

Chronicle



Winter 2021

Holidays in Hurtville

Discover Hope to Cope with Pain in Chaotic Times

Holidays in Hurtville

New Faces and Resources

Four Ways to Manage Chronic Pain

Voter Rights

Hiking Superhero

Note From a Pain Specialist

Mental & Physical Health

Cold and Flu Season

Featured Support Groups

Physical Activity Guidelines

Myth... No Pain No Gain

Studies and Research

ACPA Tribute to Holly

ACPA Mission



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Chronicle

The Chronicle is published four times a year by the American Chronic Pain Association (ACPA).

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We welcome original essays, poetry, articles, art, and book reviews written by people with chronic pain or their families.

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Holidays in Hurtville: Discover Hope to Cope with Pain

By Scott Farmer, MBA

Coping with Pain

The definition of “COPE” is to deal effectively with something difficult... or deal with and attempt to overcome problems and difficulties. If you are reading this, chances are we share a common problem. The causes may vary, but we share the difficulties of chronic pain. Pain is the most common cause of disability in the world. It comes in the form of physical and emotional pain, and it is relentless. We seek to cope with our pain daily. That is what makes it chronic.

Our hope in this issue of the ACPA Chronicle is to discover ways to proactively cope with pain during the Holidays and winter months.

Winter Brings Gratitude

Early in my high school football career I was sacked and essentially crushed under a pile of defensive players. I heard a strange pop in my lower back as my chest met my kneecaps. I didn't experience instant pain, and it wasn't until college did I experience another pop when working in a warehouse. I attempted to move a steel beam with my foot from right to left. The pain was excruciating... radiating up my spine like an electrical shock. Then back to my lower back, seemingly on rhythm with my pulse. The only relief I could find was lying directly on the floor. Moving an inch would result in sharp pain. You all know the story. Causes vary but the result is the same. I'm grateful to have found hope.

Our Mission

The ACPA Chronicle is our voice to help facilitate peer support and education for individuals with chronic pain and their families so that these individuals may live more fully in spite of their pain. The Chronicle is published to raise awareness among the health care community, policymakers, and the public at large about issues of living with chronic pain. *Opinions in the Chronicle are those of the Authors and do not necessarily reflect the opinions or viewpoints of the ACPA. Although some topics may seem controversial, it is important for the Chronicle to cover a variety of topics regarding pain. And as always, consult a healthcare professional on all healthcare decisions.*

Hope From Chaos

The journey with chronic daily pain has been a roller-coaster ride. I have lived twenty-two years in pain, and only recently have I found healthy coping mechanisms and solutions. Freedom from pain was a daily goal, however the severity increased as I aged, and the outlook looked dim. I found myself in Hurtville... a place I felt hopeless and alone.

Leaving Hurtville

I try to stay out of Hurtville by utilizing hope, motivation, education, lifestyle changes, confidence, and support.

In this issue you will hear from several Pain Specialists. We will offer resources on lifestyle modifications that you can utilize right now. The Holidays and the winter months can become overwhelming while coping with pain; however, this time can also become a starting point to leave Hurtville... to turn your hope into reality.

NEW BOARD MEMBERS AT THE ACPA

By Scott Farmer, MBA



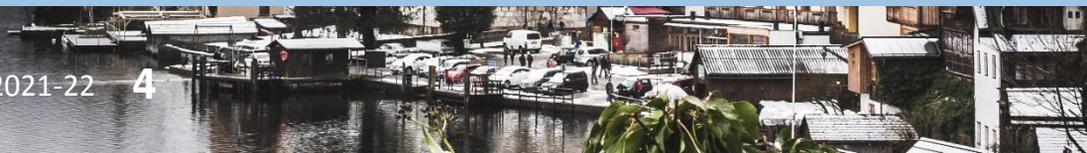
Trupti Gokani, MD

Trupti Gokani, MD is an award-winning, board-certified neurologist, health & mindset coach, ayurvedic expert and Master Practitioner of NLP, who has dedicated her life to developing a unique blend of ancient wisdom with modern approaches. By melding these approaches, she's become a highly sought-after speaker and coach, sharing holistic wellness strategies with media personalities like Dr. Oz, and coaching clients from all over the world. She has been a blogger for Huffington Post and served on the faculty for The Shift Network and Metagenics. Dr. Gokani published her first book, *The Mysterious Mind*, in 2015 and is working on her second book. She is available for speaking engagements and media appearances in addition to her ongoing work at the Zira Mind & Body Center and private coaching intensives. For more information, visit Dr. Gokani at <https://truptigokanimd.com/>.



Andreia Naomi Pierce, PhD, MBA

Dr. Pierce is a business leader at Amazon Web Services. She earned her PhD in Biomedical Sciences with a focus on Neuroscience from the University of North Texas Health Sciences Center, her MBA from Southeastern Oklahoma State University, and she served as a research fellow at the University of Texas Southwestern Medical School. She worked in many disease states including Chronic Pain & Addiction, MS, Asthma, COPD, Parkinson's Disease, and Migraine. Her work in the pain space includes a launch of one of the first FDA approved temper resistant morphine treatments, and a monoclonal antibody for the preventive treatment of migraine. She has received numerous awards for her business leadership, which speaks to her strong background in learning, developing and managing large teams. At Amazon, she oversees building a vision for Research on the AWS cloud.



