## 2010 ANNUAL REPORT

## INSPIRING HOPE, EMPOWERING ACTION, IMPROVING LIVES





#### ABOUT THE AMERICAN PAIN FOUNDATION

Founded in 1997, the American Pain Foundation (APF) is an independent nonprofit 501(c)3 organization that serves people affected by pain. APF speaks out with people living with pain, caregivers, health care providers and allied organizations, working together to dismantle the barriers that impede access to quality pain care for all.

#### **OUR MISSION**

The American Pain Foundation educates, supports and advocates for people affected by pain.



#### Dear Friends:

Now that we've said farewell to 2010 and the congressionally mandated "Decade of Pain Control and Research," we have entered a new decade populated with many hurdles to overcome. The American Pain Foundation (APF), along with the staunch support from our members, board of directors, volunteers and alliance partners, has heeded the charge to improve the lives of people living with pain and worked diligently to ensure that efforts did not live in words alone, but came to fruition through action.

I am proud to share with you just a small sampling of the work APF has done the last year of this decade to honor its mission to educate, support and advocate for people affected by pain until pain is no longer a major health care problem.

With a membership of close to 100,000 and growing, APF has enhanced and grown our education, support and advocacy services and programs to better serve our constituents. In 2010, APF rang in the New Year with the launch of our Breakthrough Cancer Pain Spotlight, an important addition to our educational spotlight series that provides in-depth information and resources on pain-related topics. Just in time for summer — when many people increase their physical activities —"Oh, My Aching Back!" Spotlight was released chock full of tips and information on preventing and managing back pain.

As the climate in our country becomes increasingly focused on the risks of pain medications, APF has focused on developing a new educational program called PainSAFE<sup>TM</sup> (Pain Safety & Access For Everyone). Experts wrote and developed materials to provide people with pain and health care professionals information and resources on how to safely use pain treatment options to help lower the risks associated with pain therapies, and in turn, improve access to effective and appropriate pain care. In September, a month designated as Pain Awareness Month, APF unveiled its new PainSAFE website and other educational activities about safety.

APF has grown into the largest advocacy organization for people with pain. APF and its volunteers have continued to make inroads in raising awareness about the need for better pain management and improving pain care policy. In 2010, staff members and volunteers participated in close to 100 policy activities from testifying at legislative hearings and scheduling meetings with state and national representatives to securing city and state proclamations for Pain Awareness Month. In September alone, more than 530 individuals submitted letters to their legislators sharing their story and urging improvements in pain care legislation.

As we move forward, APF stands firm in its commitment to improve access to pain care for all. We ask you to continue to partner with APF in this journey and persevere with us; triumphantly climbing over any hurdles and breaking down the barriers that are preventing people with pain from receiving the necessary pain care they rightfully deserve and need. We can only do this successfully if we speak out for the rights of people with pain together.

Sincerely,

Will Rowe

Chief Executive Officer

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## EDUCATION

Too often, people with pain don't receive the pain management they deserve. This can result in years of needless suffering. APF provides a wide array of educational programs and support services to help people affected by pain.

#### **EDUCATION**

When people know more about their pain, they are better equipped to make the right decisions with their health care providers and advocate for the pain care that works best for them. APF listens to the experiences of people living with pain and offers pain education and resources to help them self-advocate for optimal pain care.

Online and print publications and news alerts continue to be in high demand and provide accurate and timely information to people affected by pain. APF's newsletters, booklets, topic briefs, and online modules are filled with pain-related news, tips and practical advice to help people with pain take charge of their pain care and reclaim their lives. Topics cover different pain conditions, co-existing health issues often accompanying pain and its treatment (e.g., depression, sleep disturbances, constipation), finances, family matters, tips for coping and much more.

