this case. He also reminded the FDA that, even though it can't be seen, "chronic pain is a disease in and of itself."
- The U.S. Pain Foundation sent a letter to New York's congressional delegation asking them not to make unnecessary changes to Medicare that would jeopardize the health of those who rely on the program to assist with their prescription-drug coverage.

FOCUS ON PAIN MANAGEMENT

While it advocates publicly for access to opioids and favored the approval of Zohydro, its website offers alternative treatment options for chronic pain patients. Given pain is its primary focus, the U.S. Pain Foundation could provide more current resources on pain management. The organization is more patient-focused than professional.

Pain Advocacy
Influencers



Pain Advocacy Influencers

Organizational Leaders

Charles E. Argoff, MD

Co-director, Cohn Pain Management Center, North Shore University Hospital

Assistant Professor of Neurology, New York University School of Medicine

Editorial Board of the Clinical Journal of Pain

Medical Advisory Board, National Fibromyalgia Association

Charles E. Argoff, MD specializes in pain management and chronic headaches, predominately treating patients with chronic and neuropathic pain. He has expertise in several types of pain treatments, including interventional pain management and botulinum toxins. Dr. Argoff is part of a team of specialists who offer a comprehensive approach to care, while constantly exploring new and innovative ways to diagnose and treat chronic pain. Dr. Argoff's goal is to offer patients a better quality of life through proper diagnosis and effective treatment. Internationally renowned for his work, Dr. Argoff is a member of the International Association for the Study of Pain, the American Academy of Pain Medicine, and the American Academy of Neurology, among other professional organizations.

Paul M Arnstein, PhD, RN

Pain Education Special Interest Group Committee Co-Chair, American Pain Society

Director, Massachusetts General Hospital Cares About Pain Relief Program

Dr. Arnstein is also a clinical nurse specialist for pain relief and an associate professor at Massachusetts General Hospital. He is certified as a family nurse practitioner, clinical nurse specialist and pain management nurse with more than 30 years of nursing experience across a variety of settings. He has authored a number of publications, and he has lectured nationally to nurse, nurse practitioner, medical, and lay audiences on a variety of pain-related topics. Dr. Arnstein practices at an NIH COE in Pain Education, but is also listed as a potential KOL in the oncology pain space, as he was founder and president of the New Hampshire Cancer Pain Initiative.

James W. Broatch, MSW

Board of Directors of Eastern Pain Society, National Organization of Rare Diseases, and Milford Conservation and Land Trust

Executive Vice President, Director, Reflex Sympathetic Dystrophy Syndrome Association

James (Jim) Broatch, MSW, is the Executive Director of Reflex Sympathetic Dystrophy Syndrome Association (RSDA), whose mission is to promote public and professional awareness of complex regional pain syndrome (CRPS) and to educate those afflicted with the syndrome, their families, friends, insurance and healthcare providers on the disabling pain it causes. The organization encourages individuals diagnosed with CRPS to offer each other emotional support within affiliate groups and is committed to raising funds for research into the cause and cure of CRPS.

**Broatch is one of the individuals interviewed in our chronic pain video vignettes.*

Patricia M. Bruckenthal, PhD, RN, ANP

Clinical Associate Professor, Stony Brook University School of Nursing (NIH COE)

President Elect, Communications Committee Liaison, American Society for Pain Management Nursing

In addition to her academic positions at an NIH COE in Pain Education, Dr. Bruckenthal also is a nurse practitioner in pain management at the Pain Management and Headache Center of the North Shore/Long Island Jewish Health Care Systems. She is a member of the Long Island



Geriatric Education Consortium and teaches pain management of older adults to various healthcare team members. She also teaches pain management strategies to nursing and medical students. She is on the editorial board of *Pain Management Nursing*. Dr. Bruckenthal has been a past consultant to Cephalon, so she may be a potential future partner for Teva.

Daniel B. Carr, MD, FABPM, FFPANZCA

Director, Program in Pain Research, Education and Policy, Tufts University and School of Medicine

Senior Editor of Pain Medicine, official journal of American Academy of Pain Medicine

Carr is the Director of the Tufts' Pain Research, Education, and Policy (PREP) program that trains students to become expert pain leaders. PREP believes that access to pain treatment is a fundamental human right, and the program is tailored to those seeking to shape public health policy to uphold this right. PREP empowers professionals to innovate their practices and institutions to comply with emerging standards of pain assessment and treatment. He also serves on ASA's Committee on Pain Medicine and was a keynote speaker at PAINWeek 2012.

Jan Chambers

President and Founder, National Fibromyalgia and Chronic Pain Association

Jan founded the NFMCPA in early 2011. Her previous organization, CURE FM, became the research advocacy branch of this newly organized charitable foundation. In March of 2011, the NFMCPA received programs from the National Fibromyalgia Association (NFA) and accepted responsibility to carry programs forward with its constituents. Grateful for the chance to further its involvement with the FM community, the NFMCPA accepted all new responsibilities associated with this exchange. As an independent and self-governing organization, the NFMCPA will actively participate in the FM community on a variety of fronts, including its primary campaign to help find a cure for FM.

Charles (Charlie) Cichon

Executive Director, National Association of Drug Diversion Investigators

Prior to joining NADDI as the executive director in 1998, Cichon worked for Eli Lilly and Company in the role of brand protection representative for the Americas. Cichon's responsibilities included managing diversion and counterfeit investigations involving Eli Lilly products throughout the Americas; serving as liaison with law enforcement and government agencies; as well as training local, state and federal law enforcement in the identification of counterfeit Eli Lilly products. Cichon also served as the chief compliance investigator for the Maryland Medical Board (part of the Maryland Department of Health & Mental Hygiene), where he supervised investigations of physicians and other allied health care professionals to ensure they were complying with state regulations. Cichon has lectured extensively on the topics of counterfeit pharmaceuticals, prosecution of pharmaceutical diversion.

Roger Chou, MD

Internal Medicine Physician, Oregon Health & Science University

Chair, Clinical Practice Guidelines Committee, American Pain Society

Dr. Chou is an influencer both in the chronic and cancer pain space, as he is the American Pain Society spokesperson most often quoted as he oversees the development of the APS' clinical guidelines on chronic and cancer pain treatment. These guidelines are the topic for which APS receives the most coverage.

Dr. Chou's research interests include development of evidence-based guidelines for health screening and management of pain conditions. He has led research for the U.S. Preventive



Services Task Force, the Drug Effectiveness Review Project, the American Pain Society and the Agency for Healthcare Research and Quality and Comparative Effectiveness Program.

Steven P. Cohen, MD

Professor of Anesthesiology and Critical Care Medicine, Director of Medical Education and Quality Improvement for the Pain Management Division, Johns Hopkins School of Medicine

Editorial Advisory Board of Pain Physicians, official publication of American Society of Interventional Pain Physicians

Dr. Cohen is Professor of Anesthesiology & Critical Care Medicine at the Johns Hopkins School of Medicine, and Professor at the Uniformed Services University of the Health Sciences in Bethesda, MD. He is also the Director of Medical Education and Quality Improvement for the Pain Management Division at Johns Hopkins, Director of Pain Research at Walter Reed National Military Medical Center, and the Reserve Liaison to the U.S. Army Pain Management Consultant to the Surgeon General.

Dr. Cohen has been very active in teaching and pain research in recent years, having published more than 150 peer-reviewed articles and 50 book chapters in the past 10 years. Dr. Cohen plays an active role in many organizations. He currently serves on the Editorial Boards of *Regional Anesthesia & Pain Medicine*, *Pain Medicine*, *Pain Physician* and half a dozen other journals. In addition to his academic work in pain management, Dr. Cohen is a Colonel in the Army Reserve, and the Chief, Anesthesia & Operative Services at the 48h Combat Support Hospital in Maryland. He also serves as the Reserve Liaison to the Pain Management Consultant to the U.S. Army Surgeon General. During the past few years, Dr. Cohen has briefed or presented data on pain management issues in service members several times to the U.S. Congress and high-ranking general officers. His research was instrumental in the passage of the 2008 Military Pain Care Act, and he served as an inaugural member of the first U.S. Army Medical Advisory Board.

Penney Cowan

Founder and CEO, American Chronic Pain Association

Penney is CEO and Board Chair of the American Chronic Pain Association, the most visible chronic pain patient advocacy group. While Penney is not often quoted in media, nor has she presented in recent FDA hearings, she is a well-connected KOL in the pain space with a broad patient advocate network. She has written all manuals, publications and materials used by the American Chronic Pain Association.

Penney has received many awards for her advocacy work and was most recently appointed as a Consumer Representative for the FDA/CDER Division of Anesthesia, Analgesia and Addiction Products (DAAAP). She also created the Partners for Understanding Pain campaign, which included 80 partner organizations, to raise awareness about the need to better understand, assess, and treat pain. There are more than 80 partner organizations. Under the direction of the ACPA, the campaign successfully established September as Pain Awareness Month.

Greta Cummings, Ph.D., RN

Faculty of Nursing, University of Alberta

President, International Society of Nurses in Cancer Care

Dr. Cummings joined the Faculty of Nursing, University of Alberta on 2004 following 15 years of senior administrative leadership experience in hospital, regional and provincial health services. She is well funded both provincially and nationally and holds two investigator awards, a



Population Health Investigator award from the Alberta Heritage Foundation for Medical Research (2006-2012) and a New Investigator award from the Canadian Institutes of Health Research (2006-2011). Since 2003, her research has resulted in more than 65 peer-reviewed publications in print or in press in nursing, medical, health services and sociology journals. Dr. Cummings is sought out by local, national, and international colleagues around the world to supervise students, collaborate on research, provide addresses on her leadership research and to provide consultation.

Her extensive community service contributions include numerous editorial and professional boards. She recently completed four years as President Elect and then President of the Canadian Association of Nurses in Oncology and is currently President of the International Society of Nurses in Cancer Care. Dr. Cummings' work has been recognized nationally and internationally through several prestigious research awards, including the CNA Order of Merit for Research (2010), and the CASN Award for Research Excellence (2008).

John F. Dombrowski, MD

***Past Director of Pain Medicine Services, Washington Pain Center, Georgetown Hospital
Medical Director, Anesthesiologists Assistant Case Western Reserve
Chair of the Committee on Communications, American Society of Anesthesiologists
Board of Directors, American Society of Anesthesiologists***

A frequent speaker on pain care issues, Dr. Dombrowski is the ASA Spokesperson for The Partnership at Drugfree.org's Medicine Abuse Project and could be a good KOL to engage on topics of misuse and abuse prevention. He was recently featured in Kevin MD's [blog](#) on the Medicine Abuse Project. Dr. Dombrowski is the Medical Director of the Anesthesiologist Assistant Program and Clinical Assistant Professor at Case Western Reserve University, in Washington, DC as well as Clinical Associate of Georgetown University Medical School. He is also past president of the District of Columbia Society of Anesthesiologists and on the Board of Directors at the American Society of Anesthesiologists. His comments have appeared in the Washington Times and other publications, and he has often been interviewed on local television and radio programs. He also has made several appearances on NBC's Today Show, discussing the safety of pain-control medications and integrated approaches for treating pain.

Scott Fishman, MD

***Chief, Division of Pain Medicine, University of California (NIH COE)
Senior Editor, Pain Medicine, official journal of American Academy of Pain Medicine
Board of Directors, American Pain Society***

Scott M. Fishman is chief of the Division of Pain Medicine and professor of Anesthesiology and Pain Medicine at the University of California, Davis, and could be a potential KOL to involve in ad boards or PR initiatives, such as the documentary.

Dr. Fishman lectures on all aspects of pain and its treatment throughout the U.S. and has several books and peer-reviewed articles about pain management. He has served as the pain expert for Discoveryhealth.com and has a monthly question and answer column in Pain Monitor Newsletter for the American Pain Foundation. Dr. Fishman is past president of the American Academy of Pain Medicine and sits on the board of directors for the American Pain Society. He advocates for the field of pain medicine with consumers and lawmakers, having testified in both state and national legislatures. Dr. Fishman also has led pain education initiatives for the American Academy of Family Physicians (AAFP), including a CME presentation on Responsible Opioid Prescribing. He serves as a consultant to numerous government agencies and organizations such as the Federation of State Medical Boards, the Drug Enforcement Agency



(DEA), the Medical Board of California, the Office of the California Attorney General and the California Medical Association.

Jeffrey Fudin, B.S., Pharm.D, FCCP

Clinical Pharmacy Specialist & Director PGY2 Pharmacy Pain Residency, Stratton VA Medical Center

***Adjunct Associate Professor of Pharmacy Practice, Albany College of Pharmacy
Founder and Chair, Professionals for Rational Opioid Monitoring & Pharmacotherapy (PROMPT)***

Dr. Fudin is founder of PROMPT, a group advocating against the Physicians for Responsible Opioid Prescribing (PROP)'s Citizens Petition. Dr. Fudin is a visible KOL in the space and is often part of pain policy discussions on Twitter. He writes *The Pain Chatter* blog, a forum in which pharmacists, pharmacy students, pharmacy residents, and other healthcare clinicians discuss pain management issues.

Dr. Fudin is also a diplomat to the American Academy of Pain Management, a fellow of the American College of Clinical Pharmacy, and a member of several other professional organizations. He is a section editor for *Pain Medicine*, the official journal of the American Academy of Pain Medicine. He was a peer reviewer for the American Pain Society Clinical Practice Guidelines for Arthritis, for Fibromyalgia, and for Cancer Pain and Palliative Care. He was also a panel member for establishing guidelines on the "Use of Chronic Opioids for Chronic Non-Cancer Pain," a collaborative effort between the American Pain Society and the American Academy of Pain Medicine; these guidelines have been widely disseminated by the American Journal of Pain for use by healthcare providers worldwide. He is also a prominent speaker on REMS and has been called upon by several professional organizations to help strategize in anticipation of education on proper opioid prescribing and monitoring.

Paul Gileno

Founder & President, U.S. Pain Foundation

Paul Gileno is not only the force and creator behind the US Pain Foundation but also the primary voice. The US Pain Foundation is recommended by the New York Pain Society as a valuable chronic pain resource as they are influential within the chronic pain space. After living with degenerative disc disease, failed back syndrome and complex regional pain syndrome for over three years, Gileno founded U.S. Pain Foundation in 2006 to connect, inform, empower and advocate for the pain community. In addition to his work with U.S. Pain, Paul is on the Advisory Board for PainPathways magazine, the co-administrator of Heroes of Healing and co-director of the INvisible Project. He supports various organizations that raise awareness and fund research on behalf of the chronic pain community, as all endeavors shift perceptions about pain and motivate change. James Broatch is also on the organization's advisory council. Gileno is a vocal advocate in the pain space and is the most visible member of the organization in the media: Pharmalot, Bloomberg News, NJ.com.

**Paul Gileno is one of the individuals interviewed in our chronic pain video vignettes.*

Penny Kaye Jensen, DNP, FNP-C, FAANP

Assistant Professor, University of Utah College of Nursing

Outpatient Primary Care Clinics at the Veteran's Administration Medical Center in Salt Lake City

Immediate Past President, American Academy of Nurse Practitioners

Throughout her career, Dr. Jensen has been a strong advocate for and leader in nursing and NP issues on international, national, state, and local levels, representing AANP with the



International Council of Nurses, and as President of the Utah NP Organization, and AANP Board of Directors, AANP State Representative for Utah.

Additionally, Dr. Jensen has represented AANP at White House on numerous occasions, including the unveiling of President Obama's Healthcare Reform Bill. She currently is working closely with the First Lady's office on her "Joining Forces" initiative. Many of these initiatives translate in practice, and influence practice for NPs. In a more directly clinical venue, she has participated in Boehringer Ingelheim Health Care Professionals Effective Communication Committee as well as their Accountable Care Organization Advisory Board; she is also involved in many research initiatives with Pfizer and other pharma-related organizations. She has more than 40 publications and presentations.

John H. Klippel, M.D.

President and CEO, Arthritis Foundation

John Howard Klippel, M.D. is president and CEO of the Arthritis Foundation, the largest voluntary health organization serving the 50 million Americans living with the nation's number-one cause of disability. Dr. Klippel has held the position since October 2003. Prior to joining the Arthritis Foundation, Dr. Klippel served as Clinical Director of the National Institutes of Arthritis and Musculoskeletal and Skin Diseases (NIAMS). During his professional career at the National Institutes of Health, he authored or co-authored 190 peer-reviewed publications and textbook chapters related to arthritis. He has served as editor of the Primer on the Rheumatic Diseases and the textbook Rheumatology. Dr. Klippel serves as a member of the Board of Directors of the National Health Council.

Laxmaiah Manchikanti, MD, ASIPP

***Clinical Professor of Anesthesiology and Perioperative Medicine, University of Louisville
Medical Director, Pain Management Center of Paducah, Paducah, Kentucky
Chairman of the Board & Chief Executive Officer, American Society of Interventional Pain Physicians***

Laxmaiah Manchikanti, M.D., is the Medical Director of the Pain Management Centers of Paducah, KY, and Marion, IL, and the Ambulatory Surgery Center in Paducah, KY, and Pain Care Surgery in Marion, IL. He is also Clinical Professor of Anesthesiology and Perioperative Medicine at the University of Louisville in Louisville, KY.

Dr. Manchikanti is certified by the American Board of Anesthesiology along with subspecialty certification in Pain Medicine and the American Board of Interventional Pain Physicians (ABIPP), American Board of Pain Medicine (ABPM), and is a Fellow in Interventional Pain Practice (FIPP). Dr. Manchikanti is a member of numerous professional societies and associations. He is the founder, Chairman of the Board and Chief Executive Officer of the American Society of Interventional Pain Physicians (ASIPP), the Society of Interventional Pain Management Surgery Centers (SIPMS), and many State Societies of Interventional Pain Physicians. He is also the founder of the Pain Physician Journal, ABIPP, and the ASIPP Foundation. Dr. Manchikanti published more than 350 publications and serves on several editorial boards. Dr. Manchikanti is also the editor of nine books designed for interventionalists.

Edward Michna, MD, JD

***Assistant Professor of Anesthesia, Harvard Medical School; Director of Pain Trials,
Brigham and Women's Hospital
Board of Directors, Advocacy Committee Chair, American Pain Society***



Dr. Michna testified at the February 2013 FDA advisory board meeting on relabeling opioids to limit use for non-cancer chronic pain, asserting that relabeling would have “unintended negative consequences for patients.” He was quoted in *The Wall Street Journal* about APS’ position. Dr. Michna also serves as head of the APS’ Pain Care Coalition and REMS Activities subcommittees.

Robert D. Kerns, Ph.D.

National Program Director for Pain Management, Veterans Health Administration (NIH COE)

Professor of Psychiatry, Neurology and Psychology, Yale University

Senior Editor, Pain Medicine, official journal of American Academy of Pain Medicine

Dr. Kerns led the development of the Veterans Health Association’s “National Pain Management Strategy: Implementation of the Stepped Care Model.” Kerns is the National Program Director for Pain Management for the Veterans Health Administration (VHA), Director of the Pain Research, Informatics, Medical comorbidities, and Education (PRIME) Center at the VA Connecticut Healthcare System and Professor of Psychiatry, Neurology, and Psychology at Yale University. In his role as National Program Director for Pain Management, he has programmatic responsibility for policy development, coordination, and oversight of the VHA National Pain Management Strategy.

He serves on the editorial board of several scientific journals, including the *Annals of Behavioral Medicine*, *Clinical Journal of Pain*, *Health Psychology*, *Pain Medicine*, *Psychological Services*, and *Cancer Pain and Palliative Care*. He has published nearly 200 peer-reviewed articles, chapters, and books, and he frequently delivers invited addresses at professional and scientific meetings. His research has been funded through the VA and through other federal and private sources for more than 25 years.

Timothy A. Pedley, MD, FAAN

Professor of Neurology, Columbia University Medical Center

President, American Academy of Neurology

Dr. Pedley was elected President of AAN in March 2013 at the Academy’s 65th Annual Meeting. He is Professor of Neurology at Columbia University’s College of Physicians and Surgeons and Attending Neurologist at the Neurological Institute of New York and New York Presbyterian Hospital at the Columbia University Medical Center. He served as Chair of Columbia’s Department of Neurology and as Neurologist-in-Chief at the Neurological Institute from 1998 to 2011. Pedley previously served as President of the American Neurological Association, the American Clinical Neurophysiology Society, the American Epilepsy Society and the Epilepsy Foundation of America where he was later Chairman of the Board. He also served as Chairman of the American Board of Clinical Neurophysiology.

Karen Lee Richards

Co-founder, National Fibromyalgia Foundation

As co-founder and VP of the NFA, Karen has been quoted in the *New York Times* about her personal journey through diagnosis and the stigma associated with fibromyalgia. She is vocal in FMA publications and holds a full-time job advocating for fibromyalgia awareness.

Richard W Rosenquist, MD

Chairman, Pain Management Department, Cleveland Clinic

Chair, American Society of Anesthesiologists Committee on Pain Medicine



As the chair of the ASA Committee on Pain Medicine, Dr. Rosenquist could be a prominent KOL to consider engaging for Teva initiatives. With research interests in regional anesthesia and pain medicine, Dr. Rosenquist has presented his work at numerous international conferences. He received the “Best Doctors in America 2011-2012” award and the “Top Doctors in America” award in *Good Housekeeping* magazine. Beyond his numerous certifications and accomplishments, he is actively involved in various professional organizations, including the American Society of Anesthesiologists, the International Anesthesia Research Society, the American Society of Regional Anesthesia and Pain Medicine, and the Iowa Society of Anesthesiologists. He is also Co-Editor of the American Society of Regional Anesthesia Newsletter. His research has been published in several book chapters and peer-reviewed journals, including *Regional Anesthesia and Pain Medicine*, *the Journal of Burn Care and Research*, and *the Journal of the American Academy of Orthopedic Surgeons*.

Bob Twillman, Ph.D., FAPM

***Clinical Associate Professor of Psychiatry, University of Kansas School of Medicine
Director of Policy and Advocacy, American Academy of Pain Management***

The face of AAPM, Bob has written a number of articles on policy issues. He most recently authored the AAPM statement against the FDA Ad Comm’s recommendation to move hydrocodone products from a Schedule III to Schedule II class. He wrote about his testimony on [LIVESTRONG blog](#), emphasizing AAPM’s concerns of differentiating between cancer and non-cancer pain. The Lance Armstrong Foundation noted at the top of the post that “The foundation supports the AAPM in their efforts to advance patient-centered federal and state pain policies to ensure balanced legislation and regulations.”

He has been featured on Purdue’s In the Face of Pain and may be a strong patient advocate and KOL with whom to engage.

As the director of policy and advocacy for the American Academy of Pain Management, Dr. Twillman is responsible for overseeing federal and state pain policy developments and advocating for those supporting an integrative approach to managing pain. He also serves as Chair of the Prescription Monitoring Program Advisory Committee for the Kansas Board of Pharmacy. Dr. Twillman received his Ph.D. in Clinical Psychology at the University of California in Los Angeles, and maintains a volunteer faculty appointment as Clinical Associate Professor of Psychiatry and Behavioral Sciences at the University Of Kansas School Of Medicine in Kansas City, KS. Prior to taking his current position, Dr. Twillman was a full-time faculty member at the University of Kansas Medical Center, where he founded and directed the inpatient pain management program and was a co-founder of the hospital’s Palliative Care Team.

Heikki Uustal, MD

***Wound Care Physician, St. Peter's University Hospital Wound Care Center
Associate Clinical Professor, UMDNJ-Robert Wood Johnson Medical School
Chair, American Academy of Physical Medicine and Rehabilitation Program Planning Committee***

Dr. Heikki Uustal received his medical degree from the University of Vermont and completed his residency in Physical Medicine and Rehabilitation (PM&R) at Baylor College of Medicine in 1987. He has been board certified in PM&R since 1988. Dr. Uustal has focused his clinical career in the subspecialty of Prosthetics and Orthotics, and Amputee Rehabilitation. He is nationally recognized as a leading educator and clinician in the field of prosthetics/orthotics.



Centers of Excellence Practitioners

Vincent P. Clark, PhD

***Assoc. Professor of Psychology & Neuroscience, University of New Mexico
Scientific Advisory Committee, American Academy of Pain Medicine***

Dr. Clark and his associates use a variety of tools to investigate the relationship between mind and brain. He is the Founding Director of the newly built Clinical Neuroscience Center in the Department of Psychology at the University of New Mexico, and is an Editor for *NeuroImage*, the most highly cited journal in the field of neuroimaging (www.journals.elsevier.com/neuroimage). Before this he was the Scientific Director of the MIND Institute and Research Network (www.MRN.org). His most important occupation is that of being a father for his 11-year-old son, who was diagnosed with a pain and movement syndrome two years ago.

Mark Cooper, PhD

***Assoc. Professor, Department of Biology, University of Washington
Scientific Affairs Co-Chair, Reflex Sympathetic Dystrophy Syndrome Association***

Mark S. Cooper, PhD is an associate professor at the University of Washington, where he studies connections between neuroinflammation, pain, and movement disorders. He also serves on the medical advisory board of the Spasmodic Torticollis Association. Dr. Cooper has been a Presidential Young Investigator of the National Science Foundation, and a neuroscience fellow of the Alfred P. Sloan Foundation.

Colleen J. Dunwoody MS, RN.BC

***Advanced Practice Nurse for Pain Management, University of Pittsburgh Medical Center
Advisory Board Member, American Chronic Pain Association***

Colleen is an advanced practice nurse for pain management at the University of Pittsburgh Medical Center Presbyterian Shadyside, a NIH COE in Pain Education. She is also a past president of the American Society for Pain Management Nursing and a past president of the American Chronic Pain Association Board of Directors. She serves on the Ethics, Pharmacy and Therapeutics, and Adverse Drug Events Committees of the University of Pittsburgh Medical Center and Co-Chairs the Pain Management Council. She is also highly published and has given presentations nationally and regionally on pain management.

