



CONQUERING PAIN
Together

 *American Pain Foundation*
A United Voice of Hope and Power over Pain

September is

Pain Awareness Month

National Day of Action

September 26, 2009



**ACTION
TOOLKIT**

Welcome!

Thank you for joining us to help sound the alarm in communities across the country about the barriers to accessing appropriate and effective pain management and the desperate need for better pain care. This year's campaign is themed "Conquering Pain Together," encouraging a unified effort to make a difference in pain care.

Everyone experiences pain at some point—a pounding headache at the end of a long day, a throbbing toothache warning of a cavity or infection, an open wound or sprained ankle from a fall or a stinging burn. Pain is the body's natural alarm system, alerting us that something isn't quite right. But, imagine having pain that never goes away? Millions of Americans live each day with persistent pain, and it can wreak havoc on a person's physical, emotional and spiritual wellbeing. Unfortunately, chronic pain is not always assessed and treated appropriately, resulting in needless suffering—many people can't work, take part in their favorite activities or even be hugged by a loved one for fear the resulting pain will be crippling.

As part of Pain Awareness Month (PAM), the American Pain Foundation will spearhead the first **National Day of Action on September 26** to generate widespread awareness about pain and its management through:

- community events,
- local media outreach,
- meetings with legislators and other key decision makers, organized by pain advocates like you; and
- An online petition to declare, "I COMMIT to improving appropriate and effective pain care for all!"

We need you! In this toolkit, you will find ideas and template materials to help you plan, promote and conduct successful Pain Awareness Month activities. These are just some ideas to get you thinking about ways you can spread the word that we are united in Conquering Pain Together!

These efforts renew our collective commitment to work towards better access to appropriate and effective pain care for all, and has the potential to change minds and hearts and we invite you to be a part of that!

If you have any questions or would like more information, feel free to contact [the Conquering Pain Together](#) Campaign team.



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Access to Pain Care - Key Messages



- **Pain is a growing national public health crisis** that affects an estimated 76.5 million people and has serious economic ramifications. More than one-quarter of Americans (26%) age 20 years and over report that they have had a problem with pain that persisted for more than 24 hours in duration. This number does not account for acute pain. A hallmark of many chronic conditions, pain affects more Americans than diabetes, heart disease and cancer combined.
- Despite this prevalence, **access to appropriate and effective pain care remains a barrier** for many Americans. These barriers include:
 - Limited access to health care systems, including health insurance or choice of provider;
 - Limited access to prescribed pain treatments once within those systems;
 - Limited access to sites of care or pharmacies that carry prescription pain medication;
 - State, legal and regulatory policies that interfere with the medical use of appropriate medicines for pain relief;
 - Limited access to pain specialists who have been appropriately trained in the full spectrum of knowledge available for pain management;
 - Limited pain research funding which limits the scope of treatment and curative possibilities for specific pain conditions; and
 - Negative stereotypes about pain patients that prevent early and aggressive treatment.
- **These barriers disproportionately affect women and minorities:**
 - Medically underserved populations endure a disproportionate pain burden in all health care settings; and
 - Disparities exist among racial and ethnic minorities in pain perception, assessment, and treatment for all types of pain, whether chronic or acute.
- **Improving access to care makes sound financial sense:**
 - Undertreated pain drives up the cost of healthcare; it extends lengths of stay in hospitals, increases emergency room visits and leads to unplanned clinic visits;
 - The cost of pain not only includes direct costs associated with doctor's visits, diagnostics and medication, but indirect costs such as lost wages and productivity of both people with pain and their caregivers;
 - American employers lose billions of dollars a year on employee absenteeism as a result of pain; and
 - Lost productive time from common pain conditions among active workers costs an estimated \$61.2 billion per year. The majority (76.6%) of the lost productive time was explained by reduced performance while at work and not work absence.
- **When pain is treated properly, many people can resume their lives:**
 - Successful pain treatment is individualized and there is evidence that multi-modal approaches are most effective; and
 - By improving access to pain care, Americans in pain can receive the services they need in order to lead healthy, productive lives.
- The Bottom Line: **People in pain have a right to timely, appropriate and effective pain care.** Visit the American Pain Foundation for more information.

→ “I Commit” Petition

Make your voice heard. By signing this petition, you are telling your legislators that you are a part of a national movement working towards improving access to appropriate and effective pain care for all.

Go to www.conqueringpaintogether.org and click on the [Sign the Petition](#) link to add your signature. Make sure to forward it to your family members, friends, neighbors and co-workers. Remember, pain affects more Americans than diabetes, heart disease and cancer combined—so chances are someone you know is affected by this growing public health crisis.

The more people who sign this petition, the more impact the petition will have to convince our decision makers to make policy choices that work to improve our access to good pain care.

By signing this petition, you are telling your decision makers and gate keepers to access that you are part of a national movement working towards improving access to appropriate and effective pain care for all.



“I COMMIT to improving access to appropriate and effective pain care for all.”



Getting Started

There are many activities that you can plan in honor of Pain Awareness Month and to lead up to the National Day of Action on September 26. Local efforts may range from raising awareness by setting up information tables in key locations around town or by community education through health fairs or by meeting with your legislators and other community leaders who can help get pain on the local and state agenda. As pain knows no boundaries, the broad range of events and the communities we reach will demonstrate that diversity is our strength! Activity and event ideas can be found in this toolkit in the areas of **community outreach**, media **outreach** and policy **advocacy**. Many of these are simple to do and can result in big returns in terms of visibility and impact in your community. You may have the connections, resources, time, and good health to organize a large event. Or, you might want to think smaller. Either way, EVERY activity has the potential to have a positive impact, regardless of its size!

Spread the word and engage others. Reach out to your friends, family, colleagues, and people you know in your community and encourage them to get involved. Ask them to join your efforts, create their own activity, or attend an event you're hosting. Refer them to this toolkit for ideas. Send announcements about Pain Awareness Month to local service groups such as Kiwanis and Rotary Club. Consider posting information/posters in churches, synagogues, mosques or other faith-based gathering places.

Reach out to your local news media. If you are having a media worthy event, be sure to use the **Media Outreach section** of this toolkit for help in contacting the media. You will also find sample letters to the editor, an op-ed (which stands for opinion editorial because that's where it appears in the paper and gives you the opportunity to voice your concerns about the undertreatment of pain), and template press releases to help promote your event.

Contact elected officials and other well known community leaders. Set up a meeting with your elected officials or if you are doing an event, invite them to attend- this can be a way to bring better visibility to your event and educate decision makers about the issue of pain and its undertreatment.

Be prepared. Make sure to bring postcards, posters, and a camera to chronicle your event.

Build a groundswell of support. Encourage people to join the American Pain Foundation year-round in our commitment to improve pain care, by joining on this site or by going to www.painfoundation.org. Make sure people go online to the Conquering Pain Together website and sign the petition.

See - [**10 THINGS YOU CAN DO TO RAISE AWARENESS THAT TAKE LESS THAN 10 MINUTES**](#). Share it with others!

We want to hear from you. Let us know how your event turned out by completing our simple on-line **post-event form**. We will use this information (where the event was held, how many people attended, and what you did) in our contact with policymakers and future media outreach. It will also help us in planning future Pain Awareness Month activities.

Together we will make this September memorable!