#### Here is just a sampling of APF resources:

- Pain Community News, APF's esteemed quarterly newsletter, has a print circulation of more than 68,000 and many more online readers. In 2010, PCN explored such issues as health decision making, cancer pain, the pain-sleep cycle, the healing power of gardening, medication safety, nutrition and pain and much more. Book reviews, APF's volunteer corner and fast facts were recurring items.
- Pain Research & Practice Update in 2010 provided conference coverage of the American Academy of Pain Medicine's 26th annual meeting and reported on studies related to chronic pain after breast cancer surgery, migraine and stroke, texting and shoulder/neck pain, acupressure and tai chi for pain relief, the role of vitamin D in chronic pain and much more.

- *Pain Monitor* is a monthly electronic newsletter that provides links to the latest pain-related news and research, legislative updates and highlights of APF events.
- Core educational booklets Pain Resource Guide: Getting the Help You Need; Targeting Chronic Pain: Your Personal Notebook; Access Matters: Making Sense of Health Coverage; and Treatment Options: A Guide for People Living with Pain — continue to help those living with pain and their caregivers.
- Top 10 Tips provide practical advice on making your voice heard to advocate for better pain care, coping with cancer-related pain, preventing and finding relief from back pain and medication safety.

All APF materials are created to meet the unique and growing information needs of people affected by pain and their caregivers.

#### Is Fibro the Cause? Pilot Project in Missouri

Fibromyalgia affects up to six million Americans, making it one of the most common musculoskeletal pain conditions in the United States. Yet it often remains undiagnosed and misunderstood, resulting in unnecessary pain and disabling symptoms for many. To raise awareness about fibromyalgia, APF partnered with community and state-based alliance groups and fibro advocates in Missouri to pilot a fibromyalgia project. More than 8,000 print copies of APF's *Is Fibro the Cause*? online toolkits were provided free to Missouri residents at community events and presentations on fibromyalgia and at designated locations throughout the state. The toolkit contains helpful tips and resources including how to recognize the signs and symptoms, a worksheet to help track symptoms and facilitate communication with your health care provider, and tips for living well with fibro.



## EDUCATION

**APF's educational Spotlight series** sheds light on various pain-related topics, including:

- Cancer pain
- Fibromyalgia
- Pain and end of life
- Let's Talk Pain (a coalition effort that focuses on supporting positive patient-provider communications)
- Military/Veterans and pain
- Shingles/Postherpetic neuralgia (PHN)

#### "Oh, My Aching Back!"

As part of this educational series, APF launched "Oh, My Aching Back!" in 2010. Back pain will affect a majority of Americans — eight out of 10 — at some point in their lives, and it's only expected to become more common as our population ages and obesity rates continue to soar. This practical online guide educates readers about back pain and arms them with information and tools to talk with their health care provider about it. This new resource includes articles (e.g., The ABCs of Back Pain, Who's Who in Treating Back Pain, Finding Relief, Back Pain & the Workplace), tips for preventing and managing back pain, worksheets and self-care strategies, as well as personal stories from people living with back pain.





#### Breakthrough Cancer Pain — Breaking Through to Improve Cancer Care

Although millions of Americans now live long after their cancer treatment ends, the cancer experience frequently leaves a high-cost legacy of pain for individuals, families and the health care system. Results from an online survey commissioned by APF and released on January 28, 2010, revealed that breakthrough cancer pain (BTCP) — sudden, temporary flares of severe pain that occur even when pain medication is used — is one of the most challenging aspects of having cancer according to three out of four U.S. adults who have ever been diagnosed with cancer and experienced this type of pain.

To raise awareness about BTCP — which is often unrecognized and untreated as a distinct problem even though it disrupts lives and increases medical needs — APF created online content about the basics of BTCP; tips to make sure pain management is an integrated part of cancer care; treatment options; and answers to commonly asked questions. APF also produced a video featuring leading cancer experts, people who have experienced BTCP and their caregivers.

#### PainSAFE™

No single treatment option for pain management is without risk, and that also includes the decision not to treat pain. But these risks can be managed by educating consumers and health care providers about different treatment modalities and their safe use.



In September 2010, APF proudly unveiled PainSAFE (Pain Safety & Access for Everyone) — a new initiative to educate people with pain and health care providers on the appropriate and safe use of various pain management therapies. PainSAFE provides up-to-date information, programming and resources.