John T. Farrar, MD PhD

***Associate Professor of Anesthesia and Critical Care, Associate Professor of Neurology,
University of Pennsylvania
Director-at-Large, American Pain Society***

Dr. Farrar is active within the American Pain Society and is co-chair of its "Measurement of Pain and Its Impact" special interest group committee. He also holds leadership positions at the University of Pennsylvania, an NIH COE in Pain Education, as vice chair of the Drug Use and Effects subcommittee and chair of the pain management subcommittee. Dr. Farrar is also noted as an Oncology Pain Management KOL because of his work with the University's Abramson Cancer Center to help drive collaboration with the pain medicine center palliative care program to provide patient care focusing on all aspects of the management of pain and other cancer-related symptoms.

Steve Feinberg, M.D.

***Adjunct Clinical Professor, Stanford University Pain Service and in the Physical Medicine
& Rehabilitation Department***

**Board of Directors, American Chronic Pain Association**

In addition to Dr. Feinberg's influence within the ACPA and academic position at an NIH COE in Pain Education, he is also a diplomat of the American Board of Physical Medicine and Rehabilitation, the American Board of Pain Medicine and the American Board of Electrodiagnostic Medicine. He is a past president (1996) of the American Academy of Pain Medicine. Dr. Feinberg has special interest in the areas of delayed recover and early intervention and in Functional Restoration chronic pain management, which may provide an opportunity to connect with Dr. Feinberg regarding Teva's commitment to helping patients accomplish daily tasks.

Mark Jensen, PhD

Professor and Vice Chair for Research, Department of Rehabilitation Medicine, University of Washington

Editorial Board Chair, The Journal of Pain, American Pain Society

In addition to holding top academic positions at the University of Washington, an NIH COE in Pain Education, Dr. Jensen is also an advisory board member of the American Chronic Pain Association. Dr. Jensen is active in editing and writing several pain-focused publications. He is the author or co-author of more than 250 articles and book chapters, has served as a consulting editor of the *Annals of Behavioral Medicine* and as an associate editor for the *Clinical Journal of Pain* and the *Archives of Physical Medicine and Rehabilitation*. He is currently the editor-in-chief of the *Journal of Pain*.

John D. Loeser, MD

Professor of Neurological Surgery and Anesthesiology, University of Washington School of Medicine

Editorial Advisory Board of Pain Physicians, official publication of American Society of Interventional Pain Physicians

Dr. Loeser is recognized as an expert in the surgical treatment of pain and multidisciplinary pain management. He was the Director of the Multidisciplinary Pain Center from 1982-1997. His career also focused upon pediatric neurosurgery. His research and teaching efforts have included the development of the human nervous system, neuropathic pain, low back pain and multidisciplinary pain management.

Sean Mackey, M.D., Ph.D.

Chief, Pain Management Division, Stanford University School of Medicine

Advisory Board Member, American Chronic Pain Association

Vice President of Scientific Affairs, American Academy of Pain Medicine

Dr. Mackey is one of the core faculty at the Stanford Pain Management Center providing care to patients with acute, chronic and cancer pain. Dr. Mackey has served as principal investigator and investigator for multiple NIH, foundation and industry-sponsored protocols to investigate chronic pain and evaluating novel analgesics for acute and chronic pain. He is vice president of scientific affairs for the American Academy of Pain Medicine (AAPM) and a reviewer for scientific journals in the areas of pain, psychology, anesthesiology, and neurology. He annually presents papers and lectures at both national and international Pain Management and Anesthesiology meetings.

Dennis C. Turk, PhD

Professor of Anesthesiology and Pain Research, Director of the Fibromyalgia Research Program, University of Washington



Board of Directors, Chair of the Professional Advisory Committee, American Chronic Pain Association

In addition to Dr. Turk's influence within the ACPA and academic position at an NIH COE in Pain Education, he is also editor-in-chief of *The Clinical Journal of Pain*. Dr. Turk is a past President of the American Pain Society (2004-2006). He most recently published an article, *The Pain Survival Guide: How to Reclaim Your Life*. Dr. Turk was identified in 2000 as one of the Top 10 Leaders in Pain Research and Treatment Development by an international survey conducted by the University of Regina, Saskatchewan, Canada.

Judith A Turner, PhD

Professor of Psychiatry and Behavioral Sciences and Rehabilitation Medicine, University of Washington

Board of Directors, Liaison to International Association for the Study of Pain, American Pain Society

Dr. Turner's academic focus is to identify collaborative best practices to help patients learn new, more effective approaches and strategies for managing challenging health problems, particularly as it relates to pain, and reversing the negative impact of health problems on quality of life. While Dr. Turner is not highly visible in the media, her leadership within the American Pain Society and her practice at the University of Washington (NIH COE in Pain Education), makes her a potential partner.

Debra K. Weiner, MD

Associate Professor, Departments of Medicine, Psychiatry, and Anesthesiology, University of Pittsburgh School of Medicine

Advisory Board Member, American Chronic Pain Association

Dr. Weiner is Director of the Older Adult Pain Management Program and Director of the Geriatric Medicine Fellowship Training Program at the University of Pittsburgh, an NIH COE in Pain Education. She is also a faculty member of the Geriatric Research, Education and Clinical Center in the VA Pittsburgh Healthcare System. Dr. Weiner also serves on the editorial board of *Pain Medicine* as section chief of *Pain & Aging*. She teaches medical students, residents, nurse practitioners, and geriatric medicine fellows, as well as lay groups, about comprehensive evaluation and management of persistent pain in community dwelling and institutionalized older adults. Dr. Weiner is recognized nationally and internationally as an expert in pain evaluation and management in older adults. She has received NIH funding for researching chronic low back pain, but often tests non-pharmaceutical pain treatments.



Monitor for Activity

Avi Israel

Founder, Save the Michaels of the World

Avi Israel created Save the Michaels of the World in honor of his son, who took his own life after battling addiction to prescription pain medications. Avi has since been prominent in the media, online and among New York and federal elected officials to increase prescription drug monitoring programs and limit opioid use. He has testified at FDA ad comms both on behalf of Save the Michaels of the World and other organizations, and is highly connected in the space. He has partnered with New York legislators to pass legislation and has been featured in their press conferences. Avi has been quoted in prominent media including *The Wall Street Journal* and *The New York Times*. His group has received widespread online support and has initiated several online petitions on various pain prescription abuse initiatives that have generated several signees.

Andrew Kolodny, MD

Chair, Psychiatry Department, Maimonides Medical Center

Founder, President, Physicians for Responsible Opioid Prescribing

Dr. Andrew Kolodny is the chair of Psychiatry at Maimonides Medical Center in Brooklyn, NY. Board certified in Psychiatry and Addiction Medicine, Dr. Kolodny is a national expert on the opioid addiction epidemic. In his clinical practice, he specializes in the treatment of opioid addiction. Previously, as Medical Director for Special Projects in the Office of the Executive Deputy Commissioner for the New York City Department of Health and Mental Hygiene, he helped develop and implement city-wide buprenorphine programs, naloxone overdose prevention programs and emergency room-based screening, brief intervention and referral to treatment (SBIRT) programs for drug and alcohol misuse.

Dr. Kolodny is currently President of Physicians for Responsible Opioid Prescribing (PROP), which sponsored a highly visible Citizens Petition in July 2012 to limit opioid use for non-cancer chronic pain, which generated significant media coverage, response for other advocacy groups and an FDA ad comm. Dr. Kolodny is active in Washington, DC to change policy and has testified at recent FDA ad comms and has lobbied on the Hill to promote the 2013 Safe Prescribing Act, which would reschedule hydrocodone.

Michael E. Schatman, PhD, DASPE, CPE

Executive Director, Foundation for Ethics in Pain Care

Dr. Schatman feels special interest groups and industry have "tainted" pain medicine the ability to treat patients effectively. This includes Universities, medical schools, some pain groups and pharma and is a KOL that Teva should monitor for activity.

Dr. Schatman is a clinical psychologist who has spent the past 26 years working in multidisciplinary chronic pain management. He is currently the Executive Director of the Foundation for Ethics in Pain Care in Bellevue, Washington, and maintains a part-time practice in pain psychology, also in Bellevue. Dr. Schatman is on the editorial review boards of Pain Medicine and Psychological Injury and Law, and is the Secretary of the Western Pain Society, the Chairperson of the Ethics Special Interest Group of the American Pain Society, is a member of the Ethics Committee of the American Pain Society, and is a member of the Executive Advisory Board of the Association for Scientific Advancement in Psychological Injury and Law. He served for 2 years on the Clinical Advisory Board of the American Society of Pain Educators, on whose Board of Directors he now sits.



Oncology Advocacy
Organizations

**Oncology Advocacy Organizations Index**

Acronym	Organization Name	Page Number
AAHPM	American Academy of Hospice and Palliative Medicine	1
AACR	American Association for Cancer Research	4
ACS	American Cancer Society	7
ACSCAN	American Cancer Society Cancer Action Network	11
ASCO	American Society of Clinical Oncology	15
ASTRO	American Society for Radiation Oncology	18
BTL	Beat Liver Tumors	21
BCF	Bone & Cancer Foundation	23
	CancerCare	25
HNCA	Head and Neck Cancer Alliance	27
	Hope Hospice	29
ISNCC	International Society of Nurses in Cancer Care	31
LCA	Lung Cancer Alliance	33
LCFA	Lung Cancer Foundation of America	36
NCCN	National Comprehensive Cancer Network	38
ONS	Oncology Nursing Society	41
PANCAN	Pancreatic Cancer Action Network	44
SGK	Susan G. Komen for the Cure	48
TNBCF	Triple Negative Breast Cancer Foundation	51



AMERICAN ACADEMY OF HOSPICE AND PALLIATIVE MEDICINE (AAHPM) OVERVIEW

The American Academy of Hospice and Palliative Medicine (AAHPM) is a strong potential advocacy partner for Teva. Because hospice and palliative medicine as a field values the importance of an integrated care team, the various touch points of patient care (nurses, NPs, social workers, physicians) are reached through one organization. Palliative medicine manages the uncomfortable symptoms associated with serious illness; pain is a significant focus. There are many pain specialists who are AAHPM members, but even those who are not specialized are treating patients in pain. AAHPM has 24 special interest groups (SIGs). Two of those are ideal targets for Teva: cancer as well as abuse and diversion. The membership organization is fairly small (fewer than 5,000), but highly targeted. The field of hospice and palliative medicine is quickly gaining attention with the aging population. AAHPM members are particularly social media savvy, with a key member, Dr. Christian Sinclair, highly regarded as one of the first physician social media influencers.

ORGANIZATIONAL RESOURCES (2011)

- Total revenue: \$5.4 million dollars (\$3.7 million dollars from program services; contributions and grants only generated \$323K dollars)
- Total expenses: \$4.3 million dollars (\$4.2 million dollars are "other expenses")

MEMBERSHIP

- Nearly 5,000 members; more than 80 percent are physicians. Other members include: nurses, social workers, chaplains and affiliates.
- AAHPM claims 300 volunteers and a 17-member Board of Directors.
- AAHPM does not have local chapters or members.

VISIBILITY

- AAHPM is the leading organization in the specialty of palliative and hospice care, a discipline that is gaining increasing visibility in the media, and on the Hill, for its role in improving quality of life and reducing costs.

Publications and Congresses

- AAHPM hosts a joint annual assembly in March with the Hospice and Palliative Nurses Association. It is attended by 2,500 nurses, physicians, PAs, pharmacists and social workers from the U.S.
- AAHPM's *Quarterly* newsletter is distributed quarterly to 5,000 members practicing hospice and palliative medicine.
- *PC-FACS* (Fast Article Critical Summaries for Clinicians in Palliative Care), AAHPM's electronic publication provides palliative care clinicians with concise summaries of the most important findings from more than 100 medical and scientific journals. It was created by Amy P. Abernethy, MD, FACP, FAAHPM (Duke), who is respected and well-known in the space. Current editors are Donna S. Zhukovsky, MD, FACP, FAAHPM (MD Anderson) and Mellar P. Davis, MD, FCCP, FAAHPM, AAHPM (Cleveland Clinic). All of these are centers of excellence (COEs).
- *Journal of Pain and Symptom Management* is AAHPM's international, peer-reviewed journal that publishes monthly. Dr. Russ Portenoy, a top KOL in the pain space, serves as editor in chief.
- AAHPM publishes *Hospice and Palliative Medicine SmartBriefs* two times per week to online subscribers.

Social Media

- AAHPM blog is updated one to three times per month. Posts range widely in topics and are frequently authored by board members.

Facebook: 1,027 likes

Their Facebook site posts news of interest every couple of days; it receives one to two likes and occasionally a comment or share on their postings routinely.

Twitter: 2,852 followers

Tweets are frequently news stories or blog posts about hospice and palliative medicine or end-of-life issues. Medication news is of interest.

LinkedIn Group: 4,211 members



The LinkedIn Group is a very active one, which prompts lively discussions.

YouTube: 14,200 views, 26 subscribers, 5 videos

The videos on YouTube explain how palliative care works. No videos have been posted in the last two years.

Media Coverage

- AAHPM has been quoted in 62 articles in the past year. 25 were in relation to pain.
- *The New York Times* health blog in February 2013 quoted Eric Widera, a palliative care specialist at the San Francisco V.A. Medical Center, who served on the AAHPM working group regarding treatment procedures for patients with irreversible diseases.
- In reference to pain, AAHPM is often cited about the growing use of hospice and palliative care methods for pain control.

PARTNERSHIPS

- There are plenty of opportunities for Teva to establish a presence at medical meetings through advertising, symposia, exhibit booths and market research. Current industry partnerships include:
 - Endo: Bronze Level Support \$5,000 dollars
 - Evercare Hospice and Hospice INSPIRUS: Bronze Level Support \$5,000 dollars
 - Mumms: Bronze Level Support \$5,000 dollars Hotel Key Cards
 - 4FlexCare: Bed In-Kind Support equal to Bronze Level Bed
 - Carefusion: Circle of Support \$1,000 dollars
 - Purdue Pharmaceuticals: PC-FACS \$55K dollars in annual support
 - External Awareness and Advocacy Initiatives 2011-2012: \$65K dollars in annual support
- Companies can join AAHPM's Industry Relations Council for \$7,500 per year. Members include: Purdue Pharmaceuticals, Janssen, Pfizer, Evercare and Teva CNS.
- AAHPM created a patient-facing website, PalliativeDoctors.org, sponsored by Wyeth, which provides patients and caregivers with information about hospice and palliative care.

ISSUES

- Pain management issues comprise two of AAHPM's five public policy priorities. Pain management is central to hospice and palliative care, so it is a top priority for the organization.
- AAHPM has not issued a position on the rescheduling or relabeling of hydrocodone.
- Four of AAHPM's five legislative priorities are:
 - Ensuring timely access to prescription medications, especially opioid analgesics, for patients with medically appropriate indications.
 - Promoting care coordination and interdisciplinary teams.
 - Advocating for involvement of patients and their families in the design, delivery, and evaluation of care.
 - Encouraging and participating in the ongoing development of strategies that help reduce prescription medication diversion and misuse.
- AAHPM has issued no position on abuse-deterrent requirements.

INFLUENCE

- AAHPM's Public Policy Committee tracks state and federal legislative and regulatory issues impacting the field and advocates for the interests of hospice and palliative medicine. It is chaired by Stephen A. Leedy, MD, FAAHPM.
- AAHPM has formal advocacy partnerships with the American Medical Association (AMA) and the National Coalition for Hospice and Palliative Care (NCHPC).
- AAHPM's Legislative Action Center allows members and the public to:
 - Review AAHPM issues and legislation
 - Find media and Congressional contacts
 - Receive action e-alert
 - Use a "Write to Congress" widget that other groups can put on their site.



- AAHPM posts seven position statements. None are explicitly about pain management, however it's Statement on Clinical Practice Guidelines for Quality Palliative Care asserts pain control as the number one element of palliative care.
- Of all the bills AAHPM is following, many are also Teva priorities, including the Prescription Drug Abuse Prevention and Treatment Act.
- AAHPM has lobbied for four bills in the last Congress. Most of its resources are focused on increasing hospice care; palliative care education and workforce; increasing reimbursement and payment as well as improving patient access.

FOCUS ON PAIN MANAGEMENT

- AAHPM's foremost priority is increasing palliative care education and the workforce, and improving access to palliative care for patients. Pain management is a component of palliative care. The organization has taken action to ensure pain medications are accessible.

**AMERICAN ASSOCIATION FOR CANCER RESEARCH (AACR) OVERVIEW**

The American Association for Cancer Research (AACR) fosters research in cancer and related biomedical science; accelerates the dissemination of new research findings among scientists and others dedicated to the conquest of cancer; promotes science education and training; and advances the understanding of cancer etiology, prevention, diagnosis, and treatment throughout the world. In addition, the AACR Foundation funds programs deemed by the AACR to be of the highest priority and impact in achieving this shared mission. It appears as though Teva is one of 24 significant donors to the AACR. As one of the leading and reputable cancer research organizations, the AACR is a beneficial partner for Teva. The organization does have information available on cancer pain in their various publications (six current articles) and on their website. However, pain management is not a main focus of the organization and is an opportunity for growth. AACR journals are well-respected and utilized frequently by healthcare professionals given the fact that articles in AACR journals were accessed more than 40 million times in 2011. Members of the AACR are able to prescribe opioids, as many of their members and researchers are physicians and specialists, so partnering with AACR to create additional resources in pain management would be beneficial.

Address:

615 Chestnut Street, 17th floor
Philadelphia, PA 19106
<http://www.aacr.org/default.aspx>

ORGANIZATIONAL RESOURCES (2011)

- 169 employees
- Total revenue: \$67.2 million dollars (\$26.3 million dollars in grants and contributions; \$28.9 million dollars in program service revenue).
- Total expenses: \$51.7 million dollars (50 percent on scientific research, grants, awards and prizes; 28 percent on educational conferences and workshops; 14 percent on support services; 8 percent on public education).

MEMBERSHIP

- AACR has more than 34,000 members in more than 90 countries and territories around the world; 29 percent of members live outside the United States.
- AACR has 19 members on its Board of Directors and 5,000 volunteers.

VISIBILITY

The AACR is a leader in its field and extremely active. With national and international visibility, the AACR has distributed more than \$85 million dollars in research funding since 2001. The AACR Foundation provided \$15 million dollars in research grants and awards in 2010 to fund and to recognize innovative, meritorious research.

- Now in its ninth year, the AACR's Survivor and Patient Advocacy Program has
 - Collaborated with more than 120 advocacy organizations.
 - Exposed more than 300 graduates of the "Scientist to Survivor" Program to the latest findings in cancer research.
 - Launched *Cancer Today*, a magazine that reaches an estimated 380,000 cancer patients, survivors, and the friends and family who care for them.
- In 2011, collaborating with the Melanoma Research Alliance, Stand Up To Cancer (SU2C) awarded \$6 million dollars to a new SU2C Dream Team. This donation brought the total awards to interdisciplinary, multi-institutional Dream Teams for translational research to \$79.6 million dollars. The AACR is a scientific partner of SU2C, and provides grants management through the Scientific Advisory Committee.
- In 2011, SU2C awarded \$9.74 million dollars for SU2C Innovative Research Grants raising the total given since 2009 to \$19.42 million dollars. In all, SU2C currently supports 26 investigators and their projects hold great promise for improving and saving the lives of cancer patients.



Publications and Congresses

- The AACR has seven peer-reviewed scientific journals: *Cancer Research*; *Clinical Cancer Research*; *Cancer Epidemiology*; *Biomarkers & Prevention*; *Molecular Cancer Therapeutics*; *Molecular Cancer Research* and *Cancer Prevention Research*. Articles in AACR journals were accessed more than 40 million times in 2011. *Cancer Research*, the AACR's oldest journal, is cited more than 100,000 times a year.
- AACR is launching a new journal, *Cancer Immunology Research*, at the AACR Annual Meeting in April 2013.
- The 2013 AACR Annual Meeting is April 6-10, 2013, in Washington, DC, and features the theme "Personalizing Cancer Care Through Discovery Science."
 - More than 16,000 scientists and other cancer professionals are projected to attend from around the world
 - In 2011, nearly 6,000 scientific abstracts were selected for presentation.
 - The AACR convened 22 scientific meetings, conferences and workshops in 2011, including AACR's first meeting in India, "New Horizons in Cancer Research: Biology to Prevention to Therapy."
 - AACR Annual Meeting attendees are laboratory scientists and clinical investigators specializing in all aspects of cancer research, including: experimental therapeutics, molecular targeted therapies, chemistry, molecular biology and genetics, immunology and immunotherapy, tumor biology, virology, toxicology, prevention, and clinical and translational research.

Online Presence and Social Media

The AACR has a robust website, featuring several resources mainly geared toward healthcare providers (HCPs) and members, but also a survivors and advocates page.

Facebook: 9,381 likes

The Facebook page provides links to AACR-sponsored events, photos and YouTube videos. Since its inception in 2010, the Facebook feed is active with the majority of conversations led by the AACR administrator.

Twitter: 10,692 followers and 4,773 tweets

- Their Twitter handle is very active and draws attention to upcoming events and registration deadlines, along with cancer news and research stories. The left-hand side of the Twitter page features information on their annual medical meeting.
- AACR Foundation also has a Twitter handle @AACRFoundation, with 2,486 followers and 75 tweets. This feed is not nearly as active and only had one tweet in 2010.

YouTube: 371 subscribers, 176 videos, 137,300 video views

LinkedIn: 178 members

Members on LinkedIn are not active. The last conversation was posted two months ago.

Media Coverage

- There were 4,089 articles in the last year regarding the AACR, 182 of these articles referenced pain. The vast majority of media coverage highlights clinical trial data and research advancements. Additionally, there was significant annual medical meeting coverage.
- At the 2012 annual medical meeting:
 - More than 110 press representatives were present onsite, and nearly 30 attended by teleconference.
 - More than 21 trillion media impressions resulted from press coverage of hot topics in 2012, up from 3 billion in 2011.
 - There was press coverage of the opening plenary and other plenary sessions in major media outlets including: *The Wall Street Journal*, *The New York Times*, *Time Magazine*, *Los Angeles Times*, *USA Today*, *NBC Today Show Online*, *ABC World News Tonight*, *CBS Evening News*, *U.S. News & World Report*, *The Washington Post*, *CNN*, *BBC*, *Nature*, *Oncology Times* and more.
- The AACR held a press conference in 2012 to announce the "AACR Cancer Progress Report" which highlighted the impact of budget cuts to the National Institutes of Health (NIH). It received moderate



media coverage, but more importantly was cited in many other patient advocacy group communications.

PARTNERSHIPS

- While the membership directory is only accessible for members, the donor recognition page includes Amgen, Eli Lilly, Merck, BMS, Novartis, Millennium Pharmaceuticals, Pfizer, Celgene, Genentech, Teva, Abbot, GSK, Janssen, Astellas, J&J, Astex, AstraZeneca, AVEO Pharmaceuticals, Bayer, BI, Taiho Pharmaceuticals, Daiichi Sankyo, Gilead and Roche.
- As one of the leading, reputable cancer research organizations, the AACR would be a beneficial partner for Teva. It appears as though Teva is a significant donor already. While there are resources on their website regarding pain management, this is an area that could grow.
- Other partnerships of interest:
 - Stand Up To Cancer (SU2C) – a collaboration uniting major television networks, entertainment industry executives and celebrities, and prominent leaders in cancer research and patient advocacy in a new initiative to move groundbreaking cancer research out of the lab and into the clinic. As the scientific partner for SU2C, the AACR conducts expert review of the research projects and provides grants management via their Scientific Advisory Committee.
 - Rally for Medical Research – a unified call to action with millions of Americans across the country to call on the nation's policymakers to make medical research funding a national priority. This raises awareness about the critical need for a sustained investment in the NIH to improve health and spur more progress.
 - The Love and Avon Army of Women – a partnership between the Dr. Susan Love Research Foundation and the Avon Foundation, in collaboration with the AACR and the National Breast Cancer Coalition (NBCC), aimed at accelerating breast cancer research by linking researchers with dedicated volunteers who are willing to donate time, biospecimens and data.

ISSUES

The AACR does not take a public stance on pain medication accessibility and rescheduling of hydrocodone. While AACR has resources for pain management on their website and in their publications, their primary cause is cancer research funding.

INFLUENCE

The AACR has actively influenced others in the past. They are already a major influencer in the cancer space, and will continue to be, especially given their national and international ties.

FOCUS ON PAIN MANAGEMENT

The AACR has a plentitude of information available on cancer pain in their various publications (six current articles) and on their website. However, pain management is not a main focus of the organization. Members of the AACR are able to prescribe opioids, as many of their members and researchers are physicians and specialists.

**AMERICAN CANCER SOCIETY (ACS) OVERVIEW**

The American Cancer Society (ACS) is the most influential cancer nonprofit in the U.S. While most of their resources are aimed toward patients and caregivers, its research and guidelines are often cited in media, by policymakers, and used by HCPs. ACS receives millions of dollars in contributions from pharmaceutical companies and other major corporations, but it is not evident that the ACS visibly partners with pharmaceutical companies on initiatives. As of 2010 (most recent year available), Teva did not donate in a major way to ACS, so there is room to develop more of a relationship.

ADDRESS

www.cancer.org

250 Williams Street NW
Atlanta, Georgia, 30303

ORGANIZATIONAL RESOURCES (2011)

- 1,592 employees (national office only); each division employs about 500 people, bringing the total to 7,092 employees
- Revenue: \$954 million dollars (\$888.3 million dollars in grants and contributions [\$385 million dollars in Relay for Life events], \$48.8 million dollars in investment and \$10.9 million dollars in government grants).
- Expenses: \$947 million dollars (\$148 million dollars in research grants, \$149.7 million dollars in prevention programs, \$103 million dollars in detection programs, \$279.7 million dollars in patient support).
- ACS is the largest health charity in the U.S.

