Fall Migration Brings Change

Seasonal Movement Leads To Relief

Multiple Sclerosis Pain
ACPA Progress
Musical Journey
One of Many Documentary
Achieving Acceptance
Grab That Helping Hand
Colleen-Dunwoody
Giggles and Grit
In Memory

Also...
Osteoarthritis
Research and Resources
Support Groups
ACPA Mobile App is Here
CRPS

September is
Pain Awareness Month!
The Theme of Pain Awareness Month is
ONE OF MANY
Our Mission

The ACPA Chronicle is our voice to help facilitate peer support, education, and hope for individuals living with pain conditions. We strive to raise awareness among the health care community, policymakers, and the public at large about issues of living with physical and emotional pain. Our vision is to motivate those with pain conditions to seek quality care, to optimize healthcare office visits, and to prevent chronic disease. Our goal is to provide those with pain conditions the resources needed to make educated and shared decisions with their healthcare provider. 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.
Fall Migration and Multiple Sclerosis (MS) Pain

By Scott Farmer, MBA

I find fall migrations fascinating. Birds, elk, and many other animals all go from one place to another to find more food and better weather. There are many challenges along the way, but the promise of finding something better becomes a greater motivator than fear.

During Fall in North America, waterfowl, including ducks and geese travel from the Arctic and down to the Gulf of Mexico, and with stops everywhere in between. The snowline and freezing temperatures continue to push waterfowl south as the food supply and roosting waters become scarce.

Like waterfowl, elk also choose fall to migrate from high altitudes above timberline, down through lower altitudes, foothills, and into lower ranges and valleys in search of water and food access.

The waterfowl and elk migration share common obstacles, as these movements provide opportunity for predators and exposure to harsh environments. But again, the promise of finding something better becomes a greater motivator than fear.

Moving From One Place to Another

These migrations are where I found the similarities of navigating chronic pain and mental health. Migration is defined as the action of passing periodically from one region or climate to another. Likewise, as pain, negativity, and stress overshadows my environment, my physical and mental health tend to reach an unbearable level. At this point I must migrate to find something better.

We have all taken a road trip or vacation in which we have traveled down a two-lane road. On the way out, there is a feeling of excitement and anticipation. On the way back, potentially on the same section of road, there is a feeling of enriched sadness (I can’t believe it’s already over). Experiences and memories gained from the road trip added something meaningful to our life. Migration is necessary for us to experience life, so we know when to leave our unpleasant environment, and when to search for a positive/healthy environment.

Inspired from MS and Crohn’s Disease

The importance of migration became more apparent when my friend Mike was at his lowest of lows. Mike was in what seemed to be an impossible battle of managing MS and Crohn’s Disease. His journey became a test of survival... physically and mentally. He was experiencing Chronic Multiple Sclerosis-Induced Neuropathic Pain, Abdominal Pain due to Crohn’s Disease, as well as major depression, migraine, fatigue, and sleep issues.

In the Fall of 2022, Mike was invited on a trip to Montana. When given the choice to remain in his closed environment or venture out... he chose to add the adventure to his life. It was a challenge, as he knew his physical and mental conditions would be an obstacle... but it was worth it’s weight in gold, Mike said.

Mike eventually chose the promise of finding something better for himself. The trip to Montana helped him overcome his fears and face his conditions head-on. The trip gave him inspiration and has given him a new perspective on life. Today, he is leading a support group for MS and Crohn’s Disease so that he can help others succeed.
Navigating a Musical Journey Through Chronic Pain

By Chris Lewis

Living with chronic pain is an intricate challenge that shapes every aspect of life. For me, this challenge has been particularly pronounced in my pursuit of a music career. As I release my latest song, Fire Below, on September 22nd, I reflect on my journey in crafting music while contending with unrelenting pain that has been my companion for decades.

The origin of Fire Below traces back to an agonizing experience at a walk-in clinic that left an indelible mark on my soul. Having endured chronic pain since adolescence, I've seen its insidious progression, its gradual erosion of comfort and mobility. In my younger years, optimism colored my expectations, thinking that a universal remedy existed. Yet, as the years rolled by, that hope faded, replaced by the unwelcome companionship of osteoarthritis, spondylosis, scoliosis, and sarcoidosis. Lots of different doctors, none of whom would commit the time to help me figure it out and it always ended with a referral for pain management, more imaging, and thousands of dollars out of pocket.

