

Conquering Pain Together — September is Pain Awareness Month

The State of Pain Care in America



According to the Centers for Disease Control and Prevention, one in four adults (26 percent) report issues with pain that last for more than a day. That translates to approximately 76.5 million Americans — more than diabetes, heart disease and cancer combined.

Left untreated, pain can disrupt every aspect of a person's life, interfering with one's ability to get a good night's sleep, hold down a job or maintain relationships with friends and family.

Not only does chronic pain impact the individual, it costs the nation more than \$100 billion each year in medical expenses and lost work days, according to the National Institutes of Health, and recent studies suggest that costs may be far higher than that.

The last decade has seen major advances in the science of pain and its treatment, but despite the fact that Americans have more options than ever for managing their pain, millions remain undertreated or receive no treatment at all.

"We've made tremendous breakthroughs in our understanding of the pain process, and it's very exciting," said Perry Fine, MD, professor in the Department of Anesthesiology of the School of Medicine at the University of Utah. "But these discoveries have not yet translated to better access to care for pain patients. In terms of improving our systems of care and applying what we know, we have a long way to go."

BETTER MEDICAL TRAINING NEEDED

When people experience pain, they often seek help from their family doctor or another primary care provider such as a nurse practitioner or physician assistant. But research shows that most medical professionals receive little or no training in pain management, and many are unable to provide individuals with effective pain care. Along with a lack of pain care training, many providers work in busy, understaffed practices and have little time to spend with their patients and even less time to devote to keeping up with the latest advances in pain care.

While primary care providers are well versed in the management of a wide range of chronic illnesses, they are often at a loss when it comes to effectively treating people with chronic pain, according to Bill McCarberg, MD, founder of the Chronic Pain Management Program for Kaiser Permanente.

"If a patient comes in with a chronic disease like diabetes, any primary care provider in the country can list 15 questions to ask the patient, what lab tests to order, what treatments to prescribe, and how to follow the patient's progress over time," said Dr. McCarberg. "But if someone comes in with chronic back pain, the average doctor often has no idea how to address the

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Anxiety's Emotional and Physical Toll

Americans are increasingly anxious, especially amid continued news about the economic downturn and joblessness. But even everyday life pressures can leave you with a knot in your stomach, a headache, muscles that are tense and poised for action, trembling and a pounding heart — classic symptoms of anxiety. Most people experience these symptoms before an important event like taking an exam or giving a speech or during times of high stress (for example, changing jobs, getting divorced or moving).



While temporary spikes in anxiety can improve thinking and functioning, allowing us to be more focused on the task at hand, experts say anxiety that exceeds this threshold is usually harmful. In fact, prolonged anxiety has been linked to heart disease, autoimmune disorders and premature aging of the cells. Several studies also show that anxiety can worsen physical pain.

"In studies involving two groups of people with the same amount of pain, the group with the higher level of anxiety will experience the pain as being more intense," said Srini Pillay, MD, assistant clinical professor, Harvard Medical School, Boston. "This is due, in part, to the fact that anxiety biases our attention, making a person more likely to fixate on the pain."

That's because when someone is anxious, the brain is primed to be on the lookout for dangerous or threatening stimuli. Pain signals represent a threat. One of the obvious ways this happens is through the activation of the amygdala, the fear detector of the brain, explains Dr. Pillay. The amygdala sends electrical impulses not just to other areas of the brain, but also down the brain stem and the spinal cord into the rest of the body.

"This heightened pain causes more anxiety which then makes the pain even worse and this vicious cycle continues," he said.

Anxiety can also lead to muscle tension and disrupted sleep, both of which can make pain worse.

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VIRTUAL MARCH KICKS OFF

This September, APF is launching a **Virtual March on Washington** to improve pain care and the **10,000 Voices Campaign**. Join us by **signing up for the march and encourage others to do the same!** The Virtual March will be a dynamic online gathering place hosted on APF's Action Network website, www.APFActionNetwork.org, with new ways to get information, get inspired and get engaged throughout the month.

The march will include:

- 10,000 Voices campaign — let's work together to get 10,000 people affected by pain to tell and submit their stories. By uniting our voices, we can make a difference!
- A letter writing campaign — let Washington hear you! This is a key opportunity to share how pain has affected your life and encourage your legislators to make policy improvements.
- Ways for you to HELP SPREAD THE WORD — there is power in numbers and it will take a united movement to effect change.

Let others know what they can do. Reach out to friends, neighbors, coworkers, family members, organizations, senior centers, local hospitals and other institutions with a vested interest in pain care. Organizations, institutions and industry with an interest in pain care are invited to endorse the march!

Sign up at www.APFActionNetwork.org.



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WHAT TO WATCH FOR

The response to anxiety is highly individual, and is often shaped by a person's genes, health history, coping mechanisms and the intensity and cause of your pain.

Anxiety disorders are different from normal feelings of nervousness or stress. Stress is often explained as a physiologic reaction to a stimulus; whereas anxiety can be part of psychological syndrome.

"If you're hiking up a steep hill you may be stressed and your heart rate may go up, but you may not have anxiety," explains Dr. Pillay.

If you have an anxiety disorder, you may have:

- Overwhelming feelings of panic and fear
- Uncontrollable obsessive thoughts
- Painful, intrusive memories
- Recurring nightmares
- Physical symptoms such as feeling sick to your stomach, "butterflies" in your stomach, heart pounding, startling easily, restlessness, and muscle tension

You might also have difficulty concentrating or focusing, notice skin irritations or eye switches or feel lightheaded or easily fatigued. But, interestingly, some people may not even be aware that they are feeling anxious, which is why assessing one's level of anxiety is so important.

"The unconscious brain can register things between 10 and 30 milliseconds," said Dr. Pillay. "For example, when we show people in a brain imaging scanner

an anxiety-inducing picture, they won't know that they've seen this, but the brain will respond. So, when you suggest to someone, 'it may be your anxiety that's making the pain worse,' they might say 'I don't feel any anxiety.'"

Untreated anxiety disorders can also drive people to avoid situations that trigger or worsen their symptoms.

"People with excessive anxiety may over-plan and over-orchestrate things they used to take for granted, planning escape routes from activities and excuses for not doing things," said Sally Winston, PsyD, co-director, Anxiety and Stress Disorders Institute of Maryland.