Community Outreach

Throughout September and on the National Day of Action, gather with friends and loved ones, colleagues or members of your community and share the key messages for access to better pain care, sign the petition and take pictures. The activities or event can be as small as a gathering in your home or as large as health fair with thousands in attendance. Since the entire month of September will be dedicated to pain awareness, consider having an event earlier in the month to engage others in conducting activities of their own on the National Day of Action. Whatever you decide, be sure to document your activities and events, take photos and submit them online at <http://www.flickr.com/groups/conqueringpaintogether> or click on the Flickr icon at the top of the page on the Conquering Pain Together website.

Ways You Can Make A Difference

Distribute materials. It can be as simple as handing out the September Pain Awareness postcards or putting up the posters when you go to your grocery store, library, places of worship, community centers, beauty and barber shops, gyms, yoga studios and coffee shops in your area.

Distribute APF publications in your community to spread the word about the resources available for people living with pain and their caregivers. Ask to place these materials in high traffic areas at your doctor's office, pharmacy, library, gym, yoga studio, coffee shop, dry cleaners, or grocery store. There is an order form available in the Resources section of this Conquering Pain Together website or [click here](#).

Host a community gathering in your home. Bring people together to share their pain stories. Have everyone at the gathering sign the "I Commit" petition online. Encourage others to do the same. We want people to be engaged in activities even if their pain prevents them from leaving their homes.

Plan an educational talk. Plan a community presentation or visit to a local community clinic, community or senior center, library, a retirement home or at your place of business. Pain is everywhere so be creative

with the location of your event. Community colleges or universities are always a great location to

have an event, although you may need to be affiliated with the facility. It can be as simple setting up a table to distribute materials or a full day of presentations by you and/or experts from the field to provide information on pain management. Be sure your presentation fits your audience. There are template presentations available for you to use with a toolkit which will guide you through the process of hosting a presentation. [Click here](#) for the presentation toolkit.

Link up with existing, related community efforts or events. Join an event that is already taking place in your community - a health fair, Kiwanis or Rotary Club meeting, parade or street festival. Check with other organizations that may be doing something for Pain Awareness month and link with them. Register the event and then get the word out. Canvas your community with the Pain Awareness Day postcards and posters advertising the event.

Attend or host a special session of your support group on September 26th. Have additional meetings of your support group. See the social networking section to find the best ways to get the word out about your group.

Get creative, host a 'Pain and Creativity' event. Arrange with a local coffee shop, art gallery or community center to host an evening of art inspired by pain. Ask people from your community to share their work that has been inspired by their pain.

→ Build your Social Network

Social networking is the latest way to get the word out. You've probably on or have heard of Facebook, MySpace and Twitter. These sites help extend your network to people and organizations that may be difficult to find otherwise.

Once you have decided on your event or signed the petition there are several tools available to you to get the word out. For example, you can **use Facebook** to build a network of "friends" that are both people you know and people you do not, who have an interest in improved pain management. Create a profile on the site and then start to look for friends based on various key words, pain, fibromyalgia, arthritis, RSD, etc. By doing this, you will find people you can add to your network so when you are ready to host an event or share information about a colleague's event, you already have a network to distribute it to. If you find a group that seems to be doing work similar to yours or who may be interested in joining your movement contact the administrator of that group to send a message on your behalf. The message you send could simply refer people to the www.conqueringpaintogether.org website and request that they sign the petition or consider gathering for an event on the National Day of Action. You can use your "status update," to say:

- Check out www.conqueringpaintogether.org and sign the petition.
 - I am having an event for the National Day of Action on September 26th. You should too. Go to www.conqueringpaintogether.org to see how you can get involved.
- ★ **Use other websites such as Twitter** to let people know about the National Day of Action and your activities. You can post "tweets" about the National Day of Action or the petition similar to the suggested options above.
- ★ **Use sites such as www.meetup.com** to create a group or join a group of people interested in "meeting up" to talk about issues surround appropriate and effective pain management or access to care. Using your blog to tell your story is also an effective way to get the word out.

Pictures and Videos Help Spread the Message

Take a picture of yourself, friends and family with the Conquering Pain Together poster or postcards and post them to the American Pain Foundation's Flickr account by clicking on the icon on the Conquering Pain Together website or going to <http://www.flickr.com/groups/conqueringpaintogether>. You could also make a brief video that simply says, "I Commit to improving access to appropriate and effective pain care for all." and submit to **APF's YouTube Channel**. We will be streaming these videos through the APF site during the campaign.

Pain is News-- Reach out to local media to raise awareness of pain issues during September Pain Awareness Month!

September is an ideal time to reach out to local media to raise awareness of pain management issues surrounding the theme of Pain Awareness Month. As the media has such power in our lives, you might ask your local newspaper to report on the undertreatment of pain and local efforts to raise awareness.

You can help spread the word by issuing press releases about your community events and submitting letters to the editor and op-eds to your local newspapers during the month. The information included in this section will help you prepare a local media list, tailor template press releases to publicize your local event or activities, and prepare a letter to the editor or op-ed for submission to your newspaper.

The focus of the American Pain Foundation's 2009 campaign is Conquering Pain Together focused on improving access to appropriate and effective pain care for all. We have created and made available to you press materials and presentations; please download and tailor them to your efforts.

We want to hear from you!

Are you interested in helping to provide hope and inspiration to people in pain in your area by telling your personal pain story through the media? Are you interested in becoming more involved in pain advocacy through the Power Over Pain Action Network? If so, please contact the American Pain Foundation at advocacy@painfoundation.org.

Ways You Can Make A Difference

Find out who best to contact at your local media outlets and create a list. If you do not already have one, prepare local a health contact media list. This can be created through <http://www.capwiz.com/media>. Your media list should include daily and weekly newspapers, area magazines, and television and radio contacts. Ideally, your contact will be the health or features editor or producer. Your list should include the media outlet's name, your contact's name, telephone number and e-mail address.

Tailor and distribute a press release for September Pain Awareness Month, Pain Advocacy Day and/or Pain Awareness Month Proclamation and/or community pain events, if appropriate. There are several options provided in the template materials to publicize your September awareness efforts. These include:

Press Release Templates:

- 1) [Sample Press Release For Your Community Events](#)
- 2) [Sample Press Release for your Proclamation](#)
(located in the Proclamation Toolkit Section)

Fact Sheets (supporting material for that you can distribute with your press release):

- 1) General pain information [APF Newsroom].
- 2) [Access to Pain Care Backgrounder](#)

Distribute your press release to reporters at least two-three weeks before your event. *Because some newsrooms limit the size of e-mails coming in, many reporters prefer that you paste the press release into the body of the e-mail as opposed to attaching a document.* Also feel free to support your media outreach efforts with the sample fact sheets by either pasting in below the press release or forwarding to a reporter who has requested more information.

If you are publicizing an event, be sure to send material to the “calendar” section of newspapers approximately six weeks before your event.

If reporters express interest in attending your event, make sure that you bring copies of the press release and fact sheet to the event to distribute to media only - not the general audience. A folder that packages this and other information that you would like a reporter to have is called a “press kit.”



Sample Press Release for Your Community Events

Tailor this Press Release to suit your needs by replacing the information in yellow with specific information about you and your event(s).

For Immediate Release

- CONTACT: [Your Name]
- Ph: [xxx-xxx-xxxx]
- Email: [xxxxx]

Conquering Pain Together: SEPTEMBER IS PAIN AWARENESS MONTH and National Day of Action, September 26, 2009

Community Events Offered to Address Issues Relating to Access to Pain Care

- [CITY, STATE] – (Release Date) – Individuals and organizations in [your state] have announced that in recognition of September’s designation as Pain Awareness Month, community events will be held to raise awareness about pain, highlight the issues surrounding pain management and address the lack of access to pain care. According to the American Pain Foundation, pain impacts an estimated 76.5 million Americans including approximately [XX] residents in [insert your state].

