I was lucky to have the good fortune to be in the first group of patients at the Cleveland Clinic Pain Program under the direction of Dr. Edward Covington in 1979.

I must admit that I agreed to take part in this program to fail. You see, I had been looking for a cure for my pain for six years and was just worn out and hopeless. But my husband seemed to think that this was the chance we had been looking for ... a chance to feel hopeful again. So, I agreed to take part in the program to prove to him that I was hopeless. I went there to fail.

As it turned out I had not given up completely. I still needed to get my life back, be a person who could function, be dependable, and not controlled by the fear of pain. So, after a few very long weeks at the pain program, I emerged as a person once more. It was by far the most difficult experience of my life, and as I tell anyone who enters a pain program, it will get worse before it gets better! How true!

So why, after I had made the transformation from patient back to person did I start the American Chronic Pain Association? Because I now knew that it was possible to live with pain and that I was not the only person in the world who lived with pain. I also knew that I would be the one responsible for maintaining my wellness.

Even 36 years after leaving the pain program, I still remember the control pain had over me and all the emotions that go with a life of pain. But, with that new understanding, I wanted to make sure that others would also know that there was hope, that you could live with pain. So, the American Chronic Pain Association was born in 1980.

CONTINUED ON PAGE 8...
Chronic pain can be a traumatic burden for those carry it on their journey through life. But pain conditions that were once met with silence and ineffective treatments are now received by a patient-centered, more well-informed medical community. This transformation is welcomed by individuals such as these two women, and has helped them lead higher-quality lives.

Offer it Up
“Pain is your pathway to God.”
An Irish Catholic girl growing up in the 1950s, Mary Eigel heard this sentiment frequently. Born with bilateral hip dysplasia (which she wasn’t aware of until she was 25), she knew not to complain about the pain. If she did complain—or asked why this was happening—her question was either met with silence, an “I don’t know,” or a reminder to “offer it up.”

“Doctors at the time likely told my parents that my condition would likely cause me to be a cripple, and that they should make sure I did not use my legs aggressively,” Eigel said. “Being that my parents were Irish, a nationality that believed pain was the result of something bad an ancestor had done (and was now coming back to haunt the next generation), they did their best to encourage my participation in things such as the arts that redirected my mental energy into something positive.”

So Eigel immersed herself in creativity—painting, sewing, and crafts—activities she could do sitting down. Instead of running, jumping, or walking outside with her friends, she rode her bike. When pain hit, she took an 80 mg. St. Joseph’s aspirin, the only form of pain medication that was in the house.

Pain Relief: Then and Now
A lack of pain relievers to treat her discomfort wasn’t unusual in those days. While conducting research for her book Silent Courage (available at IndieBound, Amazon, and Barnes & Noble), Eigel learned that babies and children undergoing surgery in the 1970s were not given any pain medications. The doctors believed that children’s nervous systems were not developed enough to feel pain.

By the time Eigel was 14, she was earning her own money from babysitting. She went out and bought over-the-counter pain medications that she paired with her own mental efforts to counteract the physical hurt. Stronger meds came into the picture when she was in her late 20s (Naprosyn, which is now known as naproxen). However, Eigel said the side effects fogged her brain. She would forget to pick up the kids at school and would frequently forget their names.

So she began self-managing the medication—taking it only at night before bed and enduring the pain throughout the day. Then a car accident in 2003 and subsequent injuries prompted her doctor to prescribe another medication, which led to liver toxicity and illness.

With her doctor’s blessing, she tried alternative treatments—acupuncture, Chinese herbs, reiki, healing touch, preservative- and additive-free diets, meditation, and writing. Eigel said this new approach was the turning point for her, in that she became more responsible for her health. The realization hit, she said, that her spirit, body, and mind all mattered. And if she wasn’t taking care of all of them, then she wasn’t effectively managing her pain.