NEW RESOURCES COMING THIS SEASON

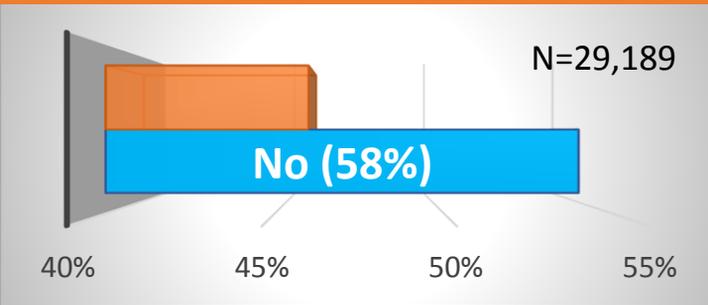
By Scott Farmer, MBA

MigrainePro 7.0 (MP7)

Reaching underserved communities, MP7 will feature text interaction with a Specialist and seven new educational videos. Going on the 7th year, MigrainePro® is a community of 100,000+ people with migraine who have become "Pros" at managing their migraines. MP7 will offer tools for those in underserved communities to do the same. You will be able to understand and track migraine, patterns, and treatments to better communicate with your healthcare professional. MP7 will help you make an appointment to discuss new treatment options and the importance of adherence. You will see a 2021 gap (right) that shows the large amount of people yet to visit their healthcare professional to discuss their headaches. MP7 will focus on improving seven (7) educational gaps that were exposed in 2021.



Have you seen a healthcare professional for your headaches?



Painful Diabetic Peripheral Neuropathy Communication Resources



Three Painful Diabetic Peripheral Neuropathy (PDPN) communication resources will be launched this season. These resources will include a printable and digital option. First, the *Guide to Discuss My Symptoms with My Healthcare Providers*. This will allow a person to quickly communicate where the pain is located, describe the symptoms, and rate the symptom severity. Second, *Define My Treatment Goals with My Healthcare Providers*. This will allow a person to quickly rate pain levels, activity levels, life impact, and treatment goals. Third, is a guide specifically for caregivers of those with PDPN.

FOUR WAYS TO MANAGE YOUR CHRONIC PAIN

By Dr. Wayne Jonas

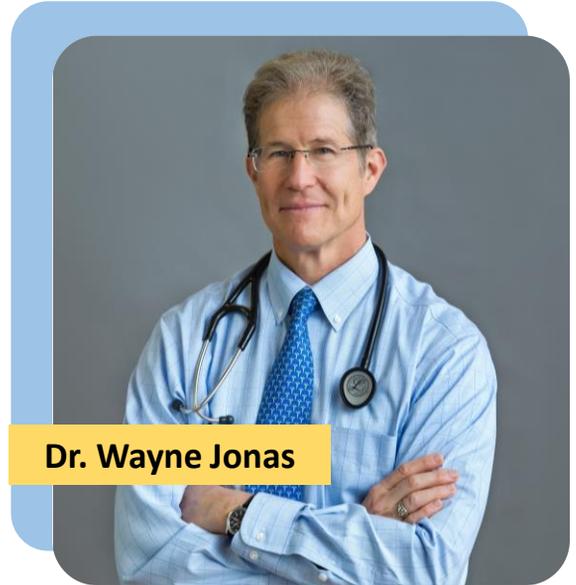
40 Years of Practice

As a physician with 40 years of practice, whenever I think about treating chronic pain, I often recall my patient Margaret and her back pain. She wasn't sure how it started – maybe it was triggered by the long hours on her feet working at the shop, or maybe she just lifted her grandson the wrong way. When it started, her doctors prescribed medications and physical therapy. She had X-rays and an MRI, which revealed arthritis in her spine. She developed severe sciatica, with pain shooting down her leg. She received an injection and a prescription for an opioid medication to take when the pain was unbearable, often at night.

Dr. Jonas is a Family Physician and Professor of Family Medicine at Georgetown University SOM USUHS School of Medicine. He is the Executive Director of Samueli Integrative Health Programs and Author of *How Healing Works*. Dr. Jonas is a Former Director NIH Office of Alternative Medicine, and a Retired Lt. Colonel of the United States Army Medical Corps

Other medications followed – for sleep, for the nerve pain, and finally for an antidepressant to lift her mood. By the time she came to me, she was on five medications, including a daily opioid. She could no longer exercise and had gained 50 pounds in 10 years. She was miserable. When she didn't take her opioid, she became agitated and irritable – classic signs of opioid dependence.

Margaret is a classic example of where our current system fails. My goal is to help you avoid the years of misery and pain like Margaret experienced.



Dr. Wayne Jonas

Three Basics of Healing

Over my years of practice, I've observed that people with chronic pain need three basic things to help them heal:

1. A Healthcare Team that works together and shares information.
2. Non-drug approaches to help improve function, cope with the pain, as well as reduce it.
3. Help managing medications with a goal of getting off or reducing opioid use.

Team-Based Care is Critical

Team-based care is critical because pain is more than just a physical hurt. It is an unwanted guest that takes over your life, interfering with your ability to work, your relationships, your mental health, and your overall quality of life. It consumes your entire being.



FOUR WAYS TO MANAGE YOUR CHRONIC PAIN

By Dr. Wayne Jonas

Engage in
Conversation

Life Impact

For example, those with low back pain are three times more likely to have limited functional ability and four times as likely to suffer psychological distress as those without low back pain. Unfortunately, finding the answer to pain relief can feel like searching for a unicorn in a horse stable; the answer just doesn't live there.

People with chronic pain are often left to bounce around from provider to provider, frequently undergoing unnecessary, costly, duplicative procedures, taking ineffective drugs, and finding their stress and anxiety only increasing with every missed opportunity to relieve their pain. And it's only gotten worse during the pandemic. Often, patients may feel as if they have "failed" and lose hope. In reality, it is the health care system that has failed them.

Evidence-Based Care Leads with Non-Drug Approaches

An October 2021 Harris Poll should be a wake-up call to physicians that their patients are looking for more information about managing their chronic pain, especially with non-drug approaches.

The national survey of more than 2,000 adults conducted for the Samueli Foundation found that large majorities of people with chronic pain are interested in using non-drug treatments: 80% are interested in trying healthy eating; 71% in

exercise; and more than 60% would like to try massage, physical therapy, and meditation.

It's up to providers across the health care system to engage in regular conversations with patients to steer them toward the best ways to manage their pain every day.