MEMBERSHIP

- ACS claims three million volunteer; they range from individual participants in their Relay for Life fundraisers to patient program support and other initiatives.
- ACS is composed of 12 separately incorporated U.S. divisions and a separately incorporated national home office; there are 900 local ACS offices across these 12 divisions.
- As of 2012, ACS is now comprised of one national board of directors (12 from the medical community and 12 from a non-medical background for a total of 24 members) that has governing authority; each division has a volunteer board of directors that works to carry out ACS' mission locally, but has no governing authority.
- Relay for Life fundraisers are present in 5,100 communities in the U.S., with participation by more than 3.5 million people.
- No members of the Board of Directors are from NIH centers of excellence (COEs) in pain education. Two members of the Board of Directors are from NIH Oncology COEs: Board President Vincent T. DeVita Jr., MD is chair of the Yale Cancer Center advisory board and professor of internal medicine and of epidemiology and public health at Yale's medical school; Board Director at Large Kevin Oeffinger, MD is director of Memorial Sloan-Kettering's adult long-term follow-up program.
- Gary M. Reedy, volunteer ACS board chair, is the worldwide vice president of government affairs and policy for Johnson & Johnson.

VISIBILITY

- In 2011, ACS patient information and programs reached 589,500 cancer patients, 42 percent of all cancer patients.

Publications and Congresses

- Website received more than 22 million unique visitors in 2011.
- Expert Voices blog publishes stories once a week about various cancer-related topics from 29 contributors, most of whom are HCPs.
- ACS Chief Medical Officer Dr. Len Lichtenfeld authors [Dr. Len's Blog](#), which is featured on the newsroom page. Stories are posted about once a week and include breaking cancer news, as well as opinion on new research and scientific developments.



- ACS Pressroom Blog is written by ACS media relations staff. Stories post twice per week and read more like press releases or news articles, quoting various ACS medical staff on cancer news.
- Road to More Birthdays blog is written by the ACS executive leadership about ACS initiatives.
- What's Next online community, forum and blog includes 11,255 cancer patients, HCPs and caregivers. There are seven posts about pain currently posted.
- Cancer Survivors Network online community includes 168,000 cancer survivors and caregivers. Pain management and medications issues are discussed in several discussions, posts and other areas.
- Series of Support Emails are sent to patients and caregivers at various times throughout their cancer journey. Distribution numbers are not available.
- New Connections electronic newsletter is published every other month to caregivers and patients.
- CEOs Against Cancer newsletter is distributed quarterly. No information on distribution is available.
- ACS has no annual meeting. However, division and state chapters often host annual volunteer and event-specific meetings and trainings. ACS's most prominent fundraising events are:
 - Relay for Life
 - Making Strides Against Breast Cancer
 - DeterminATION
 - Coaches vs. Cancer
- ACS has an annual CEOs Against Cancer National Meeting that typically takes place in mid-June.
- ACS state and regional chapters hold several annual meetings for various committees and volunteers throughout the year.

Social Media

ACS not only has several Facebook and Twitter accounts, but they make sure to make each unique and not overlap content. Local ACS divisions, chapters, fundraisers and other initiatives have hundreds of other accounts.

Facebook: 1.2 million total (users may overlap)

American Cancer Society: 360,000 likes

- Posts daily about ACS news, events and fundraisers, patient stories, cancer news in the media and other areas of interest.

American Cancer Society Making Strides Against Breast Cancer: 105,500 likes

- Posts daily about breast cancer-specific news, patient stories and events.

American Cancer Society Relay For Life: 248,000 likes

- Posts daily about Relay for Life-specific news, patient and fundraiser stories, tools and fundraising tips.

Birthdays: 480,200 likes

- Posts daily about survivors who have received more birthdays, research news, and other pertinent topics.

Hope Lodge: 2,700 likes

- This page is less active than others and allows users to post their Hope Lodge experiences.

Coaches vs. Cancer: 5,500 likes

- ACS also has a "Fight Cancer: Support the American Cancer Society" Facebook Cause

Twitter: 524,000 total followers (followers may overlap)

@ACSNews: 124,400 followers; 240 following

- This handle is the ACS media relations Twitter account that retweets other ACS handles, as well as top-tier media cancer-related stories. Tweets are disseminated about three times per day.

@AmericanCancer: 358,500 followers; 195,500 following

- Official Twitter page for ACS. Tweets about twice per day.

@RelayForLife: 23,500 followers; 1,100 following

- Posts about once a day and interacts with local Relay for Life events and volunteers.

@Morebirthdays: 7,800 followers; 2,241 following

- Posts about twice a day about ACS initiatives, news and other pertinent topics.

@acsglobal: 4,000 followers; 1,700 following

- Focuses on global cancer news and ACS initiatives

@CoachesvCancer: 825 followers; 327 following



- Tweet dissemination from this handle is inconsistent and hasn't posted routinely since September 2012.
@OtisBrawley: 1,730 followers; 60 following
- Otis Brawley is chief medical officer at ACS; Dr. Brawley often participates in conversations with top-tier media as well as Twitter chats.
@DrLen: 3,500 followers; 70 following
- Dr. Len is deputy chief medical officer at ACS; Dr. Len often participates in conversations with top-tier media as well as Twitter chats.
YouTube: 5.4 million video views, 5,000 subscribers, hundreds of videos
ACS uploads approximately six new videos per month; several include prominent ACS executives and HCPs, celebrities, PSAs and patient stories.
Pinterest: 3,700 followers, 300 pins
LinkedIn: 19,800 members
- ACS has several dozen groups, many of which are organized by local chapters and fundraising events. The most prominent, public groups are:
 - American Cancer Society Supporters: 7,900 members
 - American Cancer Society Relay for Life: 7,500 members
 - American Cancer Society Making Strides Against Breast Cancer: 4,400 members
 - ACS also has a free More Birthdays app offered on iTunes, which allows users to link their Facebook birthdays with the app, to customize birthday greetings and to donate to the ACS.

Media Coverage

- ACS has been mentioned in 22,000 articles in the past year, excluding obituaries. Coverage peaked in October 2012 during breast cancer awareness month, a topic it is overall quoted most about. Chief Medical Officer, Dr. Otis Brawley, is quoted most often.
- ACS (excluding ACSCAN mentions) was quoted in 976 articles about pain. However, pain is often mentioned only briefly as a common cancer symptom, or result of treatment and/or screening tests (colonoscopy). The articles are not specifically about cancer pain.
- ACS (excluding ACSCAN mentions) was quoted in five articles about opioids, all of which were about World Cancer Day. The statistic that 90 percent of global opioid consumption is in five regions was mentioned as a way to illustrate the need to increase pain care in developing countries. Dr. Otis Brawley was quoted in these articles.

PARTNERSHIPS

- ACS' Corporate & Systems initiative develops relationships with major Fortune 1,000 companies to 1) help the companies' employee base get and stay healthy; 2) help the companies raise money for ACS through corporate participation in fundraising events, cause marketing and similar initiatives.
- ACS' Corporate Alliance Program collaborates with top-tier companies who support the ACS cause, branding platforms and generate significant revenue.
- ACS has received \$1.6 million dollars in grants from the Pfizer Foundation for regional cancer and tobacco control programs in Latin America, Southeast Asia and North Africa, in addition to a few smaller grants to help further ACS programs in developing countries. Pfizer Corporation gave ACS approximately \$1 million dollars in 2010.
- Amgen gave approximately \$175K dollars in 2010; Genentech, Merck and Purdue Pharmaceuticals gave approximately \$125K dollars; Abbott, Astellas, Covidien, Lilly, GSK Foundation and Merck Partnership for Giving gave approximately \$75K dollars.
- Abbott, AstraZeneca and Roche were among the companies that won the 2010 Corporate Impact Award: Excellence in Philanthropy.

ISSUES

- ACS offers sufficient patient information on pain management. The key topics addressed are:
 - Cancer pain can, and should, be treated.
 - Pain management is part of a patient's cancer treatment. HCPs should ask about pain at every visit and patients should not feel like they're complaining when talking about their pain. They have a right to ask about pain relief.



- Opioid medicines are some of the medicines to treat cancer pain. Addiction problems are rare among cancer patients.
- Most people do not get "high" or lose control when they take cancer pain medicines the way they are told to administer them.
- Better pain management allows for better quality of life, including the ability to sleep and eat better, maintain better family and friend relationships, and avoid depression.
- ACS does not take policy positions on pain management; those are made through its sister organization, ACSCAN.

INFLUENCE

- ACS guidelines and data are highly regarded and often quoted in media, peer-reviewed journals, government documents and other publications.
- ACS has a presence in most cancer treatment facilities throughout the U.S. Many are served by ACS Patient Navigators who serve to help newly diagnosed and veteran cancer patients navigate treatment, insurance coverage and other issues.
- According to its 2012 Financial Stewardship Report, ACS has lost about 5 percent market share in the past decade due to the increase of niche cancer organizations and cancer hospitals seeking public fundraising. However, ACS maintains 29 percent market share among large (\$50+ million dollars) health and hospital nonprofits and 4 percent market share among all health nonprofits.

FOCUS ON PAIN MANAGEMENT

- ACS has a page dedicated to cancer pain. However, the page is not particularly prominent on the website and falls under its "physical side effects" of cancer treatment section. It includes a guide for patients and loved ones to control pain; a video and accompanying guidebook on managing pain; a pain diary; a home pain care guide; an online class on relieving cancer pain and information on getting help for cancer pain.
- ACS has more than 5,000 articles, blog posts, patient resources and information on various pain topics on its website. There are articles about pain management in general, as well as specific to various types of cancers.
- ACS offers a specific webpage explaining breakthrough pain, and general information on medication treatment.
- ACS has a webpage that details different types of opioids, including brand names.



AMERICAN CANCER SOCIETY CANCER ACTION NETWORK (ACSCAN) OVERVIEW

The American Cancer Society Cancer Action Network (ACSCAN) is the American Cancer Society's 501c4 sister organization. It can be assumed that both groups share the same positions, but their funding must remain separate. Given ACSCAN's recent focus on palliative care as their primary focus in quality of life issues, there is sufficient room for increased focus on pain management. ACSCAN may be receptive to a partnership with Teva, as Cephalon was the only pharmaceutical company co-signatory on a 2011 ACSCAN letter urging lawmakers not to restrict access to ER oxycodone. However, Teva is not currently listed as a corporate sponsor, while Purdue Pharmaceuticals and Endo are. If Teva wants to work with ACSCAN, it likely will have to become a sponsor.

ADDRESS

www.acscan.org

901 E St NW, Suite 500
Washington, DC 20004

ORGANIZATIONAL RESOURCES (2011)

- 112 employees
- ACSCAN is a 501c4, meaning it can lobby. All funds raised by the ACS must be kept separate.
- Revenue: \$19.4 million dollars (\$19.3 million dollars in grants and contributions, \$94K dollars in program service revenue).
- Expenses: \$19.6 million dollars (\$10 million dollars in salaries, employee compensation; \$9 million dollars in "other expenses").

MEMBERSHIP

- ACSCAN claims 400,000 volunteers, which includes patients, caregivers and HCP ambassadors representing every U.S. Congressional district in every state.
- ACSCAN's Board of Directors does not include any HCPs.

VISIBILITY

Publications/Congresses

- Blog Cancer CAndor is written by ACSCAN president, Chris Hansen; posts twice weekly about various cancer-related policies, legislative and regulatory news, as well as ACSCAN's positions.
- Each state chapter of ACSCAN sends monthly state-specific newsletters (distribution numbers are not available).
- ACSCAN sends state-specific and federal legislative alerts to those who opt-in with their email addresses (distribution numbers are not available).
- There are four pre-written action alerts that visitors can send to their elected officials; none are related to pain or palliative care.
- ACSCAN sends opt-in volunteers legislative alerts via text messages about twice a month.
- 1,600 volunteers have ICAN pages, which allows users to share their cancer story and fundraise
- Each state chapter holds an annual lobby day at their state capitol.
- ACSCAN hosts an annual "Celebration on the Hill" national lobby day in which 7,000 volunteers representing each U.S. Congressional district meet with their members of Congress and some federal agencies regarding that year's ACSCAN priorities.

Social Media

Local ACSCAN chapters divisions, chapters, fundraisers and other initiatives have hundreds of other accounts.

Facebook: 16,873 likes

The ACSCAN posts daily about policy positions; media stories about political events; policy and local action items as well as other topics.

Twitter: 7,561 followers; 2,942 following

Tweets are sent out about five times a day, often engaging members of Congress and other KOLs. Frequently enters the general political conversation by using hashtags and leads Twitter chats.



YouTube: 334 subscribers; 185,145 video views, 61 videos

Many videos are of ACSCAN President, Chris Hansen, sharing ACSCAN's position on various policies and current political events; other videos include PSAs and advertisements.

LinkedIn: 1,367 members

Members are not particularly active; the last discussion was one month ago.

Media Coverage

- ACSCAN has been mentioned in 458 articles in the past year. In addition to being frequently quoted in top-tier national media, it is often quoted in local top-tier publications about local legislation and policy issues.
- ACSCAN has been mentioned in 25 articles in the past year in reference to "pain." ACSCAN was mentioned in coverage by several top-tier publications about its opposition to rescheduling hydrocodone.
- ACSCAN spokespersons are mentioned in top-tier media about 10 times a month.
- ACSCAN publishes about four to five press releases per month about research that furthers their policy priorities, ACSCAN legislative wins and ACSCAN positions.
 - They published a January 2013 press release about rescheduling hydrocodone (ACSCAN is against it) detailed more below.

PARTNERSHIPS

- EMD Serono, Inc., GlaxoSmithKline and Pfizer donated between \$100K to \$250K dollars in 2010, which grants them:
 - Annual one-on-one meeting with ACSCAN president
 - Presenting sponsorship and logo placement at high visibility Washington, DC event
 - Exclusive presenting sponsorship for regional ACSCAN event (mutually determined)
 - Three issue briefings with ACSCAN senior leadership
 - Bi-monthly calls with ACSCAN senior leadership
 - Monthly newsletter
 - Recognition in annual accomplishments report
 - Recognition on ACSCAN's website and at ACSCAN's headquarters
- Abbott, Amgen, AstraZeneca, BMS, Celgene, Endo, Lilly, Johnson & Johnson, Kaiser Permanente, Purdue Pharmaceuticals and Novartis donated between \$25K to \$100K dollars in 2010, which grants them:
 - Bi-monthly calls with ACSCAN senior leadership
 - Three issue briefings with ACSCAN senior leadership
 - Sponsorship and prominent logo placement for high-visibility Washington, DC event
 - Opportunity to sponsor visible regional ACSCAN events (mutually determined)
 - Monthly newsletter
 - Recognition in annual accomplishments report
 - Recognition on ACSCAN's website and in ACSCAN's headquarters
- Astellas, Genentech, Millennium (Takeda), Onyx Pharmaceuticals, sanofi-aventis donated between \$10K to \$25K dollars, which grants them:
 - Bi-monthly calls with ACSCAN senior leadership
 - Monthly newsletter
 - Recognition in annual accomplishments report
 - Recognition on ACSCAN's website and in ACSCAN's headquarters
 - Participation and logo placement at annual Lobby Day event
- ACS partnered with the Lance Armstrong Foundation, Susan G. Komen and the University of Wisconsin Pain & Policy Studies Group to issue the annual "Achieving Balance in State Pain Policy: A Progress Report Card," which examined how state policies affect pain management. The next report is scheduled to be published in early 2013; a report hasn't been issued since 2008. After publishing the report, ACS called upon lawmakers to improve policies.



ISSUES

- ACSCAN's major campaigns are:
 - Appropriations for cancer research, prevention and early detection.
 - Access to health care for cancer patients, survivors and their families.
 - Advancing patient and survivor quality of life: central to this is supporting the passage of the Cleaver-Bachus Patient Centered Quality of Life Act and the Wyden-Engel Palliative Care and Hospice Education and Training Act pending in the House and Senate. ACSCAN will advocate for legislative and regulatory change to make coordinated palliative care available to all cancer patients and survivors in all care settings.
- ACSCAN's top priorities are:
 - Cancer prevention and early detection
 - National Breast and Cervical Cancer Early Detection Program and the National Colorectal Cancer Control Program
 - Tobacco control
 - Disparities
 - Nutrition and Physical Activity
- ACS director of quality of life and survivorship, Rebecca Kirch, testified at the January 2013 FDA advisory committee meeting against rescheduling hydrocodone because it would reduce patient access to needed pain medications; ACSCAN issued a [press release](#).
- ACSCAN has not offered any position on abuse deterrence.
- ACSCAN signed a 2011 [letter](#) to the House Commerce Subcommittee and Chair Rep. Mary Bono Mack in opposition of legislation that would limit ER oxycodone for patients with moderate chronic pain. Cephalon (Teva) was the only pharmaceutical company to sign the letter.
- In a 2012 [letter](#) to the Senate HELP committee about the Prescription Drug User Fee Act (PDUFA), ACSCAN singled out opioid REMS as one of six areas of concern. ACSCAN supports REMS, but called upon legislators to allow more stakeholder input to help design, implement and evaluate REMS.
 - The letter cited a 2009 prescriber survey of 2,600 HCPs in all 50 states by ACSCAN and two other hospice and palliative organizations, which found that some patients were seriously harmed by a REMS-based FDA decision to review and further restrict certain prescription opioids.
- ACSCAN opposed relabeling opioids and believes all legitimate patients with moderate-to-severe pain – regardless of if their pain is caused by cancer – should have access to appropriate pain care, which may include opioids.

INFLUENCE

- ACSCAN is highly influential and activates volunteers in almost every district of the U.S. to act on its policy agenda when necessary, including speaking at hearings, meeting with members of Congress and speaking to media. ACSCAN's major policy wins are:
 - Led 35 states, Washington, DC and Puerto Rico to enact smoking bans.
 - Passed a 62-cent increase in the federal cigarette tax.
 - Helped secure FDA regulation of tobacco products.
 - Increased NIH cancer research funding.
- ACSCAN has a major presence on Capitol Hill. It has shown its influence not only in the cancer space, but also in the pain space.

FOCUS ON PAIN MANAGEMENT

- The organization's focus on pain management falls under their [quality of life and palliative care priority](#). While pain care is not the focus, it is an element and evidently on ACSCAN/ACS' radar given its testimony in recent FDA advisory committee meetings on the topic.
- ACSCAN launched an [advertising campaign](#) in July 2012 to support legislation that increases access and utilization of palliative care. The campaign appeared in major beltway publications.
- The organization's focus on palliative care is new as of 2012; it has never focused on this issue before. Within this space there is room for ACSCAN to focus more on pain management, but that palliative care is its main priority under quality of life issues is substantial.



- In 2009, ACSCAN partnered with health professional organizations to conduct a study which found regulatory changes at the time interfered substantially with patient access to quality pain care and resulted in needless suffering. In testimony during a January FDA advisory committee hearing on rescheduling hydrocodone, ACSCAN urged the panel to consider the study.
- ACSCAN has a pain-specific advocacy fact sheet (2007) about the need to reduce barriers to effective pain management.



AMERICAN SOCIETY OF CLINICAL ONCOLOGY (ASCO) OVERVIEW

In 2014, the American Society of Clinical Oncology (ASCO) will celebrate its 50th anniversary as the world's leading professional organization representing physicians who care for people with cancer. ASCO enjoys a strong reputation as a respected medical organization. ASCO is supported by its affiliate organization, the Conquer Cancer Foundation (CCF), which funds ground-breaking research and programs that make a tangible difference in the lives of people with cancer. Teva is one of 120+ corporate and/or non-profit donors to the Foundation. Through CCF, ASCO is well-suited as a potential partner for Teva. ASCO strives to be recognized as the most trusted source of cancer information worldwide, and it does not currently have a strong focus on pain management.

ADDRESS

www.asco.org
2318 Mill Road, Suite 800
Alexandria, VA 22314

ORGANIZATIONAL RESOURCES (2011)

- 303 employees
- Total revenue: \$83.1 million dollars (\$72.4 million dollars in program service revenue, \$7 million dollars in contributions and grants).
- Total expenses: \$72.4 million dollars (\$55 million dollars in program services, \$13 million dollars in administration, \$2.7 million dollars in "other").

MEMBERSHIP

- ASCO has 30,000+ members from every oncology subspecialty, as well as allied physicians, doctoral scientists, allied health professionals, students and non-oncology residents.
- ASCO claims 1,200 volunteers and 18 members of its Board of Directors.

VISIBILITY

Publications and Congresses

- The peer-reviewed *Journal of Clinical Oncology* is the official journal of ASCO. It is published three times per month in both print and electronic form. Original Reports remain the focus of *JCO*, but this scientific communication is enhanced by appropriately selected Editorials, Commentaries, Reviews, and other work that relate to the care of patients with cancer.
- The peer-reviewed *Journal of Oncology Practice (JOP)* provides oncologists and other oncology professionals with information and tools to enhance practice efficiency and promote a high standard for quality of patient care. The goal of *JOP* is to be the authoritative resource on clinical and administrative management for practicing oncologists. The *Journal* includes original research, feature articles, and section columns on various issues pertinent to daily practice operations.
- *Educational Book* articles highlight standards of care and look toward future therapeutic possibilities. The *2012 Educational Book* contains 141 articles from 80 sessions. An expert panel reviewed each article's fair and balanced nature, as well as its clinical relevance, educational value, accuracy, and completeness.
- Guideline Endorsements – ASCO endorsement of guidelines will be considered in selected circumstances either upon request from peer professional organizations, or when ASCO seeks to endorse another organization's guideline in lieu of undertaking its own guideline on the same topic.
- Provisional Clinical Opinions (PCOs) are intended to offer timely clinical direction to the ASCO membership following the publication or presentation of potentially practice-changing data from major studies. It may serve in some cases as interim direction to the membership pending the development or updating of an ASCO clinical practice guideline.
- *ASCO Connection* is the professional networking site for ASCO's worldwide oncology community.
- *ASCO Guidelines Anthology* addresses specific clinical situations (disease-oriented) or use of approved medical products, procedures, or tests (modality-oriented). Using the best available evidence, ASCO expert panels identify and develop practice recommendations for specific areas of cancer care that would benefit from using practice guidelines. The criteria for selecting topics for guidelines includes significance of clinical importance; presence of variations in patterns of, or access



- to care; availability of suitable data; and ethical considerations.
- *Practical Tips for the Oncology Practice, 5th Edition* provides practice management assistance to oncologists with content that answers the most commonly asked billing, coding, and reimbursement questions related to oncology services. The book is directed to both physicians and their office staff. Its practical content can be applied in day-to-day operations.
- ASCO also delivers a variety of oncology mobile meetings and podcasts on the latest oncology presentations, news, and commentary.
- ASCO issues the *Oncology Practice Insider* newsletter, but information is limited as it is for members only.
- ASCO's Annual Meeting is late May or early June each year in Chicago.
 - It is attended by 31,250 people, including 25,000 HCPs (46 percent physicians, and 4000 exhibitors. 52 percent of attendees are international; 48 percent are American.
 - The Annual Meeting receives widespread media attention and top-tier media attend and coverage the latest cancer research, which is presented at the meeting.
 - The Annual Meeting utilizes social media, including hashtags, check-in points, Facebook, Twitter and member-only LinkedIn posts.
- ASCO sponsors a variety of other workshops, symposiums and summits throughout any given year.

Social Media

Facebook: 6,500+ followers

The page actively posts tips, information and profiles on cancer-related issues and topics.

Twitter: 14,000+ followers

ASCO is routinely tweeting on a variety of cancer-related issues and topics.

LinkedIn Group: 747 members, 13 discussions this month

Their linked in site is very basic.

YouTube: 94 subscribers, over 7,700 video views

YouTube has 83 videos posted on a variety of cancer-related issues and topics.

Media Coverage

- ASCO was mentioned in 2,397 articles in the past year.
- Coverage spiked (740 articles) during its annual conference in early June.
- Pain-related coverage was significantly less – 273 articles. However, pain is most often referenced in drug research as a symptom, or mentioned as a symptom of cancer. ASCO was not mentioned in any articles about pain treatment or in articles about “breakthrough pain or incident pain”.

PARTNERSHIPS

- ASCO's Conquer Cancer Foundation was established to conquer cancer worldwide by funding breakthrough cancer research and sharing cutting-edge knowledge
 - Teva is one of over 120 corporate and non-profit donors to the Foundation. Others include pharmaceutical companies, corporations, non-profit, advocacy, medical societies and families. Names are listed within the website, but no logos or links are provided.
- ASCO's virtual meeting from its 2002 Symptom Management Symposium Track on Challenges in Pain Management displays the logos (no links) of the companies that supported that online resource: Boehringer Ingelheim, Takeda Millennium, Pfizer Oncology, Quality Care Symposium.
- Beyond exhibitor information at its Annual Meeting, ASCO's website does not contain information about corporate support.

ISSUES

- ASCO's Government Relations Committee establishes policy priorities on an annual basis. These priorities are updated as needed to reflect emerging issues. Currently highlighted on ASCO in Action are the following issues:
 - Physician Payment Reform, including Repeal of the Sustainable Growth Rate
 - Drug Shortages
 - Health Equity (essential health benefits for all cancer patients, oral parity)
 - National Recognition for QOPI Measures



- NIH Funding
- ASCO regularly disseminates policy statements, issue statements, and letters on its positions on various cancer-related topics.
- ASCO regularly issues press releases on topics of interest, including new studies, legislative issues, their own initiatives, etc.
- The only information ASCO has on its website about opioids is in reference to abstracts, presentations and posters presented at various meetings. No ASCO positions are given on pain management.
- There is no information on ASCO's website about the scheduling or relabeling of hydrocodone. The only mentions of hydrocodone occur in research abstracts available through an ASCO library search.
- Prescription drug abuse does not seem to be a prominent issue for ASCO.

INFLUENCE

- ASCO is very active legislatively, regularly issuing calls to action and responses to Congressional actions and proposals.
- ASCO's ACT Network is dedicated to shaping the future of oncology by influencing Congress and other policy makers on important legislation. It provides members with opportunities to become engaged in advocacy, including the ability to send a message using pre-drafted, editable alerts; to find phone numbers and mailing addresses for elected officials; to see how members of Congress vote on the key issues and draft e-mails or letters to members of Congress.
- ASCO provides members with access to an Advocacy Toolkit to facilitate effective communication to and to establish a relationship with members of Congress. The kits includes information on how to schedule and participate in a meeting with a member of Congress (or staff); how to successfully organize a visit; how to write a meaningful email or letter that will get noticed and how to connect using social media.
- ASCO is currently an active influencer in the cancer arena.