A significant shift in my perception occurred a few years ago, catalyzed by an intense experience at an ayahuasca retreat. This visceral encounter transformed my relationship with pain, leading me to accept it and stop trying to fix it. Ayahuasca's revelation was that pain was an integral part of my identity, an inextricable thread woven into my life's tapestry. Embracing this realization, I discovered the power of compartmentalization and mitigation over the futile pursuit of a cure. This mental shift marked a turning point, allowing me to be more proactive in confronting my pain while still maintaining my artistic journey.

I have witnessed a drastic change in the medical landscape. I have been taken off opioids, once wielded to me often, they were now viewed with suspicion and caution, both for legitimate reasons and as a reaction to the opioid epidemic's repercussions. The downside of this necessary course correction is that chronic pain sufferers found themselves cut off from essential tools to manage their pain.

In this void, I slowly added alternative strategies over time to help me cope — removing drama and negativity, a positive mindset is my most valuable tool, yoga, stretching, meditation, kava, hot showers, massage, cannabis, ayahuasca, San Pedro, a good hug, chocolate, playing guitar, candy, gratitude, and above all, singing.

Singing, the very heart of my identity as a singer-songwriter, became my sanctuary. In the act of vocalization, pain receded, creating an oasis of relief. Fire Below crystallizes this profound liberation, its chorus echoing my emotionally intense experience: The fire is burning my feet below, I can feel the flames get higher and higher, the pain is going to rage until my head explodes, is this how I go?

Today, at 54, my life is a delicate dance with pain, a choreography of yoga stretches, alternative medicine, and soulful music. Pain, once a monolithic obstacle, has been demystified. It is no longer the antagonist but a part of my symphony. Through this transformation, I have channeled my pain into the creation of art and music and that is where my salvation lies. My story stands as a reminder that pain does not define us; it refines us. It tempers our spirit, forges our resilience, and nurtures our empathy. To all who bear the weight of chronic pain, I share this song with you, a reminder that amidst the flames of pain, we can still find solace, peace and understanding using the power of music.
The One of Many Documentary

697 Self-Recorded Videos of Mike
Brittany Tells the Story of...

• A Blue-Collar Hard-Working Man that Suddenly is Faced With Chronic Pain
• The Bureaucracy of Pain Management
• Becoming the Caregiver for Mike
• A Single Parent, that is facing intimate questions of meaning and self
• What Happens When Access to Quality Care is Not Found

One of Many (acpanow.com)
JOIN US!
Achieving Acceptance: Letting Go is Not Giving Up

By Randall H. Duckett

I feel humiliated to be seen in my wheelchair. On occasion, my wife will push me through a noisy crowd exiting a Philadelphia Phillies game in a rush. We’ll weave through the crush of people, then come upon someone stopped in our way. *Excuse us,* I’ll practically yell, bringing unwanted attention to myself. The folks around us step aside, but seem to stare and, to me, think, *Look at that. He’s weird.* When something like that happens, I feel the “otherness” that I’ve experienced most of my life. I try to sink into my seat as we make our way to the lot where our Acura SUV is parked. Embarrassed, I jump into the passenger seat as fast as I can, while my wife hefts the 25-pound chair into the back.

I used to be able to walk on my own, albeit with a distinct limp. I used to be able to climb steps, with difficulty. I used to be able to cross streams by stepping on slippery rocks, hike trails in America’s national parks, or stroll cities like Paris.

But beginning more than a decade ago, I couldn’t anymore because of a complex genetic disease called Multiple Epiphyseal Dysplasia (M-E-D), which causes bones and joints to deform and degenerate with age. Among other health effects, it has spread osteoarthritis and chronic pain throughout my body. I lost the ability to walk, except for short distances with my HurryCane, which I use to get around the house. It is disheartening. When I’m out in public in the wheelchair, I imagine myself judged by others. Feelings of being defective fill my mind. My stomach churns with shame.

My feeling about being seen in a wheelchair is just an example of the harshness with which I judge my condition. I may just be projecting. Perhaps people around me don’t give me a second thought. It may be that they aren’t as judgmental as I perceive them to be. It could be that they are more accepting of disability differences than I imagine. Maybe I’m just judging myself.