High levels of stress can also fuel negative emotions, which can make it harder to find the energy to take care of yourself and self-advocate for better pain care.

STEPS TO EASE ANXIETY AND PAIN

Treating or lowering anxiety is an important part of managing pain. If you think you are overly anxious or your anxiety has started to interfere with your life or your pain is more intense, get professional help.

"Talk with your health care provider or ask for a referral to a psychologist or psychiatrist. There are a number of treatments for anxiety," said Dr. Pillay. "A lot of people with pain avoid getting their anxiety treated because they are afraid they are going to have to take another medication for the anxiety. But studies show that cognitive behavior therapy can be especially helpful."

Other types of therapy, including acceptance-based therapy, are emerging. Rather than focusing on exploring why you feel anxious, these new therapies seek to understand what purpose the anxiety is serving. Attention-based exercises that can help train the brain to focus on specific tasks instead of the pain are also effective.

"When people allocate time to not worrying and being goal-oriented, it significantly reduces their anxiety," said Dr. Pillay. "If you make a list of two to three goals and aim to finish them within a specific timeframe, then you feel good and optimistic and that actually reduces the pain."

In addition, many of the things you might already be doing to help ease your pain may help to lower anxiety too.

- Take time to breathe deep and clear your head.
- Consider meditation and other complementary mind-body techniques to induce a more relaxed state.
- Get physically active. Exercising can boost your body's natural endorphins and gives you more energy.
- Eat a well balanced diet and try to avoid caffeine.
- Get enough sleep.
- Stay positive. Studies have found that people's perception of pain is somewhat dependent on their attitude and the extent to which they can be optimistic.
- Connect with others.

BENEFITS BEYOND PAIN RELIEF

Keeping your anxiety in check is not only important for reducing pain, it may be good for your heart too. While the temporary symptoms of anxiety, such as elevated blood pressure, heart palpitations and chest pains, are well known, two new studies published in the June 29, 2010 issue of the *Journal of the American College of Cardiology* suggest that symptoms of anxiety may also increase a person's risk of developing heart disease decades into the future.

Anxiety affects an estimated 40 million Americans each year, making it the most common mental health disorder. To find out if you might have anxiety, check out Mental Health America's Anxiety Screener at www.nmha.org/go/information/wellness-live-life-well/how-stress-hurts/anxiety-screener.

"One of the hardest things about being in chronic pain is that it's hard to keep your mind on the tasks at hand because the pain keeps pulling your attention away." — Dr. Pillay

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problem, because there is no standard protocol, and they're just not well trained or equipped to handle it."

According to Dr. McCarberg, this can set up a potentially frustrating interaction for both the doctor and the person with pain. Some primary care doctors may be hesitant to continue treating people with chronic pain who are not responding well to prescribed therapies, and individuals often bounce from provider to provider in search of treatments that work.

FEARS OVER PRESCRIBING PAIN MEDICATION

To further complicate matters, many providers are uncomfortable with the medication management aspects of treating chronic pain. Opioid medications (like oxycodone and morphine) have proven safe and effective in alleviating chronic pain when used as directed, but health care providers are often reluctant to prescribe them.

Over the past several years, the abuse and misuse of prescription opioid pain medication has increased dramatically leading to serious and sometimes tragic consequences, including addiction and death from overdose. Efforts to curb the escalating abuse have come at a cost to the people who need these medications, according to Myra Christopher, president and CEO of the Center for Practical Bioethics.

"As people have realized the dangers of street drugs, those who abuse drugs have increasingly turned to prescription medications thinking they are a safer alternative," said Christopher. "But the so called War on Drugs has had a dreadful unintended consequence of placing a huge burden and a lot of misunderstanding on people

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Dear Friends:

September marks **Pain Awareness Month** — a time to strengthen our efforts to honor people affected by pain and demand better pain care for all.

I hope that you will help us to raise awareness about pain and its management — whether it's by posting APF materials at your local library, securing a proclamation or planning a community forum about pain.

Without greater public knowledge about pain and the multitude of issues faced by people living with pain, we cannot effectively fight for better care and secure a greater investment in pain care and research. Only through the collective voices of the millions of people affected by pain will we be able to effectively shift the current regulatory and policy climate, which is so often focused on curbing misuse and abuse and typically fails to balance these efforts with assuring people with pain have access to pain treatments that can reduce pain and suffering. Such unified actions are also needed to educate and put pressure on health insurance companies, many of which do not provide adequate coverage of multiple therapies, which is often what is required to effectively reduce pain.

Make a difference today just by logging onto the Internet to join our Virtual March on Washington, an online gathering place for those affected by pain to make their voices heard, share their stories, and demand pain policy improvements in our country. Educate others — friends, neighbors, coworkers and family members — about pain and ask that they become members of APF. Membership is free at www.painfoundation.org.

We won't be able to measurably improve pain care in America without the millions of voices of people affected by pain. Please join us today!

Sincerely,

Will Rowe
Chief Executive Officer

Uniting Our Voices: Conquering Pain Together

Pain Awareness Month Kicks Off, Engages Communities Nationwide



Most people think of pain as something that's short-lived. Touching a hot stove, pulling a muscle at the gym or gardening, giving birth, or a nagging headache or toothache. But for many people, pain doesn't go away and it can take a tremendous toll on the body and mind.

Pain hurts — it aches, it stabs, it burns. Unlike a broken bone, a healing wound, a cancerous tumor and a host of other health ailments, pain is invisible. It's a subjective experience, making it hard for others to truly understand or relate to another person's suffering. Yet, whether we realize it or not, most of us know or will know someone — a family member, neighbor, friend or colleague — who has endured chronic pain.

According to organizers, this is why it is so important to join forces in honor of September Pain Awareness Month (PAM), *Uniting Our Voices: Conquering Pain Together* to expose the undertreatment of pain in America.

As PAM kicks off, APF's Action Network (AN) leaders are out in full force, sounding the alarm to raise awareness about pain and its impact and calling for prompt action to improve pain care nationwide.

"Most [advocates] see the right to pain care as a human rights issue and, through their efforts, they are trying to balance the scales of fairness," said Ann Corley, MS, APF's former AN regional manager.

