Pain is a difficult thing to identify. It is impossible to see, to measure, to explain to others so they understand. But, at least we know when we are in pain. . . or do we?

Have you ever experienced a burning sensation? Or perhaps experienced tingling, numbness, or a pins-and-needles sensation and just ignored it? Does the sensation intensify when you wear clothes or when fabric touches you? You may be experiencing neuropathic pain or nerve pain.

Nerve pain is a type of chronic pain that occurs when nerves in the central nervous system become injured or damaged. It is not always clear what causes nerve pain: an injury, an illness, a medical condition such as shingles, or unknown factors. When left untreated it can intensify or worsen.

More than four million people in the U.S. have nerve pain. This is a puzzling and frustrating condition that can make even the simplest act, such as walking or getting out of bed, seem impossible. People often have problems concentrating during the day and sleeping at night. People with nerve pain may become reclusive and isolated from other people. When not properly managed, nerve pain or any chronic pain can seem to take over your life. People often have problems concentrating during the day and sleeping at night. People with nerve pain may become reclusive and isolated from other people.

Over the next few months the ACPA will be presenting an educational program about neuropathic pain—It Takes Nerve—to our ACPA chapters and their communities in California and New York. Our goal is to help people understand the symptoms of nerve pain, the importance of discussing their symptoms with their health care providers, and how they can take an active role in the recovery process. Visit the ACPA web site for a list of times and locations of the It Takes Nerve programs.

Our goal is to empower people with pain through education and encourage them to take an active role in the recovery process so they can reduce their sense of suffering and improve their quality of life. Remember, anything is possible!
A s the expression says, living with nerve pain takes nerve, lots of nerve, and guts too. Just ask Cynthia Allen. Today, she has found some relief but she remembers long nights and years of unrelenting pain.

“It was like having a baby without having anesthesia,” she recalls. “I was in so much pain I couldn’t eat. The only way I could sleep was by taking sleep aids.”

Cynthia described her pain as a burning, numbing sensation that starts in her lower back and left hip, and radiates down her leg to her toes. “Something is squeezing the nerve,” she says of the sciatic nerve pain. But she is unable to explain why it has continued since 1985, other than to guess that it could be congenital. “My sister has the same thing on her right side,” she says.

But one thing Cynthia is sure of is that her emotions are connected to the pain. In 1990, her pain became much worse, affected by her frustration with long work hours and a long commute. “They wouldn’t let me work part-time. I was angry and I know emotions play into this (pain condition) too.” At the time, she was getting by on one pain pill a day. Four years later, she was taking two a day.

In 1994, she cared for her critically ill mother as well as her busy teenage daughter. When her mother died in 2000 and her daughter graduated and left home for college, Cynthia felt the losses keenly. “I sort of lost my job,” she remembers. Her economic situation changed and she lost her home as well. These factors hit her emotions hard and Cynthia tumbled into a clinical depression that lasted five years. What she had rated as “mild to moderate” pain suddenly became “severe” pain.

Seeking Relief from Nerve Pain

She began trying all the treatments familiar to people who have chronic pain. One that was especially impressive was the Alexander Technique, which she describes as “a study of body movements so you move with the least stress on your body.”

“But nothing helped the pain,” she recalls. “It was still a little alligator chomping down on my left hip.” After some time, Allen began to look at her response to the situation rather than just the situation. “For seven years I had cried myself to sleep, asking ‘What is wrong with me?’ I decided to accept it and to develop a better attitude,” she says.

Though an MRI in the 1990s didn’t explain her pain, a visit to a pain specialist was more encouraging. After examining her and talking with her, the specialist said words she will never forget: “You have been under-treated for a long time for a serious pain problem.”

Hope poured into her heart and mind like water into a parched throat. The pain specialist added to that hope with news of anti-seizure medications that were useful in treating nerve pain. It took a lot of trial and error, but Allen found a combination of medications that work for her today (an anti-depressant, morphine, and medication for breakthrough pain). She also found a physical therapist who taught her how to relax the muscles that commonly tighten around a pain area.