For me and other chronic pain sufferers, negative attitudes about ourselves are poisonous. They fly in the face of the reality we live in. They reinforce the idea that we are rejects, broken, and strange because we have something “wrong” with us.

I’m working to reject this type of thinking in favor of another: acceptance.

I daily deal with the effects of MED, which occurs in about one of every 20,000 births. To explain my situation, I’ve written in the past, *I lost the genetic lottery* as compared to winners like Tom Brady, Paul Rudd, and Rob Lowe.
Achieving Acceptance: Letting Go is Not Giving Up

By Randall H. Duckett

I now regret that sentiment. It reinforces a mistaken notion that I’ve carried since childhood: to be born with a particular piece of DNA is to be a loser. It ignores that all humans are on a spectrum; one variation is not better or worse than another. Yes, we can give sympathy (not pity) to those in more unfortunate circumstances than ours. People in chronic pain—whether from genetics or causes such as car accidents—suffer more than most, but also less than many. Life is not a contest to decide who has the heaviest or lightest cross to bear. The point is to accept everyone, including yourself, and to provide help for those who need it. This is not so radical an idea (see also Jesus).

Acceptance is a gift to yourself. It means achieving a truce in the battle between your mind and body. It means shedding the *shoulds* in favor of the *is*. It means recognizing reality and living in it.

My toddler granddaughter’s favorite movie is Disney’s Frozen. Any parent of young kids is probably sick to death of “Let It Go,” the biggest hit to come out of it. The song has a specific message in the movie, but I see a greater lesson in it. It’s an idea that applies to what people with chronic pain must do in our lives. We must let go of our old life and accept the new as it really is.

Some call this “radical acceptance.” Jennifer Caspari, Ph.D., a licensed clinical psychologist in Denver, wrote in a post on the Psychology Today website, “Radical acceptance is defined as being willing to fully accept the present moment as it is. Radically accepting chronic pain does not mean you like it or are resigned to it. You can practice tools to improve your quality of life even with pain. Radically accepting chronic pain simply means you completely acknowledge what is happening in the moment without struggling against it.”

Such an attitude can prevent people from abusing pain medications such as opioids. Michiganmedicine.com quotes Anna Kratz, Ph.D., an associate professor in the Department of Physical Medicine and Rehabilitation at the University of Michigan and a lead author of a recent study on severe chronic pain: “What is especially interesting is that the association between being more accepting of pain and using fewer pain medications was above and beyond the effects of how intense and widespread [patients’] pain was. That means people who are more accepting aren’t reaching less for the pills just because their pain is lower.”

By the way, by acceptance I don’t mean giving up hope of feeling better. Hope is healthy. To visualize a better life and make a plan to get there is also a fundamental part of being human. I’ve done that by trying all kinds of treatments, from epidurals to acupuncture to medication and more, seeking relief. Some helped; most failed. As my body deteriorated and my hurt grew worse, my pain tolerance also increased. Now it’s a constant buzz in my consciousness, like ringing of the ears if it caused severe discomfort.
Achieving Acceptance: Letting Go is Not Giving Up

By Randall H. Duckett

I haven’t given up on science or the possibility that something might come along to revolutionize pain care. You never know.

I’ve now achieved, however, a kind of standoff with my pain: It tries to ruin my life and I won’t let it. My days range from bad to less bad; I never know what I’m going to get when I wake up.

Agonizing sensations to almost acceptable ones come from moment to moment. How I feel depends on the meds I’m on as well as my mindset. I’ve come to accept that my pain will always be there, for the rest of my time on earth, regardless of what I or my doctors do. It’s a fundamental part of my life’s story. On HealthCentral.com, Steven Aliano, a former associate editor of Practical Pain Management, adds: “Acceptance does not mean willfully accepting the pain, but rather, it means that you are ready to accept yourself—and your diagnosis—without judgment. You can move toward living in the moment and find peace despite your pain.”