- “A hallmark of many chronic conditions, pain affects more Americans than diabetes, heart disease and cancer combined according to the National Centers for Health Statistics,” said [Name].

➔ The following events are being offered throughout the month [or on the Day of Action]:

- ➔ • [Program title, location, date, time]
- ➔ • [Program title, location, date, time]
- ➔ • [Program title, location, date, time]

“Despite the high prevalence of pain, access to appropriate and effective pain care remains a barrier for many Americans including those right here in our own community. These free events are designed to help educate people in pain and their caregivers about the resources available and empower them to overcome the barriers preventing them from receiving effective pain management. These barriers may include limited access to health insurance or choice of physicians, limited access to prescribed pain treatments, limited access to pain specialists who have been appropriately trained in pain man-

➔ Agement and negative stereotypes about pain patients,” [NAME] continued.

➔ To register for any of these events, contact [Name] at [Phone]. For additional information on pain or to learn more about the American Pain Foundation or this campaign, visit www.conqueringpaintogether.org.

About Pain in America

According to the National Center for Health Statistics National Household Survey:

More than one-quarter of Americans (26%) age 20 years and over- or, an estimated 76.5 million Americans- report that they have had a problem with pain of any sort that persisted for more than 24 hours in duration. This number does not account for acute pain.

- Adults age 45-64 years were the most likely to report pain lasting more than 24 hours (30%).
- More women (27.1%) than men (24.4%) reported they were in pain.
- Non-Hispanic white adults reported pain more often than adults of other races and ethnicities (27.8% vs. 22.1% Black only or 15.3% Mexican).

About the American Pain Foundation

Founded in 1997, the American Pain Foundation is an independent nonprofit 501(c) 3 organization serving people with pain through information, advocacy, and support. APF’s mission is to improve the quality of life of people with pain by raising public awareness, providing practical information, promoting research, and advocating to remove barriers and increase access to effective pain management. To learn more about APF, visit www.painfoundation.org.

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Tailor and submit a “letter to the editor” and opinion-editorial (op-ed) for print media distribution.

The template materials provide a starting point for opinion pieces in terms of topic, messages and format/length. Rapid response to breaking issues are also important for opinion submissions, so you are encouraged to write and submit your own pieces if you have the time and energy. If you submit a letter to the editor, you do not need to follow up. If you submit an op-ed, you should plan to follow up to ensure receipt.

Many local newspapers offer guidance on their Web sites in terms of writing and placing op-eds and letters to the editor. Read and follow this guidance. A few more reminders are below:

- DO NOT submit the same op-ed to multiple publications; if you submit to more than one, select a separate topic.
- DO take the time to personalize with your story. Localize with relevant statistics such as state pain policy grades or incidence.
- Print out your letter to the editor or op-ed to proofread prior to submitting.

Template Opinion Materials, these can be downloaded online at www.conqueringpaintogether.org :

- **Op-Ed: Lack of Access to Pain Care Costing us Billions**
- **Letter to the editor: Lack of Access to Pain Care Costing us Billions**



Sample Opinion-Editorial

Tailor this Opinion-Editorial to suit your needs by personalizing to with specific information about your pain story or perspective.

Lack of Access to Pain Care Costing Us Billions

Pain is a national health crisis that has serious economic ramifications. A staggering 76.5 million Americans report that they have had a problem with pain that has lasted longer than a day. This number does not account for acute pain. A hallmark of many chronic conditions, pain affects more Americans than diabetes, heart disease and cancer combined. While a number of effective treatments and therapies exist, many Americans lack the ability to access care that, in some cases, is the difference between life and death.

The growing rate of uninsured in America has been the subject of considerable examination during the past decade, a burden that disproportionately affects minorities and women. While pain does not discriminate among gender, ethnicity or socioeconomic status, the treatment of pain, sadly, does.

A troubling trend is for those who are insured to be denied coverage for proven and effective pain

treatments. Used as a cost-saving measure for the insurer, “step therapy” patients are required to fail other, less expensive, treatment options before the insurer will cover the treatment that was originally prescribed. With another tactic, “therapeutic switching,” less expensive or alternate medications listed in insurance formularies are substituted for what was originally prescribed, often without the knowledge of the prescribing physician. These medications may have more side effects and be less effective for the person with pain. Pharmacists’ and doctors’ offices are faced with confronting insurers in order to provide the patient with the prescribed treatment.

I ask that insurance companies remove roadblocks and obstacles that prevent people with pain from receiving the appropriate and necessary pain management and treatment options they are prescribed.

➔ *[Include personal story **100 words or less**- add color to the facts; add to a compelling argument (I myself have been bounced from doctor to doctor; I have been turned away at a pharmacy because they no longer carry my pain medication; my doctor has chosen to limit my pain medication so as to not attract attention from the DEA - a choice that leaves me suffering needlessly from pain; initial pain therapy was blocked by my health insurer, which led to disease progression costing the insurance company countless dollars more and costing me my ability to return to work; I have fought within my own healthcare system for better access to pain care, etc.)]*

Ironically, undertreated pain drives up the cost of healthcare: it extends lengths of stay in hospitals, increases emergency room visits and leads to unplanned clinic visits. The cost of pain not only includes direct costs associated with doctor’s visits, diagnostics and medication, but indirect costs such as lost wages and productivity, of both the person with pain and often their families. A study published in the Journal of the American Medical Association showed that lost productive time from common pain conditions among active workers costs an estimated \$61.2 billion per year. The majority (76.6%) of the lost productive time is explained as reduced performance while at work and not work absence.

When pain is treated properly, many people can resume their lives. Successful pain treatment is individualized, and there is evidence that multi-modal approaches are most effective. By improving access to pain care, Americans in pain can receive the services they need in order to lead healthy, productive lives. For those of us living with pain, we wish for a life worth living; one that permits us to enjoy our family and friends, as well as contribute to our economy.

This September, Pain Awareness Month, I hope that people with pain, their families and caregivers, healthcare professionals and policy makers stand up to demand improved access to pain care. You have the power to advocate for yourself or your loved one’s pain care rights at your doctor’s office, in your pharmacy and to state and federal healthcare policy decision makers. Contact the American Pain Foundation at www.painfoundation.org to learn more about pain care advocacy. People in pain have a right to timely, appropriate and effective pain care.

➔ NAME
ADDRESS

.....



Sample - Letter to the Editor - 150 words

Lack of Access to Pain Care Costing Us Billions

Pain is a national health crisis with serious economic ramifications. A staggering 76.5 million Americans say they have had a problem with pain lasting longer than a day.

Access to pain care remains a barrier for many Americans, including insurance policies requiring a person with pain to “fail” on other therapies before receiving their prescribed medication. Insurance companies must remove roadblocks preventing people with pain from receiving the appropriate and necessary pain management and treatment options they are prescribed.

Undertreated pain drives up the cost of healthcare: it extends lengths of stay in hospitals, increases emergency room visits and leads to unplanned clinic visits. Lost productive time from pain conditions costs an estimated \$61.2 billion per year.

When pain is treated properly, many people can resume their lives. By improving access to pain care, Americans in pain can receive the services they need in order to lead healthy, productive lives.

→ NAME
ADDRESS

Media Alerts - Background and Tips

Gaining media attention can be challenging and is primarily appropriate for high visibility events. If one of your goals for your September Pain Awareness Month events is to gain media attention, it is important to plan with this in mind and ask yourself - what's the news here? Why would a reporter want to cover the story?