Ups and Downs

At the University of California San Francisco Pain Center, Cynthia tried a series of injections in specific points to determine the origin of her pain, but these did not result in any improvements. The anesthesiologist concluded she had phantom limb pain, but she was determined to keep fighting to improve her life.

In 2005 Cynthia started an ACPA pain support group and found friends to replace those who “didn’t understand.” She learned to pace herself to achieve what she could, without draining her resources by going ahead full tilt.

Now the 55 year-old “people person” is enjoying life much more. “I feel like I am pulling out of the depression I’ve had since my mother died,” she says. She is doing water exercises to help manage arthritis and considering adding more exercise by walking on the alternate days.

Her positive attitude keeps her emotionally balanced through conflicts with her insurance carrier and other stressors. “I know I can go from a 3 to an 8 (in pain levels) just by feeling sorry for myself,” she says.

Through the ACPA group, she helps herself and others live a satisfying life despite pain. Her other goals are to care for feral cats (by trapping, neutering, and releasing them), to memorialize her late father’s art work, and to work again in nonprofit social work helping children and the elderly.

One thing’s for certain. Cynthia has recovered from incapacitating despondency and pain. “I feel I’m in the driver’s seat now. I’m more in control,” she says.

* Cynthia is alias for a person with pain living in Richmond, California, who wished to remain anonymous in this article.

In 2005 Cynthia started an ACPA pain support group and found friends to replace those who “didn’t understand.” She learned to pace herself to achieve what she could, without draining her resources by going ahead full tilt.
Nerve Pain Symptoms Can Be Perplexing

More than four million people in the U.S. have what is called neuropathic pain or nerve pain. This is a puzzling and frustrating condition that can make even the simplest act, such as walking or putting on socks, agonizing.

When the nervous system is working properly, nerves connect your brain and body, sending a message that you are touching something. But, like wires that short circuit, nerves can become injured and stop working the way they should.

If the nerve isn’t working properly, it may begin sending the wrong signals to the brain, such as sending the sensation of burning or electrical shocks when nothing has actually happened.

How Nerve Pain Occurs

Nerves can become damaged from an injury to the spine or from a medical illness like diabetes, shingles, a stroke, HPV infection, or cancer and its treatments. Nerve pain often causes discomfort to the hands, legs, or feet.

Nerve pain is often hard to diagnose. While muscle pain makes you feel sore and achy, it generally is caused by an injury and usually stops when the injury is healed. Nerve pain is different. In identifying nerve pain, you will notice that the pain is not triggered by an event or trauma and is a constant and/or recurring pain that doesn’t seem to go away. Common pain medicines like aspirin do not stop the pain.

Nerve Pain Feels Like…

Many people with nerve pain don’t describe this feeling as “painful.” Instead, they may describe it as:

- being pricked with pins and needles or shocked by electricity. Symptoms are often worse at night and are described as:
  - Allodynia—a pain caused by something that is generally non-painful, such as light touch
  - Hyperesthesia—an exaggerated response to touch, such as to bed sheets
  - Hyperalgesia—an exaggerated painful response to something that is normally painful
  - Hyperpathy—pain that persists even after the cause of pain has been removed
  - Paresthesias and dysesthesias—abnormal and unpleasant sensations that are described as tingling and pins and needles

When nerve pain is not properly managed, it can end up controlling the way you live, because even the simplest actions—like wearing clothes or walking to the market—can be agonizing. As a result, people who have nerve pain may have difficulty working, sleeping, concentrating, socializing, and enjoying daily life.

Although nerve pain can be incapacitating and disabling, there are ways people can effectively manage it and continue to live productive lives. These can involve:

- Talking to a doctor about nerve pain and about how best to manage it
- Asking about medicines that are developed specifically to treat nerve pain
- Learning how to relax and set realistic goals
- Identifying a moderate exercise program that can be done safely

Other symptoms common to neuropathic pain are:

- Other symptoms common to neuropathic pain:
  - Pins and needles
  - An electric shock-like feeling
  - A stabbing pain, like a spike being driven into your hand or foot
  - Walking on broken glass
  - Burning pain
  - Tingling
  - Numbness

Survey Shows Need for Education

The American Chronic Pain Association (ACPA) launched the It Takes Nerve campaign in 2004 to raise awareness about nerve pain and help educate people to recognize the symptoms of this common, yet often under-recognized and under-treated, problem.