Like Aliano, I see acceptance as the path to my ultimate goal: peace of mind. With a therapist’s guidance, I’m imagining what that might look like. I’d like to be more at ease with my life, as difficult as that is with my disability. I’m working to escape my conditioning about what is and isn’t normal. I’m moving forward toward acceptance in all its forms—acceptance of myself, acceptance of others, true acceptance of what it is to be human.

In the 1960s, Elisabeth Kübler-Ross identified five stages of grief, which others eventually extended to seven. Acceptance and hope make up the final phase. For me, there has been a lot of heartache getting there. I’m working through it with the help of a counselor I’ve come to trust. Hell, I’m even coping by thinking through this essay. I’m slowly learning to be more comfortable with who I am.

It’s comforting that I have companions—my wife, my family, my counselor—to support me. Wish me well on truly achieving acceptance. If you are on a similar journey, I wish you well too.
We Are Proud of What the ACPA Has Accomplished in the Last 3-Months

ACPA CME Conference (350+ Clinicians)

ACPA Chronicle Landmark (26K+ Readership)

2024-29 Impact Plan (Resources)

ACPA PROGRESS

Five New Partnerships (Reach)

ACPA Scientific Posters (AAPM and ASPMN)

ACPA Mobile App (Launch)

ACPA App Downloads

APPLE Download

Android Download
People with pain can play an important role in the development of new therapies by taking part in clinical trials. Find a listing of IRB-approved clinical trials that might be of interest to you at www.ACPANow.com/research/. New trials are posted often, so check back regularly.

Current Research Studies
• Knee Osteoarthritis
• Cannabinoids
• Fibromyalgia
• Rheumatoid Arthritis
• Dermatomyositis
• Anxiety and Pain
• Opioids and Alcohol

FDA Study on the Use of Digital Health Technologies for Opioid Use Disorder
FDA is funding a study to learn about how digital health technologies (e.g., apps, programs, or devices that are used for monitoring, tracking, or providing education about health topics) can be used to help people with opioid use disorder (OUD) manage their condition. As part of this study, a researcher from RTI International (www.rti.org) will conduct a focus group with people who have been diagnosed with OUD and are either currently or have recently been in treatment for OUD. The discussion will take place over Zoom, an online video platform and will last 90-minutes. In appreciation of your time, you will receive a $75 gift card after the discussion.

To see if you qualify, please click the link below to complete a short survey.
https://redcapedc.rti.org/ccs/surveys/?s=NEMDXDWL79MTYW3A
If you have any questions, please contact the study team at 877-212-7218 or FDADigitalHealthTechnologies@rti.org.
Grab That Helping Hand
By Jennifer Weisbrod, MS

Summer 2023 delivered not only warmer weather, longer days, and favorite holidays, but also life challenges greater than my body could handle. My stubborn disposition was not amused by this disagreeable turn of events. Only when I reached a state of complete overwhelm was I ready to accept help. But what did accepting help even mean? I was soon to find out, picking up valuable life lessons along the way.

What Accepting Help Means
Accepting help means acknowledging vulnerabilities and exposing them to others. This requires courage, a valuable personal attribute that may offer encouragement and inspiration to others.

Accepting help means shoudering responsibility for contributing to the best possible outcome. Exercising agency in a stressful situation is a tremendous confidence booster. This becomes an asset in managing even tougher times later.

Accepting help means opening the door for someone as they travel on a journey to become their best self. Graciously accepting another’s support may pave the way for their increased self-esteem or competence in a skill. Perhaps they are seeking a chance to reciprocate a previously received kindness. Or maybe they are exploring ways of expressing compassion. Accepting help is a unique gift given to another at what may be the precise moment they could most benefit from it.

What Accepting Help Does NOT Mean
Accepting help does not mean failure, weakness, lack of resilience, or the inability or unwillingness to face adversity. Is there anyone who has achieved greatness in some endeavor who has not at some point relied on others? For that matter, does any person get through life without occasionally needing an assist?

ATTENTION HEALTHCARE CLINICIANS
Medical Education Coming Soon
ACPAnow.com/2023-cme
Helping Hand
Grab That Helping Hand
By Jennifer Weisbrod, MS

Accepting help does not mean that the same or a similar difficulty, if it occurs in the future, will require as much or perhaps any assistance. Each troublesome episode yields lessons in how to best address subsequent occurrences.