A one-page media alert is used to give reporters the who, what, where, when and why of your event. It should be sent to reporters or producers who cover health issues or community news roughly two weeks before the event. If you expect there will be newsworthy photo opportunities (perhaps the local mayor or governor will be in attendance or community members gathering to write or make art about pain experiences on a honor wall, be sure to include that information as well (see more examples of activities throughout this Toolkit). Some papers won't cover the full event, but might send a photographer to include a photo with caption.

Factors to consider when seeking media interest:

- The size of your market
 - In smaller and mid-size markets it's much easier to develop relationships with the members of the media and get print and broadcast coverage than in larger ones where many stories are competing at the same time.
- The “newsworthiness” of your outreach activities
 - Activities that involve large numbers of people, involve high profile individuals, have ele-

ments of controversy, or reveal a widespread and serious problem are apt to attract media attention, while smaller, informational workshops probably will not get covered (unless you're in a small town or could draw attention to the plight of participants).

- Your ability and resources to create news
 - Particularly in mid- to large-size markets, you will not get media coverage with a news release alone. Gaining media attention will take some work (research, planning, idea development, copy writing, pitching, and follow-up). Tap into resources that may be available to you through your hospital (if you are a medical professional), university or corporate PR department for assistance with media lists, press material development or other outreach support.

Other resources

- Power Over Pain Action Manual - [Media Guide](#)
- Media Channel - Get Heard: [The Media Access Toolkit](#) - general tips and strategies for gaining grassroots media attention
- [Reporter's Guide](#)



Sample Media Alert for Your Community Events

Tailor this media alert to suit your needs by replacing the information in yellow with specific information about you and your event(s).

→ **For Release:** [DATE]

MEDIA ALERT

→ **[Town or City Name]** *Residents Join National Movement in Honor of Pain Awareness Month
Event Calls Attention to Undertreatment of Pain*

→ **WHAT:** In an effort to raise awareness about issues surrounding pain and the lack of access to pain care, [INSERT as appropriate, local residents, healthcare providers, advocates, etc.] are hosting [INSERT event -- a forum, health fair, town hall meeting, press conference] in honor of September Pain Awareness Month. This is part of the American Pain Foundation campaign, "Conquering Pain Together."

→ **WHO:** [INSERT NAMES/AFFILIATIONS OF PEOPLE OR GROUPS THAT WILL BE SPEAKING/TAKING PART] In addition, people living with chronic pain, their families and local community leaders are expected to attend the event.

→ **WHEN:** [INSERT DATE AND TIME OF EVENT/PHOTO OPPORTUNITY]

→ **WHERE:** [INSERT ADDRESS OF EVENT LOCATION AND ANY SPECIAL INSTRUCTIONS FOR PARKING]

WHY: The undertreatment of pain is a national public health crisis. A hallmark of many chronic conditions, pain affects more Americans than diabetes, heart disease and cancer combined.

Despite its prevalence, many barriers prevent access to appropriate and effective pain care for members of our own community. These include limited access to pain specialists who have been properly trained in pain management, insurance policies that require a person with pain to 'fail' on other therapies before being reimbursed for their prescribed medication, limited access to pharmacies that carry prescribed pain medication and negative stereotypes about patients with pain. Communities across the country are uniting to help sound the alarm for better pain management.

➔ **CONTACT:** [INSERT NAME, PHONE NUMBER, EMAIL ADDRESS]

➔ **PHOTO OPPORTUNITY:** [ADD DETAILS FOR ANY UNIQUE OR NEWSWORTHY PHOTO OPPORTUNITIES FOR PRINT AND TV OUTLETS]

Visit www.conqueringpaintogether.org to learn more about how you can help.

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Tips for Placing Radio Public Service Announcements

Radio stations often run free public service announcements (PSAs) on behalf of government agencies and non-profit organizations. Community radio stations, in particular, may have staff dedicated to producing, scheduling and airing PSAs.

Compile a List. Compile a list of local radio stations in your area. Take a look at the station's web site and consider the audience and programming to determine whether it would be a good fit. This will also help you focus your efforts.

Make an Introductory Pitch. Call the station to verify the contact information for the PSA director or producer, as well as how this person prefers to receive requests for airing the PSA (for example, email, or fax). You'll also want to ask for information about PSA submission requirements, such as format and length (:15, :20 or :30 second spots). Many stations may not accept unsolicited PSAs, so it's important to take time upfront to build rapport with station staff and explain why this issue is relevant to their audience.

Submit Your PSA. Send your PSA to the radio station. You may even consider dropping it off in person along with a printed copy of the Conquering Pain Together poster.

Follow Up. Follow up with your station contact to find out if and when they plan on airing the PSA. Be prepared to send additional campaign materials if they want more information.

Let Us Know. If you know your PSA will get air time, let us know when and how many times they plan

to run it. You can do this by using the “REPORT BACK” tab on the homepage of this Conquering Pain Together website.

Other helpful hints:

If you are using the PSA to help promote a specific event, make sure it arrives at your local stations at least three weeks in advance of the date.

Include your name and daytime phone number just in case the station has questions or needs more information. Be sure to tell them not to broadcast your phone number on the air. Instead, they should direct listeners to the Conquering Pain Together web site, www.conqueringpaintogether.org.



Sample Pain Awareness Month Public Service Announcements

Cut and paste these onto your letterhead and be sure to add your contact information.



Please air through the month of September, which is Pain Awareness Month.

→ **Contact: [INSERT]**

→ **Telephone Number: [INSERT]**

Lengths: 20, 30, 60 seconds

:20 SECOND SPOT

LIVE COPY (ANNOUNCER):

Pain affects more Americans than diabetes, heart disease and cancer combined, and is a leading cause of disability in the United States.

If you or a loved one lives with pain, you're not alone. This September, help raise awareness about pain and its management. Visit [WWW DOT Conquering Pain Together DOT O R G](http://WWW.DOT.ConqueringPainTogether.DOT.ORG) and sign our petition.

A message from the American Pain Foundation.

:30 SECOND SPOTS

LIVE COPY (ANNOUNCER):

Millions of Americans wake up every day to face another day of pain—a condition that is woefully misunderstood and undertreated. Chances are likely that you or someone you know is suffering in silence. Unrelenting pain can wreak havoc on a person's physical, emotional and spiritual wellbeing.

Commit to improving access to effective and appropriate pain care for all. Visit [WWW DOT Conquering Pain Together DOT O R G](http://WWW.DOT.ConqueringPainTogether.ORG) and sign our petition.

A message from the American Pain Foundation.

LIVE COPY (ANNOUNCER):

Pain affects more Americans than diabetes, heart disease and cancer combined, and is a leading cause of disability in the United States. Yet, it remains woefully undertreated and misunderstood, resulting in needless suffering.

If you or a loved one lives with pain, you're not alone. This September, help raise awareness about pain and its management and commit to improving access to effective and appropriate pain care for all. Visit [WWW DOT Conquering Pain Together DOT O R G](http://WWW.DOT.ConqueringPainTogether.ORG) and sign our petition.

A message from the American Pain Foundation.

:60 SECOND SPOT

LIVE COPY (ANNOUNCER):

Everyone has experienced pain at some point—a pounding headache, a throbbing toothache, a sprained ankle or a stinging burn from touching a hot pan. Pain is the body's natural alarm system, alerting us that something is wrong.

But, imagine having pain that never goes away?