More Support, Engagement, and Social Awareness
Thankfully, she and others living with chronic pain have much more support from the medical community today. Eigel said that in her experience, younger doctors have been more open to medicinal and non-medicinal pain approaches. Insurance companies are slowly beginning to cover medically prescribed holistic treatments. And primary care physicians are more likely to refer patients to an integrative medicine facility, pain center, or specialist for more focused and individualized treatment.

But the biggest change, Eigel said, is that people are taking ownership.

“The Internet has given individuals a way to take control of their conditions. We can read about things, see things, and then take that information back to our doctors. We can participate in ACPA support groups, talk with friends or other acquaintances that may have chronic pain, or connect with people on Facebook or other social media support groups.
More information and more tools are being made readily available. Depending on your doctor for all the right information is a thing of the past,” Eigel said.

On a societal level, Eigel said the psychology surrounding all pain is evolving. People are more accepting of those who may need a little more help, even if the condition may not be obvious. Some parents even create organizations to address the special needs of a child with pain. Eigel’s own father, who was ahead of his time, made her custom furniture to accommodate the casts she wore after surgery to reposition her femurs at 1 ½ years old.

Communication is Key
Eigel says the biggest transformation for her has been learning to communicate effectively, whether through writing or speaking. She shares this with others on similar paths, explaining that communicating needs in an appropriate way isn’t viewed as complaining; it’s asking for help in a positive way. Sometimes, a change in attitude or viewpoint is all that’s needed.

“Pain is what I’ve been given, but suffering is what I can control,” Eigel said. “And it’s up to me to adapt. In writing my book, I found that when we can step back and separate what has happened to us from who we want to be, then we are clearing some pathways for better things to come.”

Silence is Not Golden
When she was growing up, Rita-Marie Geary distinctly remembers the silence that surrounded her pain.

Starting at the age of 3, she experienced near-constant earaches. Her mother, although somewhat supportive in her actions, chose not to speak much about it. By her preteens, as the ear pain began to fade, Geary’s abdominal pain started. Her mother took her to a family doctor, who after five years of labs and testing, directed them to a gynecologist. For whatever reason, said Geary, her mother and the doctor remained quiet on the diagnosis. And Geary was simply prescribed frequent doses of ibuprofen and Tylenol with codeine—common pain relievers for that time.

For an entire decade, she followed this doctor’s prescription, which her body became dependent on, even during times when her pain was manageable. Geary incorporated her own self-treatment methods—self-hypnosis, distractions, hobbies, prayer, and warm compresses—to power through the rough times. She also realized that she needed to become her own advocate, learn her true diagnosis and figure out a way to take charge of something that had plagued her for most of her life. “I was in my 30s before I learned I had endometriosis—something my mom knew very early on, but never shared with me,” Geary said. “Perhaps it was because she didn’t really know what to do. There were also several times that I didn’t have insurance, so treatment would have been costly. Patients were not aware of available treatment plans. So, instead, doctors merely wrote a prescription.”

Evolving Knowledge and Treatments
Thankfully, as the years have passed, physician understanding and approaches have evolved. Thanks to the Internet and support groups, people are more well-informed than ever. Doctors are helping people better describe their various types of pain—as a gynecologist had done for Geary. Geary, like Mary Eigel, finds that her physicians are more open-minded about emerging pain management techniques because they learn from people with pain. “If a provider hasn’t had many patients with chronic pain, then a lot of times, they don’t have the instinct, or may lack the experience and knowledge to diagnose and treat accurately. And that’s where people with pain come in—and the need for us to be vocal about our conditions, what we are experiencing feeling, or how we are reacting or not reacting.
We live with it; we know it inside out. The shift takes place when we find a doctor who is willing to treat more than just the pain.” And, she continued, medical care is even more effective when doctors seek out the “root” cause of the symptoms.

Geary is fortunate in that she has doctors who listen—and who are open about other ways of treating chronic pain. Her primary doctor supports her use of laser therapy and chiropractic care. Her podiatrist recently prescribed a compound cream, reiki, and acupuncture.