Here are three non-drug treatments that don't get talked about often enough:

Movement

Movement includes exercise, physical therapy, and chiropractic care. Incorporating movement into your day can decrease discomfort—even for cancer-related pain. Physical movement boosts your immune system, reduces fatigue, relieves anxiety, and builds strength, flexibility, and pain tolerance.

Mind-body Approaches

According to the American College of Physicians, mind-body practices such as tai chi, yoga, mindfulness, and cognitive-behavioral therapy can all relieve pain effectively. Moving meditations such as Tai Chi and Qigong combine the use of slow and deliberate movements with meditation and breathing practice.



FOUR WAYS TO MANAGE YOUR CHRONIC PAIN

By Dr. Wayne Jonas

Practices like these impact muscle control and balance and have even been linked to improving cognitive function. It is an ideal exercise for those focused on mindfulness and can be less risky than traditional exercises, though it may require specific training.

Muscle Control + Mindfulness

Eating for Pain Relief

Research shows nutrition greatly affects pain because of two conditions: obesity and inflammation.

Obesity

Obesity can cause pain because the excess body weight puts a heavier load on your bones and joints. Just like an overloaded piece of equipment, your joints can start breaking down faster than normal. They might change shape or rub against each other in ways that cause pain. The discomfort is often exacerbated because you might also stand, sit, or walk uncomfortably.

Inflammation

Inflammation can be caused by specific types of food, which can contribute to long-lasting or chronic pain. Other foods and drinks, however, can fight inflammation, which helps reduce pain. Those foods that can decrease chronic pain and help improve your mood include whole grains, vegetables, beans, nuts, seeds, fruit, olive oil, fish, white meat chicken and turkey, and herbs and spices.

Other Non-Drug Treatments

There are many other non-drug treatments such as massage, guided imagery, acupuncture, and biofeedback, which can all offer patients substantial relief. Importantly, the side effects are minimal to non-existent—especially when compared with medications.

Getting a Better Handle on Pain

Once you as the patient feel that you have more options and a better handle on your pain, you can work with your providers to reduce opioids. But reducing opioids without other options is a no-win situation for both the patient and the health care provider.



Strong Healthcare Relationships

One final tip: Focus on building a strong patient-doctor relationship – one that helps you improve your quality of life. Make sure your doctor knows you are interested in talking about options other than pills and procedures at your next appointment. For those looking to move away from opioids, remember that there are effective, accessible, non-drug options. With the right team supporting you, you can be in control of your own **path to healing**.

THE PAIN COMMUNITY SHOULD SUPPORT VOTER RIGHTS

By Lynn R. Webster, MD

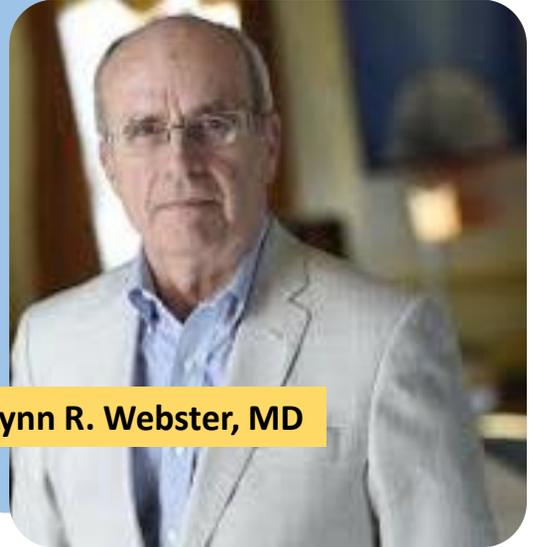
Fair, Accessible, and Secure

Ensuring our elections are fair, accessible, and secure is essential to maintaining our democracy. All people should be able to vote without experiencing intimidation or hardship. People who are in chronic pain—many of whom require opioids to enjoy any quality of life—live outside of society's safety net. They don't run for political office, because they can't. They don't make the laws that oppress them. And now they're in danger of being unable to vote against those laws.

Lynn R. Webster, MD, is a Senior Fellow, Center for U.S. Policy (CUSP) and Chief Medical Officer of PainScript. He consults with the pharmaceutical industry. He is the author of "The Painful Truth" and co-producer of the documentary "The Painful Truth" which aired nationally on public broadcasting stations. You can find him on Twitter: @LynnRWebsterMD.

Over the past several months, Congress has proposed several voting rights bills. But, thus far, Congress has not been able to even debate the bills for several reasons.

The revised bill is called the John Lewis Voting Rights Advancement Act. It is designed to restore provisions of the 1965 Voting Rights Act that were diminished by the U.S. Supreme Court in 2013 and further gutted last year. Essentially, the 2013 ruling allowed some states to change their election laws without receiving federal approval. While the Voting Rights Act passed in the House of Representatives, it is stalled in the Senate due to parliamentary rules that require 60 votes to move forward.



Lynn R. Webster, MD

Making Voting Difficult Impacts the Most Vulnerable Among Us

On August 28, 2021, I marched in Salt Lake City in support of easier and more practical ways to vote, and to protect the right of everyone to participate in our democratic process. When I attended this rally, I learned that voter suppression is a much broader problem than I had realized. It isn't only an issue involving people of color. Intentionally or not, voter suppression prevents many subsets of Americans from having a voice in our democracy.

Although the voting rights movement has been championed mostly by people of color, everyone should be involved. This affects all of us. It targets people who are poor and can't afford to take a day off to vote, and those who can't leave their home because they can't pay for childcare.