“The It Takes Nerve initiative is designed to help people living with nerve pain learn that this is a disorder that they can do something about,” said Penney Cowan, founder and executive director of ACPA. “If you feel a tingling, stabbing, or shock-like sensation, talk to your doctor. As with all chronic pain disorders, you don’t have to just endure the pain. There are ways to manage pain and not let it control your life.”

Though nerve pain affects four million Americans, it is not well understood, according to the It Takes Nerve chronic pain survey conducted by Roper Worldwide on behalf of the ACPA. A total of 999 telephone interviews were conducted from among a nationally representative sample of 1,004 U.S. adults. An analysis of results revealed:

- Nearly 34 percent of Americans have or know someone who has experienced nerve pain symptoms—tingling, “pins and needles,” burning, or an electric shock-like sensation—yet only six percent of people recognize these symptoms as nerve pain.
- Most adults (76 percent) are not aware of what to call pain that causes these symptoms.
- Nearly two-thirds of adults did not know that the central nervous system causes this type of pain.

The findings of the It Takes Nerve survey highlight the need for increased education and awareness about nerve pain. People with pain need to understand the cause of their condition and have a candid discussion with their physician to identify the most appropriate course of treatment.

- Among the one in four adults surveyed who were diagnosed with a health condition related to nerve pain, such as diabetes, shingles, and carpal tunnel syndrome, only 12 percent knew symptoms such as tingling, burning, electric shock sensation, or sensitivity to touch are related to nerve pain.

- Getting family and friends involved
- Contacting the ACPA at 1-800-533-2331. We can help you find a support group in your area or start a group with information and support from the national office.
- Find a Doctor

There are physicians who are specially trained and board certified to deal with ongoing pain problems. If you want to talk to a specialist, you can find a list of those in your area on the American Board of Pain Medicine web site at www.abpm.org. Click on the menu item titled, “List of Diplomates.”

You also can learn more about selecting a physician at the American Board of Psychiatry and Neurology, www.abpn.com/geninfo/what_neurol ogist.html, and at the American Board of Medical Specialties www.abms.org. Additional useful information about nerve pain can be found at the ACPA’s web site It Takes Nerve at www.theacpa.org/nerve. You might also be interested in exploring interactive tools to help understand nerve pain by clicking on “Tools for People with Nerve Pain.”
Many medications are available for the treatment of neuropathic pain. However, the definitive drug therapy remains elusive. (See "2006 Medication Supplement"). Oftentimes triple drug therapy—with tricyclic antidepressants, anticonvulsants, and a systemic local anesthetic—is used. The best approach for treating neuropathic pain is often through multidisciplinary functional restoration. Functional restoration teams include pain physician specialists, psychologists, and physical or occupational therapists. The hallmarks of neuropathic pain are chronic allodynia (pain in response to something that should not cause pain) and hyperalgasia (abnormally increased pain sensation).

Examples of neuropathic pain include:
- Radiculopathy from a herniated disc or nerve compression
- Trigeminal neuralgia: periods of sharp, stabbing facial pain located near the nose, eyes, lips, and ears interspersed with pain-free periods
- Postherpetic neuralgia: pain persisting or recurring at the site of herpes zoster (shingles) rash
- Phantom limb pain: a sensation of pain arising from an area of an amputated limb
- Diabetic peripheral neuropathy
- Compression neuropathies, such as carpal tunnel syndrome, pain in the hand and wrist
- Complex regional pain syndrome (CRPS)
- Various peripheral neuropathies, and
- Pain related to multiple sclerosis, stroke, HIV, or cancer

With neuropathic pain, the nervous system seems to be more sensitive and functions abnormally. Even though the injury may occur to a nerve in the arm or leg, changes in spinal cord and brain may last long after the injury has healed. Neuropathic pain tends to be only partially responsive to opioid therapy.