Through the collective efforts and voices of AN leaders, scores of other APF advocates and volunteers and collaborating organizations across the country, APF is striving to make pain visible by telling the pain story and how much it can rob people of their lives when it's not appropriately treated.

A SHARED AND PERSONAL MISSION

"Many of our leaders are people with pain who have had to trudge through years of searching for relief to find a health care provider who would actually take their pain seriously. They want to spare others that kind of torment and are, themselves, willing to endure more pain to achieve that end," Corley said.

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who struggle with chronic pain. Patients who have heard a lot of negative messages about opioids in the media are afraid they'll become addicted, and doctors don't want to prescribe the medications for fear of getting into trouble."

State medical boards and the Drug Enforcement Administration (DEA) closely monitor physician prescribing practices, and physicians are faced with the fear of losing their medical licenses or even facing criminal charges if they overprescribe.

Many states have passed pain relief acts aimed at decreasing barriers to needed medication for people with chronic pain by providing protection for health care providers who prescribe controlled substances, but the guidelines about what is acceptable aren't always clear. Some states require that providers consult with pain specialists prior to prescribing, but there are a limited number of pain specialists in the U.S. and most are isolated to large, urban areas. This leaves people with pain in some areas without access to local providers who are willing or able to prescribe needed medications.

"Primary care doctors are really stuck between a rock and a hard place when it comes to prescribing opioids," said Dr. McCarberg. "On one hand, they are being told they should prescribe, but then they turn around and they're being told not to prescribe too much, but they have no way of knowing how much is considered too much. Chronic pain is undertreated in America because our health care providers don't have the training to recognize it and then they're scared to treat it when they do."



COST NOT COVERED FOR MANY EFFECTIVE TREATMENTS

In most cases, pain is best managed using a combination of options ranging from traditional treatments to complementary and alternative

therapies. But more often than not insurance companies don't support this multidisciplinary approach to pain care. Many effective treatments aren't covered, and primary care providers aren't reimbursed for the time it takes to provide comprehensive care to people with chronic pain, even though this could reduce costs and suffering over the long term.

"We have evidence that an integrated approach to pain care is often the most effective, but reimbursement systems don't always support best practices," said Christopher. "They'll sometimes pay for steroid injections or some prescription medication, but when it comes to things like massage, acupuncture or nutrition counseling, the support just isn't there, even though we know these things work. Providers receive incentives to push patients toward particular types of treatment that might not necessarily be the best choice for relieving pain."



MORE RESEARCH FUNDING NEEDED

Funding for pain research has long fallen short in comparison to funding committed to other chronic diseases that affect millions. In fact, less than two percent of the National Institutes of Health research budget is currently dedicated to pain. "If you look at the impact and cost to society and individuals, pain barely measures on the radar compared to other high impact conditions in terms of research dollars," said Dr. Fine. "We'd be a lot further down the road if we had even a fraction of what's been committed to researching cancer, cardiovascular disease, and even substance abuse. We have to ask ourselves why we, as a society, value certain things over others. Why aren't we paying more attention to this extremely common and costly condition of chronic pain?"

WHERE DO WE GO FROM HERE?

While there are multiple challenges to pain care in the U.S., experts agree that the news isn't all bad. Pain care advocates are building momentum toward achieving greater awareness and more comprehensive policies, and better training and research may be on the horizon.

"The reality is we have the knowledge, therapy, interventions and technical know-how to address almost all pain, but we just haven't done it yet," said Christopher. "What we need is a comprehensive national plan to address the problem. The only way things will ever change is if everyone who has a stake in the issue — patients, advocates, policy makers, medical professionals, and law enforcement — stand shoulder to shoulder and work together in a rational, coordinated and integrated way."

Recognizing the impact that pain has on individuals and the health care system, federal policymakers included provisions related to pain care in the Patient Protection and Affordable Care Act of 2010. The new law calls for an Institute of Medicine Conference on Pain to address key medical and policy issues affecting the delivery of quality pain care, along with the expansion of pain research and pain care education and training.

"I expect that we'll see a much bigger emphasis on better pain care education for our nation's primary care workforce," said Dr. McCarberg. "New policies will encourage treatment of the whole patient, and this can't be achieved without addressing the proper treatment of pain."

At the same time, the Food and Drug Administration has recently called on manufacturers of opioid pain medications to develop risk evaluation and mitigation strategies (REMS) to ensure the benefits of these medications continue to outweigh the risks, including misuse, abuse and accidental overdose.

The American Pain Foundation (APF), along with organizations such as the American Academy of Pain Medicine (AAPM), the American Pain Society (APS) and the American Society for Pain Management Nursing, lead efforts to promote research, improve

We asked leading pain care experts to share their thoughts about what will be the most promising areas of pain research over the next decade. Some of their predictions are:

- Gaining a better understanding of pain involving the nervous system, spinal cord and brain, and its relationship to immune and hormonal regulatory systems.
- Understanding the role of genetics in the development of chronic pain, and how it might be prevented.
- Understanding how to motivate lifestyle change in people with many chronic conditions, including obesity, diabetes, hypertension, and chronic pain. Current research is looking at the use of computer models to help people with pain learn cognitive behavioral strategies for lifestyle change.
- Understanding how to identify individuals at risk for addiction if exposed to opioids, and how to prevent addiction from occurring.
- Developing and understanding new medications which are fundamentally different from current drugs, and improved ways of demonstrating safety and effectiveness of pain medications for both short- and long-term use.
- Developing the means to identify who will benefit from certain pain therapies and how to best match individuals with appropriate treatments.

professional education and skills, and raise awareness and advocate for better pain care for people with pain and their caregivers. Along with these and other organizations, APF has been working diligently to ensure that FDA protects the rights of people with pain and takes a balanced approach when finalizing their recommended REMS for opioid medications. Over the past few years, APF has delivered multiple testimonies about REMS before the FDA, as well as coordinating the submission of comments for the public record. APF's position statement on REMS is available at: <http://www.painfoundation.org/newsroom/position-statements/fda-rems.html>.



Have you ever read a compelling article in your local newspaper about a disease or health condition and the plight of those affected and thought, “This would be a great place for a story about pain — I wonder why they haven’t covered this important topic?” Or, wondered why, when pain does receive media coverage, it often centers only on prescription drug abuse or misuse?