THE PAIN COMMUNITY SHOULD SUPPORT VOTER RIGHTS

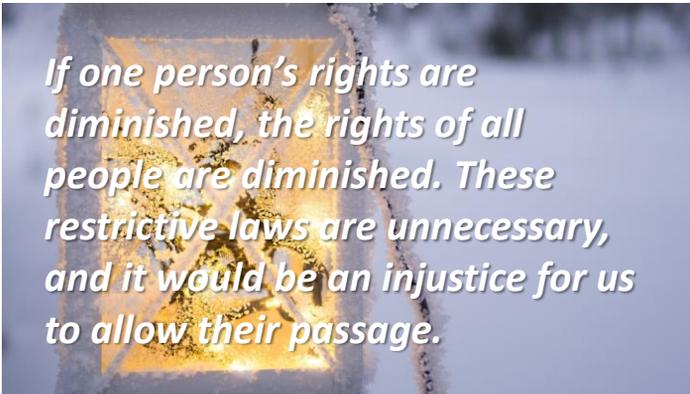
By Lynn R. Webster, MD

Continued...

Some are caregivers for the elderly or sick or are sick or disabled themselves. People with severe, disabling pain and those who provide care for them are affected by voter suppression laws as much as those of any other minority.

During my walk from Utah's state capital to Washington Park on that hot Saturday, I was sweating and thirsty. Fortunately, the organizers provided us with cold water. I realized my 40-minute hike was nothing compared to the challenges that many had to endure during the last election, and that many may have to experience in future elections, including standing in line to vote for hours—potentially, with no bathroom facilities available to them. In Georgia, restrictions have recently been passed to prevent voters standing in line from receiving water. The laws also limit absentee ballots and the number of ballot boxes, which makes it more difficult for caregivers, the disabled, and people with disabling pain to vote. The revised Voting Right Act prohibit restricting people in line to vote from having access to food and water.

As I marched, I began to wonder how people in pain would be able to tolerate standing in a long line. How could people who use a wheelchair or walker, or who suffer from chronic migraine headaches, fibromyalgia, or severe arthritis, endure the wait? Even healthy senior citizens and others who must void their bladders frequently may be unable to stand in a long line to have their voice heard.



If one person's rights are diminished, the rights of all people are diminished. These restrictive laws are unnecessary, and it would be an injustice for us to allow their passage.

We Need a Voice

The Pain Community Needs a Voice. There are 20 million people with disabling pain. This represents more than 12 percent of the total number of people who voted in the last presidential election. That is more than three times the difference in votes between Biden and Trump. It is a consequential population.

Pain and addiction don't preferentially affect Republicans, Democrats, or Independents. They harm all people equally, and people with pain and addictions are not tied to any political tribe. People in pain do not have a collective political voice. They have been marginalized and forced into the darkness. People with substance use disorders also have been silenced. Our drug laws are punitive and utterly disastrous. The only way to change this is by voting for those who will represent our interests. Therefore, it's important for the pain and addiction communities, regardless of their political allegiances, to support the John Lewis Voting Rights Advancement Act.

THE PAIN COMMUNITY SHOULD SUPPORT VOTER RIGHTS

By Lynn R. Webster, MD

Continued...

The law would help restore the rights granted under the Voting Rights Act of 1965. It would go further to empower the federal government to enforce those rights.

What We Can Do

I suggest everyone call or email their senators, even if their senators support the bill. They need to know where their constituents stand. If possible, join and donate to an organization fighting for your right to vote. Write an op-ed for your local newspaper or media outlet expressing your views on how to make it easier, not harder, to vote.

Disenfranchised people are in danger of losing their right to vote, and people in pain are an important constituency. Forming a collective voice to advocate for all people who suffer chronic pain is just as important, although it is a topic for another day. The time to support these voting rights bills is now... before it's too late.

WINTER BOOK REVIEW



Lycanthropy and Other Chronic Illnesses

By Kristen O'Neal

Released: April 27, 2021

Summary:

After a sudden chronic Lyme disease diagnosis derails her pre-med dreams

at Stanford, Priya heads home to her supportive but overbearing family in NJ and joins an “oof ouch my bones” support server with her online pal, Brigid. When Brigid suddenly goes offline, Priya does something out of character: she steals the family car to check on Brigid in PA. Priya doesn't know what to expect, but it's definitely not the horrifying werewolf shut in the basement. Inspired by O'Neal's experience navigating celiac disease, this sharply observed and hilarious novel of friendship and chronic illness explores what it means to come of age when your life seems to be coming undone by a diagnosis—whether it's of the textbook or spellbook variety.



AN ACPA HIKING GROUP SUPERHERO

By Alexis Arle

Starting at the Finish Line

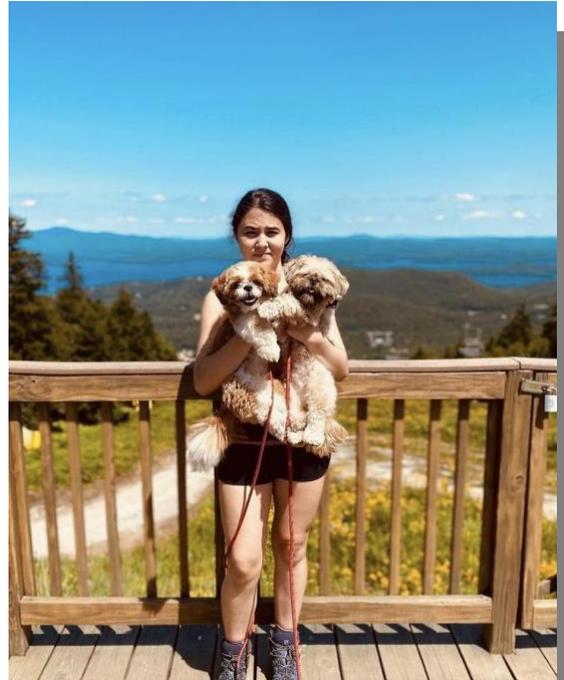
The greatest strength comes when you least expect it. I used to love running, the wind in my hair as I picked up the pace and sprinted to the finish line. However, my “finish line” came a lot earlier than anticipated. The facts of my story are easy to tell. I could talk about the seven years I spent on the exam table waiting to hear about my fractured feet, hip, or sacrum. But doctors have been analyzing my bones for seven years.