FOCUS ON PAIN MANAGEMENT

- ASCO does not have a dedicated pain management section of their website, but offers research abstracts on the topic, as well as a virtual meeting from its 2002 Symptom Management Symposium Track, entitled "Challenges in Pain Management," which is inaccessible to non-members.
- The opportunity seemingly exists for pain management to become a larger focus for ASCO.



AMERICAN SOCIETY FOR RADIATION ONCOLOGY (ASTRO) OVERVIEW

The American Society for Radiation Oncology (ASTRO) is dedicated to improving patient care through advancement of science and advocacy, education and clinical practice. Members make up the radiation therapy treatment teams that are critical in the fight against cancer. ASTRO provides members with continuing medical education, health policy analysis, patient information resources and advocacy. Because radiation is often linked to breakthrough pain, radiologists often prescribe TIRF products to help manage this pain. The organization is active and influential on the Hill, most recently advocating against payment cuts to cancer care. Although open to partnerships, the organization did not have any sessions on pain management, nor is information regarding this available online. Additional conversations with organizational leaders need to take place to determine their interest in pursuing pain topics.

ADDRESS

www.astro.org

8280 Willow Oaks Corporate Drive, Suite 500
Fairfax, VA 22031

ORGANIZATIONAL RESOURCES (2011)

- 74 employees
- Revenue: \$16 million dollars (\$8.5 million dollars for annual meeting, \$2.9 million dollars from membership dues, \$1.6 million dollars from other educational meetings)
- Expenses: \$15.1 million dollars (\$5.7 million dollars in employee benefits and compensation, \$1.3 million dollars in events, \$800k in grants)

MEMBERS

- More than 10,000 members, including oncologists, medical physicists, dosimetrists, radiation therapists, radiation oncology nurses, biologists, physician assistants (PAs) and practice administrators.
- ASTRO lists 575 volunteers and 13 members on its Board of Directors.

VISIBILITY

Membership Visibility

- Publications include:
 - *Red Journal: The International Journal of Radiation Oncology, Biology, Physics*, also known as the *Red Journal*, is the leading journal dedicated to radiation oncology and the official scientific publication of ASTRO. Published 15 times per year, both online and in print, this journal offers authoritative articles linking new research and technologies to clinical applications.
 - *PRO: Practical Radiation Oncology (PRO)* is the official clinical practice journal of ASTRO. Published quarterly, both online and in print, *PRO* is a journal dedicated to improving the quality of radiation oncology practice, documenting the state of current practice, and providing background for those in training and the continuing education of practitioners.
 - ASTROgram: Emailed to members weekly, this communication provides insight into issues surrounding radiation oncology today and includes links to areas of particular interest.
 - *ASTRONews*: ASTRO's quarterly magazine includes columns from influential society members; updates on legislative issues; updates on changes to coding and billings; in-depth feature stories on membership and issues affecting the specialty and news from the larger cancer community.
 - ASTRO issues various guidelines, white papers, and best practices documents.
- Live meetings include:
 - State of the Art Techniques Symposium
 - Spring Refresher Course: this course provides updates in technology and research; an in-depth overview of standard practices and insight into the current management of malignancies most commonly encountered within radiation oncology.
 - Cancer Imaging and Radiation Therapy: A Multi-disciplinary Symposium
 - Multi-disciplinary Head and Neck Cancer Symposium
 - Chicago Multi-disciplinary Symposium in Thoracic Oncology
 - ASTRO/AAPM/NCI Workshop: Technology for Innovation in Radiation Oncology



- Best of ASTRO: Science of Today, Hope for Tomorrow
- As part of ASTRO's commitment, they provide self-assessment learning modules and CME credits for continuing education.
- Their upcoming annual meeting is September 22-25, 2013, in Atlanta, Georgia.

Social Media

ASTRO's private, online community, ROhub, enables members to make connections, share information and documents and conduct business with other members within restricted and open member online communities.

Facebook: 3,373 likes

- The page most frequently posts information about the society, meetings, and publications every couple of days. Followers engage with ASTRO primarily by reacting to ASTRO posts.
- There were zero mentions of "pain" in February.

Twitter: 3,051 followers

- Tweets are disseminated daily by posting information about society, meetings, and publications. Very occasionally there are retweets of tweets of interest. Tweets mirror Facebook posts.

LinkedIn Group: 5,054 members

- They have a relatively small number of posts in the past week and members initiated some discussion, mostly linking to articles they'd like to share with group members.

YouTube: 13 subscribers; 7,583 video views

- 20 videos have been uploaded since its creation in July 2009. The most recent video upload was 2 years ago.
- Most videos are recorded conversations with physicians at the ASTRO 2010 convention. A handful of videos are intended to enable patients to advocate for themselves throughout the course of their treatment.

Media Coverage

- ASTRO's News and Media Center provides access to ASTRO Daily News, articles on cancer, and top stories related to ASTRO's mission.
- ASTRO has been referenced in approximately 408 articles in the past year. Most mentions refer to the society's stance on clinical practice guidelines or studies presented at the annual meeting.
 - ASTRO has not been mentioned in any media in reference to pain management or opioids.
- Chairman Michael Steinberg has been quoted on the society's advocacy efforts. He was quoted in a Reuters article on November 12, 2012 opposing over-use of steroids and narcotics for pain management: "(Narcotics and steroids) are not necessarily solutions, this is more like warehousing very old patients and something to be avoided, if you can control the pain with a short course of radiation, there is a value proposition," said Steinberg.
- President Colleen Lawton has also been quoted; her messages are generally intended to encourage patients to advocate for themselves by questioning their physicians' treatment plans.

PARTNERSHIPS

- ASTRO has numerous corporate members. Industry corporate members include Boehringer-Ingelheim, Bristol-Myers Squibb, Amgen, and Bayer.
- Industry partners also have the opportunity to support numerous educational activities throughout the year, including the ASTRO annual meeting.
- ASTRO clearly partners with industry, but a list of industry partners is not available on the website: "ASTRO's Industry Relations effort provides opportunities for ASTRO and industry to collaborate and form long-term, quality relationships. Through the development of meaningful partnerships, industry and ASTRO stand better prepared to meet the challenges of today's health care marketplace and positively shape the future of radiation oncology."

ISSUES

- ASTRO supports policies that:
 - Improve the safety of radiation oncology



- End self-referral abuses
- Stabilize Medicare physician payments
- Protect access to radiation oncology services
- Increase investments in cancer research
- ASTRO has issued no explicit mention of issues relevant to Teva and/or pain management.
- Most recently, ASTRO submitted a letter to the Centers for Medicare and Medicaid Services (CMS) opposing proposed policy changes for 2013 that would cut nearly \$300 million dollars for cancer treatment, particularly cuts to radiation therapy.

INFLUENCE

- ASTRO works closely with lawmakers, and public and private payers, to ensure patients have access to the safest, most effective cancer treatment.
- ASTRO Political Action Committee (ASTRO PAC) provides ASTRO with the opportunity to more fully participate in government affairs and ensure their voice is heard by key policy makers in Washington. ASTRO feels representation on Capitol Hill is critical to creating and maintaining the most positive environment for cancer treatment and research.
- ASTRO's annual Advocacy Day in Washington, DC is held in March. ASTRO does not pay for physician attendees to travel to participate. Radiation oncologists, radiation oncology residents, radiation physicists and radiation oncology nurses attend (no total attendance number is provided).

FOCUS ON PAIN MANAGEMENT

- Mentions of pain on their website and in publications are most commonly from the perspective of using radiation therapy for pain management. For example: Palliative radiotherapy for bone metastases: An ASTRO evidence-based guideline (2011)
- They do not seem to prioritize pain management using drug therapy.

**BEAT LIVER TUMORS (BLT) OVERVIEW**

Beat Liver Tumors is a true grassroots advocacy and education organization with a strong network of patient and caregiver volunteers, as well as connections to other patient advocacy groups. However, in keeping with this “true grassroots” approach, the group can often appear informal. There could be great opportunity for Teva to collaborate with the organization; not only have they partnered with pharmaceutical companies before, but the organization is focused on turning what is typically a fatal diagnosis into a chronic disease that must be managed. Pain is a primary symptom of these patients.

Address

<http://beatliver Tumors.org>
791 Arnold Paul
Canton, TX 75103

ORGANIZATIONAL RESOURCES

- N/A – this information could not be readily located.

MEMBERSHIP

- Beat Liver Tumors includes 3,000+ volunteers, many who are extremely active and connected in program initiatives.
- Beat Liver Tumors was co-founded by stage IV liver cancer survivor Suzanne Lindley, who continues to lead the organization. Suzanne has extensive relationships with a wide range of other patient advocacy groups like Fight Colorectal Cancer and LIVESTRONG among others.

VISIBILITY**Social Media**

Facebook: 2,128 likes

There are multiple posts throughout the course of the day, and a great deal of interaction with volunteers, media and other patient groups. Posts include patient stories of survival and hope; video, photos and news from events and news about liver tumors.

Twitter: 3,028 followers; 1,764 following

Twitter posts average once a day and include links to patient stories; retweets of cancer-related media tweets; other patient group news and advocacy calls to action. The organization is very interactive with other tweeters.

Media Coverage

- Beat Liver Tumors has appeared in 10 media articles in the past year. Most feature local patient stories and their involvement in Beat Liver Tumors events.
- In the past, founder Suzanne Lindley has been featured in top-tier national press, including *The Today Show*. She is also a guest blogger for *CURE Magazine*. In addition, several of the organization's volunteers have been featured in local and national news to share their stories.

Publications

- Beat Live Tumors publishes a weekly e-newsletter distributed to more than 3,500 people, as well as a more traditional print quarterly newsletter.

PARTNERSHIPS

- The organization lists Amgen, Bayer Healthcare, Genentech, ImClone, Lilly, Onyx Pharmaceuticals and Sirtex Medical, Inc. as supporters of its 2012 programs.
- Beat Liver Tumors' Capitol Hill advocacy event and Congressional briefing was funded by educational grants from the Access to Medical Imaging Coalition, Genentech, Sirtex Medical and WAKO Diagnostics.
- They worked with multiple hospitals and groups including Society of Interventional Radiology, Association of Radiological Nurses, Chemo 101, CaringBridge, Survivor Celebration, Yoga for Cancer Survivors, Immerman Angels, Fight Colorectal Cancer, Access to Medical Imaging Coalition and Voices of Survivors on a successful PSA campaign about liver tumors.



- Beat Liver Tumors is closely tied to LIVESTRONG; many of the organization's volunteers and leaders are active volunteers with LIVESTRONG.
- Beat Liver Tumors links to several prescription medication financial assistance support websites, many of them directly run by pharmaceutical companies.

ISSUES

- They have not taken a stance on pain-related key issues.
- Beat Liver Tumors' top policy priorities are:
 - Improve HCP education about detection, surveillance, and treatment of liver cancer
 - Increase liver cancer surveillance
 - Increase federal research for liver cancer surveillance and treatment
- While pain is not a top issue, the organization includes a page on end-of-life care on its website.

INFLUENCE

- Beat Liver Tumors' most influential initiatives are its advocacy programs, as well as its patient programs and services that reach a wide range of cancer patients and caregivers. It offers a 24-hour help line that receives 350 calls per month. More than 1,000 members participate in its online support program, as well as a weekly telephone support group.
- Additionally, they have other advocacy initiatives including:
 - Annual Capitol Hill advocacy events in Washington, DC where 30-40 patients and caregivers meet with members of Congress. Sometimes, other patient groups participate as well.
 - Founder Suzanne Lindley has testified at three Congressional briefings about the need for improved access to medical imaging and liver tumor surveillance.
 - Beat Liver Tumors has a Rally Congress where it encourages advocates to write letters to Congress and/or the FDA. Currently there are two letter campaigns: one with 1,103 letters for the FDA to fast-track approval of French ethiodol replacement for U.S. cancer patients; a second with 104 letters to oppose funding cuts to cancer research as part of the sequester agenda. The site also allows users to locate their members of Congress.
 - Mass-participation by Beat Liver Tumors volunteers in other patient group Capitol Hill advocacy events.
- Beat Liver Tumors also holds several patient education events, including:
 - The Liver Symposium: an annual event at which HCPs present new developments in liver tumor treatment and surveillance to caregivers and patients (approximately 50-60 total) from around the country
 - Liver Seminar Series: several events throughout the U.S. hosted by HCPs in their local areas to discuss treatment options and share advice with patients who live nearby.
 - Beat Liver Tumors also participates in several national medical conferences, such as ASCO.
- Beat Liver Tumors also prides itself on achieving insurance approvals for nearly 200 treatments for patients who were otherwise denied coverage.

FOCUS ON PAIN MANAGEMENT

- Beat Liver Tumors is not focused on pain management, but there is certainly potential for pain to become a larger focus of the organization because:
 - Once cancer metastasizes to the liver, this is often a sign to HCPs of late-term cancer. Pain is a common symptom, of progressed liver tumors.
 - Liver metastases are most common for the following often painful cancers: breast cancer, lung cancer and pancreatic cancer.
 - Many of the group's members are long-term cancer survivors who deal with chronic pain and continued relapses.
 - The organization focuses on turning late-stage cancer into a chronic condition, not a terminal disease. Their focus is on improving the quality of life and functionality of current patients.
- While the group does include several oncologists on its scientific advisory board, most of its members are patients and caregivers.



BONE & CANCER FOUNDATION (BCF) OVERVIEW

The focus of Bone & Cancer Foundation (BCF) is providing educational resources for cancer patients and healthcare professionals (HCPs). BCF is a fairly small organization, under the auspices of The Paget Foundation for Paget's Disease of Bone and Related Disorders, with minimal influence and visibility. BCF may be a potential partnership opportunity for Teva, as they currently do not seem to have any corporate sponsors, nor do they seem to have a policy prohibiting such arrangements. BCF addressed the subject of pain management through a 2011 brochure, so the issue is of some interest and importance to them.

ADDRESS

www.boneandcancerfoundation.org
120 Wall Street, Suite 1602
New York, NY 10005-4035

ORGANIZATIONAL RESOURCES

- There is no information available regarding revenue and expenses for BCF.

MEMBERSHIP

- There is no information available about BCF membership.

VISIBILITY

Publications

- 11 Bone and Cancer Foundation publications are available on the BCF website and in print, including *Managing Pain Related to Cancer and Bone*.
- The first and only issue of *The Bone Cancer Foundation Newsletter* was issued in the summer of 2010.
- A subsequent joint newsletter, *The Newsletter of The Paget Foundation and The Bone Cancer Foundation*, was issued in the spring of 2011.

Membership Visibility

- They do not list any current conferences on their website.
- BCF most recently worked with the International Bone and Mineral Society, as well as the Cancer and Bone Society to jointly organize the 11th International Conference on Cancer-Induced Bone Disease, which was held in Chicago, IL, on November 30-December 3, 2011.
- The organization does not have a newsroom on its website. There is no evidence that BCF conducts media outreach.

Social Media

BCF does not have any social media presence.

Media Coverage

- In the past 12 months, the Bone and Cancer Foundation has been mentioned in three articles, one article linked to pain. This article linked to a clinical trial focusing on Lyrica, which focuses on neuropathic pain associated with spinal cord injury. The article provided general information on the drug and a summary of the FDA approval.

PARTNERSHIPS

- BCF does not seem to have any corporate or industry partners.

ISSUES

- BCF addresses pain, radiation therapy, physical therapy, surgical procedures, Vitamin D deficiency and different types of cancers in its brochures.
- The BCF website does not mention hydrocodone and abuse does not seem to be a prominent issue for them.



INFLUENCE

- BCF is not active legislatively, nor do they appear to be a major influencer.

FOCUS ON PAIN MANAGEMENT

- BCF does not have a dedicated pain management section on their website.
- BCF's brochure, *Managing Pain Related to Cancer and Bone*, contains a list of medications commonly used to treat cancer in the bone, but Fentora is not mentioned.
- The opportunity seemingly exists for pain management to become a larger focus for BCF.



CANCERCARE OVERVIEW

CancerCare is a national nonprofit organization providing free professional counseling, educational programs, practical help and financial assistance. Services include support groups, counseling, educational publications, workshops and financial assistance. Services are provided by professional oncology social workers and are offered free of charge. This group uses educational resources to actively support patients seeking information about pain management and they offer prescription assistance for pain medications. They work with a number of industry sponsors and the leadership team speaks positively in the media about oncological drug developments. For those reasons, CancerCare may be a suitable partner for Teva.

ADDRESS

www.cancercare.org
275 Seventh Avenue
New York, NY 10001

ORGANIZATIONAL RESOURCES (2011)

- 126 employees
- \$18.8 million dollars revenue (\$17.7 million dollars in contributions and grants)
- \$18.3 million dollars in expenses (\$7.8 million dollars in salaries/employee compensation; \$5.3 million dollars in other expenses)

MEMBERS

- 250 volunteers and 32 members on its Board of Directors.
- The organization doesn't have members, but it serves people with cancer and caregivers for people with cancer.

VISIBILITY

Membership Visibility

- Publications include booklets and fact sheets covering a variety of topics related to specific cancer types, caregiving, interacting with HCPs, financial and insurance information, grief and loss, and side effect management.
- Two fact sheets directly related to pain management exist:
 - Controlling Cancer Pain: What You Need to Know to Get Relief
 - Opening the Door to Effective Pain Management: Getting the Facts and Getting Help
- The organization offers ConnectEducation Workshops on a variety of topics; one workshop is dedicated specifically to cancer pain: Coping with Cancer Pain: What You Need to Know
- There is a monthly eNewsletter for subscribers.
- Fundraising and special events include:
 - Team CancerCare, which enables individuals to create their own fundraising events to build awareness of and to support CancerCare
 - Girls' Night Out
 - Walks and Runs for Hope
 - Annual galas
 - Golf tournament

Social Media

CopeLink is the CancerCare blog featuring news about CancerCare services, programs and events as well as commentary about coping with cancer and other cancer-related topics.

Facebook: 5,988 likes

- The page posts links to fact sheets and information about upcoming events every couple of days.
- Followers engage with CancerCare primarily by reacting to AANP posts. Some followers post questions or concerns about loved ones.



Twitter: 3,471 followers

- Tweets are posted daily and link directly to news articles of interest, engage with followers, and retweet tweets of interest. Tweets mirror Facebook posts.

LinkedIn Group: 190 followers

The LinkedIn site is a very basic one with no information outside of a brief description of the organization.

YouTube: 12 subscribers; 5,410 video views

- 17 videos have been uploaded since its creation in April 2008.
- Most videos showcase special events and patient "stories of help and hope".

Media Coverage

- CancerCare has been referenced in approximately 700 articles in the past year. Most mentions refer to fundraising events and obituaries (families solicit donations to the organization in the name of a deceased family member).
- Helen Miller, who is the current CEO, is occasionally quoted. She was quoted in a PR Newswire release on February 13, 2013 about Astellas' presence at ASCO GU in Florida: *"We applaud companies such as Astellas that are committed to developing medicines for difficult-to-treat cancers," said Helen Miller, LCSW, CancerCare CEO. "We share their commitment to put cancer patients first."*
- Rosalie Canosa, program division director of CancerCare, has also recently been quoted in favor of oncology drug development: *"For patients with CML and Philadelphia-positive ALL who become resistant or intolerant to TKI treatments, the approval of Iclusig is very positive news," said Rosalie Canosa, program division director at CancerCare. "The addition of Iclusig to the arsenal of anti-leukemia medicines is a significant development and one that offers hope for patients coping with CML and Philadelphia-positive ALL."*

PARTNERSHIPS

- Corporate partners include AVON, Mary Kay, Revlon, Caribou Coffee, and Tic Tac.
- Industry provides grants to sponsor many of the ConnectEducation workshops.
 - Wyeth Pharmaceuticals sponsored "Coping with Cancer Pain".
 - Other industry sponsors include Amgen and Eisai.

ISSUES

- There is no explicit mention of issues relevant to Teva and/or pain management.
- They are not active on the Hill and do not seem to issue position statements.

INFLUENCE

- Given the organization's history in speaking positively about drug developments in oncology, CancerCare may be a suitable partner for Teva.

FOCUS ON PAIN MANAGEMENT

- Pain management is not a top priority for CancerCare. However, CancerCare does offer prescription assistance for pain medication.

**HEAD & NECK CANCER ALLIANCE (HNCA) OVERVIEW**

The Head and Neck Cancer Alliance seeks to enable an organized and strategic alliance of all stakeholders to dramatically shift the stage of discovery of head and neck cancers through united and collaborative efforts in prevention, early detection and research. There is, however, no focus on the management of pain. The laser focus on this organization is to raise awareness of oral, head and neck cancers since according to their recent survey, 64 percent of respondents were not aware of these cancer types. Given their limited financial and educational resources along with their focus on awareness with an omission of treatment, they are not a relevant partner for Teva at this time.

ADDRESS

<http://headandneck.org>

PO Box 21688

Charleston, South Carolina 29413

ORGANIZATIONAL RESOURCES

- Total revenue: \$260,721 (\$253,721 in contributions, gifts or grants; \$509 in investment income)
- Total expenses: \$240,673 (\$105,602 in fees for service, \$5,000 in advertising and promotion, \$101,851 in "other expenses")
- Total income: \$14,770

MEMBERSHIP

- The Head & Neck Cancer alliance has 3 chapters: Indiana, South Carolina and Louisiana, all of which have a local focus on screening events.
- The Head & Neck Cancer alliance has 15 board members, none of whom are currently a part of Fentora's speaker bureau. One for consideration, Dr. Jatin P. Shah, MD, is a board member who is the chief of the head and neck service, leader of the head and neck disease management team, and holds The Elliott W. Strong Chair in head and neck oncology at Memorial Sloan-Kettering Cancer, a leading oncology organization. Dr. Shah is a national and international leader in the field of head and neck surgery, having served as president of The New York Cancer Society, The New York Head and Neck Society, The Society of Head and Neck Surgeons, The North American Skull Base Society and the International Academy of Oral Oncology. He has served in varying capacities for The American Board of Surgery, and the American College of Surgeons.

VISIBILITY

- They launched a video contest in February 2013 among young adults who are increasingly affected by this disease. Contest participants, ages 18-24, submitted 30-second videos encouraging increased education and awareness of oral, head, and neck cancers. This ongoing contest closes at the end of March 2013.
- In addition to year-round events and awareness efforts such as public service announcements, benefit concerts, walkathons and ad hoc local chapter screening events, the Alliance sponsors Oral, Head and Neck Cancer Awareness Week (OHANCAW), a week-long series of events to promote early detection and public awareness of this disease. The event will be held this year on April 14-20, 2013.
- In 2012, their overall screening sites increased by 14 percent and received financial funding by Bristol-Myers Squibb. Results from OHANCAW in 2012 included:
 - Total number of OHANCAW sites: 337
 - Total number of people screened: 10,303
 - Total number of people referred for routine follow-up: 4,894
 - Total number of people referred for further evaluation: 1,387
 - Total number referred for immediate consultation for suspected neoplasm: 263
 - Potential lives saved due to early detection: 1,650

Social Media

Facebook: 158 likes for their organization. OHANCAW has 2,877 likes



Twitter: @OHANCAW has 341 followers

They do not have an organizational Twitter page, but manage the handle @OHANCAW for their Awareness Week activities, like the video contest.

Publications and Congresses

- Board member Itzhak Brook, MD, published a book in 2010 following a diagnosis of throat cancer and tells the story of how he faces and deals with medical and surgical treatments and adjusts to life afterwards: *A Physician's Personal Perspective with Throat Cancer*.
- E-newsletter and text alerts available from the Head & Neck Cancer Alliance.
- No annual meeting for the organization.

Media Coverage

- They received quite a bit of trade coverage regarding the launch of their national video contest as a prelude to OHANCAW in 2012.
- Contributions were requested for the Head and Neck Cancer Alliance in Richard Bay's obituary, who was a longtime publisher of the *Review of Optometry*, and, later, founder of *Review of Ophthalmology*.
- The group was recognized as a MM&M 2011 finalist - MCS Public Relations and Head and Neck Cancer Alliance—Oral, Head and Neck Cancer Awareness Week (OHANCAW)
- The Head and Neck Cancer Alliance research statistics are often used in publications (e.g. *"According to the Head and Neck Cancer Alliance, oral, head and neck cancers claim approximately 12,000 lives per year."*)
- There was significant coverage regarding the Head and Neck Cancer Alliance-sponsored cancer screenings throughout the U.S.
- Recording artist, actor and former member of The Monkees, Peter Tork, who is himself an oral cancer survivor, urged Americans to get screened for cancer during the 15th annual OHANCAW sponsored by the organization
- During throat cancer survivor Michael Douglas's interview on the Oprah Winfrey Show, the show listed a website for the Head and Neck Cancer Alliance (www.headandneck.org). The website and Douglas's treatment facility received significant attention.

PARTNERSHIPS

- Bristol Myers-Squibb (BMS) supported their screenings efforts for OHANCAW in 2012; there is currently no mention of any BMS 2013 support.
- The Head and Neck Cancer Alliance Support Community is sponsored by Head and Neck Cancer Alliance in partnership with Inspire, an online community.

ISSUES

- The Head and Neck Cancer Alliance is really focused around OHANCAW as a flagship program, and does not currently focus on any pain management resources and/or information.
- They are focused on DTP programs, and do not have a policy presence.

INFLUENCE

- The Head and Neck Cancer Alliance does not appear to be vocal in policy discussions, but is very patient driven. They do list larger organizations such as the AMA, ACS and ADA as additional resources since their organization online offering is light.

FOCUS ON PAIN MANAGEMENT

- No pain management resources or discussions are taking place.