News and feature reporters are always looking for new sources to speak with and topics to report on. Some of the best journalism involves storytelling, and that’s where you come in. Reporters rely on people like you to help tell the story — how has pain affected your life, how many people in your community might be going through the same thing, but might suffer in silence. Through your words, you can help illustrate the severity and impact of pain and make it relevant to their audiences.

By contacting your local media outlets, you can help increase awareness about pain and barriers to effective pain care; help build a national movement community by community; and combat negative stereotypes portrayed in the media about people with pain. While getting the media to tell your story can take time, be persistent — your voice is important!

Here are a few tips to help you in getting your story told:

- 1. Be a consumer of your local media.** Watch the news, listen to talk radio and read your local newspaper to learn what is newsworthy. Compile a list of your daily and weekly newspapers, radio stations and television stations, as well as contact information for health reporters or assignment editors.
- 2. Identify what is newsworthy about your story.** A good news story is timely, informative and relevant. It speaks to the audience and makes them care about the issue. You may want to provide the local angle to a national story on pain or offer a different perspective.
- 3. Develop key messages.** What are the three or four key points you want to get across? Priority key messages are available at www.conqueringpaintogether.org. Click on the Action Tools tab.
- 4. “Pitch” your personal story and how it might help others.** Send an email to the editor or producer at your local newspaper, radio and television stations, introducing yourself, sharing details of your story and asking for an opportunity to be interviewed. Build your pitch around your key messages and remember to include your contact information.
- 5. Follow up on your pitch.** Reporters receive hundreds of emails each day. If you do not hear back from a reporter within a few days, send a second email or phone them. If you still do not receive a response, don’t take it personally; try reaching someone else at the same news outlet.
- 6. Make sure you are available when the reporter calls.** Reporters work under tight deadlines, so be prepared to do a phone interview when they call you. If you miss their call, return it as soon as possible or you may not get a second chance. Have notes available with key messages you want to include.
- 7. Be prepared for an interview.** Role play before the interview to rehearse your key messages and anticipate questions. Know what resources and information you want to highlight (for example, the prevalence of pain, APF materials and website addresses, etc.). Be ready for questions like: “Tell me about yourself?” “What do you want people to know about pain?” “How has pain impacted your life?”
- 8. Control the interview.** Only answer questions you are qualified to answer. If you don’t know the answer, tell the reporter that the question is outside your area of expertise. When you can, use your answer to transition back to one of your key messages. Avoid being argumentative with a reporter who appears biased. Calmly state your position in your own words.
- 9. Take advantage of the “gift” question.** Reporters will often end an interview by asking: “Is there anything else you’d like to add?” This is a great opportunity to drive home your key messages or include anything you may have forgotten earlier. Have something prepared for this question!
- 10. Thank the reporter for the opportunity.** Professionalism and gratitude can go a long way. The next time the reporter is covering pain, he/she will remember you and likely contact you first.

For additional tips and resources, please visit APF’s Conquering Pain Together website. Here you will find samples of press releases, letters to the editor and opinion editorial articles.

Pain is news — voice by voice, community by community, we can make a difference!

Uniting Our Voices: Conquering Pain Together (continued from page 3)

Three such leaders, Deana Luchs, Annette Keys and Lori Roach, are sharing their personal journey in an effort to educate and rally others to stand up for better pain care.

Since attending the Advocacy Summit in April 2010, Luchs has been putting her advocacy training to work. She started a chronic pain and meditation support group within her adult living community and is busy organizing a pain conference at the Robert Wood Johnson University Hospital on September 28 in New Brunswick, NJ. Luchs has also set up information tables at local libraries to help educate the public and advertise the conference, which will feature a variety of speakers.

She knows the trials and tribulations of suffering with pain all too well. It wasn’t until she was well into adulthood that she was finally diagnosed with fibromyalgia.

“I remember being in the nurse’s office in school more than most [kids], but no one knew what it was,” said Luchs, who was frequently dismissed as a hypochondriac.

With the encouragement of her sister, Lonnie Zeltzer, MD, an expert in pain management and an APF board member, she started advocating for herself and using complementary therapies like yoga, acupuncture and meditation to find relief. Luchs is now helping other people speak up.

A retired speech pathologist by training, Luchs says she is used to helping people find their voice. “People shouldn’t suffer silently,” she said.

Keys is inspiring support for pain through music. A singer and musician who also suffers with back pain, she is planning POPfest, an evening jam session, on Sunday, September 26 in Cincinnati. People can come to listen to music and learn about pain from a variety of health care providers from the Cleveland Clinic. APF materials and pain-related resources will also be on display.

Roach is working with nursing students at Owens Community College in Perrysburg, Ohio, to give presentations about caring for people in pain. She will share her personal pain story and emphasize the important role nurses, who are often on the front lines of patient care, play in improving communication between doctors and patients.

AN EXTENSION OF THEIR LIFE-LONG COMMITMENT

For Karen Keifer, RN; Jody Kohn, MSW, MA; Dee Browsers, MSCP; and other health professionals, pain advocacy is an extension of their life’s work, and much of their passion and motivation centers around changing the system from within.

Kiefer, Luchs’ mentor and counterpart in New Jersey, secured Governor Chris Christie’s formal proclamation of Pain Awareness Month in partnership with the American Cancer Society. She is setting up informational displays at local libraries, contacting her local news media and collaborating with the New Jersey chapter of ASPMN to coordinate a nursing conference in October at Overlook Hospital in Summit, NJ, to

coach them on how to best intervene for patients and get involved in the legislative process to help expose grossly unmet pain care needs.

“People are beginning to see pain as a critical public health issue, but we have a long way to go,” said Kiefer, who is strategically placing PAM flyers and postcards throughout her community to generate awareness. “Pain isn’t sexy, so it doesn’t lead to big stories, but people don’t have to suffer.”

Michigan AN leader Kohn, who has a private psychotherapy practice and runs a chronic pain support group that includes an hour of yoga, has lived with chronic pain since a bad car accident in 1983 and the multiple injuries that followed.

“At various times in my life, I was told I would never drive, work or function again,” said Kohn. “But I’ve been determined to get my life back mostly by integrating holistic measures.”