Accepting help does not mean that even more formidable obstacles cannot be overcome without assistance or, at most, with only minimal support. Looking back at earlier storms successfully weathered is heartening as well as instructive. Coping strategies do build on one another and are generally applicable to a wide variety of situations.

In retrospect, accepting help to navigate the “speed bumps” suddenly appearing on my road was simply the right decision to deal with my own “perfect storm.” Each issue eventually found its own path toward resolution (some rather creative), and slowly the “speed bumps” were less disruptive to the drive of daily living.

The lessons I’ve shared here were not easily learned but have certainly been worth the effort. They are not unique to me, but are available to all of us, anytime and anywhere. I present them in gratitude for the help I was offered … and accepted.

Accepting help does not mean that one’s self-image should change. The self-reliant, competent, and self-assured individual is still that same person, even if unexpected, and especially unwelcome, events provoke uncharacteristic behavior (I was reminded recently that behaving normally in a “perfect storm” is truly cause for concern!).

Accepting help does not mean being perceived negatively. Most people will empathize, having been in the same spot themselves. And many will recognize the wisdom of grabbing a helping hand, and even admire the courage it takes to make that choice.
A Tribute and Dedication to Colleen Dunwoody
By ACPA Staff with Information from Darlene J. Lovasik, MN, RN

The ACPA would like to recognize Colleen Dunwoody for her devoted work in pain management. The people that knew her the best would describe her as an accomplished woman, friend, and extraordinary nurse. Colleen's nursing career began at Presbyterian-University Hospital, where she continued for 45 years. Beginning as a staff nurse, she worked her way up to Head Nurse and Clinical Instructor and became an Advanced Practice Nurse in Pain Management.

Pain Management was a developing field at the time and continued to be her life-long passion. Although she was a member of several professional organizations, she was invested in the American Society for Pain Management Nursing (ASPMN) where she served as President and Past-President. She served the community through the ACPA, including as a President and Past-President, and as a volunteer for Forbes Hospice and the Ethics Committee at Forbes Hospital.

Her numerous publications encompassed journal articles and book chapters on orthopedic nursing and pain management. She was an outstanding presenter and commanded the attention of the participants at scores of classes and conferences regionally, nationally, and internationally.

Her professional awards included the Outstanding Alumna Award (Presbyterian Hospital School of Nursing Alumnae Association), Service Excellence Achievement Award (University of Pittsburgh Medical Center), Clinical Practice Award (American Society of Pain Management Nurses), Cameo of Caring Advanced Practice (University of Pittsburgh School of Nursing), Legacy of Nursing Award (UPMC), and the Distinguished Service Award (ASPMN).

Colleen had a special relationship with her mother Bissie that was more loving when Colleen moved into a bigger apartment to include her Mom. Colleen took care of Bissie for much of her last 5 years until it was time for a move to a skilled nursing facility. She visited Bissie every day.

Colleen was a force to be reckoned with. She was fiercely proud of her Irish heritage and enjoyed all the festivities around St. Patrick's Day. She was stern, she was polite. She was a dictatorial but kind editor, an ultimate professional with standards higher than most. Her integrity was unquestionable. She always supported nurses and nursing, and the education and mentoring of our younger nurses. She enjoyed traveling, shopping, dining out, and white wine. She loved beautiful clothes, expensive shoes and purses, coordinated jewelry and accessories, and always was the epitome of a magnificently dressed woman.

In remembrance of Colleen Dunwoody and her generous bequest and support of the ACPA, the ACPA will be dedicating the NEW ACPA Mobile Application in Colleen Dunwoody’s name.
Giggles and Grit
By Devika Desai

In the summer before sophomore year of high school, I was in the passenger seat of a moving truck my dad was driving. Unfortunately, the truck was too tall to pass a bridge we encountered on the way, and it crashed. Within moments, I was thrown from my seat to the front of the truck -- just missing the dashboard due to the seat belt -- and flung back to the seat again. This resulted in a muscle spasm that caused radiating pain in my upper body. Overnight, my life changed. Getting out of bed every day was a struggle. I could no longer open water bottles, turn doorknobs, carry anything in my arms, or move my neck much. I couldn’t write or type. The slightest things aggravated my pain.