Millions of Americans live each day with persistent pain. If not properly managed, chronic pain can result in needless suffering. It can prevent you from working, doing your favorite things or even receiving a hug from a loved one for fear of triggering a bout of crippling pain.

Fortunately, with proper care, many people with pain are able to lead productive and fulfilling lives.

Join the American Pain Foundation during Pain Awareness Month to help raise awareness about pain and the urgent need to improve its care. To get involved and sign our petition, go to [WWW DOT Conquering Pain Together DOT O R G](http://WWW.DOT.ConqueringPainTogether.ORG).

A message from the American Pain Foundation.



Policy Advocacy

There are many options for involving your legislators in September is Pain Awareness month. These are just some ideas to help guide you.

Host a letter writing gathering in your home. Write letters to your state legislators telling them about the importance of protecting access to appropriate and effective pain care or if there is specific legislation in your state request they support that legislation. Do a search of your state government's website looking for pain or contact organizations in your area that may have knowledge of current legislation in your state. They are our decision makers and depend on our votes, make sure they hear about the issues that are most important to you. There is a [sample letter template](#) available for you to use as a starting point.

Arrange meetings with key legislators in your state. Set up a meeting with your political representatives to talk about access to pain care issues. Use the [Key Messages document](#) as a means of sharing the problems that affect people with pain, their families and our communities.

Acquire a Proclamation from your Governor or Mayor. Make sure to check with state organizations such as your Pain Initiative or Power Over Pain Action Network (POPAN) Leader in order to find out if a proclamation request has already been submitted in your state. You can contact your POPAN leader by going to www.popactionnetwork.org and looking under directory for their contact information. See below the Proclamation Toolkit for more specific details on this option.

Work with other organizations and healthcare institutions. As suggested above, search the web for pain organizations in your state or other health advocacy organizations, as pain can be a major challenge with so many conditions, such as the arthritis, cancer and fibromyalgia. Your search might identify patient and professional organizations, such as the [American Chronic Pain Association](#), [Alliance of State Pain Initiatives](#), or chapters of national pain organizations, such as the [American Society of Pain Management Nursing](#) or the [American Cancer Society](#). Contact them and see if they are planning advocacy activities for September as Pain Awareness and explore how you might help their efforts.



Sample Letter to a State Legislator

Tailor this letter to suit your needs by replacing the information in yellow with specific information about you. If you know of a specific piece of pain-related legislation, include reference to it and any action you want your legislator to take on it, as well.

→ Legislator's Contact info

Date

→ Dear [salutation]

As constituent of your district, I wanted to let you know that September is National Pain Awareness and to take this opportunity to reflect with you for a moment about the state of pain here in

→ [your state].

Pain is a national health crisis that knows neither political parties nor constituent boundaries. It is the number one reason people seek medical help. Chances are you know someone who lives with persistent pain - maybe it's you. A staggering 76.5 million Americans report that they have had a problem with pain that has lasted longer than a day. A hallmark of many chronic conditions, pain affects more Americans than diabetes, heart disease, and cancer *combined*. While a number of effective treatments and therapies exist, many Americans lack the ability to access care that, in some cases, is the difference between life and death.

The growing rate of uninsured in America has been the subject of considerable examination during the past decade. Another troubling trend is for those who are insured to be denied coverage for proven and effective pain treatments. Used as a cost-saving measure for the insurer, "step therapy" patients are required to fail other, less expensive, treatment options before the insurer will cover the treatment that was originally prescribed. With another tactic, "therapeutic switching," less expensive or alternate medications listed in insurance formularies are substituted for what was originally prescribed, often without the knowledge of the prescribing physician or the patient. These "cost-saving" are not only inhumane, they are potentially dangerous and in the end, more costly, as the patient may still be in pain and seek yet more medical help or may suffer adverse effects from the 'switched medication'.

→ [Include a personal statement of 3 - 4 sentences (keep it short!) to add color to the facts. Examples: I have been turned away at a pharmacy because they no longer carry my pain medication; my doctor has chosen to limit my pain medication so as to not attract attention from the DEA - a choice that leaves me suffering needlessly from pain; initial pain therapy was blocked by my health insurer, which led to disease progression costing the insurance company countless dollars more and costing me my ability to return to work; I have fought within my own healthcare system for better access to pain care, etc.)]

The cost of pain not only includes direct costs associated with doctor's visits, diagnostics and medication, but indirect costs such as lost wages and productivity of both people with pain and their

caregivers. Estimated direct and indirect costs in the United States exceed \$100 billion annually. Up to 700 million workdays are lost annually from pain-related disabilities.

Restoring balance in accessing effective and prescribed pain treatments makes sound financial sense, and as a policymaker you can help make this happen. During the upcoming legislative session, bills proposing solutions to these 'access to care' issues may be introduced. Please support them, or better yet, please consider sponsoring such a bill so that people in pain **[like me]** get the care we need and deserve.

If I can be of any assistance in helping to educate you or your fellow policymakers about the challenges pain sufferers face, please feel free to contact me. For additional information on pain visit the American Pain Foundation at www.painfoundation.org.

Regards,

→ **Your Name & Contact info**





Proclamation Toolkit

What exactly is a Proclamation?

A proclamation is an official public announcement of a celebration. State or local governments (governors or mayors) can issue proclamations. Proclamations can use dry, official language, or straightforward, simple language. Proclamations usually follow a format that includes several WHEREAS statements followed by a proclamation statement. The document is signed by a public official. Some states and cities have a particular procedure that must be followed for proclamations.

Checklist for Submitting & Securing a Pain Awareness Month Proclamation

1. If you don't have contact information for your Governor or are not sure of how to go about requesting a proclamation type the following phrase into a search engine (like Google) see what comes up. Phrase: "submitting a proclamation request to Governor [your Governor's name] in [state name]"
2. Once you have the contact information for state governor's office, initiate contact and find out:
 - the protocol and timeline for requesting a proclamation
 - name and contact information for the administrative assistant in charge of proclamation requests
 - if any other group or organization has already submitted a request for a PAM proclamation
 - if there is a signing ceremony with the governor and, if so, the date and time
 - how to submit some draft language (fax, e-mail, snail mail)
3. If another group or organization has already submitted a request for a PAM proclamation, ask the Governor's office contact if your organization's name or the American Pain Foundation can be added to the list of supporters in the proclamation language.
4. If no other group or organization has submitted a request, you can either a) proceed with submitting your request OR b) let the Governor's office contact know you will be submitting a request soon but first want to make some contacts with other groups whom might like to collaborate with you on the request.
5. Other collaborators to consider:
 - Your state's Power Over Pain Action Network - A leader directory can be found at: <http://www.painfoundation.org/poweroverpain/default.asp?file=map.htm>
 - Your State Pain Initiative - Contact list can be found at: <http://www.aspi.wisc.edu/stcont.htm>
 - American Cancer Society Chapter - e-mail ican@acscan.org to get contact info for your state
 - State Hospice Organization - try Googling "[state name] hospice and palliative care organization"
 - Local chapter of American Society for Pain Management Nursing - Chapter list can be found at: http://www.aspmn.org/Organization/chapter_list.htm
 - State nursing organization - try Googling "[state name] nurses association"
 - National Association of Social Workers state chapter - Contact list can be found at: <http://www.socialworkers.org/chapters/default.asp>.
 - Other self-help groups, i.e. Arthritis Foundation, MS Society, Lupus, Sjogrens, etc. Chapters can be found by Googling the organization's name.