She has explored water therapy, TENS, biologics, mindfulness, music and art therapies, massage therapy, and more. Each one has offered relief in its own unique way. Unfortunately, many insurance companies don’t cover them, which makes long-term use largely unaffordable. This prevents people with pain from therapies that could help them find a better quality of life.

Taking Charge of Change
Outside of the medical community, a societal shift in perception is slowly under way. Geary believes the media and Internet have helped in terms of education. There are also more health fairs and support groups. It’s a kinder, more open-minded environment than the one she grew up in, when she was viewed as a “frail and sickly child,” one that was to be avoided so that the “affliction” wasn’t passed along.

But there is still progress to be made. Many people in Geary’s life still don’t understand why she can do something one day, but then not be able to do it another day. Folks still have the mindset that “lots of people have pain. Get over it.” But mostly, she’s had a strong support system.

And attitude is half the battle, Geary said.

“I can’t change the fact that I have chronic pain, but I have changed my attitude about how to live my best life with it.”
Pharmacogenetics for People with Pain

by Chris Duncan

Why does pharmacogenetics—also known as “pharmacogenomics”—matter to people with chronic pain?

It can matter a great deal for those using certain types of pain medication. Pharmacogenetics can be a useful tool in improving pain management treatment plans.

The study of how genetics affects the body’s ability to process medicine is called pharmacogenomics or pharmacogenetics.

The way individuals metabolize (process and absorb) medicine is often influenced by their genes. Genetics vary from one individual to another, as we are all unique. Our bodies all react differently to medications and use medicine in different ways.

Pharmacogenetics research is leading to a new kind of “personalized medicine.” Ultimately, improved health outcomes may come not through medication alone, but through the use of specific medication selected for an individual person based on their unique genetic fingerprint.

This applies to medications used to treat pain, as well as other conditions including cardiovascular disease, high cholesterol, and depression. These medications all are metabolized in the body in a similar way. This allows for a simple pharmacogenetic test that reveals valuable information that can then be used to make therapy selection more effective.

Affordable Personal Testing

Many medical laboratories can analyze saliva samples for pharmacogenetic testing. One company, Harmonyx Diagnostics, is currently the only provider that offers the testing service for under $100, instead of more typical fees of 10 times that amount. With this pricing model, individuals do not have to gain approval of their health insurance companies to obtain the testing.

The pharmacogenetic swab test provides individualized details about which medication may be a good genetic match for the person, along with guidance for dosing and potential side-effect risk. The test examines the effects of eight genes on a patient’s metabolism and efficacy of more than 20 pain medications.

The Harmonyx® Test for Pain can be accessed through a Harmonyx partner pharmacy. Detailed results are returned to the pharmacist and treating physician in as little as 24 hours, once the laboratory receives the test. Learn more at www.harmonyxdiagnostics.com.

This is not experimental science or something that is years away. These tests, and the knowledge to make treatment decisions based on the results, are ready today and very accessible.

Pharmacogenetic Testing

The way it works is very quick, simple, and painless. Your healthcare professional takes a sample of saliva from your mouth with a swab. He or she sends the saliva sample to a lab that specializes in pharmacogenetic testing. Within a few days, your healthcare provider receives a customized report that explains your specific metabolic characteristics.

With this information, your healthcare professional can assess which medications you will respond to best and those to which you may have an adverse reaction. For example, if Mary is taking oxycodone for her pain, but has needed increasingly higher doses to achieve the pain relief she needs, a pharmacogenetic test may help. It could reveal that Mary is a very rapid metabolizer of oxycodone, meaning her body processes it very quickly. She requires large doses to “get through” and obtain the needed effect.

With the same test results, Mary’s doctor can also see what other medications Mary may metabolize more normally. She could take these in lower doses to achieve acceptable pain relief. As a result of having this test done, Mary’s doctor has a better understanding of her unique genetic makeup and can prescribe a different medication that is just right for her.