The first sections to launch at **www.painsafe.org** featured information and tips for safely using opioid analgesics and implantable pain therapies. PainSAFE continues to expand in 2011 and beyond to include new sections on over-the-counter pain medications, such as nonsteroidal anti-inflammatory drugs (NSAIDs) and acetaminophen, as well as complementary and alternative therapies and other safety topics (for example, how to travel safely with pain medications).

PainSAFE strives to educate consumers and health care providers in tandem to encourage consistent and parallel communication about important safety issues.

#### Staying PainSAFE for People with Pain...

PainSAFE educates the public and helps build their skills for safely using pain treatments. APF believes a more informed consumer will result in better treatment choices, safe use of these therapies and, in turn, improve outcomes.

#### Staying PainSAFE for Health Care Providers...

In parallel, PainSAFE offers health care providers a central hub of evidencebased information and practice-based tools to focus on safety and reduce the risks associated with various pain treatments.

PainSAFE is part of the APF's ongoing commitment to advocate for timely access to safe and appropriate pain care for those affected by pain.



"Knowledge about how to safely use pain treatment options will result in better treatment choices with lowered risk and, in turn, improve access to pain care."

— Lynn Webster, MD, FACPM, FASA, clinical reviewer and the original creator of PainSAFE

## EDUCATION

"American Pain Foundation has done wonderful things for so many people — like myself — who are in desperate need of proper pain care and advocacy. APF has given me hope that soon all will be treated with the care and respect they need so much."

— Person living with pain

APF's website, which was visited by nearly 275,000 people in 2010, underwent a major redesign and reorganization. Integral to this undertaking was feedback solicited from a working group consisting of people with pain and caregivers. Their insights helped inform the new design, which is not only aesthetically pleasing and more engaging, but also provides better functionality. Through improved search capabilities, reorganized content and upgraded social media sharing options, members can more easily and effectively access information and communicate with APF and each other. The website redesign and reorganization provides areas to incorporate the educational materials gifted to APF by the National Pain Foundation (NPF) in 2009. Full integration of the NPF website will be complete in 2011.



"Not only does your website offer a world of knowledge, it's practical, understandable and very patient-centered and guided!"



## SUPPORT

People living with persistent pain often feel unheard, stigmatized and alone. APF continues to serve as a central hub for understanding and support. APF's support services and programs are designed to connect those affected by pain with others to help them cope and better navigate their pain care.

**PainAid**, APF's online support community is available 24/7. In 2010, more than 25,000 people participated in PainAid's discussion boards and chats. Its 16 trained volunteer moderators and experts spent more than 4,000 hours interacting with members in these venues.

Discussion boards include:

- General topics such as specific chronic pain disorders, diagnosis and treatment, personal and family issues and more
- Ask the Experts featured physicians, nurses, pharmacists, a podiatrist, a massage therapist and other practitioners of complementary therapies
- Military/Veterans and the international discussion boards

In 2010, APF hosted

- 372 chats
- More than 6,000 discussion board posts
- Two webinar series on techniques for coping with and communicating about fibromyalgia and breakthrough cancer pain

**Pain Information Center (PIC)**, APF's toll-free information line (1-888-615-PAIN) and personalized email response service, provides people with pain and their caregivers current information, resources and support. In 2010, PIC responded to thousands of calls and emails from people — many desperately seeking someone who could help them.

**Pain Resource Locator** is a searchable database of local resources and disease-specific organizations that may be helpful in managing pain.

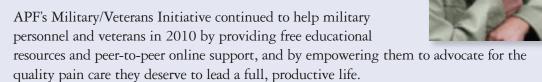
**Clinical Trials Center** provides up-to-date information about the latest pain-related clinical trials in partnership with CenterWatch. This searchable database includes a complete listing of National Institutes of Health-funded studies, as well as recent U.S. Food and Drug Administration (FDA) medication and device approvals.