Early Response Critical
Early recognition and aggressive treatment of neuropathic pain is critical to a good outcome. Treatment can include medications, various invasive interventions, physical rehabilitation, and psychological care.

Because most neuropathic pain responds poorly to NSAIDS and opioid analgesics, the mainstream of treatment is predominantly antidepressants, anticonvulsants, and anesthetics. Steroids, topical therapy, autonomic drugs, and NMDA receptor antagonists have also proven useful. (A review of medications useful for chronic pain can be found at www.theacpa.org under "2006 Medication Supplement").

The Neuropathic Pain Network (NPN) was launched in May 2004 and is currently comprised of seven organizations including the German Pain League, American Chronic Pain Association, Action on Pain, and Swedish Pain League.

Pain Network Reaches to Europe
The NPN maintains a Web site solely dedicated to provide support for people with neuropathic (nerve) pain that is available in English, French, German, and Spanish at www.neuropathic-painnetwork.org.

In European countries, the estimated prevalence of neuropathic pain is:
- 3 million people, or 7.7 percent in the United Kingdom
- 2.5 million people, or 6.4 percent in France
- 2.1 million people, or 7.7 percent in Spain

The NPN maintains a Web site solely dedicated to provide support for people with neuropathic (nerve) pain that is available in English, French, German, and Spanish at www.neuropathic-painnetwork.org.

The person with pain should expect to receive:
- respect and dignity
- assessment of psychosocial strengths and weaknesses
- analysis of the support system
- patient and family education
- expectation management
- functional goal setting, and
- ongoing assessment of participation and compliance, complicating problems, and progress toward achievement of goals.

Drug Therapy Remains Elusive
Many medications are available for the treatment of neuropathic pain. However, the definitive drug therapy has remained hard to pin down. Oftentimes triple drug therapy—with tricyclic antidepressants, anticonvulsants, and a systemic local anesthetic—is necessary. Occasionally, patients require chronic opioid therapy in conjunction with the above medications. When patients fail systemic treatments, implantable systems, such as a spinal cord stimulator or intrathecal morphine pumps, are potentially available.

Many people with neuropathic pain find that a functional restoration approach is best.

Further information about neuropathic pain can be found at The Neuropathic Pain Network (NPN) www.neuropathic-painnetwork.org.
A s people with pain know all too well, many things influence the intensity of daily pain. These can include stress, sleep, money worries, and even the weather. The ACPA has a new tool that can help you track the everyday things that have an impact on your pain. The new “Live Better with Pain” log book will help you chart and understand what makes your pain worse.

Increased understanding may help you to be less afraid and better able to manage your pain. The log has charts that will help you record how you body reacts to key pain triggers like quality of sleep, social isolation, activity levels, alcohol use, the weather, and nutrition. You can easily see, as you track your experience over time, how these factors affect your disposition and your pain.

We encourage you to complete this log and take it with you to doctor visits. It can help you talk more openly with your healthcare provider so that together you can work on treatment that is better suited to your life style and situation.

Pain is a complex condition that affects both body and mind. These charts can help you learn about key physical factors that affect your mind and body. As you learn good pain management skills and apply them in daily life, you can achieve a good quality of life and live well with pain.

To order your “Live Better with Pain” Log, go to www.theacpa.org and click on ACPA Catalog in the left menu bar. Or call us at 1-800-533-3231.

Web Site Redesign

Plans are in the works for an improved Web site for ACPA, coming later this year. Some of the new features we can look forward to are:
- Easier navigation
- A new search function
- Weekly tips for managing pain
- Ask ACPA email section
- Members-only newsletters

The Web site redesign is being funded by Purdue Pharma. Many thanks!

Creative Teaching Award Winner

Bridget Calhoun, president of the ACPA Board of Directors since October 2005, received a Creative Teaching Award for 2006 from Duquesne University, in Pittsburgh. Calhoun, MPH, PA-C, is assistant professor and chair of the Department of Physician Assistant in the Rangos School of Health Sciences at Duquesne. The Creative Teaching Award Winners are faculty who have implemented and assessed innovative ways of teaching a particular topic or subject matter area. Bridget has also done a great job of increasing awareness of chronic pain issues among her students and colleagues.