My Broken Bones Don't Define Me

My broken bones don't define me. I spent every day on the sidelines watching my team, patiently waiting for my turn to run alongside them. However, fracturing my sacrum changed everything. I trained all summer to get strong again, and I was eager to finally ask my trainer if she would clear me for the fall cross country season. I was told that “I would not be able to run again.”

A Part of My World Ended

Sophomore year was a new experience for me. I began rowing at a local community rowing center. I made it through the fall season without an injury, but eventually, the residual pain from my old back injury was beginning to flare up again. After many tests and evaluations, it was apparent that an underlying arthritic process was occurring. I was given medication to try, but there was no benefit.



Alexis spent her summer raising money for the ACPA through a GoFundMe page. The name of her fundraiser is *Hiking to Help Children Living With Chronic Pain*.

Pain Doesn't Define Me

I knew at this moment that I had to make a decision as to whether or not I was going to let this pain define what I can and cannot do with my life. I was inspired by a family friend who hikes in the mountains with her dogs. I was so drawn to this idea that I decided to take my two dogs up to the White Mountains for a day hike. For some reason, unexpectedly, I was able to venture up into the mountains much further than I ever thought possible.

AN ACPA HIKING GROUP SUPERHERO

By Alexis Arle

Finding Hope in My Capabilities

I still remember standing in admiration watching my two Shih Tzus trudge through the snow to summit our first mountain. Through them, I found hope in my own capabilities, and I was so exhilarated by this adventure that I decided to go again the following weekend.



Structure Something Meaningful

I decided to structure this mountain climbing into something more meaningful, not just for myself, but for others as well. After hiking both the forty-eight 4,000-foot mountains in New England, I decided to start a program for children living with Chronic Pain.

The sponsors of my hiking group donate to The American Chronic Pain Association each time I summit one of these mountains. I have climbed over 10 mountains thus far and have raised over \$400.



Thank you, Alexis for Hiking, to Help Children With Chronic Pain. You are an inspiration to the ACPA Community!

Feeling Fortunate

My story makes me who I am - a hiker, a dog lover, and a girl who will not give way to any obstacle. If I can't run, I will walk. I might not be soaring at a cross country race, but I have never felt more fortunate.



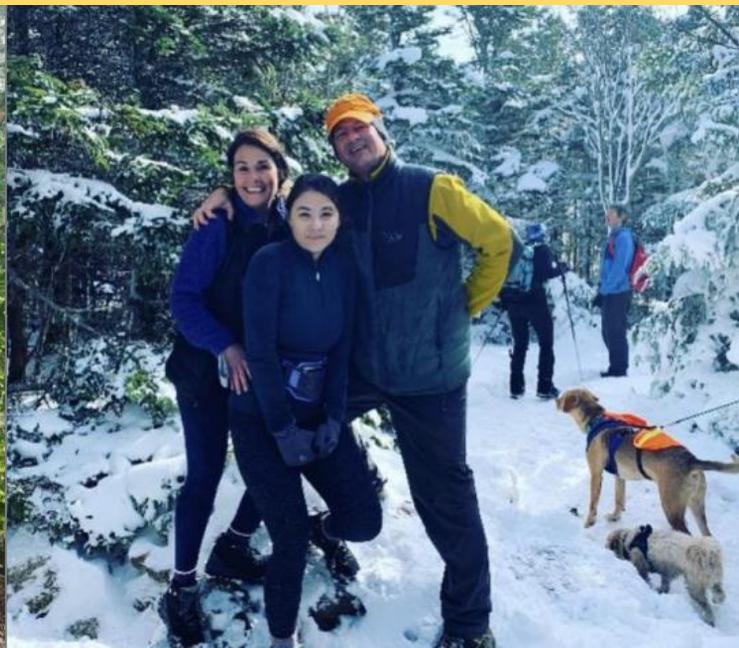
NOTE FROM A PAIN SPECIALIST: PERIPHERAL NERVE STIMULATION



Xiang Qian, MD, PhD
Stanford Medicine Endowed Director
Clinical Associate Professor of Anesthesiology
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Co Director of Stanford Facial Pain Program
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Management Center

In the United States chronic pain affects approximately 100 million people and millions of others experience acute pain following surgery. Many of these people rely on opioids chronically, resulting in a national opioid crisis. The need for non-opioid pain management options has never been higher. FDA-cleared peripheral nerve stimulation (PNS) was developed to help address this need. Although PNS was initially described as a treatment for pain as early as in the late 1960's, it was not until recently that PNS has become a standard of care to treat both acute and chronic pain conditions. Recent developments in waveform and nerve stimulation technology have further brought promising potential advancements to the PNS field.

More Pictures From the ACPA HIKING GROUP SUPERHERO



PLEASE CONSIDER SUPPORTING THE ACPA

By Kathy Sapp

DONATE FOR
PAIN FREEDOM



Dear Friends,

Since 1980, over 40 years, The American Chronic Pain Association has advocated for people living with pain and provided them with resources. Our efforts have reassured people with pain that they are not alone and offered support and the hope they deserve. The ACPA has shown millions of people in pain how to achieve reduced suffering and a better quality of life.

ACPA understands the battles you fight everyday. This is why we continue to advocate for your rights and provide pain management strategies and tools for you, your caregiver, and your healthcare team to better understand your condition. We believe resources are needed to provide empowerment for shared decision-making.

We are grateful for your partnership. When you support the ACPA, you help fight for people living with pain to be heard, respected, and treated equally. Your support makes the important work of the ACPA possible, so please make a generous gift today. Thank you for bringing hope to those living with pain and those who are newly diagnosed.

We at the American Chronic Pain Association wish you a Wonderful Holiday Season.