**HOPE HOSPICE OVERVIEW**

Hope Hospice provides exemplary care, comfort and education to all affected by life-limiting illness, grief and loss. As a not-for-profit hospice organization, Hope Hospice aligns itself on every level with mission-driven values of patient-centered care, stewardship of valuable patient and community resources, an expert staff committed to excellence, being responsive to the needs of those we serve, and integrity in all they say and do. Hope Hospice does not have any public partners listed, nor do they have any pharmaceutical ties. The organization is not an influencer in this space and is more of a supportive resource for patients and their families during critical illness and end-of-life care. Given the fact that they focus more on end-of-life care and grieving, Hope Hospice would not be a good partner for Teva.

Address:

611 N Walnut Ave
New Braunfels, TX 78130
<http://www.hopehospice.net/>

ORGANIZATIONAL RESOURCES

- 105 employees.
- Revenue: \$6.5 million dollars (\$6 million dollars in program service revenue).
- Expenses: \$5.7 million dollars (\$4 million dollars in salaries and employee benefits).

MEMBERSHIPS

- There is no membership opportunity afforded by Hope Hospice aside from Board Members. None of the Board of Directors and key members of the organization are visible and seem to do more behind-the-scenes work.
- Hope Hospice has 15 members of its Board of Directors and 170 volunteers.

VISIBILITY**Publications and Congresses**

Hope Hospice has no publications, but they have informational resources on end-of-life care of their website. Additionally, Hope Hospice does not have an annual medical meeting. The only events they offer are grief counseling retreats and support groups for people who lost a loved one. As for annual events, they sponsor the following events:

- Tree of Lights
- Pete Forney Golf Tournament
- Super Summer Salad Supper
- Annual Memorial Services

Social Media

Twitter: 660 followers and 45 tweets

The handle has not been active since 2011. It was created in April 2009.

Media Coverage

- Hope Hospice has been quoted in 30 articles in the past year; however, most are not significant articles.
- Most articles are about new CEO Deb Houser, who restructured the organization.

PARTNERSHIPS

- Hope Hospice does not have any public partners listed. They do not have any pharmaceutical ties and would not be a good partner for Teva as they do not publicly focus on pain management.

ISSUES

- There are no foreseeable issues with Hope Hospice as they're a smaller support organization that is more patient-focused. Their Board of Directors is not speaking publicly.



INFLUENCE

- The Hope Hospice organization is not an influencer. They are more of a supportive resource for patients and their families during critical illness and end-of-life care.

FOCUS ON PAIN MANAGEMENT

- Hope Hospice does not have a focus on pain management. The resources provided are on death and grieving.



INTERNATIONAL SOCIETY OF NURSES IN CANCER CARE (ISNCC) OVERVIEW

As a global nursing community, ISNCC fosters the improvement of health, through cancer control. The mission of ISNCC is to maximize the role of nurses to reduce the global burden of cancer. ISNCC is focusing on building coalitions and partnerships, influencing health policy and cancer control awareness internationally, advancing and applying knowledge, and developing and engaging cancer nurse leaders. Teva research has shown that oncology nurses are often frontline caregivers who are most responsible for managing patients' pain. While not as prominent in the media, this group actively addresses pain issues in cancer. They issued a position paper in August, 2012 noting it is the responsibility of all nurses to identify and control cancer pain. They are also open to partnerships.

ADDRESS

www.isncc.org/
375 West 5th Avenue, Suite 201
Vancouver, BC V5Y1J6

ORGANIZATIONAL RESOURCES

- Not available (not published on website and not available on guidestar.org).

MEMBERS

- Globally, more than 60,000 members.
- Includes national cancer societies, regional cancer societies, oncology institutions, and individual cancer nurse practitioners, researchers, and educators.

VISIBILITY

Publications and Congresses

- Publishes a quarterly society e-newsletter, International Cancer Nursing News; distributed to 11,000 cancer nurses worldwide.
- Hosts the International Conference on Cancer Nursing (ICCN) every two years. At the last meeting in Prague, 600 delegates from 51 countries attended. The next meeting is September 11-14, 2014 in Panama City, Panama.

Social Media

ISNCC Insight: member discussion board intended to be used to share information among members.

Facebook: 213 likes

Fairly inactive on Facebook: actively posted in the days prior to and following ICCN. Most recent post was on February 18th asking for feedback on how to dispel myths and misconceptions of cancer pain control. No one has responded, but the post earned 10 likes. There have been no other Facebook mentions of pain in 2013.

Twitter: 46 followers

Tweets come out a couple of times per month to promote ICCN. Tweets mirror Facebook posts. A tweet on February 18th encouraged followers to visit the Facebook page and talk about experience dispelling myths and misconceptions of cancer pain control. No other mentions of pain.

Media Coverage

- ISNCC has been referenced in six articles in the past year. Bristol-Myers Squibb has been mentioned in three of the six articles for its financial contributions to advancing cancer nursing skills. The other three articles reference David Makumi, who won the ISNCC's Past President's Award.

PARTNERSHIPS

- Bristol-Myers Squibb Foundation is conducting a Grantee Summit, Addressing Cancer Disparities in Central and Eastern Europe, in September 2013.
- ISNCC is working with the Bristol-Myers Squibb Foundation to implement a two-year smoking cessation program, Eastern Europe Helping Smokers Quit, beginning in January 2013.
- Novartis Oncology supported a Cancer Patient Safety Framework starting in January 2012.



- GlaxoSmithKline supported Nurse-Led Small Molecule Chemotherapy Patient Education Program in January 2012.
- Pfizer supported the Clinical Trials Awareness on a Global Level Program through December 2012.
- Corporate members include Lilly and Amgen.

ISSUES

- Issued a position statement on cancer pain in October 2012, which supports strategies to improve the control of cancer pain and that ensure access analgesic medications and other effective measures to control cancer pain. Specific recommendation for nurses to advocate for change to restrictive legislations that hinder access to adequate analgesia.
- No explicit mention of other issues relevant to Teva.

INFLUENCE

- ISNCC has a Knowledge Development and Dissemination Committee dedicated to identifying opportunities to promote the role of nurses in achievement of policy objectives.
- ISNCC develops policy materials targeting key messages about cancer and the nurses role in cancer that can be used by members to promote the nurse's role locally.
- Also involved in creating international position statements on key cancer issues and providing guidelines on the use of those position statements.

FOCUS ON PAIN MANAGEMENT

- A few presentations in last year's ICCN focus on pain and pain management, including: Laying the Foundation for Nursing Management of Patients Receiving Intrathecal Analgesia for Refractory Cancer Pain and Perspectives on Patient Concerns and Considerations Regarding Treatment of Breakthrough Cancer Pain.
- Although it is not an explicit objective of the organization, ISNCC prioritizes patient access to pain management therapies.



LUNG CANCER ALLIANCE (LCA) OVERVIEW

The Lung Cancer Alliance (LCA) is a major player in the cancer patient advocacy space. Lung cancer kills by far the most amount of people, research funding lags far behind other cancers. Lung cancer is also one of the most painful cancers. While LCA receives a great deal of funding from pharmaceutical companies, it appears to be less in the form of “partnerships” and more in line with general sponsorships. LCA does not focus on pain, so there is opportunity to grow its focus, but Teva would likely not have any jurisdiction over content.

Address

<http://www.lungcanceralliance.org/>
888 16th St, NW, Suite 150
Washington, DC 20006

ORGANIZATIONAL RESOURCES

- LCA reported \$5.51 million dollars in revenue in 2011. LCA's net revenue was \$3 million dollars subtracting expenses, which is significantly higher than 2010, when their net revenue was \$205k.
 - The vast majority of 2011 revenue (93 percent) was in non-government contributions and grants. Only \$330k was from fundraising events.
 - LCA spent 33 percent of its expenses on “public awareness,” 22 percent on community and support services, and 27 percent on advocacy.
- According to its 2011 Annual Report, Pfizer and Genentech both donated \$100K+ dollars. Lilly, Celgene, GSK and OSI Pharmaceuticals donated between \$50K and \$99K dollars. Boehringer Ingelheim, Bristol-Myers Squibb, Novartis, Sanofi-Aventis and TEVA Neuroscience, Inc. donated between \$25K and \$49K dollars. Bayer and Astellas donated between \$10K and \$24K dollars.

MEMBERSHIP

- In its 2011 990 form, LCA reports 13 employees and 4,000 volunteers.
- LCA's nine-member Board of Directors includes only three physicians. Notable members include: Deborah Morosini, MD, Principal Pathologist for AstraZeneca and sister of the late Dana Reeve and Cheryl Heaton, PhD, President & CEO of the American Legacy Foundation.
- LCA recently began a 12-person National Advocate Advisory Council that comprises patients and caregivers.
- Three of its 36-member Med Ad Board are from NIH COEs in Pain Education.
- LCA includes six chapters. Most are organized by state; some are joint-state chapters. These state chapters host local LCA awareness events and fundraisers, as well as push state-based advocacy. Each chapter has one or two directors.

VISIBILITY

The LCA is the foremost lung cancer advocacy and awareness group in the space. They are pushing the bar legislatively and in their latest public awareness campaign to make lung cancer a more central focus in terms of funding, prevention and research in comparison to other cancers (i.e. breast, colon, prostate).

Social Media

Facebook: 11,202 likes

Posts daily similar to Twitter: patient and caregiver stories shared with the hashtag #Catalysts to Keep Fighting, donation asks, and lung cancer “Fact Fridays”.

Twitter: 1,071 followers; 940 following

Tweets multiple times a day, including patient and caregiver stories (all tweeted with the hashtag #CatalyststoKeepFighting), lung cancer news and research, LCA services, programs and events; handle interacts with other patient groups, KOLs, media and medical centers handles.

LinkedIn: 40 followers

Posts about once every three days with much of the same info shared on Twitter and Facebook.

YouTube: 65 subscribers, 38,848 video views, 31 videos

Videos include several PSAs, as well as ads for the “No One Deserves to Die” campaign, a recap of their 2012 Capitol Hill lobby day, survivor stories and other event videos.



Media Coverage

- In the past year, LCA has been mentioned in 169 articles. This excludes obituaries. It is often mentioned in articles along with the Pancreatic Cancer Action Network.
- Laurie Fenton Ambrose, President and CEO, is quoted most often.
- Most articles are generated by LCA or other patient advocacy organization press releases about lung cancer or general cancer policy, including increased screening, research and implementation of the ACA.
- Coverage spiked around Lung Cancer Awareness Month in November (45 articles), as LCA led several local "vigil" events and increased their communications.
- In June 2011, the LCA launched a multi-faceted national awareness campaign across 31 markets called "No One Deserves to Die" that gained a great deal of attention for its audacity. The campaign generated 281 million impressions and focused on eliminating the stigma of lung cancer.

Publications

- LCA sends news, policy and legislation alerts, as needed, to its database of more than 80,000, two per month on average.
- The president of LCA, Laurie Fenton-Ambrose, posts to their blog about once per week. No posts are about pain.
- LCA publishes two newsletters: a biannual Lung Cancer Alliance Newsletter and an annual Lung Cancer Alliance Clinical Trials Newsletter. However, neither has been published since 2011.
- They provide several patient education materials, but none of them are about pain.
- Their online patient community, LungLoveLink, comprises 1,137 members. Patients are active and can hold discussion forums, write blog posts, access LCA services, etc. There are about 90 topics and blog posts on various pain issues, including medication.

PARTNERSHIPS

- They often partner with the Legacy Foundation on a variety of lung cancer-centric initiatives.
- LCA partnered with numerous local HCPs for its Screen for Lung Cancer program, which designates where patients can get a scan.
- Outside of the general sponsorships from pharmaceutical companies (listed above), it does not appear that LCA has outright partnered with any pharmaceutical company on an initiative.
- LCA is a member of the Access to Medical Imaging Coalition, which includes several medical imaging companies like Siemens and GE, as well as medical societies and patient advocacy groups.
- LCA is a major player in the cancer patient advocacy space and has partnered with numerous medical societies and patient advocacy groups, including the American Cancer Society, the Pancreatic Cancer Action Network, Vietnam Veterans of America, etc. on a number of policy issues and support programs.

ISSUES

- LCA offers patient information about palliative care, hospice care, end-of-life care and chemotherapy pain side effects. However, while the information appears to support these issues when appropriate, LCA does not offer positions, nor does it prioritize these issues.
- LCA has no positions on any Teva issues.

INFLUENCE

- LCA is the world's largest lung cancer advocacy organization.
- More than 150 medical centers across the U.S. have adopted the LCA's 2011 National Framework for Lung Screening Excellence and Continuum of Care and have established lung cancer screening programs within their continuum of care.
- LCA worked with Milliman Inc. to conduct and publish a study in *Health Affairs* that demonstrates the cost-benefit results of lung cancer screening, serving to advance the LCA's advocacy priorities.
- LCA has three signature national awareness events: National Shine a Light on Lung Cancer Vigil, and Team Lung Love, which it uses to build grassroots advocacy in each state.



- LCA has garnered the support of 50 leading international organizations to join its call to action to have the government make lung cancer mortality reduction a national priority.
- LCA sponsors an annual “Storm the Hill” advocacy event. It’s last reported event included 70 participants representing 27 states.
- LCA is ranked #11 among the country’s leading cancer charities on Philanthropedia. LCA also received the Leadership in Advocacy Award by the Congressional Black Caucus.
- LCA has garnered more than 50 patient advocacy groups, medical institutions and medical societies to support its Lung Cancer Mortality Reduction Act. Its priority legislation has been introduced in the last three Congresses and currently has 46 House cosponsors and 28 Senate cosponsors.
- In addition to its annual Capitol Hill lobby day, LCA says it visits the Hill multiple times per week (its office is one block from the White House) and encourages patients visiting DC to organize office visits.
- LCA has a [CapWiz website](#) that allows for users to locate and contact their members of Congress.

FOCUS ON PAIN MANAGEMENT

- LCA does not focus on pain management. While it has patient education information on palliative, hospice and end-of-life care, much of its related resources are simply links to other organizations.
- Its members do not prescribe. The organization is largely patient-focused.
- Pain management could certainly be a larger focus of the organization, as lung cancer is one of the most painful types of cancers. However, most of the LCA’s advocacy is prioritized on increasing lung cancer research, early detection, etc., not on improving quality of life when patients are diagnosed.



LUNG CANCER FOUNDATION OF AMERICA (LCFA) OVERVIEW

Lung Cancer Foundation of America (LCFA) is strongly focused on raising money to fund research that will improve the five-year survival rate of lung cancer. LCFA is a relatively new organization, established in 2007, and does not seem to be a major influencer in the cancer arena, nor is it a very visible organization publicly. LCFA accepts pharmaceutical companies as sponsoring partners, but Teva is not currently one of them. Opportunities may be limited with LCFA, as pain management does not seem to be a focus of their organization.

ADDRESS

www.lcfamerica.org
15 S. Franklin Street
New Ulm, MN 56073

ORGANIZATIONAL RESOURCES

- Total revenue: \$275K dollars (\$260K dollars in contributions, \$15K dollars in special events, \$324 dollars in investments).
- Total expenses: \$227K dollars (\$116K dollars in program services, \$67K dollars in administration, \$42K dollars in "other").

MEMBERSHIP

- LCFA's website does not offer any information about its membership size or composition.
- According to Guidestar, the group has no volunteers and six members of its Board of Directors.

VISIBILITY

Despite its seeming lack of visibility, the LCFA has a well-designed website, professional website.

Publications

- LCFA published the *Targeted Therapies Brochure*, addressing testing and therapies. The only therapy mentioned by name is Genentech and Astellas' Tarceva (erlotinib), but there is no mention that the brochure is funded by them.

Membership Visibility

- There is one fundraiser posted for 2013. A local biker is biking 75 miles to fundraise.
- LCFA does not have an annual meeting.

Social Media

Facebook: 1,800+ followers

Semi-regular posts about research updates, events, organization news.

Twitter: 95 followers

Semi-regular tweets by founder Lori Monroe.

Media Coverage

- Excluding obituaries, LCFA was mentioned in three articles in the past year.
- Two were not original stories – one was a press release about LCFA's new website launch in February 2013, the other a media advisory about a local fundraising event.
- Kim Norris, LCFA president, was quoted in a *Times Union* article about the need for increased lung cancer research funding.

PARTNERSHIPS

- LCFA provides links to pharmaceutical patient support and assistance programs on their website for the following companies (Teva is not included): AstraZeneca, Astellas, Boehringer Ingelheim, Celgene, Genentech, Lilly, Novartis, Pfizer, Sanofi.
- LCFA lists the linked logos of their sponsoring partners on their Donor Honor Roll page: Genentech, Pfizer, Infinity, Biodesix. There is no information as to what level of support constitutes a sponsoring partnership.



ISSUES

- LCFA's main issues are information dissemination and fundraising to endow researcher grants. However, LCFA does not sponsor many active fundraising events.
- LCFA's research page provides information on trials, events and topics related to lung cancer, but it is not consistently updated, nor does it seem to be a comprehensive reflection of the most cutting-edge scientific work.
 - There is no information on LCFA's website about the scheduling or relabeling of hydrocodone or about pharmaceutical abuse, nor about other pain issues of interest.

INFLUENCE

- LCFA is not active legislatively, nor is it a prominent influencer in the cancer arena.

FOCUS ON PAIN MANAGEMENT

- LCFA does not have a dedicated pain management section to their website, nor does pain management seem to be a focus of their organization.
- There may be an opportunity for pain management to become a larger focus for LCFA.



NATIONAL COMPREHENSIVE CANCER NETWORK (NCCN) OVERVIEW

The National Comprehensive Cancer Network (NCCN) is focused on ensuring the quality of cancer care and treatment for patients. NCCN is an alliance of 21 leading cancer centers around the world devoted to patient care, research, and education. Teva has an active involvement with NCCN, serving on the Corporate Council, being listed on the NCCN home page as a website supporter, and providing educational grants for nursing programs on cancer pain. Although not active legislatively, NCCN is influential in the cancer arena. NCCN appears to be a good option for continued Teva partnership, with the potential for additional focus on pain management initiatives.

ADDRESS

www.nccn.org

275 Commerce Drive, Suite 300
Fort Washington, PA 19034

ORGANIZATIONAL RESOURCES (2010)

- Total revenue: \$25 million dollars (\$22 million dollars in contributions, \$2.8 million dollars in program services, \$236K dollars in "other". \$152K dollars in investments)
- Total expenses: \$26 million dollars (\$23 million dollars in program services, \$2.8 million dollars in administration, \$825K dollars in "other").

MEMBERSHIP

- NCCN is comprised of 21 leading US cancer centers, including eight oncology COEs:
 - City of Hope Comprehensive Cancer Center, Los Angeles, CA
 - Dana-Farber Cancer Institute
 - Brigham and Women's Cancer Center
 - Massachusetts General Hospital Cancer Center, Boston, MA
 - Huntsman Cancer Institute at the University of Utah, Salt Lake City, UT
 - Memorial Sloan-Kettering Cancer Center, New York, NY
 - Moffitt Cancer Center, Tampa, FL
 - The University of Texas MD Anderson Cancer Center, Houston, TX
- There are nearly 108,000 NCCN.org users, including a primary audience of more than 32,000 physicians. The audience includes oncologists and other physicians, advanced practitioners, oncology nurses, hospital and practice administrators, and representatives from health plans.

VISIBILITY

NCCN sponsors a variety of nursing programs, the Academy for Excellence and Leadership in Oncology, a Fellows Recognition Programs and a webinar series.

Publications and Congresses

- The *Journal of the National Comprehensive Cancer Network* is a peer-reviewed, indexed medical journal that provides the latest information about best clinical practices, oncology outcomes, and new research initiatives. *JNCCN* features updates on the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®), timely reviews and commentaries elaborating on guideline recommendations and expanding on important themes and emerging practices, and health services and clinical research papers. *JNCCN*'s goal is to improve the quality of cancer care by addressing oncology practice for all disease stages and presentations. Content covers the entire spectrum of oncologic health care, from prevention and screening to treatment and supportive care.
- *NCCN Clinical Practice Guidelines in Oncology* (NCCN Guidelines®) include:
 - Treatment of Cancer by Site
 - Detection, Prevention, & Risk Reduction
 - Supportive Care
 - Age Related Recommendations
 - Patients
- The *NCCN Drugs & Biologics Compendium* (NCCN Compendium®) contains authoritative, scientifically derived information designed to support decision-making about the appropriate use of



- drugs and biologics in patients with cancer.
- The *NCCN Biomarkers Compendium*™ contains information designed to support decision-making around the use of biomarker testing in patients with cancer.
- NCCN Chemotherapy Order Templates* (NCCN Templates®) are a library of chemotherapy order templates to improve the safe use of drugs and biologics in cancer care. They are intended for personal and practical use only and include chemotherapy, immunotherapy, supportive care agents, monitoring parameters, and safety instructions.
- The *NCCN Guidelines for Patients*® are meant to help patients with cancer speak with their treating oncologists, about their best treatment options.
- NCCN Flash Updates™ is a subscription service from NCCN that provides timely access to updated and new information appearing in the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®), the NCCN Drugs & Biologics Compendium (NCCN Compendium™), and other NCCN Content.
- NCCN eBulletin* is an electronic newsletter delivered every other Monday to all registered users of NCCN.org. *NCCN eBulletin* features articles on topics including clinical and operational trends in the delivery of cancer care and the oncology health policy environment, notification of recent updates to the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®), and links to notable advances in treatment and research at NCCN Member Institutions. Content bridges clinical, policy, and operational perspectives and includes notifications of NCCN updates and news.
- NCCN's 18th Annual Conference: Advancing the Standard of Cancer Care™ was March 13-17, 2013, in Hollywood, FL
- NCCN 8th Annual Congress: Hematologic Malignancies™ is September 20-21, 2013, in New York, NY.

Social Media

Facebook: 3,100+ followers

Actively posts news, information and profiles on cancer-related issues and topics.

YouTube: 85 subscribers, over 8,100 video views

101 videos posted on a variety of cancer-related issues and topics.

Media Coverage

- NCCN was mentioned in 735 articles in the past year.
- The vast majority of articles referenced NCCN's clinical practice guidelines and recommendations, especially in pharmaceutical company research news announcements. Other articles often mention a person is a member of NCCN, or NCCN resources. Some hospitals like City of Hope list that it is a founding member of NCCN in their boilerplate, which generates about 1/7 of coverage.
- NCCN really was only quoted in one article about pain; the article noted NCCN recommends regular moderate exercise as a non-drug therapy to alleviate chemotherapy pain.

PARTNERSHIPS

- NCCN website supporters include Teva, Sanofi, Onyx, Genomic Health, Epocrates and Ariad. Linked logos are listed at the bottom of the NCCN home page.
- NCCN Health Information Technology Licensees include 15 pharmaceutical and other healthcare companies. Teva is not included. Linked logos are listed at the bottom of the NCCN home page.
- The NCCN Corporate Council is comprised of 39 pharmaceutical companies, including Teva. Logos and links are provided.
- There is no information on the cost of a Corporate Council membership.
- NCCN made the following statement related to pharmaceutical and advocacy financial ties: "We also appreciate the recognition of NCCN's necessary autonomy in all decision-making regarding the conclusions, recommendations and outcomes of NCCN programs and Resources" (see link above).
- NCCN offers the following collaboration opportunities:
 - o Live NCCN International Congresses and Symposia
 - o eBulletin International Newsletter
 - o Global Leadership Exchange



- Oncology Outcomes Database
- NCCN Trends™
- Oncology Research Program (ORP)
- Select advertising placements offer opportunities for organizations to position their products and services in NCCN eBulletin.

ISSUES

- In December 2010, NCCN partnered with the National Business Group on Health to develop and launch, *An Employer's Guide to Cancer Treatment & Prevention*. The Guide is intended to be a resource that can be readily applied to many aspects of an employer's benefit life cycle, including: benefit planning and implementation; request for proposal (RFP) development, review, and scoring; vendor management; and plan administration and evaluation. When completed in late 2013, the Guide will address issues related to cancer across the continuum of care, including prevention and wellness; medical, pharmacy, and behavioral health benefits; employee assistance programs; and disability and family medical leave.
- Through NCCN.com, the group provides people with cancer and the general public state-of-the-art cancer treatment information in easy-to-understand language. The goal of this website is to educate people about cancer so they can have more informed conversations with your doctors and other HCPs and ultimately live longer and better quality lives. NCCN.com includes information on all facets of cancer, from prevention and screening through life after cancer.
- The NCCN website does not mention hydrocodone.
- Prescription drug abuse does not seem to be a prominent issue for NCCN.

INFLUENCE

- Through private philanthropy and grants, the NCCN Foundation advances the mission of the National Comprehensive Cancer Network to improve the quality and effectiveness of care to patients with cancer. Chaired by Sam Donaldson, ABC News veteran and a cancer survivor, the NCCN Foundation Board of Directors is comprised of members from various corporations, academic medical institutions, and advocacy groups who are committed to gaining philanthropic support for resources and programs for patients with cancer as well as research dollars to further the advancement of cancer treatments.
- NCCN is not active legislatively.
- NCCN can be considered an influencer in cancer treatment.

FOCUS ON PAIN MANAGEMENT

- NCCN does not have a dedicated pain management section of their website.
- NCCN's 2012 Nursing Program: Advancing Oncology Nursing webinar series, "Cancer Pain: Current Challenges and Breakthroughs" provided oncology nurses with comprehensive and clinically relevant information regarding the management of patients with cancer. This program was supported by education grants from TEVA Oncology, Bayer HealthCare Pharmaceuticals Inc., Genentech, Janssen Biotech Services, LLC, Merck Oncology, Pfizer, sanofi-aventis U.S. and Regeneron Pharmaceuticals. This activity was supported by an educational donation provided by Amgen. The objectives of this program were to:
 - Describe current challenges for successful cancer pain management, including management of breakthrough pain.
 - Describe recent advances in the pharmacologic therapy of cancer pain.
 - Discuss cases that illustrate these challenges and breakthroughs
- The opportunity seemingly exists for pain management to become a larger focus for NCCN.