Sharing Results for Personalized Medicine

This personalized medicine is available today. People just need to have this test done once, and then they can use the same results for any other conditions for the rest of their lives. They will have valuable information that other healthcare providers can use to make the best possible treatment recommendations.

As always, medication alone is not the ultimate answer to effective pain management. But with pharmacogenetic testing, pain management using medication can be more customized and, potentially, more effective for each individual person.

Some health insurance may not yet pay for pharmacogenetic testing. It depends on the drug, the insurance plan, the person’s condition, and the physician’s experience using a lab and getting reimbursement.

More information is available from the Personalized Medicine Coalition at www.personalizedmedicinecoalition.org/About_Us/About_PMC.

Chris Duncan serves on the Board of Directors of the ACPA. He is a business development consultant with BelHealth Investment Partners, working in specialty pharmacy, pharmacogenetics, toxicology, and data analytics.
Thirty-Five Years of Helping People with Pain

by Alison J. Conte, Editor, The Chronicle

As the American Chronic Pain Association (ACPA) celebrates its 35th anniversary, it continues to follow its initial vision: to help people with pain and their families live full lives through education and peer support and raising awareness about pain issues for the healthcare community, policy makers, and the public.

Penney Cowan, founder and executive director, started the ACPA with seven peer support groups. Now it has 225 support groups, along with manuals for facilitators, workbooks for members, and a wide array of pain management tools on the website.

Chuck Lidz, Ph.D., was one of ACPA’s first board members in 1982. Today, he is Professor Emeritus of Psychiatry at the University of Massachusetts Medical School. Lidz recalls Penney Cowan’s first steps as ACPA founder and executive director.

“Penney started out as a housewife from Pittsburgh, with limited contacts in the world, but she had a vision of what this could be. If someone has a vision of how to make things better, and they are persuasive as Penney is, they can usually get people to help,” said Lidz.

Edward Covington, M.D., director of the Neurological Center for Pain in the Neurological Institute at the Cleveland Clinic Foundation, was one of those people who joined Cowan in her vision. He promoted the ACPA to people with pain and medical pain specialists, and also edited the book she wrote, Patient to Person.

Nicole Kelly is a writer and a communications strategy consultant who has served on the board for more than 30 years, with several terms as president. She has helped ACPA use the media, websites, social media, and newsletters to reach more people.

Committed and Perseverant
Penney’s belief in the need for the ACPA has never faltered. In 2005, her perseverance was recognized with the American Pain Society’s (APS) John and Emma Bonica Award for Service, for distinguished contributions to the field of pain. In 2013, she was again recognized with APS’s Elizabeth Narcissian Award for Outstanding Educational Achievements in the Field of Pain.

“She is unique in that she has insight into what this looks like from the other side,” said Lidz. “She can be the voice of the person with pain, and she has always kept that person as the focus of ACPA. The medical profession needs to hear what real people think about their pain treatments. They need to remember that we are people first and patients afterwards.”

“The ACPA’s ability to be independent, yet secure funding for its needs, speaks to its integrity,” said Joe Baim, Ph.D., another early board member. Baim, a management consultant, was on the board for 20 years, also serving as president.

“The ACPA is a significant and respected advocate for people with pain. The fact that we are respected by professional organizations in the pain field is compelling evidence of our credibility,” said Baim. “The ACPA has extraordinary resources, not only for people with pain, but also for physicians and other caregivers.”

Ongoing Awareness and Education
The ACPA has had many notable accomplishments over the past 35 years. Many of these efforts are still ongoing:

* Expanding manuals, workbooks, relaxation tools, newsletters, coping calendar, and other resources into new technologies and new languages.
* Updating the Resource Guide to Chronic Pain Medications & Treatments annually. This guide to mainstream, complementary, and alternative treatments for pain has been edited by Dr. Steven Feinberg for the last 15 years. (thecpa.org/Consumer-Guide).
* Continuing to celebrate September as Pain Awareness Month, which was established by the ACPA as part of its Partners for Understanding Pain campaign, and distributing tool kits for nurses, pharmacists, and older adults.
* Supporting young people with pain through Growing Pains (growingpains.org).
* Developing the It Takes Nerve educational program about neuropathic pain.