Coordinator Named Valedictorian

Amanda (Maggie) Chesnut has been named valedictorian of her graduating class at Putnam Valley High School in New York. She is founder and coordinator of ACPA’s Growing Pains group, and will speak at the PVHS 2006 Commencement Ceremony on June 23, 2006.

In addition to having the highest grade point average in the class of 2006, Maggie participates in many extracurricular activities and is student representative to regional organizations. In 2004 she founded Growing Pains, a national, online, ACPA affiliated support group for chronically ill teenagers, following her own 10-year struggle with celiac disease. Maggie is also a talented musician, artist and softball player. A member of the National Honor Society, she plans to attend Smith College in the fall.

“I have always worked hard at my studies, not because I want to excel, but because I love to learn,” said Maggie. “My goal is to make a difference in the world, my students’ lives, and my own life, by exploring and sharing my love of learning.” She is the daughter of Richard and Ann Chesnut of Lake Peekskill, New York.

ACPA at APS

Hundreds of pain-care professionals from many disciplines stopped by the ACPA booth at this year’s American Pain Society meeting in San Antonio, Texas, May 3 to 5, 2006. They perused our extensive array of materials and listened with interest to the many ways we seek to support people with pain as they work toward fuller lives.

It was encouraging to see how many of our visitors were eager to learn more about how to engage the person with pain as a partner on the treatment team. After many years of being eclipsed by single-modality strategies (medication or surgery alone), the multidisciplinary approach is beginning to be valued as the most effective way to help people with pain. Let’s hope this concept continues to spread!

Knox Todd, M.D., and Penney Cowan presented a poster session on our recent online survey of the experiences of people with pain in the emergency department. Among those attending was a reporter from UPI. You can see the resulting coverage in News on our web site: www.theacpa.org.

To order your “Live Better with Pain” Log, go to www.theacpa.org and click on ACPA Catalog in the left menu bar. Or call us at 1-800-533-3231.

Gearing up for Pain Awareness Month

For September 2006, the ACPA and Partners for Understanding Pain are planning a grass-roots campaign to support HR 1020. Watch our web site for a Congressional Visit Tool Kit to help you plan a meeting with your congressperson in September. Our online Pain Awareness Activity Tool Kits can help you organize community events to raise awareness of the ways pain impacts our lives.
When Lynn Dickerson started the ACPA support group in Orangevale-Sacramento, California almost two years ago, she was looking for people who shared her concerns and interest in chronic pain. Soon, a group of 25 people was meeting twice a month. “We found that you need the right balance,” says Lynn. “We spend some time each meeting sharing literature, but always save some time for open discussion. We like it when members can take away some new knowledge they can use.”

As they learned about normal pain and chronic pain, the members developed “Understanding Pain: Eleven Steps to Freedom,” a short guide to living with chronic pain. “It’s something to turn to when you are on your own, a way to reinforce what we discuss in meetings,” says Lynn. “It can also help newcomers adjust to this lifestyle.”

The booklet’s dedication states: “Inspired by and a Tribute to Lynn Dickerson, Primary Founder and Facilitator of the Orangevale-Sacramento, CA group of the ACPA, April 2006.”

“I feel so honored that the group dedicated the book to me,” adds Lynn. “It was truly a group effort.” While Lynn will soon be moving away, she hopes to make frequent visits to the support group that means so much to her.

The Diagnosis

I remember that he was talking to me but I did not hear any of his words. Already vulnerable, dressed only in a paper gown, I frantically gasped for my next breath. I couldn’t cope with the life-altering fate before me, let alone understand the significance of the one sided conversation we were having. Did I hear him correctly? Did he use the words tumor and brain in the same sentence? Tumor? Brain? Tumor? Brain Tumor? No, I heard wrong. He is not talking about me.