- 6.** Download the proclamation template. Fill in the blanks with the needed information and then save as a Word file on your computer so you can print it, fax it, e-mail it or mail it, as needed. If some of your collaborators want to co-sign the letter, add their organizational name.
- 7.** Download the cover letter. Fill in the blanks with the needed information and then save it as a Word file on your computer desktop. If some of your collaborators want to co-sign the letter, add their contact information and e-signatures.
- 8.** Even if you submitted it on-line using a template provided to you, consider sending a hard copy draft proclamation and cover letter to Governor's office.
- 9.** After a week, check back with the Governor's office contact to make sure the request was received. At that time also confirm the following:
 - When the final version on the proclamation will be ready
 - Date, time, and locale for signing ceremony - be sure to ask is there will be an official photographer present and, if so, how you can get order a copy of the official photo.
 - If there is no signing ceremony, request that the office send the finished proclamation directly to you as soon as it is finished. Be sure your contact information is included on all correspondence. And, it can't hurt to ask if there is any possibility the Governor will pose for a photo with you (your group) at his/her convenience.
- 10.** Convey this information to any collaborators, and make needed travel plans (if needed).

Tips for Leveraging Your Pain Awareness Month Proclamation

- 1.** Let the Governor's office know how you intend to use the proclamation. For example, let them know that recognition of September as Pain Awareness Month is a way to raise awareness about the under treatment of pain and the barriers to effective pain management. Give them examples of the types of outreach you plan to do in the community to highlight the proclamation, such as media coverage of the proclamation or a community outreach event. Be sure to let the Governor's office know of any events which occur as a result of the proclamation, this will improve your chances of getting their attention for another proclamation in following years.
- 2.** Ask them if they will issue a press release for PAM (see example following these instructions and download at www.conqueringpaintogether.org) to the media and also on their official website.
- 3.** Issue your own press release mentioning proclamation and/or signing ceremony where appropriate. Examples available on website.
- 4.** Ask any PAM collaborators who worked with you on submitting the proclamation request to issue their own PAM release, including an acknowledgement that the Governor issued a proclamation. Forward your press release and invite them to use any of the content they find helpful. Ask them to notify you if a release goes out.
- 5.** If you submit an op-ed piece or letter to the editor, mention that the Governor/city official declared September as Pain Awareness Month. Think about using an op-ed as a way to promote your PAM events.
- 6.** Use the proclamation as an opportunity to reach out to your elected officials and remind them of the important role they play in helping to remove the barriers to the adequate assessment and treatment of pain.
- 7.** Give copies of the proclamation to non-profit health organizations, support groups, etc. so, they, in turn, can promote awareness month and their services to persons in pain as well.



Sample Pain Proclamation Request Cover Letter

Tailor this letter to suit your needs by replacing the information in yellow with specific information about you.

→ [DATE]

→ [CONTACT INFO]

→ Dear Governor [Last Name]:

→ On behalf of the [your organization, collaborating organizations, people with pain], we are writing to you today to ask for your support in declaring September 2009 as Pain Awareness Month in [STATE NAME].

Pain is a national healthcare crisis. It is our Nation’s hidden epidemic, affecting tens of millions of Americans. It is the number one reason people seek medical care. Pain affects people of all races and economic status at all stages of life—the young, the middle-aged, and the elderly. Women and minorities suffer disproportionately.

Undertreated pain has serious physiological, psychological, and social consequences. Pain weakens the immune system and slows recovery from disease or injury. Uncontrolled pain diminishes quality of life. It adversely impacts almost every aspect of a person’s life including sleep, work, and social and sexual relations. Pain costs our economy \$100 billion in medical costs and lost workdays. Undertreated pain drives up the cost of healthcare, because it extends lengths of stay in hospitals, increases emergency room visits, and leads to unplanned clinic visits.

When pain is treated properly, many people can resume their lives. Treatments are available today to manage or greatly ease most pain, so people with pain should not suffer needlessly. People often mistakenly believe that pain is something they “just have to live with.” They are often made to feel that the pain is “just in their heads.”

Unfortunately, many barriers prevent effective pain treatment. Limited access to health care systems, prescribed pain treatments, or sites of care is seriously impeding pain sufferers’ ability to get their pain appropriately assessed and treated. Furthermore, a dearth of trained pain specialists, overly restrictive regulatory policies, and the public’s – including doctors and people with pain – negative stereotypes about pain are standing in the way of ensuring appropriate and effective pain care for all.

In late 2000, Congress declared the 10-year period that began January 1, 2001, as the Decade of Pain Control and Research. While progress has been made, much is left to do. We hope that we can count on your support to let your constituents know that having their pain taken seriously is a concern we jointly share. We hope you will find the enclosed draft language helpful in crafting a proclamation declaring September

→ 2009 as Pain Awareness Month in [STATE NAME].

Thank you for your attention to this very important issue. Please don’t hesitate to contact one of us should you have any questions.

Sincerely,

→ [Name]

[Name]

→ [Contact info]

[Contact info]



Sample Pain Proclamation

Help speed the proclamation process along by providing some sample language. Be sure to replace the information highlighted with the needed information.

WHEREAS, physical pain affects tens of millions of Americans and untreated or inadequately treated pain can harm quality of life by diminishing the ability to function, socialize and be productive; and

WHEREAS, despite this prevalence, access to appropriate and effective pain care remains a barrier for many Americans due to limited access to health care systems, appropriately trained pain specialists, prescribed pain treatments, or sites of care or pharmacies, as well as, negative stereotypes about pain, and

WHEREAS, pain takes an economic toll on our country, costing billions of dollars each year in medical expenses, lost wages, reduced productivity, and other costs; and

WHEREAS, improved pain management education and an effective multi-disciplinary treatment approach can help reduce suffering and remove barriers to pain-free living; and

- ➔ WHEREAS, [your organization and list other supporting organizations], and a variety of other professional and consumer organizations exist to advocate for people experiencing pain by increasing awareness and promoting access to appropriate pain treatment for all [NAME - e.g. Ohioans],
- ➔ NOW THEREFORE, I, [NAME], GOVERNOR OF THE STATE OF [STATE NAME], do hereby proclaim September 2009 as:

PAIN AWARENESS MONTH

- ➔ IN TESTIMONY WHEREOF, I have hereunto set my hand and caused to be affixed the Great Seal of the State of [STATE NAME], in the City of [CITY NAME], this 1st day of September, 2009.



Sample Pain Proclamation Press Release

Once you have gotten a Proclamation, use this template to let the media know about the proclamation AND about any events you have planned. They may be interested in following up with you for more detail or background, so be prepared. You can refer back to the media section of this toolkit for help.

For Immediate Release

- ➔ CONTACT: [Your Name]
- ➔ Ph: [xxx-xxx-xxxx]
- ➔ Email: [xxxxx]

[OFFICIAL'S NAME] PROCLAIMS SEPTEMBER AS PAIN AWARENESS MONTH Community Events Planned to Address Pain Issues Including Lack of Access to Care

- ➔ [YOUR CITY, STATE] – (Release Date)–In an effort to raise awareness about issues surrounding pain
- ➔ and the lack of access to pain care, [official's name] proclaimed September as Pain Awareness Month
- ➔ and encouraged citizens to [insert information from proclamation]. According to the American Pain Foundation, pain affects an estimated 76.5 million Americans.

A hallmark of many chronic conditions, pain affects more Americans than diabetes, heart disease and cancer combined. Despite this prevalence, many barriers prevent access to appropriate and effective pain care for members of our own community. These include limited access to pain specialists who have been properly trained in pain management, insurance policies requiring a person with pain to 'fail' on other therapies before being reimbursed for their prescribed medication, limited access to pharmacies that carry prescribed pain medication and negative stereotypes about pain patients.