ONCOLOGY NURSING SOCIETY (ONS) OVERVIEW

The Oncology Nursing Society (ONS) is a professional organization comprised of more than 25,000 oncology nurses from the U.S. that promotes excellence in oncology nursing and quality cancer care. Cephalon Oncology is listed as an ONS Lifetime Sustaining Member and joins the ranks of other organizations and corporations such as University of TX MD Anderson Cancer Center (COE). However, there are several opportunities for Teva CNS to gain more visibility with the organization and help them make pain management more of a priority. For example, Teva could work in conjunction with ONS to sponsor informational sessions at their annual meeting, much like what Purdue Pharmaceuticals and Endo have done previously. ONS has a strong focus on pain management and acknowledges the many issues experienced in this area of expertise. While they have pain management resources available on their website, there is still room for growth.

ADDRESS

125 Enterprise Drive
Pittsburgh, PA 15275
<http://www.ons.org/>

ORGANIZATIONAL RESOURCES

- 152 employees.
- Annual revenue: \$21.6 million dollars (\$10 million dollars in program services, \$4.5 million dollars in contributions and grants, \$6.5 million dollars in other revenue).
- Annual expenses: \$21.4 million dollars (\$17.6 million dollars for programming, \$2.9 million dollars in administration, \$416K dollars in fundraising).

MEMBERSHIP

- Over 37,000 members of ONS represent nurses from all over the world and from many different practice areas.
- ONS members are a diverse group of professionals who represent a variety of professional roles, practice settings, and subspecialty practice areas. Registered nurses, including staff nurses, advanced practice nurses, case managers, educators, researchers, and consultants, and other healthcare professionals, benefit from membership.
- It has grown to include 232 chapters and 28 special interest groups.
- ONS has 10 members of its Board of Directors and 150 volunteers.

VISIBILITY

Publications and Conferences

- *Oncology Nursing Forum*: An official journal of the Oncology Nursing Society, the *Oncology Nursing Forum* is a bi-monthly publication with a circulation of over 35,000. Its mission is to convey research information related to practice, technology, education, and leadership; disseminate oncology nursing research and evidence-based practice to enhance transdisciplinary quality cancer care; stimulate discussion of critical issues relevant to oncology nursing.
- *Clinical Journal of Oncology Nursing (CJON)*: An official publication of the Oncology Nursing Society, it is directed to the practicing nurse specializing in the care of patients with an actual or potential diagnosis of cancer. CJON is a bi-monthly publication with a circulation of over 35,000 and is a vehicle to advance the mission of ONS, which is to promote excellence in oncology nursing and quality cancer care. The CJON mission is twofold: to provide practical information necessary to care for patients and their families across the cancer continuum and to develop publication skills in oncology nurses.
 - Libraries and healthcare institutions in 22 countries subscribe to the Oncology Nursing Forum and Clinical Journal of Oncology Nursing.
- *ONS Connect*: The official magazine of ONS and reaches more than 37,000 oncology professionals every month. It provides timely news and resources to oncology nurses that can be incorporated easily into daily practice. It also communicates ONS updates and news and reinforces ONS as an industry leader and an authority in the healthcare field.



- Connections: Advancing Care through Science meeting: November 8-10 in Dallas, TX; this one-of-a-kind event brings an elite group of cancer nursing leaders together to discuss and disseminate knowledge to drive evidence-based practice. The meeting showcases the cause and effect of nursing science and practice on the quality of cancer care. It highlights the importance of collaboration between nurse scientists and clinicians to ensure they are working together for the good of patients with cancer.
- Annual Congress: April 25-28 in Washington, DC; Participants number nearly 3,000 oncology nurses, including staff nurses, nurse practitioners, educators, administrators, nurse scientists, and others involved in the care of patients with cancer.
 - As part of the Annual Congress, participants can spend one day on Capitol Hill lobbying members of Congress. ONS recognizes Congressional leaders at these events.

Social Media

Facebook: 11,186 likes

Since its founding in October 23, 2008, posts occur several times a week, and sometimes, several times a day. It brings attention to the latest news in the oncology space and features information on the annual congress.

Twitter: 6,639 followers; 1,926 tweets

Posts mirror Facebook content and are sent out multiple times a day.

YouTube: 83 video views, 11 playlists and 41,784 views

- ONS does not have an official YouTube page; however, an account has been created by “Eric Marchetta” and features various ONS videos.
- Videos feature ONS members, congress seminars and presentations, highlights of oncology nursing month, and educational and learning opportunities.

Media Coverage

- There have been 170 stories mentioning ONS in the past year. Of those stories, 10 of these have also mentioned pain.
- Many of the articles appear in oncology trade publications and feature the latest news out of the ONS Annual Congress.
- There are also articles covering new advancements in the oncology space.

PARTNERSHIPS

- ONS offers a wide range of sponsorship opportunities to connect with members and reach your target audience at our national conferences and other popular ONS venues.
- ONS’ Seal of Approval program assists HCPs and consumers in selecting quality educational materials related to cancer care. The ONS Seal of Approval ensures that the information presented—in educational seminars, publications, or other resources—is reliable and credible.
- The new ONS Strategic Sponsor Program is an exclusive, high-level sponsorship available to a limited group of industry supporters.
- Strategic partners include: Millennium Pharmaceuticals, Inc., Amgen, Inc., Eisai, Inc., Lilly USA, LLC, Genentech, Inc.
- Lifetime sustaining members include more than 25 pharmaceutical companies, and one academic institution: University of TX MD Anderson Cancer Center. Cephalon, Pfizer Oncology and Purdue Pharmaceuticals are among the sponsors.
- Endo Pharmaceuticals and Purdue Pharmaceuticals sponsored a “Cancer Pain in Special Populations” seminar in conjunction with ONS in 2012. The seminar provided a comprehensive overview of pain assessment, diagnosis, and management of cancer pain syndromes, along with networking opportunities with local oncology nurses.

ISSUES

- ONS joined the U.S. Department of Health and Human Services in the Partnership for Patients program to make hospital care safer, more reliable, and less costly by decreasing preventable hospital infections and re-admissions. ONS pledged to reduce harm and preventable re-admissions and improve care transition and coordination.



- ONS' health policy office worked with U.S. Representatives Steve Israel (D-NY), Patrick Tiberi (R-OH), Lois Capps (D-CA), and Steven LaTourette (R-OH) on ONS's signature legislation to provide for Medicare reimbursement for the time of registered nurses to educate people diagnosed with cancer and their caregivers about their treatment plans. The bill was reintroduced in the House in early 2012.

INFLUENCE

ONS is recognized in Washington as an influential voice on matters related to the oncology nursing profession and cancer care. ONS members make their voices heard on Capitol Hill and in their own home towns while continuing to advocate for cancer services reimbursement, access to care and clinical trials, and nursing practice issues.

- In 2011, ONS leadership met with senior directors of the National Institute of Nursing Research, National Cancer Institute, and the U.S. Food and Drug Administration, and nominated eight ONS members to five federal agency regulatory advisory boards.
- ONS member Patrick Coyne, MSN, APN, FAAN, testified before the Subcommittee on Commerce, Manufacturing, and Trade, of the Energy and Commerce Committee, on the need for appropriate prescription pain medication for patients with cancer who suffer from unrelieved pain. Coyne reminded the committee that although risks exist for the misuse of opioid medication, discussions about prescription pain medications needs a balanced approach to consider the benefits to patients experiencing moderate or severe pain.
- Since 1981, the ONS Foundation has provided more than \$22 million dollars to fund local and national oncology nursing education, research to advance oncology nursing science, and leadership opportunities.
- ONS also has a for-profit subsidiary, ONS:Edge, which provides clients access to ONS' 37,000 members and KOLs for healthcare advisory boards, ancillary events at oncology nursing conferences, speaker bureau programs, strategic planning and marketing support, market research, and communications and awareness campaign development and support. Clients have included large pharmaceutical, biotech, and medical equipment industries.
 - Its leadership comprises pharmaceutical industry reps (Anne Marie Robertson, MBA of Pfizer is president), as well as leadership from ONS and other academic medical centers.

FOCUS ON PAIN MANAGEMENT

- ONS has a strong focus on pain management and acknowledges the many issues experienced in this area of expertise.
- ONS member Patrick Coyne, MSN, APN, FAAN, testified before the Subcommittee on Commerce, Manufacturing, and Trade, of the Energy and Commerce Committee, on the need for appropriate prescription pain medication for patients with cancer who suffer from unrelieved pain. Coyne reminded the committee that although risks exist for the misuse of opioid medication, discussions about prescription pain medications needs a balanced approach to consider the benefits to patients experiencing moderate or severe pain.
- ONS PEP Resources (Putting Education into Practice) are designed to provide evidence-based interventions for patient care and teaching. ONS has an entire PEP page focused on pain management and provides handouts and resources, such as a pain definition list.
- ONS also posted their position on cancer pain management on their website. They provide 18 topline stances regarding pain management. For example:
 - All people with cancer have a right to optimal pain relief that includes culturally relevant and sensitive pain education, assessment, and management.
 - Regulatory, legislative, economic, and other barriers to effective cancer pain management must be eliminated.
 - Healthcare professionals, particularly nurses, pharmacists, and physicians, are accountable to manage cancer pain effectively.



PANCREATIC CANCER ACTION NETWORK (PANCAN) OVERVIEW

The Pancreatic Cancer Action Network (PANCAN) is the national organization focused on better awareness of and treatment for pancreatic cancer through research, patient support, community outreach and advocacy for a cure. The organization raises a significant amount of money for direct private funding of research and vocally advocates for more aggressive federal research funding of medical breakthroughs in prevention, diagnosis and treatment of pancreatic cancer. Although their communication does not currently specifically focus on pain and pain management, because pancreatic cancer is a cancer that often causes breakthrough cancer pain and the breadth and depth of PANCAN, this organization can provide a strong channel to disseminate pain care messaging.

Address:

www.pancan.org
1500 Roscrant Avenue, Suite 200
Manhattan Beach, CA 90266

They also have a bi-coastal office in Washington, DC.

ORGANIZATIONAL RESOURCES

- Total 2011 revenue was \$16.5 million dollars (an increase of more than \$3 million dollars from 2010); total 2011 expenses were about \$15 million dollars (net income \$1.3 million dollars).
 - PANCAN receives the most funding (\$17 million dollars) from contributions and fundraising, but had a \$1.5 million dollars loss in 2011 on fundraising event costs, dropping its total revenue.
 - PANCAN's largest single expense is its grant money (\$3.4 million dollars), as well as \$1 million dollars in conferences/symposia, nearly \$1 million dollars in "occupancy" but a modest salary investment of \$346K dollars) due to the fact that it is largely driven by 2,000 volunteers, with 93 full-time employees on staff.

MEMBERSHIP

- PANCAN has a national board of directors, a scientific advisory board, emeritus scientific board, medical advisory board, emeritus medical advisory board and a volunteer advisory council.
 - The Volunteer Advisory Council (VAC) is a group of Pancreatic Cancer Action Network volunteers who provide feedback and advice to the Pancreatic Cancer Action Network with regard to the Community Outreach program, volunteer affiliate network and other initiatives of the organization.
- PANCAN's leadership team is a group of individuals, several who have been personally touched by the loss of a loved one from pancreatic cancer, who have worked some of the largest non-profit and for profit organizations including: Susan G Komen Foundation, The American Heart Association, Microsoft Corporation, Deloitte and the American Cancer Society.
- PANCAN has a scientific advisory (12), an emeritus scientific (6) and a medical advisory board (14). The scientific advisory board is comprised of physicians who specialize in the care of people with pancreatic cancer. None of the advisory board members correlate with the current Teva speakers' bureau.
- However, 6 of the Scientific Advisory board members are affiliated with the NIH pain education Centers of Excellence (COEs):
 - Johns Hopkins: Anirban Maitra; Christine Iacobuzio-Donahue
 - University of California: Frank McCormick; Margaret Tempero
 - University of Pennsylvania: Robert Vonderheide; Anil Rustgi
- Three of the Scientific Board Emeritus members are affiliated with pain COEs:
 - Johns Hopkins: Ralph Hueban; Elizabeth Jaffee
 - University of Washington: Teri Brentall
- Two of the Medical Advisory board members are affiliated with pain COEs:
 - Johns Hopkins: Joseph Herman; Marcia Canto
- While not listed as an NIH COE, leading cancer organization Memorial Sloan-Kettering is the listed affiliation for two of the board members (1 Scientific: Craig Thompson; 1 Medical: Eileen O'Reilly).
- This highly connected group of board members may present opportunities to further engage with pain COEs.



VISIBILITY

PANCAN has significant grassroots reach. Because pancreatic cancer is such an impactful disease, its volunteers tend to be very engaged. It has two grassroots local events that contribute to its local visibility:

- PurpleStride Signature Events: PANCAN coordinates more than 50 walks and runs nationwide.
- TEAMHOPE provides an opportunity to participate in a variety of athletic events, while raising funds and awareness for the fight against pancreatic cancer, through either its National Marathon Team, and established team of runners and walkers for several marathons and half-marathons throughout the year or the Individual Program that allows runners and walkers to participate in the race of their choice as Hope Athletes or Hope Champions.

Social Media

PANCAN is incredibly well connected through social media channels, including Facebook, YouTube, LinkedIn, Twitter and Pinterest and is engaged across all channels with its communities. All social media channels are displayed on each Web page on PANCAN.org

Facebook: 818 likes

Very active FB page with daily posts, mainly focused on its fundraising events and opportunities to get involved.

Twitter: 8,557 followers

YouTube: 612 subscribers and nearly 1 million video views; 13 videos

- The PANCAN YouTube page includes an easy donation "click" button for a POP opportunity to contribute while watching the videos.
- Videos highlight the ability to get involved in clinical trials, personal testimony and information about the PALS program for better patient assistance.

LinkedIn: 1,308 members

The group is a professional group and is locked for members only.

Pinterest: 18 boards, 836 pins, 1,567 followers.

The PANCAN Pinterest board is robust with sharing photos from fundraising efforts and PANCAN activities nationwide.

Media Coverage

PANCAN had significant media coverage ranging from recent legislation and awareness events to contribution suggestions in obituaries.

- Julie M. Fleshman, president and CEO of the Pancreatic Cancer Action Network, is vocal in the media.
- January enactment of the federal "Recalcitrant Cancer Research Act of 2012," representatives of the PANCAN including President and CEO Julie M. Fleshman and the widow of actor Patrick Swayze, Lisa Niemi Swayze, and U.S. Sen. Sheldon Whitehouse spoke.
 - Substantial media coverage of Lisa Niemi Swayze and PANCAN's fight to get legislation passed.
- Rhode Island Democrat Sen. Sheldon Whitehouse was presented with an award from PANCAN for his work to increase research on cancers that are difficult to detect and treat, including those of the pancreas, liver, lungs and ovaries.
- An overwhelming number of obituaries came up in the PANCAN search, as many people requested contributions be made to the organization in honor of deceased loved ones.
- Local event coverage for fundraising efforts for PANCAN.
- PANCAN research statistics are often used in publications (ex: According to PANCAN's website, about 2 percent of federal funding distributed by NCI is given toward pancreatic cancer initiatives.)
- PANCAN issued a press release on behalf of Celgene Corporation that reported ABRAXANE(R) clinical trial success in patients with metastatic pancreatic cancer.
- PANCAN call to action for increased clinical trial participation to help improve patient outcomes for pancreatic cancer in conjunction with National Pancreatic Cancer Clinical Trials Awareness Month.
- PurpleStride and PurpleSwim event coverage.
- The National Comprehensive Cancer Network and PANCAN announced the latest addition of patient-friendly translations of the NCCN Clinical Practice Guidelines in Oncology.



Publications

- PANCAN published *The Alarming Rise of Pancreatic Cancer Deaths in the United States: Why We Need to Stem the Tide Today*, written by the organization's Research and Scientific Affairs team, and led by their VP of Scientific and Medical Affairs Lynn Matrisian, PhD. This publication is an impetus for their 2020 vision to double survival rate by the year 2020 (see Issues below).

PARTNERSHIPS

- PANCAN is highly respected and engaged with a variety of consumer, pharmaceutical and individual memorial foundations given the volume of sponsors and contributors to the organization across many levels. Some highlights include:
 - Visionary Donors (\$1 million dollars): Genentech, Temper-Pedic
 - Platinum Donors (\$500K to \$999K dollars): Celgene, Eli Lilly, Palette Fund
 - Gold Donors (\$250K to \$499K dollars): BMS, Jones Day, Z Galleries
 - Silver Donors (\$100K to \$249K dollars): Bank of America, OSI Pharmaceuticals, Pfizer, Roche, Sanofi, *Star Magazine*
 - Bronze Donors (\$50K to \$99K dollars): Abraxis Bioscience, LLC, Amgen, Infinity Pharmaceuticals, Cancer Treatment Centers of America, Millenium Pharmaceuticals, Inc., Polo/Ralph Lauren, Honda
 - Patron Sponsors (\$25K to \$49K dollars) ImClone Systems, Clovis Oncology, MGI Pharmaceuticals, Novartis, Sealy, Sprint and Wolfgang Puck
- They have also named Lisa Niemi Swayze, wife of the late Patrick Swayze, as "Chief Ambassador of Hope," and she is featured on the site with a message about getting more involved in the fight against pancreatic cancer. Mindy Kaling, star and writer of "The Office" and "The Mindy Project" is a PANCAN supporter and featured in one of the YouTube videos.

ISSUES

- PANCAN is focused on their 2020 Vision of Progress, which is to double the pancreatic cancer survival rate by the year 2020. The five-year survival rate lingers at just 6 percent and, because projections indicate that pancreatic cancer will move from the nation's fourth to the second leading cause of cancer death by 2020, the organization is vocal on the Hill and focused on securing additional funds for research.
- Since 2003, PANCAN has funded 80 research grants totaling nearly \$13 million dollars.
- They have a strong office in Washington D.C. focused on educating elected officials about pancreatic cancer and the need to increase federal research funding dedicated to studying the disease. Their advocacy efforts have helped to increase federal funding for pancreatic cancer research from just over \$17 million in 1999 to nearly \$100 million dollars in 2011, an \$82 million dollars increase.
- Just recently in January 2013, President Obama made history in the fight against pancreatic cancer by signing the *Recalcitrant Cancer Research Act* into law. The legislation, formerly known as the *Pancreatic Cancer Research and Education Act*, passed the U.S. Congress on December 21 after it was attached to the *National Defense Authorization Act*. It requires the National Cancer Institute (NCI) to examine its current research efforts on cancers with very low survival rates and work to develop early detection methods and better treatment options to help improve outcomes for those diagnosed with the most deadly forms of cancer, including pancreatic and lung cancer.

INFLUENCE

PANCAN is focused on achieving its mission through: research, government affairs and advocacy efforts, patient and liaison services, community outreach and donor and corporate relations.

- Through PANCAN's research grants and advocacy efforts to increase federal funding for pancreatic cancer research, they attract investigators with innovative ideas and early career scientists to study pancreatic cancer. They continue to build a comprehensive research community through recruitment, poised to make significant scientific discoveries.
- PANCAN brings together the research community - scientists, government, and industry - to share information and resources and to form collaborations, offering educational webinars for scientists and they are worked with the American Association for Cancer Research (AACR) to develop the only national scientific conference focused specifically on pancreatic cancer in 2012.



- To date, the Pancreatic Cancer Action Network has awarded 66 grants at biomedical research institutions throughout the US, with a total investment surpassing \$10 million dollars.
- The PANCAN Patient and Liaison Services (PALS) has connected more than 65,000 people (patient and caregivers with staff) who provide comprehensive information and resources about the disease, including treatment options, clinical trials, and diet, all free of charge. As of 2012, more than 65,000 individuals have been served by the PALS program.

FOCUS ON PAIN MANAGEMENT

- Although pain management is not explicitly mentioned or focused on, PANCAN's comprehensive PALS program may be an excellent opportunity to engage on including discussion about pain management. This robust program connects families and loved ones to staff to discuss diagnosis and disease management.
 - Because PANCAN is a highly respected and visible organization focused on a cancer that has a high propensity of breakthrough cancer pain, this could be an opportunity to begin engaging with them to get pain management messages out to a wide audience through a multi-channel approach.

**SUSAN G. KOMEN FOR THE CURE (SGK) OVERVIEW**

Susan G. Komen for the Cure (SGK) is a major influencer in the breast cancer arena, and can largely be credited with initiating the global breast cancer awareness and prevention movement. SGK is highly visible and active legislatively, as well as on social media. SGK has a strong grassroots presence in local communities around the country. SGK accepts corporate partners, although pharmaceutical company involvement has been limited to date and Teva is not a current partner. SGK does not currently have an active focus on pain management, so an opportunity potentially exists for Teva in that space, as a corporate partner.

ADDRESS

<http://www.komen.org/>

5005 LBJ Freeway, Suite 250
Dallas, TX 75244

ORGANIZATIONAL RESOURCES (2012)

- 346 employees
- Total revenue: \$209 million dollars (\$175 million dollars in contributions, \$34 million dollars in program services, \$6 million dollars in investments, \$1.5 million dollars in "other").
- Total expenses: \$192 million dollars (\$156 million dollars in program services, \$22 million dollars in "other" and \$14 million dollars in administration).
- SGK also has the Susan G. Komen Breast Cancer Foundation and the Susan G. Komen for the Cure Advocacy Alliance.
- SGK has nine members of its Board of Directors.

MEMBERSHIP

- SGK has 120 U.S. affiliates and three international affiliates (Germany, Italy and Puerto Rico). SGK is active through partnerships in more than 30 countries around the world.
- SGK conducts ground-breaking research, community health outreach, advocacy and programs in more than 50 countries.

VISIBILITY

- SGK's Circle of Promise campaign seeks to raise awareness and support for breast cancer among African American women.

Publications and Congresses

- *Komen Perspective* is a monthly column authored by members of the SGK Scientific Advisory Board and a number of invited experts in the field who share their perspective on a variety of current breast cancer topics. The column reviews relevant research findings on the causes, prevention, early detection and treatment of breast cancer, examines the medical literature behind the popular news in the media and puts the latest findings into context for women at risk of breast cancer and for those already diagnosed with the disease.
- *Komen Newsletters* provides timely information about breast health, breast cancer and Komen's programs and initiatives, as well as information on how to get involved in the cause.
 - Regular dissemination of press releases on issues, research, initiatives, etc., related to all aspects of breast cancer.
- SGK hosts 140 annual Race for the Cure globally each year. In 2011, events had more than 1.6 million participants and more than 100,000 volunteers. There are no national pharmaceutical company sponsors.
- SGK has no annual meeting

Social Media

Facebook: 651,000+ followers

Actively posts information on breast cancer-related issues and topics.

Twitter: 57,000+ followers

Regular tweeting on a variety of breast cancer-related issues and topics.



YouTube: 912 subscribers, over 1.1 million video views

189 videos posted on a variety of breast cancer-related issues and topics.

Media Coverage

- In the past 12 months, the Susan G. Komen organization has appeared in 7,700 media articles; 16 articles linked to pain, mostly in relation to pain as a symptom of breast cancer. No articles mentioned the organization in relation to opioids.
- Penny Westberry, director of the Treasure Coast office of the Susan G. Komen for the Cure was quoted in an article regarding mammograms and that even though it is painful for women and how the health care district has a good system for making sure women have access to the test.
- An article from CBC News focused on the observation process after treatment for breast cancer patients. They recorded both physical and psychological aspects, pain being one of them.
- An article highlighting the Breast Global Health Initiative (BHGI) and how new guidelines for acute treatment-related symptom control includes pain management.
 - A trend in articles is the pain that breast cancer causes and how support groups can help.
 - Articles(s) have focused on pain management and women avoiding mammograms because of the pain.

PARTNERSHIPS

- Susan G. Komen for the Cure Tissue Bank at the IU Simon Cancer Center: acquires biomolecule and tissue specimens from the entire continuum of breast development.
- SGK partners extensively with the American Society of Clinical Oncology on:
 - **Research Initiative** - an extramural grants initiative to support research and projects related to the quality of, access to and delivery of cancer care with general applicability in the breast cancer arena.
 - **Quality of Care Initiative** - through which SGK provides funding to support TACF/ASCO in its work on quality of cancer care, including workforce issues, with general applicability in the breast cancer arena.
 - Annual **Breast Cancer Symposium** through 2010 - sponsored by ASCO and co-sponsored by other organizations with Komen for the Cure serving as Primary Supporter.
- SGK has granted the American Association for Cancer Research close to \$6M in conference support and educational programming since 2007. Specific programming includes scientific educational sessions, scientific travel scholarships, Scientist Survivor Program and outstanding investigator awards.
- Translational Breast Cancer Research Consortium – Komen-sponsored since 2007, TBCRC is a collaborative group of 16 research centers conducting innovative and high-impact clinical trials for breast cancer.
- SGK has four levels of sponsorships and partnerships:
 - Million Dollar Council Elite – companies (no pharmaceuticals) that have committed to invest \$1 million dollars annually.
 - Million Dollar Council – companies (no pharmaceuticals) that have contributed a minimum of \$1 million dollars.
 - Race for the Cure® National Sponsors – companies (no pharmaceuticals) with long-standing and highly integrated partnerships that generate more than \$12 million dollars annually.
 - Corporate partners – over 140 companies, largely non-pharmaceuticals. Teva is not a sponsor (<http://www5.komen.org/CorporatePartners.aspx>).

ISSUES

- SGK is focused on research to stem metastatic and aggressive disease, find scientifically sound preventive strategies, and investigate environmental links to breast cancer development.
- There is no information on SGK's website about the scheduling or relabeling of hydrocodone.
- Prescription drug abuse does not seem to be a prominent issue for SGK.