"The people I have met through PainAid have become my friends and extended family. Thank you for providing this vital source of support!"

### SUPPORT

## MILITARY/VETERANS PAIN INITIATIVE

Pain continues to rank among the top medical complaints of active duty military personnel and veterans. An estimated nine out of 10 Iraq and Afghanistan veterans reportedly return home with some type of pain.



APF's Military/Veterans Initiative played an influential role in policy efforts that eventually led to the passage of the military and veterans pain care legislation in 2008, which has since had a profound effect on pain care within the Departments of Defense (DoD) and Veterans Affairs (VA). After the legislation became law, the DoD and the VA joined forces to create a pain task force and in May of 2010 they released a final report: *Providing a Standardized DoD and VHA Vision and Approach to Pain Management to Optimize the Care for Warriors and their Families* detailing 109 recommendations to improve pain care. A report on these recommendations and their implementation will be given to Congress in summer 2011 and APF will continue to follow and advocate for these improvements within the DoD and VA health care systems.

#### In 2010, APF:

- Participated in 17 speaking engagements on military/veterans topics, reaching more than 10,000 people
- Responded to more than 400 emails and 250 online posts seeking resources and support for military personnel, veterans and their families
- Participated in eight media interviews reaching more than three million people
- Partnered with the Fisher House Foundation to distribute 4,000 copies of Exit Wounds: A
   Survival Guide to Pain Management for Returning Veterans and their Families to wounded
   warriors and their families staying in these houses. Another 500 copies were distributed free
   of charge to veterans attending the 2010 National Convention of the Disabled American
   Veterans.

"I had no idea this or anything like it was available to veterans. I want to personally thank you for all you do for the many that suffer. Please keep up the good work."

— Veteran living with pain



## ADVOCACY IN ACTION

In 2010, APF led the charge to improve access to appropriate pain care and, in turn, prevent needless physical, emotional and financial suffering for the millions of Americans who wake up in persistent pain every morning.

Through calls to action, organized activities and awareness-building efforts, people with pain, caregivers and health care providers heeded the charge and advocated for better pain care by demanding change in policy and practice in their own communities and nationwide.

#### **Action Network**

APF's volunteer grassroots network of people living with pain, caregivers and health care providers provide the critical infrastructure for organized national and state-based advocacy efforts to improve pain care and policy in the United States. Serving on the front lines of the pain movement, APF Action Network (AN) leaders, advocates and members give a face and a voice to the multitude of issues that comes with living with pain or caring for someone in pain.

With 95 AN leaders representing 35 states, the District of Columbia and Puerto Rico, a sampling of their vital work and contributions this past year include:

- Organizing and participating in more than 340 community events nationwide
- Distributing pain resources and educational materials to approximately 10,000 people
- 36 media placements featuring their advocacy efforts and personal struggles with pain
- Participating in 98 pain policy activities ranging from testifying at legislative hearings and scheduling personal meetings with their representatives to securing pain proclamations

"I'm bonored to speak out for the rights of people with pain. Unless you suffer with pain on a daily basis, you have no idea of what living with pain is all about."

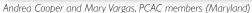
— Action Network member

## ADVOCACY IN ACTION

#### **Annual Advocacy Summit**

Under the central theme of "Finding our United Voice: Conquering Pain Together," a record 127 AN leaders, pain advocates, national alliance partners, state-based collaborators and supporters from 37 states gathered together in Minneapolis for a three-day advocacy summit in April. In its fifth year, the summit provided participants an opportunity to network with others interested in transforming pain care in America; hands-on training and resources in community outreach, media advocacy, national and state policy advocacy; and an arena to showcase the accomplishments and impact leaders are making in their own communities.







Jannie White, AN leader (Michigan)



Summit roundtable discussions

"The summit was fabulous! APF makes it possible for all of us to continue our important work in a connected and united [way]. We will change pain care in America for all Americans!"