In recognition of September's designation as Pain Awareness Month, the following events are being offered throughout the month:

- ➔ • [Program title, location, date, time]
- ➔ • [Program title, location, date, time]
- ➔ • [Program title, location, date, time]

- ➔ To learn more about these events, call [name] at [phone]. For additional resources on pain or to learn more about the American Pain Foundation visit www.painfoundation.org.

About Pain in America

According to the National Center for Health Statistics National Household Survey:

- More than one-quarter of Americans (26%) age 20 years and over- or, an estimated 76.5 million Americans- report that they have had a problem with pain of any sort that persisted for more than 24 hours in duration. [This number does not account for acute pain].
- Adults age 45-64 years were the most likely to report pain lasting more than 24 hours (30%).
- More women (27.1%) than men (24.4%) reported they were in pain.
- Non-Hispanic white adults reported pain more often than adults of other races and ethnicities (27.8% vs. 22.1% Black only or 15.3% Mexican).

About the American Pain Foundation

Founded in 1997, the American Pain Foundation is an independent nonprofit 501(c) 3 organization serving people with pain through information, advocacy, and support. APF's mission is to improve the quality of life of people with pain by raising public awareness, providing practical information, promoting research, and advocating to remove barriers and increase access to effective pain management. To learn more about APF, visit www.painfoundation.org.

#

→ Building and Involving Alliances

In order to build a larger movement to transform how pain is managed in America, it is critical to build alliances to broaden our reach and unify a massive voice for change.

There is power in numbers!

If we have a movement that is big and broad enough, it can represent and become the majority we need to win our battles for the rights of people with pain.

September as Pain Awareness Month and the National Day of Action provide an excellent opportunity to build alliances, extend our reach and mobilize a united voice to improve access to appropriate and effective pain care for all.

Included in this section are tools to support your work to build alliances with other organizations and groups for Pain Awareness Month and beyond.

Tools:

- **Stakeholder Checklist** - to stimulate ideas to identify possible allied organizations and groups
- **American Pain Foundation's Power Over Pain Action Network Stakeholder's Map** - offers a visual map of others who have a "stake" in improving pain care
- **Sample Letter to a Potential Ally** - available to modify for your purpose
- **General Tips for Advocates Building Alliances:** A Guide to a First Meeting with an Ally - ideas to consider when preparing for a meeting.

Examples of requests to organizations or groups:

- An announcement or article about the undertreatment of pain, Pain Awareness Month or the National Day of Action in their newsletter to their membership.
- A link to this website - **Conquering Pain Together** on their website or posting the toolkit on their site.
- A link to the 'I Commit' petition (which can be found on the Conquering Pain Together site) on their website.
- Hosting (or co-hosting) an event for Pain Awareness Month or the National Day of Action. If they already have an event, explore how you might collaborate, and request they help distribute Conquering Pain Together Postcards and Posters for the National Day of Action, September 26th.
- Work together on a joint presentation to either the public or health care professionals.
- Join forces on pain policy issues that are barriers to good pain care and collaborate on strategic targeted actions, like a joint letter writing campaign to policymakers.
- Encourage their members to conduct an awareness raising activity for the National Day of Action.
- Forward the American Pain Foundation's alerts to their membership, encouraging them to TAKE ACTION! Again, there is power in numbers!

Things to keep in mind:

- Collaborations are built on common interest and investment.
- It takes power to win.
- Organizing people for a united effort can change attitudes, policy and practice.
- More people suffer from chronic pain than those with diabetes, heart disease and cancer combined.
- By uniting our voices and actions, we can turn the tide on this silent epidemic, expose this injustice, remove the barriers, and increase access to effective pain management.



American Pain Foundation (APF) - Stakeholder Checklist

Stakeholders are defined as persons or groups with a “stake” in improving pain care or are associated in some way with the pain issue. This list is provided to assist in thinking about who you might connect with for September as Pain Awareness Month activities and on-going work to improve pain management. Collaboration is key to building a movement for change, as it can broaden our reach, maximize joint efforts and consolidate our unified voice for change.

Remember, pain affects more Americans than diabetes, heart disease and cancer combined. See APF Facts and Figures for more [details](#).

Pain Sufferers

- o Chronic pain sufferers - think of organizations associated with particular chronic pain conditions (i.e. Fibromyalgia associations)
- o Support Groups
- o Elderly
- o Caregivers
- o Military and Veterans Communities

Advocacy/Organizations

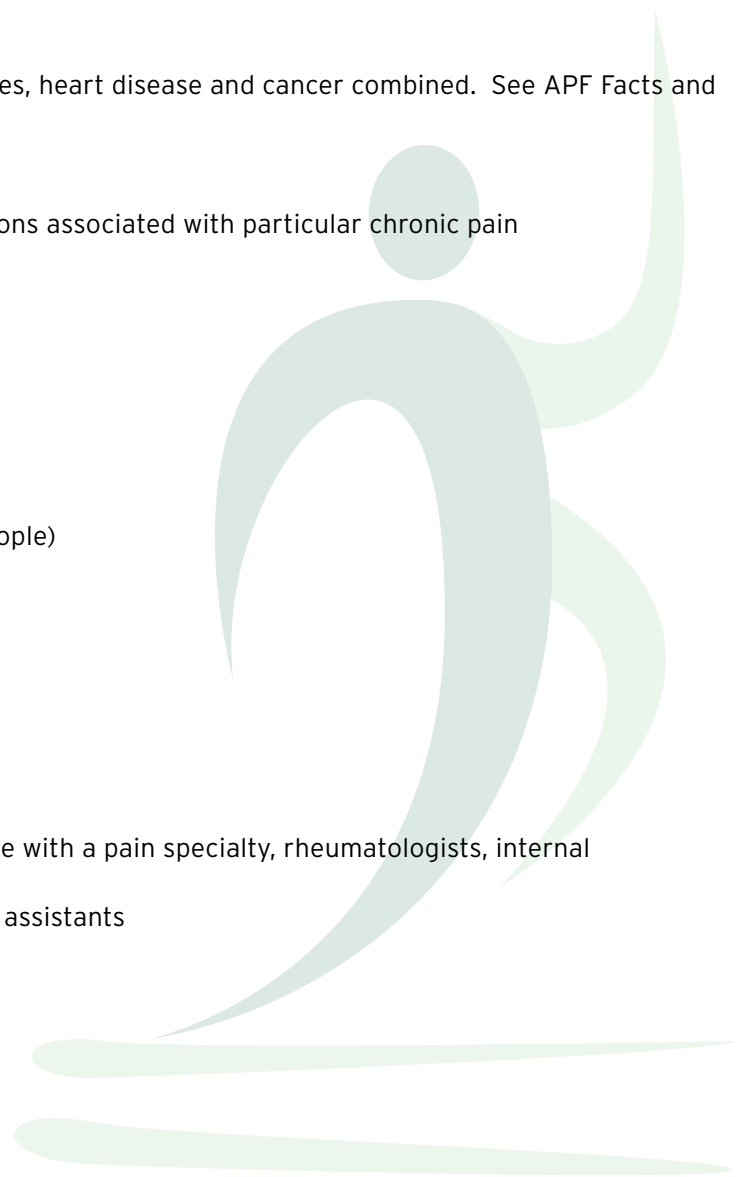
- o State Pain Initiatives
- o AARP (American Association of Retired People)
- o American Cancer Society
- o Lance Armstrong Foundation
- o Arthritis Foundation
- o American Diabetes Foundation
- o League of Women Voters
- o Community Based Organizations