I am not sure how long I sat there on the metal table holding close my paper modesty. Tears fell freely but not by my command. Frantically I tried to make some attempt at putting the pieces together and to rid myself of the dreadful images that were clouding my brain. I desperately tried to make some sense of the words but I still could not comprehend them. I held my own body hoping to find some kind of comfort, but it didn’t work. I could hear myself saying, “Change it! Fix it! Do something!”

The diagnosis, the prognosis, they didn’t belong to me. They did not fit my PTA chairman, Boy Scout leader, car-pooling mother kind of image. Later at home, I ... normal again. I felt as if a part of me was gone, the strong part, the fighting part, the part I needed so desperately.

The yellow bush. It always has been the yellow bush. Excited by the first rose of the year, I ran into the house to get a vase, but I didn’t have a vase that small. When it hit me, I was in awe by the thought that God can be so gracious. The tumor. I wasn’t thinking of the tumor, just the dumb vase.

“Understanding Pain: Eleven Steps to Freedom”

1. Avoid Isolation
   - Go to the mall
   - Visit someone
   - Go shopping
   - Enjoy some music
   - Help someone else
   - Join a support group
   - Get out of the house
   - Take a walk
   - Ask for help

2. Overcome Confusion
   - Be more assertive
   - Don’t minimize the pain
   - Articulate your pain, talk to others
   - Ask for help
   - Confront Uncertainty
   - Live with pain in a productive way
   - Accept your new lifestyle
   - Track your physical well being
   - Ask for help

3. Don’t Dwell On Your Suffering
   - Enjoy a movie
   - Read a book
   - Take care of a child or grandchild
   - Take care of animals

4. Set Realistic Goals
   - Don’t compare yourself to others
   - Set step-by-step goals
   - Strive for, celebrate small goals
   - Live in the moment
   - Ask for help

5. Recognize Your Feelings
   - Be in touch with your physical self
   - Open up to others
   - Ask for help

6. Take One Day at a Time
   - Keep a journal
   - Live in the moment
   - Face yourself
   - Ask for help

7. Let Go of Anger, Pursue Happiness
   - Are tired of discussing chronic pain over and over again.
   - Give yourself permission to feel frustrated if no one listens.
   - Realize that family and friends may not be capable of really understand your feelings.
   - Accept that other people think you can do more than you really can.
   - Know that revenge is negative thinking and that treatment may remain unsuccessful.

You will begin to turn the corner toward positive thinking and freedom. We must:

   - Remind ourselves that the pain is real
   - Focus more on our inner selves
   - Connect with others who share our experiences for support and acknowledgment
   - Accept that the medical community can help only so much
   - Work on fixing ourselves
   - Concentrate on what we can change
   - Not waste energy on “Whose pain is worse?”
   - Limit the time we spend with those who distress us
   - Ask for help

The yellow bush should bloom first,” I thought, “it always has been the yellow bush.” Excited by the first rose of the year, I ran into the house to get a vase, but I didn’t have a vase that small. When it hit me, I was in awe by the thought that God can be so gracious. The tumor. I wasn’t thinking of the tumor, just the dumb vase.

It is hard to describe that feeling. I wanted to stay there forever basking in that gift from God: a brief respite from my chronic pain. I didn’t want the feeling to end. It felt like watching the magnificent beauty of a shooting star, the moment so spectacular, I didn’t dare breathe, fearing that if I did breathe, the moment, this feeling, would be all over. I cautiously thought, “Maybe this monster that has been calling my name over and over and over again is finally beginning to rest.”

Aidred that this moment of ease would never come again, I continued on. And it did, life did go on, and the monster did return. It returns again and again, often when I want it the least, but not as often as it did at first. Eventually I came to terms with sharing a part of myself with the hideous creature. These moments of ease return more often, letting me know that I am still the person I have always been, slightly different, changed with the passage of events, but still me. Moment by moment, life becomes real again.

I began to realize that hey, I’m going to be okay. I am going to be okay.

Though the pain continues to remind me that I am not invincible, it also reminds me that I am strong, strong enough to accept my diagnosis, strong enough to live with my pain, strong enough to look forward to each new day.