Sincerely,

Kathy Sapp, CEO



HOW TO DONATE TO THE ACPA Online:

www.theacpa.org/donate/

By Mail:

American Chronic Pain Association
11936 W. 119th Street, Suite 216
Overland Park, KS 66213



MENTAL HEALTH AND PHYSICAL HEALTH ARE INTERWOVEN

By Kathleen Cady, PsyD

Influence of Philosophy

Its hard to believe the influence of the philosophy of Socrates (470-399 B.C.E), Plato (428-348 B.C.E.), and Aristotle (384-322 B.C.E.) on today's beliefs. Socrates taught by asking questions of those listening to him that motivated them to find answers. Plato recorded Socrates' statements for future generations. The most profound, he believed, was, "What you think, you become." Centuries later, Rene Descartes (1596-1650) wrote *The Meditations on First Philosophy* (1641), where he concluded, "I'm essentially a mind, not a body. I think, therefore I am." Eventually, his treatise divided the world and the individual into mind-body dualism, demolishing the connections of the human organism.

"What would it take for your healthy self to regain dominance and control?"

Reconnecting the Mind and Body

Today, the question is: How to reconnect the mind with the body? Even though many individuals have achieved success, a significant section of western medicine remains polarized. In my attempts to bring together an individual's mind and body, I explain the existence of the Healthy Self and the Unhealthy Self. As I work with those with serious medical problems, I point out that the Unhealthy Self has taken over. I ask the person... "What would it take for your Healthy Self to regain dominance and control?"

Open a Door to Health

Essentially, the question is: What do you want to do besides suffer? The answers I receive are phenomenal. The Healthy Self understands that I am challenging the person to open a door that has been shut too long. And the Healthy Self wants to burst into action, leaving the Unhealthy Self behind. The Healthy Self sometimes wants simply to take a walk or enroll in a yoga class or sit in a hot tub. But once the Healthy Self is unleashed, there is no stopping progress.

Even though medication is necessary for those with a serious medical condition, it should help, not hinder the Healthy Self. Too often, the individual believes that a mental health issue is facilitating the medical condition. If so, that too is part of the Unhealthy Self. The Healthy Self requires action, involvement, feeling worthwhile, and having fun.

As the Healthy Self emerges, the body becomes alive, communicating to the mind when a part of the body requires tender love and care from a massage, physical therapy, or other types of training. The Healthy Self orchestrates the body and mind to work together, pushing the Unhealthy Self into the background. The serious medical problem is no longer in the forefront, but it continues to need medical care and attention and the entire human organism benefits.



STAYING SAFE AND HEALTHY DURING COLD AND FLU SEASON

By the ACPA and the Know Your Dose Campaign

Getting sick is always an unwelcome disruption to our daily lives. Many of us use acetaminophen to treat our pain or fever symptoms, but we may not realize that Acetaminophen is found in more than 600 over-the-counter (OTC) and prescription medicines. With COVID-19 still a part of our lives, and cold and flu season here now, many people will be reaching for medicines that contain acetaminophen to treat their symptoms if they get sick.

Are you ready for cold and flu season?

- 1 Always read and follow the medicine label
- 2 Know if your medicines contain acetaminophen
- 3 Take only one medicine with acetaminophen at a time
- 4 Ask your healthcare provider or pharmacist if you have questions

KnowYourDose.org
Acetaminophen Awareness Coalition

Whether you're treating symptoms of cold, flu, or COVID-19, it's important to make sure you're taking your medicines safely. Taking too much acetaminophen can lead to health problems, including liver damage. And while acetaminophen misuse can happen regardless of age, research suggests that older adults (ages 65 and older) may be at an increased risk of taking too much acetaminophen. American Chronic Pain Association and the Know Your Dose campaign lay out four acetaminophen safe use steps (above) for anyone treating themselves or their loved ones:

To learn more, visit [KnowYourDose.org](https://www.knowyourdose.org) and follow @KnowYourDose on Twitter.

ACPA GROUP FROM SUNNY FLORIDA

By Marian Griffey

Gainesville Florida

I have volunteered with the ACPA as a Group Facilitator for about 8 years. Until COVID changed the world and how we do things, our Group met weekly at the local Senior Center, averaging 15 members per week. We have focused on the "management" part of pain. Addressing physical, mental, emotional, and spiritual pain matters as they relate to all aspects of Life (e.g., cultural, business, family, socio-eco-religious). We have had guest speakers from the community, covering such topics as:

- Emotional pain associated with hearing loss
- Therapeutic benefits of art
- Creating a living will, final wishes, and advanced directives
- The benefits of such "tools" as acupuncture, yoga, meditation, singing, music, tapping, yogic breathing, qi-gong, tai-chi ...

... and having access to the health-care/well-being programs offered at the Senior Center, we have the ability to address just about any type of pain/condition.

The Most Beneficial Group Tool is Education

One of the most beneficial "tools" has been education. Knowing how the brain and body work together has proven most helpful to everyone in the group.

Isolation: A Group Topic

After the COVID shut-down, our focus has been frequently on how to manage the pain of loneliness and isolation, and the disenfranchised grief that comes from the many types of loss that we have endured thus far. Additionally, the overwhelming feeling of total exhaustion associated with world crises and politicians see-sawing agendas and uncertainties regarding vaccines, etc.

Groups can help manage loneliness and isolation!

In order to hold our Group in a cohesive manner, I have maintained connection with members via email, phone, text and in-person. We practice socially-distanced small-group sessions as often as possible. We have met in parking lots, garages, driveways, and public parks. I also created a weekly mass email newsletter as of January 2020.



Thank You Marian for all you do for your group members and our community!