INFLUENCE

- To date, SGK has invested more than \$2.2 billion dollars in research and life-saving community



- programs.
- Komen's network of affiliates annually funds nearly 2,000 community organizations providing education, screening, patient navigation and emergency financial support for those facing breast cancer in their communities. Komen has invested more than \$1.3 billion dollars in community grants since 1982.
- SGK is active legislatively and is currently an active influencer in the breast cancer arena.
- The SGK Advocacy Alliance, a separate 501c(4) organization, includes 300,000 advocates in the U.S. that push for breast cancer research, early detection, and access to high-quality care. The Komen Advocacy Alliance is active in testifying before Congress on breast health legislation. It has not made any statements on pain or quality of life issues, and does not prioritize these issues legislatively.
 - Advocacy Alliance leadership and volunteers testify on the Hill as necessary. They have testified twice in the past two years.
 - They issue advocacy e-alerts to subscribers on state and federal issues.
 - They issue about five statements a year on legislative and regulatory issues.
 - Major accomplishments of the organization include:
 - Preserved \$210 million dollars in federal funding and more than \$100 million dollars in state funding for breast screening services
 - Increase federal breast cancer research funding from \$30 million dollars to more than \$970 million dollars in the last 30 years
 - Secured passage of oral chemotherapy parity legislation in Connecticut, Illinois, and Texas
- The Susan G. Komen Advocates in Science Program (AIS) brings together an inclusive community of dedicated volunteer advocates who are passionate about breast cancer research and facilitates their involvement in research advocacy.
- Komen has played a critical role in every major advance in the fight against breast cancer, including:
 - Early detection and effective treatment: Currently, about 70 percent of women 40 and older receive regular mammograms, the single most effective screening tool to find breast cancer early. Since 1990, early detection and effective treatment have resulted in a 33 percent decline in breast cancer mortality in the U.S.
 - More hope: In 1980, the five-year relative survival rate for women diagnosed with early stage breast cancer (cancer confined to the breast) was about 74 percent. Today, that number is 99 percent.
 - More research: The federal government now devotes more than \$850 million dollars each year to breast cancer research, treatment and prevention (compared to \$30 million dollars in 1982).
 - More survivors: Currently, there are about three million breast cancers survivors, the largest group of cancer survivors in the U.S.

FOCUS ON PAIN MANAGEMENT

- SGK does not have a dedicated pain management section of their website, but a search of the term yielded an article entitled "Management of Pain Related to the Treatment of Breast Cancer", in which hydrocodone was mentioned as an opioid treatment option.
- The opportunity seemingly exists for pain management to become a larger focus for SGK.

**TRIPLE NEGATIVE BREAST CANCER FOUNDATION (TNBCF) OVERVIEW**

Triple Negative Breast Cancer Foundation (TNBCF) addresses a very specific population of cancer patients, and is dedicated to being a credible source of information, a catalyst for science and patient advocacy groups, and a caring community with meaningful services for patients and their families. Supporting research that yields treatment and a cure is the organization's focus. TNBCF is not a very visible organization, nor is it active legislatively. The organization's interest in providing lifestyle management information for patients may present a partnership opportunity for Teva. TNBCF accepts corporate support from pharmaceutical companies, but Teva is not among its current partners.

ADDRESS

www.tnbcfoundation.org

PO Box 204

c/o Andrea Schackner Maline

Norwood, NJ 07648

ORGANIZATIONAL RESOURCES

- Four employees.
- Total revenue: \$817K dollars (\$815K dollars in contributions, \$1,600 in investments).
- Total expenses: \$920K dollars (\$578K dollars in program services, \$202K dollars in "other" and \$140K dollars in administration).

MEMBERSHIP

- TNBCF lists five members of its scientific advisory board and five members of its board of trustees.

VISIBILITY

- TNBCF is the primary group for women who have been diagnosed with triple negative breast cancer, a very advanced cancer with few treatment options. The group's forte is patient relations. It offers several resources on its website, including webinars, an extremely active online forum, a helpline and information on clinical trials.
 - The forum includes 5,795 participants, 109,581 posts in 10,357 topics in 16 forums.
- The inaugural Triple Negative Breast Cancer Day was held on March 3, 2013. The mission of this is a national awareness day was to bring together communities across the nation to plan fundraisers and awareness events in each state to take place on (or around) Triple Negative Breast Cancer Day.

Publications and Congresses

- TNBCF offers *100 Questions & Answers About Triple Negative Breast Cancer*, a comprehensive guide to the basics of triple negative breast cancer, risk factors and prevention, diagnosis, treatment, survivorship, and life after diagnosis.
- TNBCF developed the *Guide to Understanding Triple-Negative Breast Cancer* in partnership with Living Beyond Breast Cancer. The guide is designed to help patients understand the ins and outs of triple-negative breast cancer, whether newly diagnosed, in treatment, or years beyond treatment.
- TNBCF's main program is to convene meetings of researchers to compare results and connect findings. Their fourth Triple Negative Breast Cancer Symposium will be held in 2013 in Washington, DC.
- TNBCF hosts an annual fundraiser, the Peace, Love & a Cure Cocktail Reception and Auction, in May.

Social Media

Twitter: 560 followers

Multiple tweets per day.

LinkedIn Group: TNBCF is not on LinkedIn

YouTube: 29 subscribers, over 4,600 video views

Seven videos over past two years

Pinterest: 146 followers

Seven boards, including Facts and News & Research



Media Coverage

- TNBCF issued six press releases in 2012, most of which are organization news.
- In the past year, the Triple Negative Breast Cancer Foundation has been mentioned in the news 10 times. None of the articles were related to pain.
- The organization has received top-tier coverage, including FOX News and Examiner in 2013, and MSNBC, *Women*, *Oncology Times*, *SFGate* and *Philly.com*.

PARTNERSHIPS

- In January 2013 TNBCF partnered with the Susan G. Komen for the Cure to fund breakthrough research to support the discovery of promising new treatments for TNBC.
- TNBCF also partnered with the Cancer Institute of New Jersey – Robert Wood Johnson Medical School on biomarkers research.
- TNBCF developed *State of the Art Treatment for Triple Negative Breast Cancer: Talking with the Experts* through an educational grant from Sanofi Aventis.
- TNBCF receives corporate support from 13 companies, including Celgene, Bristol Myers Squibb, Sanofi Aventis and Genentech.
- TNBCF is partnering with Revlon and award-winning actress and Revlon spokesperson Emma Stone to host its 6th Annual Peace, Love & a Cure Cocktail Reception and Auction.
- The Triple Negative Breast Cancer Foundation partnered with CancerCare to launch the TNBC Helpline, offering free, professional support services to patients, families and HCPs coping with a diagnosis of triple negative breast cancer. The TNBC Helpline was made possible in part by a donation from Genentech.

ISSUES

- TNBCF is focused on research and treatment for triple negative breast cancer, as well as lifestyle management information for patients.
- The TNBCF website does not mention hydrocodone, nor does it focus on pain management. Some forum discussions mention pain issues, however.
- Prescription drug abuse is not an issue of concern for TNBCF.

INFLUENCE

- TNBCF is not active legislatively.
- TNBCF is most influential among patient advocates and has created a large community of women with advanced stage breast cancer.

FOCUS ON PAIN MANAGEMENT

- TNBCF does not have a dedicated pain management section to their website.
- TNBCF does not seem likely to extend its focus pain management.

Oncology Advocacy
Influencers



Oncology Advocacy Influencers

Organizational Leaders

Terri Ades, DNP, FNP-BC, AOCN

Director of Cancer Information, American Cancer Society

Dr. Ades has written recent [blog posts](#) on ACS' Expert Voices blog about cancer pain and the problem of untreated cancer pain and the need for patients to speak up about their pain. Although she also writes about other cancer-related topics, it's clear that Dr. Ades would support efforts to improve cancer pain management.

Dr. Ades is in charge of the ACS oncology medical professional staff team that is responsible for developing and maintaining the cancer information for the ACS's various delivery channels including their National Cancer Information Center, website, patient education/consumer awareness materials, consumer books, and translations. She is certified as an advanced practice oncology nurse and family nurse practitioner. She is adjunct faculty at Emory University Nell Hodgson Woodruff School of Nursing and the Winship Cancer Institute of Emory Healthcare where she continues in clinical practice in the Hematology Outpatient Clinic at Grady.

Amy P. Abernethy, MD, FACP, FAAHPM

Duke University Medical Center

President Elect, American Academy of Hospice and Palliative Medicine

Dr. Abernethy is a palliative medicine specialist and oncologist at Duke University Medical Center, and Director of the Duke Center for Learning Health Care. She oversees a large portfolio of studies that define the evidence basis for palliative interventions, including health services delivery models, cancer pain interventions, and dyspnea treatments (e.g., morphine, oxygen). Dr. Abernethy is also Co-Chair of the NIH/NINR-funded Palliative Care Research Cooperative Group and a member of the Institute of Medicine's National Cancer Policy Forum.

Laurie Fenton Ambrose

President, CEO, Lung Cancer Alliance

Laurie Fenton Ambrose is responsible for overseeing the creation and implementation of LCA's patient empowerment programs, public health policy agenda and national grassroots and awareness initiatives at the Lung Cancer Alliance (LCA). Since being hired as the organization's first president in 2004, she has refocused the LCA's focus to public policy and moved its headquarters to Washington, DC. Today, LCA is arguably the foremost national and international lung cancer non-profit. Laurie is also LCA's primary liaison to community and government leaders, national media, collaborating agencies, health care professionals, and other strategic alliances. Laurie served for many years on the Hill and maintains wide connections in the beltway.

Nancy G. Brinker

Founder, CEO, Susan G. Komen for the Cure

Nancy G. Brinker is regarded as the leader of the global breast cancer movement and is the public face of Susan G. Komen for the Cure. She was named one of TIME magazine's "100 Most Influential People" in 2008. From 2001-2003, she served as U.S. Ambassador to the Republic of Hungary and served as U.S. Chief of Protocol from 2007-2009 where she was responsible for overseeing all protocol matters for visiting heads of state and presidential travel abroad. In 2008, President George W. Bush appointed her to The Kennedy Center Board of



Trustees. Brinker is a lifetime member of the Council on Foreign Relations and has received numerous accolades for her global work, including the prestigious Mary Woodard Lasker Award for Public Service, the Champions of Excellence Award presented by the Centers for Disease Control, the Porter Prize presented by the University of Pittsburgh Graduate School of Public Health, the Forbes Trailblazer Award, Ladies Home Journal's 100 Most Important Women of the 20th Century, the Anti-Defamation League Americanism Award, and Biography Magazine's 25 Most Powerful Women in America.

Robert W. Carlson, M.D.

***Professor of Medicine, Division of Oncology, Stanford Comprehensive Cancer Center
Chief Executive Officer, National Comprehensive Cancer Network***

Dr. Carlson joined NCCN as CEO in January 2013 following an esteemed history of leadership positions within the organization including, most notably, Representative to the NCCN Board of Directors, Chair of the Breast Cancer Guidelines Panel, Member and Founding Chair of the Breast Cancer Risk Reduction Guidelines Panel, and Chair of the Survivorship Guidelines Panel. Prior to his appointment as CEO at NCCN, Dr. Carlson served as Professor of Medicine in the Division of Oncology and Stanford Medical Informatics at Stanford University Medical Center, as well as Medical Director of inpatient oncology and hematology at Stanford Cancer Institute in Stanford, California.

Dr. Carlson is a member of several medical societies, including American College of Physicians (ACP), American Association for Cancer Research (AACR), and the American Society of Clinical Oncology (ASCO). Dr. Carlson is usually the lead quote in NCCN press releases.

Keysha Brooks Coley

Director of Federal Relations, American Cancer Society Cancer Action Network

As the director of federal relations for the American Cancer Society and American Cancer Society Cancer Action Network, Keysha has been quoted in the media about the organization's position on pain management and access to opioids. In a March 2013 interview with the *Cleveland Plain Dealer* she emphasized that ACS does not focus on cancer pain versus non-cancer pain, as many cancer survivors still experience chronic pain. "We focus on the issue of pain in general and access to pain medications," she emphasized to the newspaper. She also participated in an October 2012 Interagency Pain Research Coordinating Committee Meeting at the NIH, among other KOLs.

Bassem Georgy, MD

***Valley Radiology Consultants, University of California San Diego
Editorial Advisory Board of Pain Physicians, official publication of American Society of Interventional Pain Practitioners***

Dr. Loeser is recognized as an expert in the surgical treatment of pain and multidisciplinary pain management. He was the Director of the Multidisciplinary Pain Center from 1982-1997. His career also focused upon pediatric neurosurgery. His research and teaching efforts have included the development of the human nervous system, neuropathic pain, low back pain and multidisciplinary pain management.

Hayley Dinerman

Acting Executive Director, Triple Negative Breast Cancer Foundation

Ms. Dinerman is a co-founder of the TNBCF. As such, she shared responsibility for many of the Foundation's earliest achievements, including establishing the scientific advisory board, organizing the first Triple Negative Breast Cancer Symposium, and coordinating the launch of



the groundbreaking Susan G. Komen for the Cure Promise Grant Co-Funded by the Triple Negative Breast Cancer Foundation. Because of these achievements, Hayley is extremely respected by both funders and those in the scientific community. Ms. Dinerman came to the Foundation after years of experience in the legal arena. She worked as an Associate attorney in the Business Transactions Department of Schulte, Roth & Zabel LLP in New York, NY and then as Director of Marketing at Morgan & Finnegan LLP also in New York, NY. She is a 1993 graduate of Brandeis University, and received her J.D. from New York University School of Law in 1996.

Sam Donaldson

Chair Emeritus National Comprehensive Cancer Network Foundation Board of Directors

Donaldson accepted the position of Chair to the newly established NCCN Foundation in 2010. The Foundation is the philanthropic affiliate of the National Comprehensive Cancer Network® (NCCN®), embracing the NCCN mission of improving the quality and effectiveness of care provided to patients with cancer, while providing additional information and resources for informed decision-making. Donaldson has been the public face of the Foundation and his main priority thus far with the organization has been to gain support for the development of the NCCN Patient Guidelines, which translate the NCCN Clinical Practice Guidelines in Oncology into a patient-friendly resource.

James H. Doroshow, M.D.

National Cancer Institute Division of Cancer Treatment and Diagnosis

Dr. Doroshow has been the Director of Division of Cancer Treatment and Diagnosis, National Cancer Institute, since 2004. From 1983 to 2004, Dr. Doroshow was the Chairman of the City of Hope Comprehensive Cancer Center's Department of Medical Oncology and Therapeutics Research. The Division of Cancer Treatment and Diagnosis (DCTD) focuses its activities on developing novel diagnostics and therapies for cancer. A primary goal of NCI's DCTD is to decrease the time necessary to bring anticancer drugs and biomarkers to the clinic while enhancing the ability to predict which treatments will be most useful for each patient.

Daniel Fischberg, MD, PhD

***Medical Director, Pain and Palliative Care Department, Queen's Medical Center
Scientific Committee, American Academy of Hospice and Palliative Medicine***

Dr. Fischberg is medical director of the Pain & Palliative Care Department at The Queen's Medical Center in Honolulu, HI, and Professor and Chief of the Division of Palliative Medicine in the Department of Geriatric Medicine at The John A. Burns School of Medicine of the University of Hawaii, also in Honolulu. Since completing pain and palliative care fellowship training at Memorial Sloan-Kettering Cancer Center in 2000, Dr. Fischberg has worked full-time as a palliative medicine physician, first at Mount Sinai Medical Center in New York and, since 2004, at The Queen's Medical Center in Honolulu. During the last 12 years, his professional activities have centered on the care of patients in the hospital, office, hospice and home settings, teaching, research, legislative advocacy, and public outreach.

Dr. Fischberg is active with the AAHPM. He has made more than a dozen presentations at the Annual Assembly, served as associate editor of PC-FACS, served as chair of past Annual Assemblies and has directed several influential AAHPM committees and task forces. Most recently he led the highly visible 2012 Choosing Wisely Task Force, which developed the AAHPM's Choosing Wisely guidelines.

Bruce J. Haffty, M.D.



Professor and Chairman, Department of Radiation Oncology, Robert Wood Johnson Medical School-University of Medicine and Dentistry of New Jersey, New Brunswick, N.J. Associate Director, The Cancer Institute of New Jersey, New Brunswick, N.J. President-elect, ASTRO

Dr. Haffty has published more than 190 peer-reviewed articles, 25 book chapters, and numerous editorials and letters. He has been listed as one of the country's top physicians by *Best Doctors in America*, *Ladies' Home Journal*, *Good Housekeeping* and *America's Top Doctors*. In addition to a busy clinical practice, Dr. Haffty has served on numerous national committees related to research and education in radiation oncology, serves on the editorial board of several medical journals and has mentored many medical students, trainees and junior faculty in conducting clinical and translational research. He has served on the scientific program committees of ASTRO, ASCO, AACR and ARS. He is currently associate editor of the *Journal of Clinical Oncology*, serves on the Executive Committee of the American College of Surgeons Commission on Cancer (ASTRO Representative), chairman of the Residency Review Committee in Radiation Oncology, trustee to the American Board of Radiology and assistant executive director of the ABR and president-elect of the American Radium Society.

Paul M. Harari, M.D.

Jack Fowler Professor and Chairman, Department of Human Oncology Associate Director, Carbone Cancer Center, University of Wisconsin School of Medicine and Public Health, Madison, Wis. Education Council Vice-Chairman, ASTRO

Dr. Harari has served as Chairman of the ASTRO Education Committee, Chairman of the 1st ASTRO/ASCO/AHNS Head and Neck Cancer Symposium, member of the ASTRO Strategic Planning Task Force, Red Journal (*IJROBP*) and *Practical Radiation Oncology (PRO)* Editor-in-Chief Selection Task Force, ASCO Education and Program Committees and Journal Editorial Boards including the *International Journal of Radiation Oncology Biology and Physics*, *Practical Radiation Oncology*, *Clinical Cancer Research*, *Head and Neck* and others. He has authored more than 165 original research articles and book chapters and more than 200 abstracts on cancer research topics with particular emphasis on the treatment of head and neck cancer.

Rebecca Kirch, JD

Director of Quality of Life and Survivorship, Cancer Control, American Cancer Society

Rebecca has testified in FDA advisory committee meetings regarding the American Cancer Society and American Cancer Society Cancer Action Network's positions on pain, including opposition to rescheduling hydrocodone and to relabeling opioids to limit their use for non-cancer chronic pain, emphasizing the need for access for legitimate pain patients.

At the American Cancer Society, Rebecca is responsible for working collaboratively to provide strategic direction, input, and insight to bridge the Society's survivorship-related research, policy, and program initiatives. Rebecca also serves as a quality cancer care knowledge expert for the Society's advocacy initiatives and activities to improve quality of life and reduce suffering for patients, survivors, and caregivers. She previously served as associate director of policy for ACSCAN. Her work has involved particular emphasis on activities to advance pain and palliative care policies and practices for cancer patients, survivors, and their caregivers - efforts that were honored in 2008 with the American Academy of Pain Management's Legislative Policy and Advocacy Award and a Presidential Medal of Honor from the American Pain Foundation.

Suzanne Lindley



Co-Founder and President, Beat Liver Tumors and long-term stage IV metastatic colon cancer survivor

As the head of Beat Liver Tumors, Suzanne Lindley maintains a wide network of patient advocate and advocacy group relationships. Suzanne has been involved with numerous cancer organizations including American Cancer Society, Association of Online Cancer Resources, Colorectal Cancer Coalition, LiveSTRONG, National Coalition for Cancer Survivorship, Nursing Oncology Education Program and Fight Colorectal Cancer. She has been featured in top-tier media, blogs for *CURE* and has testified before Congress about colon cancer and liver tumors. While pain is not currently her focus, she may be open to expanding the organization's focus on pain if presented with the opportunity. Because her focus is largely metastatic cancer that has spread to the liver, pain is likely a major issue for her patient advocate constituency.

Jan McDavitt

Chief Development Officer, CancerCare

As Chief Development Officer, Jan McDavitt is responsible for developing and managing CancerCare's overall philanthropic program. Prior to joining CancerCare, she held senior executive fundraising positions with several national nonprofit organizations, including Big Brothers Big Sisters of America and Girl Scouts of the USA. As the Vice President of Development for Liberty Science Center, she successfully led a \$100 million expansion campaign that more than doubled the size of the museum. Jan began her career with the American Heart Association, where she managed a vast array of grass roots, volunteer-led fund raising efforts. Over the course of her career in advancement she has orchestrated large scale, strategic corporate partnerships, signature special event initiatives, membership and annual campaigns, as well as major and planned giving program development.

Mary Lynn McPherson, PharmD, BCPS, FASPE, CPE

Professor, Department of Pharmacy Practice and Science, University of Maryland School of Pharmacy

Board of Directors Chair, American Society of Pain Educators

She serves as a consultant pharmacist for local and national hospice and palliative care programs, and has designed a critical thinking process for appropriate drug use in end-of-life patients. She serves on the Boards of the Hospice Network of Maryland and the Maryland Pain Initiative, and is the Chair of the Board of the American Society of Pain Educators.

Dr. McPherson teaches extensively in the PharmD curriculum on pain management and end-of-life care, including didactic and experiential content. Dr. McPherson also serves as a primary care pharmacist and Director of Pharmacotherapy Services at University Care Waxter in Baltimore. She also developed one of the first and few palliative care pharmacy residencies in the United States. She is a Fellow in the American Pharmacists Association, American Society of Health-Systems Pharmacists, and American Society of Consultant Pharmacists.

At PAINWeek, Dr. McPherson said there are appropriate times to use rapid onset opioids. If a patient experiences breakthrough pain, a fast acting drug will be required to help control the unanticipated pain. For patients with chronic, persistent pain, the danger with rapid onset opioids is that the level will be higher than it needs to be and the patient can suffer from sedation, nausea, or an unintended euphoric effect.

Helen Miller, LCSW

Chief Executive Officer, CancerCare



Helen H. Miller brings more than three decades of clinical and executive management experience to her role as CEO of CancerCare. A licensed clinical social worker in New York State, Ms. Miller has an extensive background directing cancer research prevention and wellness programs for major cancer centers, including the Memorial Sloan-Kettering Cancer Center and The New York Presbyterian Hospital. Her non-profit executive management experience includes five years as Executive Director of The Bachmann-Strauss Dystonia & Parkinson Foundation. Ms. Miller holds a Master of Science in Social Work from Columbia University. She is a member of the Academy of Certified Social Workers and the National Association of Social Workers, and serves on the board of the National Philanthropic Trust.

Kurt Nygaard

***Vice President, Board Member, Harwick Standard Distribution Company
Chairman, Triple Negative Breast Cancer Foundation***

Mr. Nygaard was named Chairman in 2012, at a time of rapid expansion for the Triple Negative Breast Cancer Foundation (TNBCF), when it was coming off its strongest financial year and welcoming a diverse set of new funders including General Electric, the General Electric Foundation, Celgene, the Tommy Hilfiger Corporate Foundation, and Revlon. Mr. Nygaard is extremely involved in the community and in breast cancer advocacy, serving not only TNBCF, but also as an advisor to the Susan G Komen Northeast Ohio Affiliate.

Christian T. Sinclair, MD FAAHPM

***National Hospice Medical Director, Gentiva Health Services
Director at Large, Blogger, American Academy of Hospice and Palliative Medicine***

Dr. Sinclair is a National Hospice Medical Director for Gentiva Health Services and is based in Overland Park, KS. He has experience in multiple clinical settings including home visits, palliative care outpatient clinic, inpatient hospice, IDT, hospital based palliative consults, and palliative home health. Dr. Sinclair is the editor of *Pallimed* and an advocate for responsible social media advocacy for healthcare professionals. In addition he has made multiple local TV, radio and newspaper appearances on end-of-life issues.

Dr. Sinclair has initiated several AAHPM interest groups, largely focusing on HCP education and young professionals training. In addition to other AAHPM leadership roles, he was the AAHPM representative for the Coalition to Transform Advance Care PAINS Initiative. Dr. Sinclair is hugely influential in social media.

Harold Varmus, M.D.

Director, National Cancer Institute

Dr. Varmus was nominated by President Obama as Director of the National Cancer Institute on May 17, 2010. He began his tenure as NCI Director on July 12, 2010. He is co-recipient of a Nobel Prize for studies of the genetic basis of cancer. He previously served as President and Chief Executive Officer of Memorial Sloan-Kettering Cancer Center (MSKCC) and as Director of the National Institutes of Health (NIH).

**Centers of Excellence****James L. Abbruzzese, MD, FACP, FASCO, D.Sc. (hon.)*****Department Chair******Gastrointestinal Medical Oncology and Digestive Diseases******Division of Cancer Medicine******The University of Texas M. D. Anderson Cancer Center******Member, American Society of Clinical Oncology Board of Directors***

Dr. Abbruzzese received his medical degree from University of Chicago - Pritzker School of Medicine. He has held the Waun Ki Hong Distinguished Chair in Translational Oncology, Department of Gastrointestinal (GI) Medical Oncology, Division of Cancer Medicine since 2011.

Kenneth C. Anderson, MD, PhD (Hon.)***Kraft Family Professor of Medicine, Harvard Medical School, Director of the Jerome******Lipper Multiple Myeloma Center at the Dana-Farber Cancer Institute******Board of Directors, American Association for Cancer Research***

Dr. Anderson graduated from Johns Hopkins Medical School, trained in internal medicine at Johns Hopkins Hospital, and completed hematology, medical oncology, and tumor immunology training at Dana-Farber Cancer Institute. He serves as chief of the Division of Hematologic Neoplasia, director of the Jerome Lipper Multiple Myeloma Center, and vice chair of the Joint Program in Transfusion Medicine at Dana-Farber. Dr. Kenneth Anderson is a multiple myeloma thought leader, physician and researcher at Dana-Farber Cancer Institute, where he is Director of the Jerome Lipper Multiple Myeloma Center. He also is the Kraft Family Professor of Medicine at Harvard Medical School in Boston. Dr. Anderson's research has played a key role in the development of several new multiple myeloma drugs and, more broadly, the significant improvement in treatment outcomes for myeloma patients occurring over the past 10 to 15 years.