On September 19, she is hosting a “Holistic Day of Hope for People in Pain” at the Lotus Center in Ann Arbor. This four-hour event will feature demonstrations, presentations and information sharing with a variety of integrative health practitioners including those in acupuncture, massage therapy, gentle yoga and therapeutic breathing, tai chi, meditation, cognitive behavioral therapy, chiropractic and nutrition, among others.

“Ann Arbor is an alternative friendly town — it’s a young, liberal, academic town, so I expect this type of an event will get a lot of attention and

acceptance,” she said.

She is also busy pitching articles to local papers, reaching out to radio stations and disseminating pain education materials at physician offices and holistic clinics.

Susan Ostalecki, PhD, another AN leader in Michigan, is hosting “Fibromyalgia Comic Relief Night” on September 16 in Royal Oak, Mich. “It’s a great concept and, while there is nothing funny about living with pain, it certainly promotes the idea that laughter may be the best medicine,” added Kohn.

Browsers, MSCP, NCC, LPC, has been reaching out to more than 200 organizations, hospitals, pain clinics, businesses and community groups in Ohio to encourage them to endorse and participate in APF’s Virtual March on Washington. Thanks to her efforts, educational bulletin board displays and information booths can also be found throughout the Dayton area.

This is a mere sampling of the exciting and inspiring work planned by APF’s dedicated AN volunteer advocates across the country.

RALLYING FOR IMPROVED PAIN CARE

Organized activities for PAM center on key AN focus areas including community outreach, media outreach, pain policy advocacy and collaboration. In communities near and far, official proclamations are being announced, designating September as Pain Awareness month. Health fairs, pain conferences, information booths,

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Ask a Gerontologist

F. Michael Gloth, III, MD,
FACP, AGSF, CMD



F. Michael Gloth, III, MD, FACP, AGSF, CMD is the corporate medical director for Mid-Atlantic Health Care, the medical director for HCR-ManorCare Ruxton and Woodbridge Valley Nursing Homes, and an associate professor of medicine and the former director of outpatient services in the Division of Geriatric Medicine and Gerontology at Johns Hopkins University School of Medicine. Dr. Gloth served, at the request of the President, on the Advisory Committee to the White House Conference on Aging and, at the request of the secretary of Health and Human Services, on the National Advisory Council on Aging to NIH.

Older Americans are more likely to experience pain than younger generations; yet, in many cases, they don't get the care they need and deserve.

Q: Why is it important to understand how pain affects people in later life?

A: Pain is very common as we age. About half of older folks living in the community and considerably more in nursing homes and assisted living environments suffer with daily pain. Pain, especially if it's untreated, can affect how they function. Understanding how pain presents itself in older adults and measuring changes in their pain can make the task of resolving pain far more manageable.

Also, many people incorrectly assume pain is a normal part of aging — something to grin and bear — and, therefore, don't tell their doctor. They shouldn't think they need to live with the pain. Most of the time, we can drastically improve or completely eliminate their discomfort. This means more productive and happier older adults.

Q: Are older people more sensitive to pain signals?

A: It's not so much that older people are more sensitive to pain, but that the likelihood of having pain is greater as one ages. An accumulation of injuries and diseases over time provide more opportunities for discomfort. Small insults add up and create circumstances where pain results over time.

For example, osteoarthritis — a form of arthritis caused by a

deterioration in the joints — affects three out of four older adults and tends to appear where there is some history of trauma or recurrent damage in the body. Pain associated with poor circulation or nerve damage from diabetes or other chronic illnesses can also cause pain.

Because many seniors have multiple medical problems, treating pain can be complicated. Issues like dementia or Alzheimer's disease can make evaluating pain more challenging. Some diseases may make it difficult to prescribe certain pain medications because they might worsen another underlying illness or interfere with other important medications. For example, a man with an enlarged prostate may be more likely to develop urinary retention with opioid analgesics like morphine. Older adults frequently have high blood pressure, heart disease, kidney disease, or a history of ulcers. All of these conditions make commonly used analgesics called nonsteroidal anti-inflammatory drugs (NSAID) like ibuprofen particularly dangerous. These medications should be generally avoided in seniors.

Q: Are certain types of pain more common in older adults?

A: Yes. As mentioned, arthritic conditions, like osteoarthritis, are certainly more prevalent in older adults. Post-herpetic neuralgia, a painful condition that follows an attack of shingles, is more common in older adults. For this reason,

the Centers for Disease Control (CDC) has recommended the herpes-zoster (shingles) vaccine for people over 65 years old.

Other chronic conditions like diabetes and peripheral vascular disease can cause nerve pain. Restless legs syndrome, orofacial pain and pain related to cancer also are more commonly seen in older adults.

While pain relievers may help with pain, treatment of the underlying conditions may be just as useful or more so. Therefore, it's important to seek care of a qualified health care professional whenever pain presents itself.

Q: What is your advice for older people living with pain or their caregivers in terms of making sure their pain is adequately addressed?

A: I'd say to:

- 1. Seek medical care.** A primary care provider is a great place to start; however, depending on the reason for the pain, you may be referred to a specialist.
- 2. Get information.** For example, ask your health care provider:
 - How long until relief can be expected?
 - Will the pain go away completely?
 - If not, how much improvement can I expect?
 - When should a follow-up appointment be scheduled?

You may want to bring a trusted friend to your visit so he or she can advocate for you and provide additional support.

- 3. Move your body.** Exercise is almost always helpful in pain management. Find out what exercises can be done and if a referral to physical therapy or occupational therapy would be helpful.
- 4. Remember that pain is NOT a normal part of aging.** It is no more normal or acceptable for older adults to suffer pain than it is for younger populations. If you aren't getting results, consider a

second opinion. The American Pain Foundation's website and SeniorHealthCare.org are good sites to get advice and resources.

- 5. Depression is often associated with chronic pain.** It is a mistake to think that simply improving pain will resolve these issues. Usually depression needs to be treated along with the pain to optimize results. Being aware of the biochemical imbalance that can occur in the brain related to pain and being open to such additional intervention may produce better and faster results.