CONTINUED ON PAGE 7 . . .
Using media outreach, social media tools, a web page, database, and a billboard in Times Square to reach 76 million individuals.

Developing 15 communications tools such as the quality of life and activity tracker, interactive pain logs for fibromyalgia, back pain, head pain, and nerve pain, and an opioid-induced constipation conversation guide. All are available at theacpa.org.

Sharing 23 educational videos on topics ranging from implantable medical devices, opioid safety, and NSAID use, to the effect of pain on families.

Bringing ACPA’s message to new audiences such as farmers, ranchers, and veterans (vetsinpain.org).

Participating in surveys and research projects related to pain-related outcomes, fibromyalgia perceptions, emergency room care, diabetic nerve pain, arthritis, and treatment disparities.

Serving as a reviewer for the Institute of Medicine report: Relieving Pain in America.

Being part of the Pain Matters documentary on the Discovery Channel.

Encouraging creative arts in pain management through the Art of Pain Management.

Reducing pain-related disparities among racial and ethnic minorities through partnerships, education, and a diverse board membership.

Baim said that people with pain face challenging times, further noting that it is still difficult to get reimbursement for pain treatment, and that the number of integrated, multi-discipline pain clinics has decreased in recent years. Physicians, too, face challenges. Because of what we have come to refer to as the “commercialization” of medicine, it is sometime difficult for them to justify the time to address issues related to chronic pain.

All of this will provide new challenges for the ACPA. It is committed to staying true to its mission as the needs of people with pain change. It will ensure that medical professionals, legislators, and academics continue to hear the voice of people with pain.

Over the last 10 years, when I have interviewed each new ACPA board member, I have asked them what they considered ACPA’s greatest strength or toughest challenge. Here is the ACPA through the eyes of those passionate, committed members of the board of directors and the advisory board, past and present.

—ALISON CONTE, EDITOR

“The influence of ACPA members on the federal legislation related to healthcare access is enormously important.” —KNOX H. TODD, MD, MPH, 2005

“As the landscape of this important issue changes, the ACPA will be there as a beacon of light for those who are searching for answers about how to deal with pain.” —TOMIO INOMATA, MBA, 2005

“If we look outside the health profession we can find new ways of thinking about an issue and expand our existing resources.” —BRIDGET CALHOUN, DR.P.H., P.A.-C, 2005

“ACPA is a practical, consumer-drive empowerment organization. Our view is to have a good life with chronic pain, rather than give up your life in order to avoid pain.” —JENNIFER CHRISTIAN, MD, MPH, 2006

“The ACPA is offering people with chronic pain a safety net that other single-disease organizations can’t always provide.” —CLAIRE PATTERSON, 2006

“ACPA’s work is morally and ethically important. The political and educational all blend together. Most people need to self-manage their pain. The locus of control must switch to the individual.” —STEVEN FEINBERG, MD, 2006

“Not many organizations represent the patient’s voice. The ACPA and its partners do a good job of that.” —DONNA A. K. KALAUOKALANI, MD, MPH, 2007

“The ACPA helps support groups be more inclusive. Support groups tend to be a middle class phenomenon, but pain doesn’t discriminate.” —DENNIS C. TURK, PH.D., 2006

“People say they wouldn’t have made it if not for Penney and the ACPA. They say it is important to have someone who understands what you are going through—and actually answers the phone and talks to you.” —CHRIS PASERO, MS, RN-BC, FAAN, 2008
These articles are intended to give members more insight into the interests and contributions of ACPA board members.