Doctors felt it would go away soon, but days turned into weeks. A few months later, school started, and my nightmare only got worse. It was impossible for me to go to school and sit in my seat with the pain radiating through my body. What made things worse was that this condition was invisible, so some people found it hard to believe it existed.

I have been living with pain for two years now, and I have learned to manage it better. Some days are harder than others, but the pain has decreased a bit. I am slowly continuing to rebuild my life.

I’m able to think more clearly now. Through my experience, I realized that there needs to be more awareness about chronic pain, especially on the struggles faced by the students experiencing it.

To do my part, I started a non-governmental organization (NGO) called Giggles and Grit to connect students with chronic pain and show them that overcoming, or at least managing pain is indeed possible.

By connecting students with chronic pain, Giggles and Grit aims to help them learn from each other’s struggles and inspire one another. Giggles and Grit will help connect students who have chronic pain, raise awareness about this condition and the issues faced by students experiencing it, and give these students the support they need to succeed in school and return to normal life. Knowing people who have faced issues similar to what I was going through would have helped me when everything seemed hopeless a few months ago, and I hope this initiative will help others experiencing chronic pain in the future.

Connecting kids w/ chronic pain (gigglesandgrit.org)
MOVE: A New PDPN Mnemonic
By Scott Farmer, MBA

During National Peripheral Neuropathy Awareness Week, and to officially take peripheral neuropathy awareness to the next level, we are proud to announce the mnemonic (memory aid), M.O.V.E., that was created by people living with painful diabetic peripheral neuropathy – for people living with diabetic peripheral neuropathy.

Monitor changes in sensations
Ongoing pain, tingling or burning
Voice symptoms to your HCP
Explore treatments for neuropathy

A group of community members embarked on a mission to crowdsource a memory aid to help people remember four important things to share with their healthcare provider and start a conversation about how pain is impacting day-to-day life and activities.

Remember: Although various treatment options exist for diabetic neuropathy, approximately 50% of diabetic peripheral neuropathies may be asymptomatic. Delaying diagnosis and interventions can increase risk for injuries, ulcers and in severe cases can lead to amputation.

Make a M.O.V.E. to manage your diabetic nerve pain of the feet!

Do You Have PDPN?
Access ACPA Painful Diabetic Peripheral Neuropathy Resources
CLICK HERE
In Memory

In Memory and Special Thanks

Alan Zanetell
In loving memory of Alan Zanetell. He was a dedicated facilitator of the ACPA Denver Support Group and reached the lives of many people with pain.

Don Bowman
In loving memory of Uncle Don Bowman... from S Ferris.

A Special Thanks To...

- Mark Harris... (Memorial Member in the amount of $5,000)
- Larry Kellett... (2 Lifetime Memberships in the amount of $2,000)
- Peter Labadie... (Lifetime Membership in the amount of $1,000)
- Eric Sheridan... (Premium Member in the amount of $515.38)
- Laura Brencher... (Premium Member in the amount of $300.00)
- Roger and Kathy Cady... (Premium Member in the amount of $200.00)
- William Schmidt... (Premium Member in the amount of $200.00)
- Ricardo Martins... (Premium Member in the Amount of $131.00)
- Robert Goodman... to Matt (Premium Member in the amount of $103.48)
- Gary Klien... (Premium Member in the amount of $100.00)
- Mary Ann Fastook... (Premium Member in the amount of $100.00)
- John Loeser... (Premium Member in the amount of $100.00)
- Mistie Anderson, Lyn Spens, Adele Garland, and Evan Shin
- All support group facilitators, board members, advisory board members, ACPA staff, and the ACPA conference faculty!
NEW! cMigraine

cMigraine is a coloring book that enables a parent to explain and learn about Migraine, along with a child! As you color, you will learn important migraine management techniques. With twenty pages to color, along with your child or grandchild, you will learn about migraine and coping techniques like learning the causes and triggers of migraine. The interactive coloring book will allow you and your child to learn every aspect of migraine management, including ways your child can help while you have a migraine. Likewise, if your child has migraine, how you can help. Together, you will learn how to track your migraines, prepare for healthcare visits, and communicate with a medical clinician.

Proceeds go to the ACPA!