Common Myths and Fears

Many people mistakenly think or fear that:

- Pain is an inevitable part of aging
- They will be too much of a burden on children and other caregivers
- Older people can't tolerate opioids — one type of prescription pain medication (for more information, see the American Geriatrics Society's Clinical Practice Guideline, *Pharmacological Management of Persistent Pain in Older Persons* at http://www.americangeriatrics.org/health_care_professionals/clinical_practice/clinical_guidelines_recommendations/persistent_pain_executive_summary)
- Pain is a sign of disease or failing health
- Reporting pain will prevent the person from going home from the hospital
- Side effects from pain medications will be worse than the pain

Uniting Our Voices: Conquering Pain Together (continued from page 4)

joint awareness programs with various health and community service organizations and news media coverage are also helping to put pain front and center.

"At the end of the day, the battle to improve pain care is a social justice issue and change will not happen without a united voice of the masses demanding change," said Corley.

Get involved today. For information about how to join APF and ways you can help in your community, visit www.painfoundation.org and its companion web site, www.APFActionNetwork.org. Here you will find out what is happening in your area, learn how you can help, or add your planned events or those of your organization to the "Events Calendar."

The American Pain Foundation would like to use this opportunity to sincerely thank Ann Corley, MS, for her exceptional contribution as staff to the Action Network. She is well known for her incredible organizational skills, her insights into systems change and dedication to fulfilling APF's mission. She is taking a well deserved break and is moving on to explore other venues for her wonderful skills and talents.

PEER-TO-PEER ADVICE FOR PEOPLE LIVING WITH PAIN

Eight things you should start doing today, if you haven't already:

- 1.** Become your own best advocate.
- 2.** Educate yourself and those around you. Do as much research as you can. Learn about your pain condition and the treatments that might help give you relief.
- 3.** Take care of yourself each day and honor your limitations.
- 4.** Be persistent in seeking out the care you need.
- 5.** Make sure all of your health care providers talk to one another. Pain is complex and best treated by a combination of therapies (called a multi-modal approach) and you need someone to help coordinate this care.
- 6.** Trust your instincts. Know that sometimes other people "don't get it," but that doesn't mean your pain should be dismissed. The earlier your pain is diagnosed and treated, the better.
- 7.** When talking about pain, speak in term of its impact on function. For example, "Pain has robbed me of so much. I can no longer garden, sit through a movie or drive more than one hour away from home."
- 8.** Join APF (www.painfoundation.org) and other organizations that specifically address your pain condition.



VOLUNTEER CORNER

Mark Maginn
San Francisco

Pain Community Advisory Council and State Action Network Leader for CA

“Organizations like APF are on the forefront of the effort to let people with pain know they are not alone and that they have the right to expect better treatment from the medical community.”

Mark Maginn has been living with pain for most of his life. While Maginn isn't sure what caused his pain initially, he says it began at the age of 15 when he woke up one morning after basketball practice unable to move without feeling pain.

Maginn suffered for nearly two decades and visited multiple health care providers before doctors finally discovered a break in his spine. Since then, he has been diagnosed with a host of painful disorders including Behcet's disease (a rare inflammatory disorder that affects the blood vessels), osteoarthritis, osteoporosis, arachnoiditis (caused by the inflammation of a spinal cord membrane), and fibromyalgia.

By the time Maginn reached 45, the pain was all-consuming. He was forced to give up many of the things he loved including sports and a successful career as a psychotherapist, consultant, presenter and teacher. Maginn says he felt depressed and isolated and thought his life was over, but he soon discovered that he could put his skills and talents to use by pursuing activities that were less physically demanding.

He began writing and publishing poetry, and he also started working part-time and volunteering his services as a writer and public speaker to a variety of non-profit and community-based organizations. He worked with several organizations providing disaster mental health services to employees and residents in lower Manhattan following the September 11 terror attacks, and later served as a peer counselor and organizer in California to educate patients on the safe and responsible use of medical marijuana. He also worked with policymakers lobbying for health care in California.

Maginn says his new work gave him a renewed sense of purpose in life. “Losing my career wasn't the end; it was the beginning of a new love,” said

Maginn. “Pain may take a lot from us, but it also opens new avenues for living.”

In the years following Maginn's initial diagnosis, he underwent several surgeries to repair the long-term damage to his joints, had a spinal cord stimulator implanted and began taking prescription medications to help ease his pain. When Maginn started feeling better, he became determined to help others living with pain find better medical care.

After learning about APF while searching the Internet for pain information, it wasn't long before Maginn shared his talents and became a state Action Network leader for California. He attended the annual Action Network Pain Summit in Minneapolis, served as a media spokesperson, worked with policymakers and testified before the Food and Drug Administration panel on opioid medicines.

As a member of the Northern California Pain Initiative, Maginn is currently working to build relationships with a number of organizations who serve culturally diverse populations in the San Francisco Bay area. He is currently involved with a sickle cell anemia community group, a Native American health center, and a private health facility in San Francisco that has a large homeless patient population.

“People with pain are underserved as it is, and people from minority groups have even less access to pain care,” said Maginn. “I was underserved for decades and dismissed by physicians who couldn't figure out what to do with me, so I want to share the lessons I learned with others. If someone had shared their pain experience with me decades ago, I believe that my own journey would have been far less difficult.”

In July 2010, Maginn was elected as a new member of APF's Pain Community Advisory Council

(PCAC). In this role, he will continue his work reaching out to underserved pain populations and will also take the lead in developing a program to address mental health and chronic pain.

As one of the newest PCAC members, one of Maginn's initial activities will be reviewing APF's health care provider continuing education programs to ensure that they are grounded in the experiences of people who live with pain. He will also work in collaboration with other PCAC members to bring the voice of the person with pain to all of APF's programs, communications, actions and positions.

“Organizations like APF are on the forefront of the effort to let people with pain know they are not alone and that they have the right to expect better treatment from the medical community,” said Maginn. “It's a tremendous mission; one that I am proud to be a part of.”

Maginn lives in San Francisco with his wife. When he's not advocating for better pain care, he also enjoys reading, going to the movies, walking along the bay with his golden retriever, and spending time with his college-age son. He is currently working on a memoir of his experience living with pain.

PCAC Expands

If you are a person living with pain who also has experience as an advocate and would like to be considered for a high level volunteer position with PCAC, please contact the PCAC co-chairs (Cindy Steinberg, csteinberg@rcn.com, or Malcolm Herman, herman@rockvillejustice.com) and let us know why you would like to be involved.