Keyola Panza joined the ACPA’s board of directors in 2014. For her, it was a way to continue a relationship with inspirational individuals and their mission.

When Panza worked as senior interactive project manager at New Perspective Communications, Pittsburgh, Pennsylvania, she helped to launch—and relaunch—the ACPA website.

“It was a very close relationship and when I left, I was sad to be losing contact with Penney [Cowan] and Nicole [Kelly],” Panza said. “They had really grown the organization and I was impressed with how much they helped people with pain, their families, and their healthcare providers. I was honored that they would ask me to be on the board,” she said.

After graduating from the University of Pittsburgh in 2000, Panza spent more than 14 years working in the broadcast and digital media industries. Currently, she is a product manager on the eCommerce mobile team for Dick’s Sporting Goods.

“There is so much great information on the ACPA’s websites and new content is constantly being added. We need to be sure the sites are well organized as they continue to grow in size. We want people to be able to easily find what they are looking for and access the many resources and tools,” she said.

“We also need to upgrade the organization’s main website to a responsive design for viewing on smart phones and tablets.”

“Then people with pain could track their pain levels and activity as they are experiencing it, right on their phones,” she said.

Panza also sees a role for the board in helping the ACPA extend its reach to new supporters, perhaps corporations and nonprofits who could help spread awareness.

“We can’t always expect financial support from people with pain. They can have enough expenses. So we have to get the word out to other people who would appreciate what the ACPA is doing,” she said.

Panza lives near Pittsburgh, where she works long hours and spends free time with friends and family. She also volunteers for the Ronald McDonald House of Pittsburgh charity events. Her personal experience with pain involves her younger brother, a Marine veteran with chronic back pain.

“I can see how much the ACPA could benefit someone like my brother, and the thousands of others like him who need help,” she said. “The ACPA provides so much for people with pain, at no charge. We have to make this good work known to more people, to get the support that will keep the organization strong.”

Giving Hope: Our 35-Year Mission

It has been a journey of commitment, passion, and determination, as we strive to reach that one person who feels hopeless—and reach them before they give up.

The ACPA is here for anyone who needs help, but in the end you have to be the one who makes it happen.

Every person who has reached out to the ACPA has helped us create all the materials and information available on the ACPA website today. We have listened to you, the person with pain, and tried to build tools that will help you become more active in your care and regain some joy in your life in spite of pain.

Education for people with pain and healthcare professionals is still lacking. ACPA has made a commitment to create educational materials that are easy to understand, bridging the gap of communication between patient and provider. The ACPA is a unique organization in that we focus on the needs of the person with pain. We help them reach this goal of pain management: to increase function, improve quality of life, and reduce sense of suffering. While there may always be some level of pain, there is always hope for a better tomorrow.

The ACPA never questions you and always validates you. To us, pain is what you say it is. We accept the fact that you are reaching out to us because you have pain.

We cannot help everyone. Some are looking for cures that are not available yet. But a richer, fuller life can happen if individuals travel the long, and often difficult journey from patient to person. ACPA will be there when you need us.

Oh, and if you are reading this, you should know that you have not given up yet. The fact that you are still reading this column means you still have hope.
ACPA Updates

ACPA Facilitators Share Opinions for Research
On June 9, 2015, four ACPA facilitators participated in workshops for the Patient-Centered Outcomes Research Institute (PCORI) in Washington, D.C. More than 100 people attended—from support advocates to hospital and university medical directors. There were six workshops in all with more than 20 participants in each.

“Our goal, as ACPA members, was to bring the human perspective to the table and make sure the thoughts and views of those with chronic pain were heard,” said Max Sokolnicki, facilitator of the greater Detroit area ACPA support group.

“These scientists, researchers, addiction specialists, and doctors wanted to talk with us,” said Catherine Cartwright, Regional Director of the ACPA Northern Bay Area. She attended a workshop that addressed the pros and cons of long-term use of opioids for chronic pain. “They were seeking input from people experiencing pain as they frame their research studies and questions. This way the research questions will relate to all the different aspects of chronic pain.”