-ACPA Staff-



WE HAVE FIBRO: VIRTUAL FACEBOOK SUPPORT GROUP

By Virlynda and Mike Kutson

We Have Fibro

It all started with my Mom's battle with Fibromyalgia. I had seen my Mom struggling for years. I believe that no one should go through this, at least not alone. I started a Facebook Page and Private Group called WE HAVE FIBRO in June 2020. I wanted my Mom to have a place she could communicate with people who share her struggles. Only a year later, we have 1000+ group members. Our group mission is to help fibromyalgia patients regain control of their symptoms and gain a better quality of life. Our group members experience a sense of community and support by connecting directly with others, while battling fibromyalgia.

Mom's Story

I was diagnosed with fibromyalgia in 2004. I went through so much trying to control the symptoms of my fibromyalgia and ended up addicted to Fentanyl. I was fortunate - I was able to make the serious and hard decision to break my addiction. I went through detox in 2009 and ended up taking a rehab course that used the book by the ACPA Founder Penney Cowan called *Patient or Person*. I am so grateful to the ACPA and Healthcare Professionals that helped in my recovery. It literally saved my life! You gave me a second chance to live a good life.

Our Mission

We've made it our mission to provide our group members with the proper information they need to help themselves. This includes all the ACPA resources and education.

Starting Our Group

When WE HAVE FIBRO first started, I wrote an article titled *Definition of a Fibro Warrior* which has become a popular phrase in our group. We are all Fibro Warriors struggling with the silent battle within our own bodies. Fibro Warriors understand the struggles and the battles caused by fibromyalgia. We are all looking for information and help for our daily life. We all are so blessed to have the information available to us from the ACPA.

How to Join Our Group

If you have fibromyalgia and would like to become a member of our group... the Fibro Warriors family welcomes you with open arms. The link to the WE HAVE FIBRO group is facebook.com/groups/262021578476145/

If you are a person who would like to help us inform, facilitate, or otherwise serve our group, please email us at support@fibro.net We are always looking for expert help.

We would like to deeply thank Scott Farmer and the entire ACPA team for this opportunity to introduce the WE HAVE FIBRO FaceBook group, and for all of the life changing advice that has been so transformational.

Gentle Hugs - Fibro Warriors Strong!

Mike Knutson & Virlynda Knutson

Development of Physical Activity Guidelines

By The Office of Disease Prevention and Health Promotion (ODPHP)

Physical Activity Guidelines From a Chronic Pain Perspective

The U.S. Department of Health and Human Services (HHS) is seeking public input to help inform the Physical Activity Guidelines Midcourse Report on older adults. HHS is requesting input through written comments and nominations of qualified candidates to support the development of the report.



Physical Activity Guidelines Midcourse Report



The Physical Activity Guidelines for Americans provides science-based recommendations on how physical activity can help promote health and reduce the risk of chronic disease. Despite the many benefits of regular physical activity for older adults (fall prevention, reduced risk and progression of chronic disease, etc.), only 13.9 percent of adults older than 65 years meet the recommendations for aerobic and muscle-strengthening activity. Building on the science base from the Physical Activity Guidelines, HHS intends to develop a midcourse report focused on strategies to increase physical activity levels among older adults. Report can be found at [health.gov](https://www.health.gov)

HHS will accept comments via email to PAGReviews@hhs.gov until December 8, 2021.

Myth... No Pain, No Gain

By Terry Gann, BS, CPT, ACE, MPT

Wellness and Personal Training

My journey started with sports and personal fitness goals... eventually leading me to a wonderful career in Fitness. I have run wellness programs along side of personal training for over 20 years. My career has yielded me a very rewarding opportunity to give back to my community which brings much happiness. Health and Wellness is my passion and my lifelong goal.

The Long-Standing Myth

The most common myth in fitness, is the ugly phrase of “No Pain, No Gain”. This myth suggests that if your muscles aren’t experiencing pain, then you must not be working them hard enough. This is so NOT true!!! Working as a Fitness Professional, this myth seems to plague me everyday. One of the largest battles I face, is to explain to my clients that pain is pain. I would rather see my clients move and ease through exercises they can do regularly without pain.

Move Often and Move Well

Moving often and moving well is the best thing I can use to motivate my clients to keep exercising. Clients living with pain tend to shy away from any type of exercise that causes them more pain. So, my recommendation is to lightly move through numerous types of exercise to see which ones treat you with all the benefits and without all the risks. I also recommend to start slowly and practice routines at low level and low impact. Then adjust the intensity once you feel confident and comfortable.

Virtual 5k for the ACPA!

Thank you to the Twin Cities Pain Clinic for organizing a virtual 5K. Through their generous efforts, we were able to raise funds for a great cause... all while becoming motivated to get in 5K shape.

Find a Certified Professional

Using the attention of a Personal Trainer or Physical Therapist will ensure you the confidence that will assist corrective exercise.



Terry Gann

Terry holds a bachelors in exercise science, and a minor in biology. He is a Certified Personal Trainer and CrossFit Trainer. Terry is a Veteran Fitness Specialist and Wellness Coach, along with a Weight Management and Exercise Fitness Specialist

I would like to share a true example of connecting beneficial exercise with a client that has limitations, plus lives in pain. A 50-year-old male client of mine came in 12 years ago to find assistance with his exercise needs. He has TBI (traumatic brain injury) and has some left side paralysis. Exercising without pain and then pushing himself with weight training has kept him surviving longer while enhancing the quality of his life. He doesn’t need to over push his muscles to feel results. His goal is to stay strong and keep his muscles from going away. So, intensity is what will keep him progressing and I adjust that as he goes through each workout. His strength is what keeps him happy and well. I conclude with this. What I think the statement of “No Pain, No Gain” should be changed to is **“Move without Pain and See all the Gains”**.

STUDIES AND RESEARCH

By ACPA STAFF

Talk Nerdy to Me 2021 Program

Talk NERDY to Me is currently seeking patients and family caregivers to participate in the 2021 training. Beginning in early December, participants will meet virtually between December 6-17, 2021, three times a week, for two weeks from 12:00 PM – 1:30 PM Eastern Time, to learn from researchers in the field and each other. More details on the training, including the session schedule, is available online. Participants successfully completing the workshop will receive a stipend of \$1,500 and a Certificate of Completion for participating in the training. More info: www.agingresearch.org

Research Helps Us Find Treatments for Tomorrow!