When Moving Hurts

Have you ever suffered a bout of carpal tunnel? Or been laid up after a flare up of lower back pain? Although you may not refer to it by name, these are types of musculoskeletal pain, one of the most common pain complaints brought to doctors. The musculoskeletal system is made up of bones, muscles, ligaments, tendons, joints and other connective tissue. It works as an interconnected system and allows us to move about our daily lives.

Musculoskeletal pain involves any type of pain that affects the muscles or joints. It includes back and neck pain, fibromyalgia, arthritis, and bone pain — to name a few. Although some types of musculoskeletal pain can be resolved with home remedies and rest, others have the potential to be more serious and long-lasting. When this happens, it can greatly affect people's lives, reducing their ability to perform normal activities at home and work.

Because of the burden of chronic musculoskeletal pain and need for widespread awareness, the International Association for the Study of Pain (IASP) in October 2009 launched *When Moving Hurts: Assess, Understand, Take Action, a Global Year Against Musculoskeletal Pain*. This effort is drawing international attention to the debilitating pain those with musculoskeletal disorders face. It also provides health care professionals with the education and tools they need to recognize and treat different types of musculoskeletal pain.

“Because the cause of musculoskeletal pain is often hard to pinpoint, it is difficult for clinicians to care for,” explained Kathleen Sluka, PhD, PT, leading pain expert and co-chair of IASP's global year campaign. “Because of this, treatment options for musculoskeletal pain today are often inadequate. The most significant result of this campaign is providing resources to clinicians to help them better manage this all-too-common condition.”

As part of these efforts, IASP has generated fact sheets highlighting specific topics related to musculoskeletal pain and the science behind it

and educational videos available in different languages on YouTube. Throughout the year-long campaign, the association and its chapters in more than 80 countries sponsored meetings, symposia, pain camps, speeches, publications, and other efforts to educate health workers, government officials and the public on the issues surrounding musculoskeletal pain. Organizers also hope the campaign stimulates new research into the underlying mechanisms and treatments for musculoskeletal pain.

While IASP's campaign has been well received, Dr. Sluka still sees opportunities for advancement in the treatment of musculoskeletal pain.

“We must ensure that we are continuing to educate clinicians who see and treat musculoskeletal pain every day,” she said. “This includes not only practicing physicians, but also physical therapists and other specialty doctors. It is also important to integrate pain education into the standard curriculum at all professional schools. Having a better understanding of the causes of musculoskeletal pain should lead to the development of new and better treatments for people with chronic pain.”

Three Things You Should Know About Musculoskeletal Pain

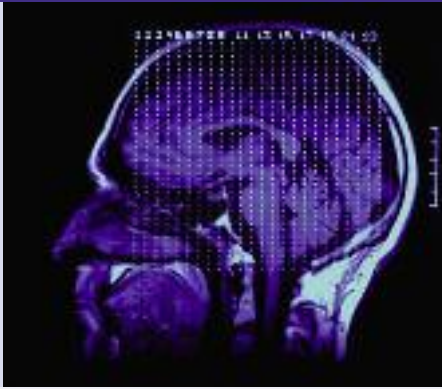
- **Musculoskeletal pain is not always associated with an injury.** Often, musculoskeletal pain can be the result of an earlier injury that has already healed by the time pain occurs. This makes it difficult to diagnose the exact source of the pain.
- **When it comes to musculoskeletal pain, a minor injury can cause major pain.** A small injury that you may dismiss, such as a slip or fall, may result in intense and/or recurring chronic lower back pain, the most common form of musculoskeletal pain.
- **To be effective, treatment plans for musculoskeletal pain should integrate multiple therapies for pain relief.** This is called a multi-modal approach. Your primary care physician as well as a physical therapist, psychologist and nurse practitioner can all help develop a custom plan to treat your pain.



To view IASP's campaign, please visit www.iasp-pain.org.

Fast Facts: Multiple Sclerosis & Pain

Multiple sclerosis (MS) is one of the most common causes of non-traumatic disability among young and middle-aged people — often robbing them of their independence and livelihood. The disease is often marked by weakness, tingling (described as “pins and needles”), numbness, loss of coordination and balance and blurred vision.



MS is believed to be an autoimmune disease, which happens when your body attacks itself. MS damages the myelin sheath (material that covers and protects the nerve cells, including those in the brain and spinal cord). This damage slows down or blocks messages between the brain and body. What many people don't realize is that people with MS may also suffer with frequent and sometimes debilitating pain. In fact, more than half of all people with MS experience related pain at one time or another, according to the National Multiple Sclerosis Society.

MS-related pain is complex and varies from person to person. The pain may be:

- due to the disease itself (pain that occurs when the nervous system does not function properly), or
- secondary to other MS symptoms (painful muscles and joints caused by spasms or cramps).

While twice as many women as men suffer from MS pain, factors like age, disability and length of time with MS do not seem to play a role in the development of pain.

Acute vs. Chronic Pain Symptoms

Acute MS pain usually has a sudden onset and may be intense, but generally lasts for a short time.

Types of acute pain may include:

- Dysesthesias — abnormal and unpleasant sensations, such as burning, tingling or numbness; these can wrap around the waistline (MS hug)
- Trigeminal neuralgia or “tic douloureux” — a sharp and stabbing pain in the face that can be brought on by simple facial movements such as yawning, chewing and sneezing. This may be the first symptom a person with MS experiences, and is often mistaken for dental pain
- Lhermitte's sign — electric shock like or burning sensations traveling from the head to the spine triggered by bending or flexing the neck
- Migraine, tension or cluster type headaches

Chronic MS pain lasts longer and may include:

- Burning, prickling or “pins and needles” feeling
- Muscle spasms or cramps
- Aching or tight joints
- Back pain, or other muscle and bone pain. This type of pain can result from staying immobile for too long or improper posture and body use when compensating for balance or coordination problems.
- Optic neuritis — stabbing eye pain brought on by an inflammation of the optic nerve. This is a common early symptom of MS, and the pain is sometimes worse with eye movement.

Treating the Pain

While pain is very common in people with MS, there are a number of therapies that can provide relief. Because MS is a complex disease, and the causes and sources of MS pain vary, treatment must be tailored to each individual and often requires a multi-step approach.