“It brought together people from all walks of life with the same concern: the best way to research chronic pain,” Cartwright said. “Where any issues at any time pertain to chronic pain we always want the voice of the American Chronic Pain Association to be there!”

Sokolnicki’s workshop was titled “Long-term use of opioids for chronic pain: Non-pharmacologic treatment options, risk mitigation strategies, and opioid dependency.” “We were tasked with choosing five of the many pre-submitted research ideas, then to rewrite the questions in such a way that the PCORI board of governors would select it to perform research with. A very daunting task,” he said.

Ernie Merritt, facilitator of the Southern Maine Chronic Pain Support Group, attended along with Tom Norris, of the Los Angeles support group.

Merritt took part in the chronic low back pain stakeholder workshop. “I was a little nervous from the beginning, one of 18 people seated around a table discussing possible comparative questions. I felt I was in the wrong place, as the others were doctors and PhDs with a lot of letters after their names,” said Merritt.

“I felt I had a big job to do and had to be ready to speak up when I felt the person with living chronic pain needed to be represented,” Merritt said. “I wanted to make that point that living with chronic low back pain was something I was kind of an expert in. I know how to deal with the healthcare system. What has worked and what has not.

“I see now how important it is to have ACPA on your side being there as an advocate. Some of these doctors need to be educated on how it is to take care of a person living with chronic pain,” Merritt said.

Tom Norris attended a workshop related to musculoskeletal pain. “Like Ernie, I was initially in awe of the credentials of the people I joined on the panel. I realized that, even though I was not a professional politician or medical expert, I was responsible for bringing the view of the person with pain to the discussion.”

“Our panel discussed questions dealing with the education and training of doctors in dealing with people with chronic pain, as well as communications between them. Everyone agreed with me when I discussed the importance of doctors’ honesty and directness in dealing with chronic pain,” said Norris.

“The discussion and debate was quite passionate, everyone bringing their unique view to each topic,” Sokolnicki said. “I know from my own experience that our view was taken with as much weight as a director of emergency medicine or similar person. Hopefully there will be thoughtful and insightful research initiatives that were born at this set of important workshops.”

Federal Workers Can Give Through CFC
The American Chronic Pain Association has been accepted by the U.S. Office of Personnel Management for the inclusion in the fall 2015 Combined Federal Campaign (CFC) as a member of Health & Medical Research Charities of America Federation. If you work for the federal government and would like to designate the ACPA for a contribution, please use CFC number 10549. This is only valid for CFC members.
Book Review

Wheel: A Recovery From Chronic Pain and Discovery of New Energy
written by Sylvia Hawthorn-Deppen

Review by Tara White, RN

This book is a very intimate and courageous tale of a life with severe depression and chronic pain. Both of the author’s conditions stemmed from a repressed memory of a childhood accident, falling down a staircase headfirst into a bucket of water. This caused a head injury that affected her behavior, memory, and judgment. It also induced chronic pain for many decades from bone spurs in her lower neck and upper back.

Hawthorn-Deppen uses a poem about a wheel as an analogy of her life—“spinning her wheels” and getting nowhere fast. As a young woman she is soon out of control, in trouble, in danger and doing illegal activities with the wrong sort of men.

Also, she cannot understand why she is so different from others, which leaves her depressed and anxious. Physicians are unable to help her various complaints of chest pain and spasms of the face and neck as she continues her downward spiral. It is a very, very detailed account, yet one only a very brave woman could write.

One of Hawthorn-Deppen’s problems, alcoholism, finally leads her to Alcoholics Anonymous. She uses the AA’s Twelve Steps to help her deal with her chronic pain. This is an interesting concept which may be helpful to many readers, as will the thread of religious references throughout the book.

Hawthorn-Deppen also credits the work of Shinzen Young in Break Through Pain. This book is a step-by-step mindfulness meditation program for transforming chronic and acute pain.