Person-Centered Integrated Care

The Duke-Margolis Center for Health Policy and Duke Orthopedic Surgery announced the release of two new studies on exemplary integrated pain management programs. These case studies focus on the People's Community Clinic Integrative Pain Management Program in Austin, Texas, and the University of New Mexico Pain Consultation and Treatment Center in Albuquerque, New Mexico. While each program has unique features, the case studies show that both programs share a focus on person-centered integrative pain care with a strong emphasis on integration with primary care and improving access to care in medically underserved communities. <https://painmanagementalliance.org/>

See all research opportunities at www.theacpa.org/clinical-trials

Levels of Satisfaction with the Available Treatments for the Management of Fibromyalgia

You are invited to participate in a research project entitled Perceived Efficacy and Patients' Satisfaction with the Most Common Interventions for the Management of Fibromyalgia Symptoms, A Patient's Survey. The research project is being managed by Dr. Caio Sarmiento from the Department of Physical Therapy at California State University, Fresno. The data extracted from this survey will help to determine the most effective treatments from the patients' perspectives and identify treatments that may need to be reformulated according to patients' perspectives and expectations. This survey is comprised of 53 questions that take approximately 15 minutes to be completed. Your replies will be anonymous, so do not put your name, address or contact information anywhere on the survey. There are no known risks involved in this survey. Participation is entirely voluntary, and there will be no penalty if you choose not to participate. You may choose not to answer any question by simply leaving it blank. Clicking the submit button indicates your consent for the use of the answers you supplied. If you have any questions about the study, you may contact Dr. Caio Sarmiento at phone: (559) 278-2065, email: caio@csufresnostate.edu By completing this survey and clicking submit, you are also confirming that you are 18 years of age or older. Thank you for considering taking this survey.

ARE YOU A WOMAN LIVING WITH CHRONIC PAIN?

By Samara Richmond

Find Meaning Within Chronic Pain Through Story Telling

I was introduced to ACPA through a colleague and have since had the pleasure of connecting with one of ACPA's peer group leaders in the Virginia/DC area. She speaks volumes to the wonderful and necessary work done by ACPA to support and connect those living with chronic pain. As a researcher, mental health practitioner, and an individual living with chronic pain, I was hoping I could possibly connect with your community to support my research. Would it be possible for you to share the following information with your community?

ARE YOU A WOMAN LIVING WITH CHRONIC PAIN?

I am a doctoral candidate at The George Washington University conducting research on how women in early to mid adulthood find meaning within their chronic pain through story telling. To be eligible to participate in this study participants must:



- identify as a woman aged 25-45 years old
- meet diagnostic criteria for chronic pain: pain lasting longer than three to six months beyond normal physiologic healing
- identify your chronic pain beginning no earlier than 13 years old
- experience pain that is not associated with a terminal diagnosis

PLEASE EMAIL SAMARA RICHMOND AT SGELB@GWMAIL.GWU.EDU TO DETERMINE ELIGIBILITY AND PARTICIPATE IN THIS STUDY

THE JAWBRAKER AND BACKBREAKER BOOKS

By Jill McGuire

Pain Strikes Twice

Jill shares her triumph over 2 difficult medical issues that occurred back-to-back. “Jawbreaker” tells of her triumph over an excruciating Jaw/TMJ issue. The sequel to her story, “Backbreaker” shares how she overcame debilitating back pain by going back to the basics. Her books offer hope and inspiration to NEVER GIVE UP and to KEEP SEARCHING until you FIND what you are LOOKING FOR.



ACPA Members

The books are concise and easy to read. Jill shares the information in an efficient and clever way. Jill will be able to offer *Jawbreaker* for free as a kindle e-book December 25th and 26th, as well as January 1st and 2nd.

Jawbreake_r

*TMJ, a Journey of Healing,
and 12 Lessons Learned*



Jill McGuire

Backbreaker

*Back to the Basics
7 Insights on Healing Back Pain*



Jill McGuire

ACPA TRIBUTE: IN MEMORY OF HOLLY HARRIS

By Mark Harris

Hello American Chronic Pain Association,

My wife Holly Harris passed away on March 16th, 2021. She had been in chronic pain and suffered serious depression for the last three years of her life. Holly was waiting on having four different surgeries and five replacement body parts. Both knees and both shoulders needed to be replaced. A few years back, before she could have scheduled one replacement surgery for her right knee, she broke her right femur. She had emergency surgery on the right knee, and it never healed, and it also needed to be replaced. The Orthopedic Surgeon was going to replace the right knee and right femur at the same time. Holly has also suffered from serious depression as well and had been on anti-depression medicine. She had been seeing a Pain Management Doctor, Psychiatrist, and Psychologist at the same time. They were not able to effectively treat her pain and depression.

Please accept this donation on behalf of Holly Harris.

If we can please apply this donation for research, it would be greatly appreciated.

Thank You,

Mark Harris

Dear Mark...

*Our deepest condolences from all of us at the ACPA.
We will proudly pursue research in memory of Holly!
-The ACPA Community-*

OUR CORPORATE PARTNERS AND CONTRIBUTORS

By ACPA Staff

Champion:

THANK YOU!



THANK YOU!

Ambassador:



Educator:



Builder:



THE ACPA MISSION

By Scott Farmer, MBA

Be Well My Friend

To facilitate peer support and education for individuals with chronic pain and their families so that these individuals may live more fully in spite of their pain.

To raise awareness among the health care community, policymakers, and the public at large about issues of living with chronic pain.

Thank You for Reading!

Happy Holidays
and
Happy New Year!

-ACPA Team-



VISIT OUR
WEBSITE!

www.theACPA.org