— Action Network leader

#### Online Advocacy Center/Alert System

APF's online advocacy center promptly alerts members about emerging state-specific and national policy issues that could intentionally or unintentionally affect pain policy and access to treatment. Alerts provide recipients with background information and resources on the issue, as well as steps for taking action.

In 2010, action alerts were sent related to:

- Prescription monitoring programs
- Step therapy legislation
- Opioid prescribing rules
- Acetaminophen safety
- Risk Evaluation Mitigation Strategies (REMS) for opioids
- PainSAFE initiative
- Breakthrough cancer pain project
- Pain awareness month activities and opportunities
- Governmental regulations preventing access to care
- Unbalanced media coverage reinforcing pain stigmas



#### Pain Awareness Month Sparks Action Locally and Nationally

APF, its members and many other health care organizations and alliance groups observe Pain Awareness Month each September. During this month and throughout the year, APF and its volunteers speak out about the undertreatment of pain and the barriers that prevent effective pain care and dedicate themselves to raising awareness about the need for better pain care in communities all across the country.

This year, APF organized an online Virtual March that served as a central hub for people participating in raising awareness about pain. Through this virtual movement, pain advocates were united and empowered to rally for improved pain policy and management from the comfort of their home or office. Participants took part in one or all of the following activities by:

- Writing and submitting a letter to decision makers a key opportunity to share how pain has affected one's life and to encourage decision makers to make policy changes
- Attending or organizing pain awareness events in their own communities
- Joining APF's Action Network
- Spreading the word using social media tools (Facebook, Twitter, blogs)
- Adding their individual stories to APF's 10,000 Voices campaign

#### APF's 2010 Pain Awareness Month campaign highlights:

- More than 9,000 people attended the Virtual March, which was endorsed by 75 organizations
- More than 530 individuals sent letters to their legislators urging improvements in pain policy
- 32 Pain Awareness Month proclamations were issued by city and state leaders
- APF's first ever online advertising campaign on Facebook reached more than 17 million people
- 300 educational and awareness activities were held throughout the country
- Securing 249 media print, broadcast and online placements reaching approximately 90 million people
- More than 17,000 pieces of APF literature were distributed, providing valuable information and resources to people with pain
- PainSAFE also launched during this time





Far left: Pain Awareness Month display in cafeteria at St. Luke's Hospital in Kansas City, MO.

Left: Action Network leaders and pain advocates receiving Pain Awareness Month proclamation for Nebraska. Shown from left to right: Action Network Leader Jan Tooker, Sharon Anderson-Towery, Lieutenant Governor Rick Sheehy, Renee Pickerel, Action Network Leader Jennifer Eurek, LaDonna VanEngen and Beth Nelsen.

## ADVOCACY IN ACTION

#### 10,000 VOICES CAMPAIGN — NEW IN 2010



During Pain Awareness Month, APF launched the 10,000 Voices campaign as part of its Virtual March. Designed to capture the voices of people affected by pain who unfortunately do not always have an outlet, the campaign featured an online virtual "wall" for people to share how untreated or undertreated pain has affected their lives and to offer messages of hope. Understanding that people voice their thoughts and feelings through different forms, APF provided easy-to-follow instructions for people to submit and upload their powerful

written statements, individual photos or moving videos to the wall for the online community to view and better understand the impact of pain on individuals and families and how people are managing their lives. For some, the campaign served as a catharsis, and for others it reinforced their desire and commitment to be part of a movement working to raise awareness and improve pain care.

## APF Lends Its Expertise to Help Inform Health Care Professional Education

In 2010, APF collaborated on 38 certified and non-certified, independent medical educational activities with four educational partners. This unique opportunity has allowed APF to incorporate the values and perspective of the person with pain into the educational paradigm of the health care provider to enhance the communication between health care professionals and patients and improve the overall quality of life for the people with pain. Activities included live symposia, Dinner Dialogues, e-newsletters, webinars and other education formats.