Finally, her passion for bicycling continues to help her with her depression and pain and gives her a wonderful sense of freedom. Hence, the wheel analogy comes full circle.

Ms. Hawthorn-Deppen now feels blessed to have lived her life, for she considers it a miracle. Her most important reason for writing this personal story of recovery is to be a voice heard by others. She states: “In turn I needed to hear theirs too because even though the details may have been different, it was basically the same—looking for comfort in the bottom of a gin bottle or from countless pills. I was finding that person in myself that I had been searching for. And I actually liked her”.

Wheel: A Recovery From Chronic Pain and Discovery of New Energy, by Sylvia Hawthorn-Deppen; Balboa Press Publisher; 239 pages, $17.99. ISBN #978-1-4525-5565; wheeldiscoveryofnewenergy.wordpress.com

The ACPA is a peer support organization: we help each other learn to live fully in spite of chronic pain. Your donations and purchase of materials keep the ACPA alive and reaching out to even more people with pain.
**Book Review**

*Silent Courage: My Lifelong Journey Through Pain to Wellness*
written by Mary Byrne Eigel

Review by Tara White, RN

Here is a book I thoroughly enjoyed and easily read in one day. From the first chapter, you are drawn in to the author's story and begin to care about her and what is going to happen next. You immediately sympathize with her pain, physical and mental, and hope that things will turn around for her.

Mary Byrne Eigel was born into a traditional Irish family in 1951. Tragically, a simple test done on every newborn to detect bilateral hip dysplasia is missed. It is not noticed until she is attempting to walk and keeps falling down. Upon taking her to the pediatrician, her parents are told about the diagnosis, and she is casted from her hips to her knees with a metal bar between her thighs. This is done in an attempt to settle her femurs in their shallow sockets. Unfortunately, her parents decide not to tell her about this until she is in her twenties and has her own child. Instead, she must grow up with many painful and debilitating obstacles while blaming herself for being different from other children.

A child with severe hip dysplasia would normally be told to protect her hip sockets by not putting any pressure on them. She would know that she would feel pain, possibly for the rest of her life. In the 1950s, many people incorrectly believed that babies did not feel pain. Possibly, her parents may have felt that she wouldn't remember this time in her childhood. Instead, she is forced to make long daily walks to school and once home, back to the market for groceries. She experiences severe pain, but decides to “tough it out” when her parents are unwilling to listen to her, a learned cultural response to life's “opportunities.”

“As I grew, my legs demanded more of my attention. Beyond their lack of flexibility and my inability to run or walk as fast as others, my legs ached at my hips. Pain would haunt me at school, my house, and before I went to bed. It misled me to mistakenly categorize myself as lazy. If I had understood the source of my discomfort, I might have been able to confidently say, ‘I'm not lazy. I'm not stupid. I have a problem with my hips. I just know they feel better when I am not being active.’

Grace strikes us when we are in great pain and restlessness … Sometimes at that moment a wave of light breaks into our darkness, and it is as if a voice were saying: ‘You are accepted.’”

—Paul Johannes Tillich

“I could not alter my compromised abilities, but I could engage in activities that allowed me to feel able rather than unable. It never occurred to me that (other kids) felt no pain. I knew how I felt, but I thought everyone else's hips ached when they walked. In addition to the physical pain, the discomfort that no one understood my complaints gave my pain a harsher edge.”

As the years go by, she faces many challenging obstacles as she goes to college, marries and becomes a mother herself. Nevertheless, life has a way of working things out. Modern medicine helps, yet many surgeries are required. She faces it all with the tremendous courage and wisdom that can only be gained through adversity.

With time and knowledge, she is able to become the woman she was always meant to be. She states it best herself:

“Our ability to converse allows people to connect with each other. Whether someone carries a visible or invisible disability is not the issue. Being courageous enough to share our unique situations is what nurtures understanding and compassion.”

Thank You!

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