Laurie Wise
My Battle With The Beast
One Woman’s Inspiring Journey with Complex Regional Pain Syndrome
by Toni Amarel
Reviewed by Emily Holzberg, MS, OTR/L

This book provides a look into the author’s personal struggle with Complex Regional Pain Syndrome (CRPS) that she nick-named “the beast.” This book hopes to validate the experiences of those with CRPS and encourage and strengthen them in their battle against the beast. Amarel states that humans function better when we feel a part of something larger than ourselves and spreads the message, “You are not alone.”

As an individual with CRPS and a healthcare provider for people with CRPS, I found some aspects of this book helpful and some aspects potentially harmful. It provides the reader with a greater understanding of the disorder and the horror the patients must endure, along with some useful information on how to manage your life and find the best medical care. This book’s graphic descriptions of the pain might help friends and loved ones empathize better. However, for some, this explicit description of the disorder and how it can destroy your life can be devastating to read.

The medical information in this book is intended for the layperson, explaining that you can get CRPS from any physical injury or emotional distress that can cause a “mysterious link-up.” As a result, the sympathetic nervous system sends the wrong information about pain, temperature, and blood flow to a certain body part.

She advises the reader to keep fighting and searching for better doctors since CRPS is often poorly understood, misdiagnosed, and mistreated. Early treatment is best so you will quickly need a treatment plan designed to meet individual needs. Recovery is better if you stay active and participate in designing your treatment plan. Use caution if you rely on the Internet for research.

The author found that the CRPS medical community is highly disorganized. She experienced frustration when side effects to her medications—such as weight gain, depression, fatigue, and urinary tract infections—were poorly explained. It is important to stay informed, stay organized, and document everything when working to find the best care.

All in My Head: An Epic Quest to Cure an Unrelenting, Totally Unreasonable, and Only Slightly Enlightening Headache
by Paula Kamen
Reviewed by Emily Holzberg, MS, OTR/L

The first portion of this book is an extremely detailed journal of all Paula Kamen’s efforts to get “cured:” her encounters with incompetent/uncaring medical professionals, severe drug reactions, and a loss of social and professional roles. As an occupational therapist as well an individual with chronic pain, I found this part of the book to be somewhat frustrating and exhausting to read. Other readers, who may feel secluded in their pain, may identify with the everyday incidents of another real person struggling with pain.

Kamen warns the reader that highly trained specialists may lack time to listen to all the details. Some doctors may want to perform certain procedures or diagnostics tests because they make the most money from them, she says, and suggests asking the purpose of these procedures before consenting to them.

She encountered a lot of doctors who didn’t take the time to listen to her and advises patients to try to work with their doctors openly. Even if your doctor may find your particular experience unique or bizarre, do report any side effects of treatments. Be sure to work with your doctor on both pain relief and prevention and discuss the use of narcotics as pain relievers.

Kamen reminds us to be careful to treat the source, not just the symptoms of headaches. She also freely exposes her political views, and expresses dissatisfaction with our society’s inclination to take visible disabilities more seriously than chronic headaches.

The author is very open with her views about how historically doctors haven’t taken women’s pain seriously, diagnosing it as “hysteria.” The simple fact that men and women process pain differently doesn’t make women’s pain less important than men’s. She also discusses her experiences with alternative healers.

Kamen introduces interesting medical theories regarding chronic pain and chronic daily headaches, as well as central sensitization and neurosomatic pain. Though these are extensively researched from a journalistic point of view, these theories should be discussed with your health care professional.

This book has an excellent list of patient resources for individuals with chronic headaches, including web sites, books, videotapes, and workbooks.
The ACPA is a peer support organization: we help each other learn to live fully in spite of chronic pain. We also need to join together to make sure the ACPA continues to be there for us all with resources, materials, and that personal contact that can make such a difference.

Your membership, donations, and purchase of materials keep the ACPA alive and reaching out to even more people with pain. Thanks for helping us help others.