Order Here: [www.acpanow.com/cb](http://www.acpanow.com/cb)

For anyone in our community interested in participating in research, a new clinical trial for Dermatomyositis is enrolling across the US. The investigational treatment is an oral pill, and researchers are inviting patients between ages 18-75 who are currently on stable treatment to explore their eligibility:

https://lpcu.re/VALORStudy

Participant Qualifications:
- Age 18 to 75 years old
- No history of cancer in the past 5 years
- No current severe liver disease
- No thrombotic events in the past year
- On a stable dermatomyositis treatment for the last 3 months

It's not always easy to know where to start with exploring clinical trial options, and the study team aims to make the process as comfortable as possible by guiding you each step of the way. If you think you might be interested, fill out a short questionnaire here:

https://lpcu.re/VALORStudy

You’ll be connected with someone on the team to determine whether it might be a good fit for you.

Note: Any personal information you fill out is secure and confidential.

Looking for Physician, Nurse Practitioner, and/or Physician Assistant for PT to 4 days/week (Mon-Thurs), of small private practice. Entails Pharmacological Pain Management of long-term Chronic Pain patients who have failed other treatments and procedures. Will need DEA Certification to prescribe controlled substances and be able to order and interpret tests to monitor patients. Will train! Call Megan 518-223-0812

Chronic Pain Management:
41 S Western Ave, Glens Falls NY 12814
Osteoarthritis Research Program

This Research Program aims to solve treatment challenges in osteoarthritis by developing new ways to help the human body regenerate its own joints.

The program, called Novel Innovations for Tissue Regeneration in Osteoarthritis (NITRO), is the first of several programs.

OA is a common and often very painful condition where bones and cartilage break down. The condition currently affects more than 32 million Americans, with numbers predicted to rise as the population ages. There is currently no therapy available to reverse the damage caused by the disease.

To get a better solution to everyone with OA, NITRO will explore technologies focused in three areas - injectable bone regeneration, injectable cartilage regeneration, and replacement joints built from human cells.

Through a Broad Agency Announcement (BAA), ARPA-H’s NITRO program will solicit proposals to develop and leverage innovative forms of regenerative medicine to create minimally invasive therapeutics that fully regenerate damaged joints. A Proposers' Day for interested research teams, or performers, is scheduled for June 15, 2023. For more on NITRO, visit the ARPA-H website at https://arpa-h.gov/engage/programs/nitro/
Remembering James M. Gray
By The Family of James M Gray

Dear ACPA,

We would like to recognize your wonderful organization in honor of James M Gray. James passed on December 12, 2022, and suffered many years with chronic pain. His family and friends are sending this memorial in his honor.

The Family of James M Gray
Omaha, Nebraska

A Netflix Documentary:
Calling Attention to Complex Regional Pain Syndrome (CRPS)

Click here: http://rsdfoundation.org/en/netflix.htm
Holly Harris

The Holly Harris Memorial Golf Outing was a huge success. On Friday, July 28th, 2023, the event was held at Sycamore Hills, Macomb MI. This is in honor of Holly Harris (12/24/64 to 03/16/21). Holly passed away of heart failure and had chronic pain. She needed two knee replacements, two shoulder replacements and her right femur needed to be replaced as well. Proceeds from the outing have been donated to the American Chronic Pain Association (www.theacpa.org).

We thank you so much Mark Harris!

Angel Flight NE’s free air transportation services.

With the need for support increasing from individuals with rare diseases, the ACPA has added Angel Flight NE to our resources. They provide FREE air and ground transportation to those who qualify. Click Here
THE TEN STEPS FROM PATIENT TO PERSON
By Scott Farmer, MBA

Endless Group Discussion
The question I here most often from other facilitators is *what do we discuss within the group?* My answer is the *Ten Steps From Patient to Person*. It provides endless topics to discuss. By following, discussing, and analyzing each step over several meetings, the steps act as goals for group members. Written by Penney Cowan (Founder of the ACPA), simply ask the questions: *what does this step mean to you?* Have you accomplished this step? How?

Step One: Accept the Pain
Learn all you can about your physical condition. Understand that there may be no current cure and accept that you will need to deal with the fact of pain in your life.