Clinicians

- o Physicians - all doctors, but especially those with a pain specialty, rheumatologists, internal medicine doctors, etc.
- o Staff nurses, nurse practitioners, physician assistants
- o Physical therapists
- o Pharmacists
- o Social Workers/Mental Health providers

Complementary/Alternative/Integrative Medicine

- o Public & private integrative medical clinics
- o Naturopathic doctors
- o Massage Therapists



- o Acupuncturists
- o Chiropractors
- o Nutritionists/Dietitians

Academia/Educators

- o Medical Schools
- o College of Nursing
- o College of Pharmacy

Researchers

- o National Institutes of Health
- o Educational Institutions (Johns Hopkins, University of Maryland, Mayo Clinic, University of Southern California)

Health Care Facilities/Institutional Providers

- o Hospitals
- o Hospice
- o Clinics
- o Long Term Care Facilities
- o Home Health
- o Rehabilitation Centers

Regulatory

- o Legislature - www.yourstate.gov (e.g. www.ca.gov) for various gov't offices (i.e. governor's office, state congressional offices)
- o State licensing - providers and facilities
- o Boards of Medicine, Health, Pharmacy
- o Office of the Insurance Commissioner
- o Drug Enforcement Agency
- o Medicaid/Medicare/Worker's Compensation

Insurance

- o Large commercial providers
- o EBMS (employee benefit management services)
- o Small business insurance pools
- o Malpractice/Worker's Compensation

Pharmaceutical Industry & Medical Supply Companies

- o Local drug stores and pharmacies
- o Large suppliers who may have an office/factory in your area

Existing and Potential Funders

- o Foundations (local, regional and national)
- o Public & private donors
- o Local/state agencies (governmental and non-governmental)

Cultural Diversity - include members of various racial, ethnic, & cultural groups in your stakeholder group. Look for community organizations, places of worship, cultural associations, or professional business associations to find those who hold a stake in better pain management. Remember pain does not discriminate.

This list is intended to start you thinking about possibilities and is not inclusive of the multitude of possibilities.

Good luck with your alliance outreach!



Sample Letter to Potential Allies

Adjust and personalize this letter for your purposes and use it to reach out to potential allies.



201 N. Charles Street, Suite 710
Baltimore, MD 21201

www.painfoundation.org

→ (insert your address)

→ [Date]

→ (place your logo here)

→ Dear (Insert contact person for the organization or groups),

→ (Customize this first paragraph to reflect who YOU are. Insert a summary of your work, and if it applies, the organization/group and mission you represent.) I am a person with pain, health care professional and a State Leader for the American Pain Foundation's Power Over Pain (POP) Action Network. We are a grassroots network of volunteers who are people with pain, caregivers, and healthcare professionals with an overall goal of transforming pain care in our country. We work to accomplish this goal through raising awareness, and promoting the best pain policy, legislation and practice. Our actions are focused on informing, motivating and harnessing the millions of voices of people affected by pain to develop a nationwide movement of pain care advocates. I am writing you today to request a meeting to explore how we might work together on activities for September as Pain Awareness Month and the National Day of Action, September 26th.

Allow me to first provide some background on the issue of the undertreatment of pain. While most painful conditions can be relieved with proper treatment, many people in pain and their healthcare providers face a wide range of barriers including a lack of medical training in pain management and social stigma about pain. According to the National Center for Health Statistics, one in four people report that they have had a problem with pain of any sort that persisted for more than 24 hours. In fact, pain is the number one reason people seek medical care. Undertreated chronic pain has serious physiological, psychological, social, and economic consequences. When pain is treated properly, however, many people can resume their lives.

Pain Awareness Month and the National Day of Action provide a powerful opportunity to call attention to this hidden epidemic of undertreated pain and galvanize our efforts by working together to increase awareness of pain issues and demand change in pain policy and practice.

As stated above, I would appreciate an opportunity to meet with you to discuss the host of potential activities and opportunities to work together on September as Pain Awareness Month and the National Day of Action, September 26th. For more information, please see the Conquering Pain Together website - www.conqueringpaintogether.org and the American Pain Foundation's website - www.painfoundation.org.

I look forward to hearing from you and arranging a convenient time to learn more about your organization and your interest in working together to improve pain care in our community.

Sincerely,

→ [Insert your name, title and address]

General Tips for Advocates - Building Alliances: A Guide to a First Meeting with an Ally

Originally developed by the American Pain Foundation for the Power Over Pain Action Network

Goals

- Begin to build relationship
- Gather information about their organization and their priorities
- Learn some of their story
- Share your story and your interests
- Begin to educate them about the importance of the issues
- Get a commitment to be involved in September as Pain Awareness Month

Preparation

1. Do some research. Ask others what they know about the organization. Check the APF website or look up the organization on the internet. Most established groups have websites.
2. Get clear about what you might ask them to do. Develop a list of possible things you could ask them to do. The list can be in order of difficulty, from simple things to the more difficult. You will make a judgment call in the meeting about which to ask, based on your instincts of how the meeting is going and your understanding of their interests. Potential “asks”: link to [Conquering Pain Together website](#), post a link to the “I Commit” Petition on their website, create article in their newsletter, or organize an event together. *All of this will depend on whether you are an individual, part of the APF’s Power Over Pain Action Network, or part of another organization (as a person with pain, healthcare professional or advocate).*

The Meeting

The key to this meeting is to begin to build a relationship and to begin to understand shared interests. You need to be clear about your interests and you want to learn about theirs. Be yourself, but be careful about talking too much or feeling like you are selling something. It’s appropriate to tell your story, share your passion and briefly inform them about the scope of the problem, but you want to create the space for them to talk.

The following is a sample and guide. Remember every meeting will be different, which is why this is fun!

1. Introduce yourself, tell them a short version of your story (3-5 minutes), why you wanted to meet and provide a short summary of why you are doing this work.
2. Ask them questions about them: what is their background, what is their story?
3. Ask about their organization: what are their priorities, how they decide priorities, how do they communicate with their members and elected officials, what do they do to impact an issue? Ask them what involvement they have had in pain issues (personal or professional)?
4. Move the conversation toward your “asks.” (As stated above, possible “asks” may include: link to [Conquering Pain Together website](#), post a link to the “I Commit” Petition on their website, create article in their newsletter, or depending on whether you are an individual or you are part of another organization, explore working together to organizing an event together.)
5. Close the meeting by summarizing what each of you will do and next steps.

Follow up

The follow up is critical. Send them a card, or an email thanking them for the meeting. Reiterate the next steps and be sure to do what you said you were going to do.

i National Center for Health Statistics. Health, United States, 2006 With Chartbook on Trends in the Health of Americans. Hyattsville, MD: 68-71.

ii Pain - 76.2 million people, National Centers for Health Statistics, 2006; Diabetes - 20.8 million people (diagnosed and estimated undiagnosed), American Diabetes Association; Coronary Heart Disease (including heart attack and chest pain) and Stroke - 18.7 million people, American Heart Association; Cancer - 1.4 million people, American Cancer Society.

iii Walter F. Stewart, PhD, MPH; Judith A. Ricci, ScD, MS; Elsbeth Chee, ScD; David Morganstein, MS; Richard Lipton, MD "Lost Productive Time and Cost Due to Common Pain Conditions in the US Workforce." JAMA. 2003;290:2443-2454.