I want to help the ACPA. Enclosed is my tax-deductible donation of $30.00

To Join The ACPA:

Name __________________________  Address __________________________

City __________________________ State ______ Zip Code ______

Phone Number ____________________  Today’s Date ______ / ______

$30.00 First-Time Membership: You’ll receive the ACPA Member Workbook Manual, Patient to Person: First Steps, a one-year subscription to the ACPA Chronicle, a 10% discount on all other ACPA materials, and a membership card.

$15.00 Renewal Membership: You’ll receive a one-year subscription to the ACPA Chronicle, a 10% discount on all other ACPA materials, and a membership card.

To Donate to The ACPA:

I want to help the ACPA. Enclosed is my tax-deductible donation of $______

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We welcome gifts in any amount:

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The ACPA is happy to acknowledge the birthdays, anniversaries, and special occasions of members or their loved ones. We also provide space in The Chronicle for tributes, memorials and thank you notices. To recognize a loved one on our tribute page, call 1-800-533-3231 or write to ACPA at P.O. Box 850, Rocklin, CA 95677.

Thanks to:

Purdue Pharma for funding the upcoming redesign of the ACPA Web site

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We Need You

The ACPA is a peer support organization: we help each other learn to live fully in spite of chronic pain. We also need to join together to make sure the ACPA continues to be there for us all with resources, materials, and that personal contact that can make such a difference.

Your membership, donations, and purchase of materials keep the ACPA alive and reaching out to even more people with pain. Thanks for helping us help others.

To Join The ACPA:

Name __________________________  Address __________________________

City __________________________ State ______ Zip Code ______

Phone Number ____________________  Today’s Date ______ / ______

$30.00 First-Time Membership: You’ll receive the ACPA Member Workbook Manual, Patient to Person: First Steps, a one-year subscription to the ACPA Chronicle, a 10% discount on all other ACPA materials, and a membership card.

$15.00 Renewal Membership: You’ll receive a one-year subscription to the ACPA Chronicle, a 10% discount on all other ACPA materials, and a membership card.

To Donate to The ACPA:

I want to help the ACPA. Enclosed is my tax-deductible donation of $______

If you don’t want acknowledgement of your donation, please check here: ______

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Please return the completed form to: The ACPA, P.O. Box 850, Rocklin, CA 95677

Or visit us at www.theacpa.org to join, donate, or purchase ACPA materials.

This is part of a series of articles intended to give readers more insight into the interests and contributions of ACPA board members.

Claire Patterson, of Philadelphia, joined the ACPA Board of Directors in 2000, but she was not new to the world of managing chronic pain. As president and executive director of the Trigeminal Neuralgia Association, which she founded in 1990, she was familiar with the need for increased public awareness, professional education, and support for those who live with pain.

“I had Trigeminal Neuralgia (TN) for 10 years and had never met anyone else who had it,” said Patterson. “After surgery in Pittsburgh, my surgeon and I started the organization. I found funding, created a national office, and established a network of support groups that spread internationally.”

TN is a nerve disorder that causes episodes of intense, stabbing, electric-shock-like pain in areas of the face and is considered to be the most painful affliction known to medical practice. “We concentrated on research in new pathologies for facial pain,” said Patterson.

In her 30 years of working for nonprofit agencies, she has a handle on the ups and downs that organizations experience as they grow. She is now able to put that knowledge to work for the ACPA.

“People need to know there is a lot going on in the research world with pain in general. It gives us hope that neuroscientists and researchers and looking into pain, that new treatments are coming, and that we haven’t been forgotten,” she said.

Patterson serves as the ACPA’s research liaison to the National Institute of Health, NIAMS (National Institute of Arthritis and Musculoskeletal and Skin Diseases), and also serves as a patient advocate at the National Institute of Dental and Craniofacial Research. “I attend their meetings and share patients’ concerns,” she said. “And I bring back news. Scientists are doing more than many of us realize.”

While working with the board, Patterson hopes to strengthen the ACPA’s infrastructure, so we can better serve our many constituencies and communities.

“The ACPA is offering people with chronic pain a safety net that other single-disease organizations can’t always provide,” Patterson added. “When all is done, after the medication and the surgery, we are still left with residual, ongoing pain. The ACPA can do a lot to help people manage their pain, feel better, and be more functional.”