Facilitator:
I explain what this step means to me, and if I have accomplished this step. If I have, I explain how. If I am still trying to accomplish this step, I explain how I plan to accomplish it. Then I open these questions for group discussion...

Repeat these questions for all ten steps

Questions:
- *What does this step mean to you?*
- *Have you accomplished this step?*
- *How did you accomplish this step?*

Step Two: Get Involved
Take an active role in your own recovery. Follow your doctor’s advice and ask what you can do to move from a passive role into one of partnership in your health care.

Questions:
- *What does this step mean to you?*
- *Have you accomplished this step?*
- *How did you accomplish this step?*

Step Three: Learn to Set Priorities
Look beyond your pain to the things that are important in your life. List the things that you would like to do. Setting priorities can help you find a starting point to lead you back into a more active life.

Step Four: Set Realistic Goals
We all walk before we run. Set goals that are within your power to accomplish or break a larger goal down into manageable steps. And take time to enjoy your successes.

Take the ACPA 10 Step Challenge
Donate $2.00 for every step you practiced this year.

DONATE HERE
We encourage you to submit your words of encouragement along with your donation, and how the steps helped you. If selected, your story will be shared with others in the next Chronicle to help us motivate more people to practice the steps. Three stories will win a $100 gift certificate.
Step Five: Know Your Basic Rights
We all have basic rights. Among these are the right to be treated with respect, to say no without guilt, to do less than humanly possible, to make mistakes, and to not need to justify your decision—with words of pain.

Step Six: Recognize Your Emotion
Our bodies and minds are one. Emotions affect physical well-being. By acknowledging and dealing with your feelings, you can reduce stress and decrease the pain you feel.

Step Seven: Learn to Relax
Pain increases in times of stress. Relaxation exercises are one way of reclaiming control of your body. Deep breathing, visualization, and other relaxation techniques can help you to better manage the pain you live with.

Step Eight: Exercise
Most people with chronic pain fear exercise. However, unused muscles feel more pain than tones, flexible ones. With your doctor, identify a modest exercise program that you can do safely. As you build strength, your pain will decrease. You will feel better about yourself.

Step Nine: See the Total Picture
As you learn to set priorities, reach goals, assert your basic rights, deal with your feelings, relax, and regain control of your body, you will see that pain does not need to be the center of your life. You can choose to focus on your abilities, not your disabilities. You will grow stronger.

Step Ten: Reach Out
It is estimated that one in three suffers with chronic pain. Once you have begun to find ways to manage your chronic pain problem, reach out and share what you know. Living with chronic pain is an ongoing learning experience. We all support and learn from each other.

*The Ten Steps From Patient to Person* are a copyright of the © American Chronic Pain Association 1985-2023.
CEO Message

Dear ACPA Members,

Since 1980, 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, as we offer the 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.

The ACPA understands the daily battles people in pain fight. Therefore, 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 more resources are needed to provide empowerment and shared decision-making in pain management.

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 consider support today.

Sincerely,

Kathy Sapp, CEO
American Chronic Pain Association

HOW TO SUPPORT THE ACPA

- Recognize someone to be featured in the Chronicle ($50.00) Click Here
- Purchase a Premium Membership ($100.00) Click Here
- Purchase a Contributor Membership ($500) Click here
- Purchase a Lifetime Membership ($1,000) Click here
- Purchase a Legacy Membership ($5,000) Click here
- Advertise in the Chronicle. Email us for pricing: acpa@theacpa.org
- Corporate Membership. Email us for pricing: acpa@theacpa.org
- Consider the ACPA in your Estate Planning: acpa@theacpa.org

IMPORTANT NOTE: STANDARD MEMBERSHIP IS FREE. EVERYONE GETS ACCESS TO ALL RESOURCES!
The American Chronic Pain Association (ACPA) is a non-profit, 501(c) (3) organization. Our Mission is to facilitate peer support, education, and hope for individuals living with pain conditions. We strive to raise awareness among the health care community, policymakers, and the public at large about issues of living with physical and emotional pain. Our vision is to motivate those with pain conditions to seek quality care, to optimize healthcare office visits, and to prevent chronic disease. Our goal is to provide those with pain conditions the resources needed to make educated and shared decisions with their healthcare provider.

Have a Wonderful Fall
-ACPA Team-

Thank You for Reading!