Smita Bhatia, MD, MPH***Ruth Ziegler Chair of the Department of Population Sciences******Associate Director of the City of Hope Comprehensive Cancer Center******Co-Leader of the Cancer Control and Population Sciences Program******Professor at City of Hope National Medical Center******Member, American Society of Clinical Oncology Board of Directors***

Dr. Bhatia received her MD in Pediatrics from All India Institute of Medical Sciences, New Delhi, India. She received an MPH in Epidemiology from the University of Minnesota. She received the Brigid Leventhal Merit Award and the Young Investigator Award from the American Society of Clinical Oncology, and the Leukemia and Lymphoma Society Scholar in Clinical Research Award. In 2006, Dr. Bhatia was elected as a Member in the American Society for Clinical Investigation.

Powel Brown, MD, PhD***Professor and Chair, Department of Clinical Cancer Prevention, University of Texas MD Anderson Cancer Center******Professor, Department of Breast Medical Oncology, University of Texas MD Anderson Cancer Center******John Charles Cain Distinguished Chair, University of Texas MD Anderson Cancer Center******Member, Susan G. Koman Scientific Advisory Board***

Dr. Brown's laboratory and clinical efforts are focused on developing novel strategies for the treatment and prevention of estrogen receptor-negative (ER-negative) breast cancer. Dr. Brown



joined MD Anderson in September 2009 from Baylor College of Medicine, where he specialized in breast cancer treatment and prevention, served on the faculty of the departments of medicine and molecular cellular biology, led the cancer prevention program of the Dan L. Duncan Cancer Center and co-directed the college's M.D.-Ph.D. program. Brown obtained his undergraduate degree from the University of North Carolina at Chapel Hill and earned his Ph.D. and M.D. from New York University. He completed his internal medicine residency at Duke University Medical Center and received training at the National Cancer Institute. He also served in the U.S. Public Health Service Commissioned Corps, rising to the rank of commander.

Victoria L. Champion, DNS

Associate Dean for Research

Mary Margaret Walther Distinguished Professor of Nursing

Center for Research & Scholarship

Indiana University School of Nursing

Member, National Cancer Institute National Cancer Advisory Board

Dr. Champion's program of research has provided a significant knowledge base from which to develop interventions that encourage primary and secondary cancer prevention activities, thus leading to the discovery of cancer at earlier and more curable stages. She has been NIH funded for more than 2 decades and is using interactive technology to test format delivery and cost-effectiveness for breast cancer screening. Dr. Champion is also identifying quality of life issues in breast cancer survivors and pilot testing interventions to increase patient/provider communication. Dr. Champion directs the Cancer Control Program for the Indiana University Simon Cancer Center and was just appointed to the National Cancer Advisory Board and the Indiana Executive Board for Tobacco. Dr. Champion received her BSN, MSN and DNS from Indiana University.

Patrick Coyne, MSN, APN, FAAN

Oncology Nurse, Medical College of Virginia

ONS Member

Coyne is an oncology nurse at the Medical College of Virginia, both active in cancer outreach and pain control in rural Virginia hospitals. Although the College of Virginia is not a COE, Coyne is important to engage. He testified before the Subcommittee on Commerce, Manufacturing, and Trade, of the Energy and Commerce Committee, on the need for appropriate prescription pain medication for patients with cancer who suffer from unrelieved pain. Coyne reminded the committee that although risks exist for the misuse of opioid medication, discussions about prescription pain medications needs a balanced approach to consider the benefits to patients experiencing moderate or severe pain. ONS is recognized in Washington as an influential voice on matters related to the oncology nursing profession and cancer care.

David Craig, PharmD, BCPS

Chair, E-News Editorial Board, American Pain Society

Director, Pain and Palliative Care Specialty Residency, H Lee Moffitt Cancer Center

Dr. Craig also serves as a clinical pharmacist specialist and at the H. Lee Moffitt Cancer Center and Research Institute in Tampa, Fla., an NIH COE in Oncology. He currently serves in various capacities within the American Pain Society, American College of Clinical Pharmacy and American Society of Health-System Pharmacists. In addition, he is a peer reviewer for *The Cochrane Collaboration – Pain, Palliative and Supportive Care* Review Group and *Cancer Control Journal* of the Moffitt Cancer Center, and he serves on the editorial board of the *Journal of Pain and Palliative Care Pharmacotherapy*.

**Lisa M. DeAngelis, MD*****Chair, Department of Neurology******Co-Executive Director, Brain Tumor Center******Lillian Rojzman Berkman Chair in Honor of Jerome B. Posner******Memorial Sloan Kettering Cancer Center******Vice President, American Academy of Neurology Board of Directors***

Dr. DeAngelis is a neuro-oncologist with extensive experience in the care of patients with brain tumors and the neurologic complications of cancer. She has led national trials of investigational drugs for primary CNS lymphoma and has conducted numerous trials of brain tumor therapeutics. Dr. DeAngelis is also Co-Executive Director of the Brain Tumor Center at Memorial Sloan-Kettering. The Brain Tumor Center is a virtual interdepartmental center that spans Memorial Hospital and Sloan-Kettering Institute to support research in brain tumors and promote its translation into clinical trials.

Vincent T. DeVita Jr., MD***Advisory Board Chair, Yale Cancer Center; Professor of Internal Medicine and of Epidemiology and Public Health at Yale Medical School******President, American Cancer Society Board of Directors; American Cancer Society Cancer Action Network Board of Directors***

Dr. DeVita is internationally recognized for his work in Hodgkin's disease and diffuse large cell lymphomas research and treatment. Dr. DeVita is also a member of several professional organizations, including the American Society of Clinical Oncology and the World Health Organization Expert Advisory Panel on Cancer to name a few, Dr. DeVita also serves on the editorial boards of numerous scientific journals and is the author or co-author of more than 500 scientific articles. He currently serves as a member of the American Cancer Society's Strategic Planning and Agenda Development Committee.

While he has not historically focused on pain, his leadership at Yale Cancer Center, an NIH oncology COE, may be relevant to Teva.

Phillip M. Devlin, MD***Associate Professor of Radiation Oncology, Harvard Medical School, Boston******Active Staff, Radiation Oncology, Brigham and Women's Hospital, Boston******Secretary/Treasurer, ASTRO***

Dr. Devlin is active staff at Dana-Farber Cancer Institute, a center of excellence. Currently serves as senior editor for the ASTROnews. He published a textbook in 2007 called *Brachytherapy: Applications and Techniques*. Her bio states that she has become increasingly involved in political aspects of practice in recent years, but no examples are provided; however, she states, "I have been awakened to the significant risks that our specialty faces with chronic threats to health care reimbursement and the need to educate legislators."

John T. Farrar, MD PhD***Associate Professor of Anesthesia and Critical Care, Associate Professor of Neurology, University of Pennsylvania******Director at Large, American Pain Society***

Dr. Farrar is active within the American Pain Society and is co-chair of its "Measurement of Pain and Its Impact" special interest group committee. He also holds leadership positions at the University of Pennsylvania as vice chair of the Drug Use and Effects subcommittee and chair of the pain management subcommittee. While University of Pennsylvania is an NIH COE in Pain Education, Dr. Farrar may also be an influencer in the oncology pain space, as he collaborates with Penn Pain Medicine Center and the Symptom Management and Palliative Care Program



(SYMPAC) providing care to patients at the Abramson Cancer Center focusing on all aspects of the management of pain and other cancer-related symptoms.

Kathleen M. Foley, MD

***Attending Neurologist, Pain and Palliative Care Service, Department of Neurology
Memorial Sloan Kettering Cancer Center***

***Professor of Neurology, Neuroscience, and Clinical Pharmacology, Weill Medical
College of Cornell University***

Member, National Cancer Institute Board of Scientific Advisors

Dr. Foley is the previous Director of the WHO Collaborating Center for Cancer Pain Research and Education at Memorial Sloan-Kettering Cancer Center. She holds the Chair of the Society of Memorial Sloan-Kettering Cancer Center in Pain Research. She was elected to the Institute of Medicine of the National Academy of Sciences for her national and international efforts in the treatment of patients with cancer pain. She is the past Director of the Project on Death in America of the Open Society Institute whose goal was to transform the culture of dying in the United States through initiatives in research, scholarship and clinical care. Dr. Foley is currently the Medical Director of the International Palliative Care Initiative of the Network Public Health Program of the Open Society Institute working to advance palliative care globally. Dr. Foley chaired three expert committees that resulted in the publication of the three WHO monographs on Cancer Pain and Palliative Care; "Cancer Pain Relief" (1996), "Cancer Pain Relief and Palliative Care" (1990), and "Cancer Pain and Palliative Care in Children" (1996).

Lewis E. Foxhall, MD

***Vice President for Health Policy, Professor of Clinical Cancer Prevention University of
Texas M.D. Anderson Cancer Center***

***American Cancer Society and American Cancer Society Cancer Action Network Board of
Directors***

Dr. Foxhall is responsible for coordinating M.D. Anderson Cancer Center's charity care program, cancer control policy development and serving as liaison with community physicians and organizations. Additionally, he leads M.D. Anderson's education and outreach program on cancer survivor management for health professionals and coordinates outreach and policy initiatives. Dr. Foxhall has extensive advocacy experience with issues related to cancer treatment and prevention for low income and disparately impacted populations, socioeconomic factors impacting cancer control including healthcare finance and government programs as well as primary care delivery and education. He is currently Chair of the ACS national Primary Care Advisory Group. While he has not historically focused on pain, his work with disparities may inspire more of a focus on pain management. His position at M.D. Anderson also may be an opportunity for Teva to engage with him.

Michael A Friedman, MD

Irell & Manella Cancer Center Director's Distinguished Chair

CEO, City of Hope Comprehensive Cancer Center

Member, National Comprehensive Cancer Network Board of Directors

Dr. Friedman was formerly senior vice president of research and development, medical and public policy, for Pharmacia Corporation. In addition, he served as chief medical officer for biomedical preparedness at the Pharmaceutical Research and Manufacturers of America following the events of September 11, 2001. Friedman had previously served as Food and Drug Administration (FDA) deputy commissioner and was later tapped by the Clinton administration to serve as acting commissioner of the agency. He helped to streamline the FDA's review and



approval process and provided oversight of evaluations for drugs, biologics, medical devices and food ingredients.

Judy E. Garber, M.D., M.P.H.

Medical Oncologist and Clinical Cancer Geneticist

Director at the Center for Cancer Genetics and Prevention, Dana-Farber Cancer Institute

Department of Medical Oncology

Past President & Board of Directors, American Association for Cancer Research

Dr. Garber received her MD and MPH in 1981 from Yale University School of Medicine. She served her internal medicine residency at Brigham and Women's Hospital, followed by fellowships in hematology at BWH, medical oncology at DFCI, and biostatistics at the National Cancer Institute. She joined DFCI as a fellow in 1985, and now works as a medical oncologist and clinical cancer geneticist. Dr. Garber's research is focused on genetic susceptibility to breast, ovarian and other cancers, and the development of novel medical strategies to prevent cancer. Her work has focused particularly on the genetics of breast and ovarian cancer, and the management of individuals at increased risk. Her translational research has recently included the evaluation of novel agents targeting DNA repair defects in the treatment and prevention of triple negative or basal-like breast cancer, particularly platinum and PARP inhibitors. She uses the tools of cancer epidemiology and biostatistics, genetics and molecular biology to identify women at high risk for breast cancer. Dr. Garber is also on President Obama's National Cancer Advisory Board.

Jennifer Rubin Grandis, M.D.

Vice Chair for Research, Professor of Otolaryngology & Pharmacology at the University of Pittsburgh School of Medicine

Board of Directors, American Association for Cancer Research

Dr. Grandis is professor of otolaryngology and pharmacology with the University of Pittsburgh School of Medicine and vice chair for Research, Department of Otolaryngology. She directs the Head and Neck Cancer Program of UPMC Cancer Centers. Her research interests include diagnosis and treatment of head and neck cancer. She has been awarded two patents in this field and has a third pending. Dr. Grandis is a member of several professional and scientific societies, including Women in Cancer Research, the American College of Surgeons, and the American Laryngological, Rhinological and Otological (Triologic) Society. She also serves on the Women In Otolaryngology Committee of the American Academy of Otolaryngology–Head and Neck Surgery. A graduate of Swarthmore College in Pennsylvania, she earned her medical degree at the University of Pittsburgh School of Medicine, where she also completed her internship and residency.

Frederic Grannis, MD

Professional Advisory Board, Lung Cancer Alliance Medical

President, City of Hope Medical Staff; Clinical Professor of Surgery, City of Hope Cancer Center

In his positions at the Lung Cancer Alliance and NIH Oncology COE, City of Hope Cancer Center, Dr. Grannis focuses largely on a multi-tiered strategy for tobacco control, as well as early detection and surgical treatments for lung cancer. In addition, Dr. Grannis is participating in a study of palliative therapies for terminal lung cancer patients. He is also involved in two ongoing studies of quality-of-life issues of lung cancer survivors and their families. Because lung cancer is often one of the most painful and deadly cancers, perhaps there is opportunity for Teva to connect with him and City of Hope Cancer Center on his palliative care efforts.

**Jimmie Holland, MD**

Wayne E. Chapman Chair in Psychiatric Oncology, Memorial Sloan-Kettering Cancer Center

Medical and Professional Advisory Boards, Lung Cancer Alliance

Dr. Holland's research focuses on psychotherapy for elderly patients with cancer. As such, she is part of the hospital-wide 65+ Program in which she both offers clinical services and conducts research in helping older patients cope with cancer and illness are provided. Although pain is not her focus, her focus on quality of life issues and psychological well-being may make her receptive to Teva initiatives.

Waun Ki Hong, MD

Head, Division of Cancer Medicine, University of Texas M.D Anderson Cancer Center

Member, National Cancer Institute National Cancer Advisory Board

Steering Committee, American Association for Cancer Research

A national and international leader in medical oncology, Dr. Hong is a foremost authority on the treatment and prevention of head and neck cancer and lung cancer. His expertise spans more than 36 years of unprecedented advances in translational and clinical cancer research. Dr. Hong has developed treatment approaches that have enabled thousands of laryngeal cancer patients to avoid radical surgery and enjoy a better quality of life, eradicating the cancer while preserving the ability to speak and swallow.

A national and international leader in medical oncology, Dr. Hong has also played an active role in shaping public policy, increasing international collaboration in cancer research, and mentoring hundreds of young physicians and scientists from around the world who will become the next generation of cancer researchers and clinicians.

Bruce E. Johnson, MD

Professor of Medicine, Harvard Medical School

Director of the Lowe Center for Thoracic Oncology, Dana-Farber Cancer Institute and Brigham and Women's Hospital

Leader of the Dana-Farber/Harvard Cancer Center Lung Cancer Program

Director and Principal Investigator of the Dana-Farber/Harvard Cancer Center Specialized Program of Research Excellence (SPORE) in Lung Cancer

Member, Lung Cancer Foundation of America Scientific Advisory Board

Graduating from Harvard University, Dr. Johnson earned his medical degree from the University of Minnesota in 1979. He continued his education through an internship and residencies in internal medicine at the University of Chicago Hospitals and Clinics. From 1982 to 1985, he was a Clinical Associate at the National Cancer Institute (NCI). Dr. Johnson spent 17 years in the NCI-Navy Medical Oncology Branch of the Naval Hospital in Bethesda, Maryland, serving as Acting Director in 1991. He came to the Lowe Center at Dana-Farber Cancer Institute in 1998, after serving for six years as the head of the Lung Cancer Biology section of the NCI's Medicine Branch.

Hagop M. Kantarjian, MD

Professor, Department of Leukemia, Division of Cancer Medicine,

Associate Vice President for Global Academic Programs

Department Chair, Department of Leukemia, Division of Cancer Medicine elcie Margaret Kana - Research Chair, Department of Leukemia, Division of Cancer Medicine

The University of Texas MD Anderson Cancer Center

Member, American Society of Clinical Oncology Board of Directors



Dr. Kantarjian received his medical degree from the American University of Beirut. He accepted a fellowship the Department of Developmental Therapeutics at MD Anderson in 1981. In the 3 decades since, Dr. Kantarjian's work has markedly advanced the field of hematologic cancers, particularly in the areas of chronic myelogenous leukemia (CML) and acute lymphocytic leukemia (ALL).

G. Douglas A. Letson, MD

Division Chief of the Sarcoma Program

Chair of Medical Education

Director of Musculoskeletal Tumor and Reconstructive Surgery

Moffitt Cancer Center

***Residency Program Director, Department of Orthopaedics and Sports Medicine,
University of South Florida***

Member, National Comprehensive Cancer Network Board of Directors

Dr. Letson received his medical degree and completed an orthopaedic residency at Louisiana State University. He continued on to complete a Musculoskeletal Tumor Surgery Fellowship at Harvard Medical School in Boston. Dr. Letson is an active member in multiple orthopaedic and oncology societies such as, the American Academy of Orthopedic Surgeons (AAOS), American Orthopedic Association (AOA), Musculoskeletal Tumor Society (MTST) and Connective Tissue Oncology Society (CTOS). He has served on the editorial board of several orthopaedic journals, including Journal of the National Comprehensive Cancer Network and the Cancer Control Journal.

Bill McCarberg, MD

Founder and Attending Physician

Chronic Pain Management Program

Southern California Kaiser Permanente Medical Center

Adjunct Assistant Clinical Professor

University of California, San Diego

Medical Co-Chair of National Fibromyalgia and Chronic Pain Association's

FibroCollective Advocacy Working Group

Dr. McCarberg is a member of the American Academy of Family Physicians, American Academy of Pain Medicine, American Pain Society, and International Association for the Study of Pain. He is the recipient of several awards, including the Shilling Compassionate Care Award, and in 1998, he was named the Highest Rated Physician by Member Appraisal of Physician Services at Kaiser Permanente. Dr McCarberg has given more than 100 presentations on pain management issues and is the author or co-author of several publications. He received his medical degree from Northwestern University Medical School, Chicago, Illinois. He completed a medical internship and residency in family practice at Highland Hospital in Rochester, New York. He is board certified by the American College of Pain Medicine and the American Board of Family Practice and is additionally certified in geriatrics.

Kevin Oeffinger, MD

Director at Large, American Cancer Society Board of Directors

Director, Memorial Sloan-Kettering's Adult Long-Term Follow-Up Program

Dr. Oeffinger is a primary care physician and Director of Memorial Sloan-Kettering's Adult Long-Term Follow-Up Program, which provides follow-up care for adults of all ages who had cancer during their childhood, adolescent, or young adult years. Dr. Oeffinger is involved in several highly regarded survivorship research studies, task forces and program initiatives. While his



work has not historically focused on pain, his work at NIH oncology COE Memorial Sloan-Kettering may be an opportunity for Teva.

Kornelia Polyak, M.D., Ph.D.

**Associate Professor, Department of Medical Oncology, Dana-Farber Cancer Institute
Board of Directors, American Association for Cancer Research**

Dr. Polyak received her MD in 1991 from Albert Szent-Gyorgyi Medical University, Szeged, Hungary, and her PhD in 1995 from Cornell University/Memorial Sloan-Kettering Cancer Center. She completed a research fellowship in oncology at the Johns Hopkins Oncology Center, Baltimore, where she analyzed the mechanism of p53-mediated cell death. Joining DFCI in 1998, she is principally involved in basic laboratory research focusing on cancer genetics and the molecular basis of breast cancer.

Charles L. Sawyers, M.D.

**Investigator at Howard Hughes Medical Institute, Chairman at Human Oncology and Pathogenesis Program, Memorial Sloan-Kettering Cancer Center
President-Elect & Board of Directors, American Association for Cancer Research**

Dr. Sawyers is President-elect of the American Association for Cancer Research and past President of the American Society of Clinical Investigation, and serves on the National Cancer Institute's Board of Scientific Councilors. He is also a Member of the Institute of Medicine of the National Academy of Sciences. Sawyers attended Princeton University for his undergraduate degree, received his medical degree from Johns Hopkins University School of Medicine in 1985 and completed his postdoctoral studies at the University of California, Los Angeles. He has received numerous honors and awards, including the Richard & Hinda Rosenthal Foundation Award (American Association of Cancer Research), the David A. Karnofsky Award (American Society of Clinical Oncology), the Dorothy P. Landon-AACR Prize for Translational Cancer Research, and the 2009 Lasker-DeBakey Clinical Medical Research Award. A member of the AACR since 1998, Sawyers has demonstrated his dedication to the AACR through his extensive leadership and involvement in the association. He is a scientific editor of *Cancer Discovery* and was associate editor for *Cancer Research* (2000-2004), all of which are journals of the AACR. Among his extensive service to the field of cancer research, Sawyers is past president of the American Society of Clinical Investigation; served on the National Cancer Institute's Board of Scientific Councilors; and is a member of the National Academy of Sciences and the Institute of Medicine.

Thomas A. Sellers, Ph.D., M.P.H.

Executive Vice President, Director, Moffitt Research Institute at the H. Lee Moffitt Cancer Center

Board of Directors, American Association for Cancer Research

Dr. Sellers is primarily involved in research. His research program seeks to integrate a basic science background in nutrition and genetics with observational research methods to try to understand questions like these why less than 20% of cigarette smokers develop lung cancer and why a proven effective cancer treatment is beneficial to only a subset of patients. His studies are based on genetic analysis of germline DNA with increasing incorporation of acquired (somatic) events. The primary focus of his research is ovarian cancer, which is a devastating disease with no clear warning signs and high mortality rates. Dr. Sellers also has active collaborations that involve cancers of the breast, lung and prostate. The underlying theme is identifying inter-individual differences in cancer susceptibility and using that to inform approaches to cancer prevention, early detection and precision medicine to enhance outcomes after diagnosis.

**Matthew Smith, MD, PhD*****Director, Genitourinary Malignancies Program******Massachusetts General Hospital******Professor, Department of Medicine, Harvard Medical School******Member, Bone and Cancer Foundation Advisory Medical Panel***

Dr. Smith earned a doctorate and a medical degree at Duke University School of Medicine in Durham, North Carolina. He completed an internship and residency in internal medicine at Brigham and Women's Hospital, a clinical fellowship in medical oncology at the Dana-Farber Cancer Institute, and a postdoctoral fellowship in molecular biology at the Massachusetts Institute of Technology. Dr. Smith serves as Associate Professor of Medicine at Harvard Medical School, Associate Physician at Massachusetts General Hospital, and Director of The Claire & John Bertucci Center for Genitourinary Cancers. An American Board of Internal Medicine Diplomate in both internal medicine and medical oncology, Dr. Smith holds membership in several professional societies, including the American Society for Bone and Mineral Research and the American Society for Clinical Investigation. Dr. Smith has authored numerous articles, reviews, chapters, editorials, and clinical communications. He is on the editorial board of *Clinical Cancer Research* and is the Genitourinary Section Editor of *Oncologist*.

Laura J. van 't Veer, PhD***Professor of the Department of Laboratory Medicine and Director of the Applied******Genomics, UCSF Helen Diller Family Comprehensive Cancer Center, University of California, San Francisco******Board of Directors, American Association for Cancer Research***

Dr. van 't Veer is a world renowned Molecular Pathologist, former Head of Diagnostic Oncology at the Netherlands Cancer Institute, and inventor of MammaPrint. She is the P.I. of the Bay Area Breast SPORE and Leader of the Breast Oncology Program in the Helen Diller Family Comprehensive Cancer Center. Dr. van 't Veer's research focuses on Personalized Medicine, to advance that patient management is based on knowledge of the genetic make-up of the tumor as well as the genetic make-up of the patient. This allows to optimally assign systemic therapy for those patients that are in need of such treatment and to ensure the selection of the therapy that is most effective. Dr. van 't Veer's research shows that molecular diagnostics and microarray genomics technology increasingly impacts patient management. Molecular Genomics contributes to the knowledge of who is at risk for breast cancer, how external factors may influence this risk, whether breast tumors are likely to metastasize or not, and which subtype of tumors will likely respond to what therapy.

Randal S. Weber, MD***Professor, Department of Head and Neck Surgery, Division of Surgery******Department Chair, Department of Head and Neck Surgery, Division of Surgery******John Brooks Williams and Elizabeth Williams Distinguished University Chair in Cancer Medicine******The University of Texas MD Anderson Cancer Center******Member, National Comprehensive Cancer Network Board of Directors***

After earning his medical degree, Dr. Weber completed a surgery internship at the National Naval Medical Center in Bethesda, Maryland, and residencies in surgery and otolaryngology at Baylor College of Medicine in Houston. He received specialized training in head and neck surgical oncology at M. D. Anderson Cancer Center and later joined the M. D. Anderson faculty, with a joint appointment at Baylor College of Medicine. He served as Professor and Vice Chair



of the Department of Otorhinolaryngology-Head and Neck Surgery at the Hospital of the University of Pennsylvania from 1996 to 2003.

Zena Werb, Ph.D.

Professor and Vice-Chair of Department of Anatomy, University of California, San Francisco

Steering Committee, American Association for Cancer Research

Zena Werb received her BSc from the University of Toronto. Under the mentorship of the late Professor Zanvil A. Cohn, Zena received her PhD in cell biology from The Rockefeller University, New York. Her post-doctoral work was completed at the Strangeways Research Laboratory in Cambridge, UK. After a year as a faculty member at Dartmouth Medical School in Hanover, New Hampshire, she joined the University of California, San Francisco, as an Assistant Professor in the Laboratory of Radiobiology. She is currently Professor and Vice-Chair of Anatomy at the University of California, San Francisco.

Eric P. Winer, MD

Chief, Division of Women's Cancers

Professor of Medicine, Harvard Medical School

Chief Scientific Advisor, Co-chair, Susan G. Komen for the Cure Scientific Advisory Board

Member, Triple Negative Breast Cancer Foundation Scientific Advisory Board

Member, American Society of Clinical Oncology Board of Directors

Dr. Winer received his undergraduate and medical degrees from Yale University. After completing internal medicine and medical oncology training at Yale and Duke, he was on the faculty at Duke Medical Center for eight years before moving to Dana-Farber Cancer Institute in 1997. Dr. Winer is co-chair of Cancer and Leukemia Group B (CALGB) Breast Committee. Dr. Winer is also the Chief Scientific Advisor and Chair of the Scientific Advisory Board for Susan G. Komen for the Cure.