Through these efforts, APF:

- Became responsible for, and owners of, all curriculum content development for the National Initiative on Pain Control (NIPC)
- Greatly expanded its reach to health care professionals and people with pain, growing membership by 1,500+
- Reached more than 1 million health care providers and increased awareness about the organization and its resources

# Extra, Extra, Read All About It

## APF AND PAIN MAKE HEADLINES!

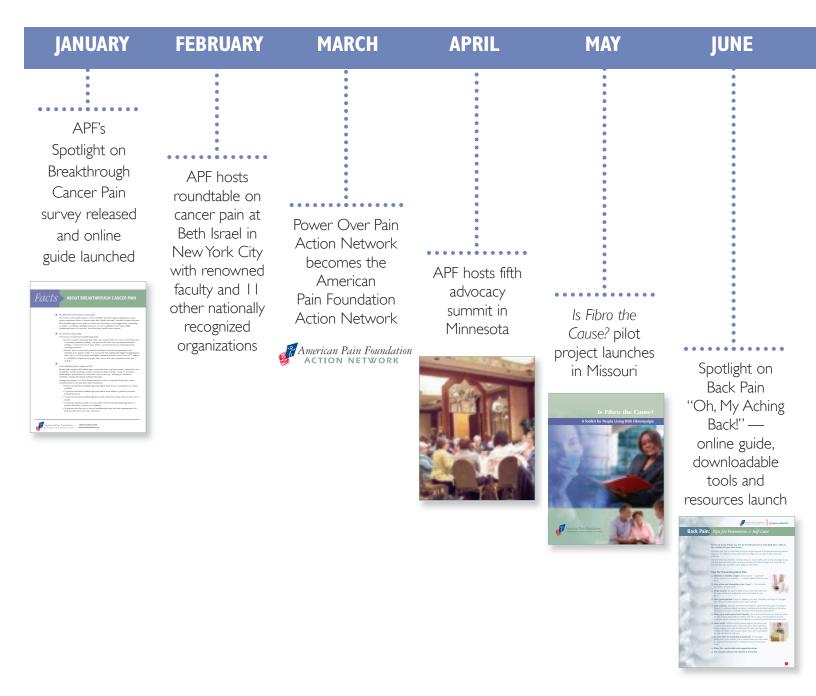
Accurate, timely and balanced news coverage about pain is a critical component of raising awareness about the scope of pain, the impact it has on daily living and the need for effective pain care for all. APF has made significant progress in fostering working relationships with members of the mainstream and trade media. The "go-to" source for reporters seeking the latest facts, information and resources on pain, APF also offers story suggestions and connects reporters with leaders in pain management and people who can speak about their specific pain issue.

Through online, print, radio and television outlets, APF's local and national media outreach efforts secured 1,600 media stories on pain in 2010 — an increase of 1,255% from 2009. Reaching more than 600 million people with important pain-related messages, APF spokespeople and advocates provided education, information and assistance to people with pain and combated the negative stereotypes and stigmas associated with pain.

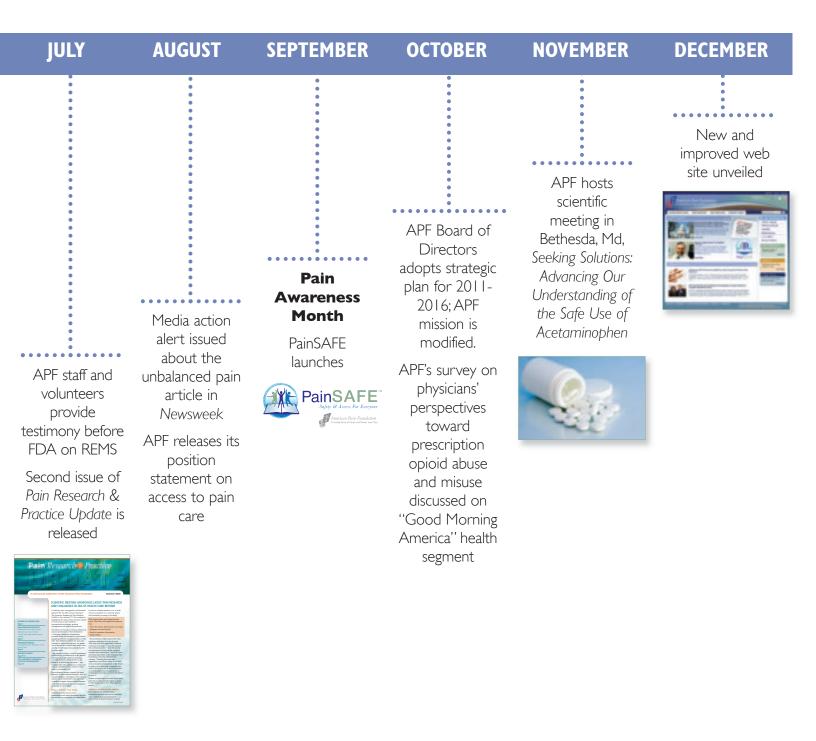
APF and the pain story was covered by a number of reputable national and local news media outlets including but not limited to:

- The New York Times
- Health
- Newsweek
- Prevention
- News 14 Carolina
- KOED

# Y E A R I N

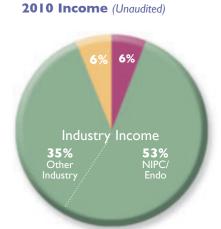


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## FINANCIAL INFORMATION

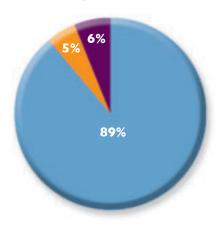
**The American Pain Foundation** is a 501(c)(3) non-profit organization. APF is proud to offer an array of programs and services to help those living with pain and their families, as well as the health care community serving them. Such efforts would not be possible without the generous support from private companies, individual contributions and foundation grants.





Income	\$	%		
Products and Services	20,684	near 0%		
Foundation Income	297,000	6%		
Industry Income				
National Initiative on	Pain Control (NI	PC)/		
Endo	2,664,408	2,664,408 53%		
Other Industry	1,751,891	35%		
Individual and Other	285,972	6%		
Total	5,019,955	100%		

**2010 Expenses** (Unaudited)



■ Program Expenses
Administrative Expenses
■ Fundraising Expenses

Total	4.778.731	100%
Fundraising Expenses	270,800	6%
Administrative Expenses	235,481	5%
Program Expenses	4,272,450	89%
Expenses	\$	%

#### 2010 DONOR HONOR ROLL

With this honor roll, the American Pain Foundation gratefully acknowledges and proudly celebrates the generosity and support of members, corporate partners, foundations and friends. This is a list of our treasured donors who made gifts that were received between January 1, 2010, and December 31, 2010.

#### **INDIVIDUALS**

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Serving as ambassadors to APF and spokespeople for people with pain, the Pain Community Advisory Council (PCAC) provides guidance and advisement to APF's Board of Directors, chief executive officer and staff to ensure that APF's programs, actions and positions are guided by the experiences of people affected by pain. PCAC's individual and collective expertise brings the voices of people with pain and caregivers to the forefront of the decision-making process.

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Excerpts from PCAC member
Mary Vargas's Keynote
Speech during the 2010
Action Network
Advocacy Summit



...In early 2000, I found APF through the Internet and within a few days of hearing the name American Pain Foundation for the very first time, I was standing in a Congressional briefing, once again telling my story. But something incredible happened. I told my story and they listened and they looked in my eyes and they cried...

...That day was a beginning for me — the first time I understood that even though I had pain, I still had the power to enact change...

...10 years for me — for some of you a lifetime. We have looked for the groundswell, we have waited for the cry of indignation that could not be silenced, we have gathered our courage and we have dared to dream of a world where we are not ruled by pain. And I know it and feel it and believe it that now is our moment. I see it in the work that you do even on bad days. I see it in your commitment to travel despite the physical toll. I see it in the outrage you carry boiling just beneath the surface. Now is the moment we will not take it anymore. In this room we have the potential to draw the line in the sand, to find our collective voice.



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