Depending on the type of MS-related pain, the following treatments may be recommended:

- Some anticonvulsant and antidepressant medications can alter the way the central nervous system reacts to pain.
- Over-the-counter pain relievers like acetaminophen and NSAIDs, like ibuprofen or naproxen, may help reduce muscle and joint pain.
- Prescription strength NSAIDs or steroids.
- Massage and physical therapy to help loosen stiff and aching joints and muscles.
- Wearing a pressure stocking can change pain sensations into feelings of pressure, help limit swelling and reduce sensitivity to hands and feet that are oversensitive to touch.
- Using warm compresses on the skin can convert pain sensations to feelings of warmth. Thermal techniques can help limit swelling and reduce sensitivity to hands and feet that are overly sensitive to touch.
- Alternative therapies such as hypnosis, yoga, meditation or acupuncture may help with relaxation and pain control.
- Doing regular stretching exercises and balancing water intake with adequate sodium and potassium can help prevent muscle spasms and cramps.

If you have MS and feel pain, talk with your health care provider about finding a treatment plan that's right for you.

For more information, visit:

National MS Society

Pain: The Basic Facts

www.nationalmssociety.org/download.aspx?id=59

WebMD

Treating Multiple Sclerosis Pain

www.webmd.com/multiple-sclerosis/guide/treating-multiple-sclerosis-pain

Sources: National Multiple Sclerosis Society, WebMD, Mayo Clinic

Is Fibro the Cause? PILOT PROJECT SPANS MISSOURI

APF is collaborating with a number of community agencies, alliance groups and individuals throughout Missouri to implement *Is Fibro the Cause?* This pilot project aims to raise awareness about fibromyalgia through media activities, educational materials and building alliances with agencies and organizations that have a vested interest in improving the diagnosis and management of fibro, a widespread pain condition that affects up to six million Americans.

Missouri-based groups are disseminating APF's *Is Fibro the Cause?* toolkit and self-assessment tool at no cost and providing educational presentations across the state. The toolkit contains helpful tips and resources such as how to recognize fibromyalgia's signs and symptoms, find treatment and effectively communicate with your health care provider.

This project officially launched on June 22 with a press release and e-alerts to APF members. More than 6,000 toolkits were shipped to 24 health service agencies and organizations, volunteer advocates and other individuals who are helping to spread the word to friends and colleagues. Collaborations with the seven regional arthritis centers and organizations on aging throughout the state are greatly increasing the outreach and impact of this project, which is continuing throughout September Pain Awareness Month.

APF hopes this project will serve as a model for similar campaigns across the country.

For a list of collaborators and places where you can pick up a toolkit in Missouri or to download a PDF copy of our toolkit, please visit www.APFActionNetwork.org/is-fibro-the-cause.

Help APF GROW its Membership



One out of four Americans experiences pain, and its association with cancer, diabetes, arthritis and other common diseases means that none of us can turn a blind eye to pain and its impact on people's lives.

As with previous health movements, there is power in numbers. That is what is needed to help build a critical mass for change.

Help us to raise public awareness and understanding. APF cannot accomplish its mission without the support and dedication of our growing membership.

Already an active member? Make a commitment to ask just one person — a friend, neighbor, coworker, family member or someone at a local support group — to join.

*We can improve pain care in America,
but not without the millions of voices
of people affected by pain.*

Not yet part of the APF family?
JOIN US TODAY.
Membership is free at www.painfoundation.org.

APF Launches PainSAFE This Fall

APF is proud to announce the coming launch of Pain Safety & Access For Everyone (PainSAFE™). This new educational initiative is part of APF's ongoing commitment to advocate for timely access to safe and appropriate pain care for those affected by pain.



PainSAFE™
Safety & Access For Everyone

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

Patient safety is one of the nation's most pressing health care challenges, and it directly affects people living with a variety of acute and chronic pain conditions. Although pain management therapies can provide significant benefits by reducing pain and suffering, improving physical function and restoring one's quality of life, they can also result in unintended or undesirable effects, from minor to life-threatening. The reality is that **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.

Visit PainSAFE's dedicated site (www.painsafe.org) and learn about all of the different pain therapies and how to appropriately and safely use them. APF will begin cultivating this large educational initiative through a phased approach. The launch will include information about opioids and implantable pain therapies with additional therapies to follow in the near future.

This initiative will be developed with expert guidance from a multidisciplinary advisory committee chaired by Dr. Lynn Webster, one of the country's leading experts in the field of pain medicine and addiction.

AMERICAN PAIN FOUNDATION (APF)

is the nation's leading independent non-profit 501(c)3 organization serving people with pain. Our mission is to improve the quality of life for people with pain by raising public awareness; providing practical information, education and support; advocating to remove barriers and increase access to effective pain management; and promoting research. APF has a comprehensive website, PainAid (online support), consumer publications, APF Pain Monitor (monthly e-newsletter), a toll-free message line and public awareness and legislative activities.

1 (888) 615-7246
www.painfoundation.org

PAIN AWARENESS MONTH

APF's Conquering Pain Together
www.APFActionNetwork.org

PAIN, HEALTH & AGING

AGS Foundation for Health in Aging
www.healthinaging.org
(212) 755-6810

Dealing with "Persistent" Pain in Later Life

www.healthinaging.org/public_education/persistent_pain_tips.php

National Council on Aging

www.ncoa.org

National Institute on Aging

www.nia.nih.gov/HealthInformation

ANXIETY & PAIN

Anxiety Disorders Association of America
www.adaa.org
(240) 485-1001

National Institute of Mental Health

Locating mental health services
www.nimh.nih.gov/health/topics/anxiety-disorders

In the Next Issue

Unraveling the Role of Inflammation and Pain, a primary care doctor and rheumatologist weigh in

Be Prepared for Mother Nature, Planning for Natural Disasters

Military/Veterans Pain Initiative Updates

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APF has a wealth of resources and educational materials to help people affected by pain get the care they deserve. These materials — publications, online guides, spotlights, topic briefs, fact sheets and much more — have been developed to meet the unique needs of people affected by pain.

Be a local champion. Help us to promote these materials in communities nationwide. If you are interested in getting these materials into your local hospitals, doctor's offices, pain clinics, community and senior centers, public libraries or other public venues, please let us know. Visit APF's store front at www.painfoundation.org/learn/publications/apf-store.html.

