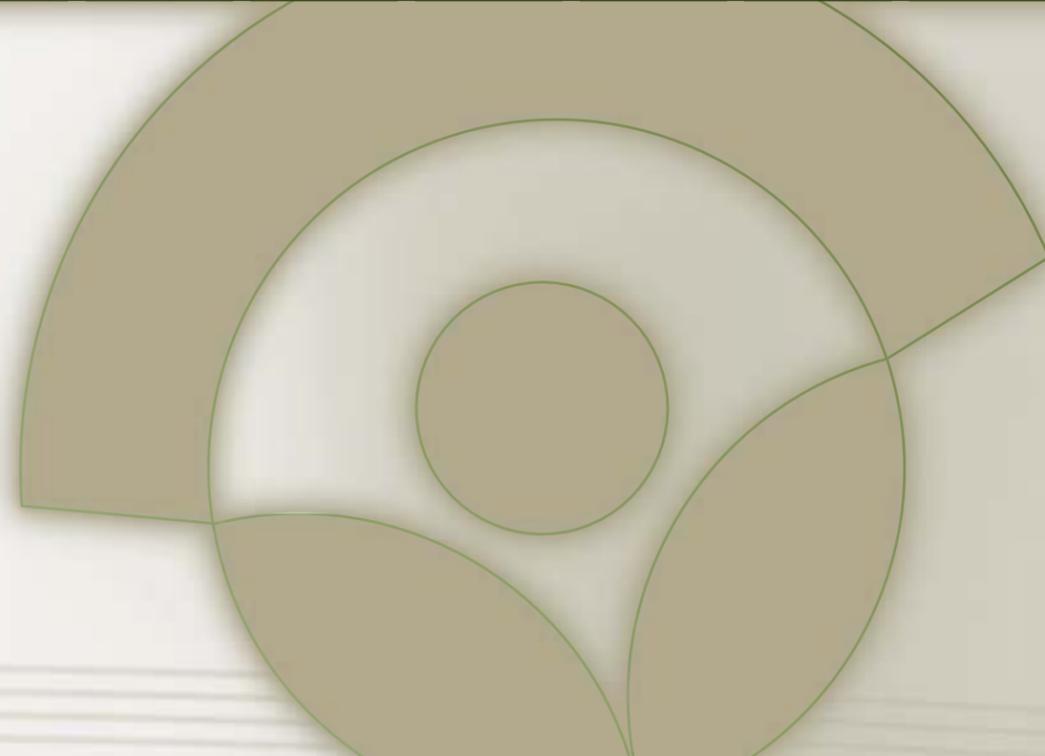


CHRONICLE

The ACPA Mission

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

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



The American Chronic Pain Association

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CHRONICLE



My Lessons of Living with Pain

by Penney Cowan, Executive Director, ACPA

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They say that everything we experience in life has some sort of lesson attached to it. But when you are faced with something so overwhelming that you can't even think straight, get a good night's sleep, or make any plans past the next minute, it is impossible to believe that there is any type of lesson at all. That is what chronic pain can do.

What I find interesting about my long six-year journey of pain was that I was so afraid of what tomorrow was going to bring—what the next moment was going to bring—that it was difficult to focus on anything else but the pain. The pain became my identity and I lost all the other parts of myself, because I was only focusing on the pain.

I believed that if only I could get rid of the pain my life would be manageable once more. The problem was that on days when I experienced less pain,

I was so afraid of the pain returning that I still did nothing. Each day my body became less conditioned, a growing problem I didn't see because I was too focused on getting relief.

About two years after I graduated from the pain program at the Cleveland Clinic it finally occurred to me that it wasn't the pain that was controlling my life, it was the fear. Plain and simple, I was afraid. I was afraid that despite everything that life held for me, I wouldn't be able to be part of it because of the pain.

Amazingly, once I realized my fear was the controlling factor, I was able to understand it, think it through, and move on with life. I guess if there is one thing that has stuck with me all these years—more than 28 years—it is that I am in control.

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The ACPA Chronicle is now available online. Go to www.theacpa.org and click on MEMBERS then on CHRONICLE. Back issues from the past two years are also available there. The Chronicle is published in March, June, September and December. If you would like to receive email notification when a new issue is posted, please contact us at ACPA@pacbell.net and let us know your email address.

If you would like to continue to receive a printed copy of the Chronicle by mail, (available to members only) you must let us know. This March 2007 issue is the last print version you will receive unless you contact us. You can write to P.O. Box 850, Rocklin, CA 95677, email ACPA@pacbell.net, or call 800.533.3231. To join ACPA as a member, complete the form on page 15.

Painful Experiences Make a Positive Difference

by Pat Merritt, Morris County, New Jersey

In my life I have learned many things about painful experiences. They hurt, they are not always welcome, and they seldom change, but always they have made a very big, positive difference in my life.

Still, I admit that sometimes I feel as though I live my life hanging onto the end of a yo-yo string, at best learning to tolerate the daily ups and downs. Anyone living with pain can tell you that there are times when the pain is under control and then there are those times when all you can do is just give in to the body's cry for help. That means giving up all normal activity, at least for a while until I can regain some strength. So every day, chronic pain is teaching me patience.

When my body is ruling my life, I find writing helps me to process my feelings and frustrations. Relaxation and affirmation tapes help me to unwind and prevent me from feeling more pain from the stress. When I am able, I do gentle yoga exercises which help my body stay limber and somewhat conditioned. On those days that I feel like doing nothing, I just allow myself to do exactly that—nothing. Chronic pain has taught me to nurture and care for myself in positive ways that support my healing process.

Experience has taught me that if I push myself and do too much, I will pay a price in increased pain levels. For a very long time, I thought that I should still be able to do everything I used to do before my condition. This thinking led to me being very uncomfortable all of the time. Now I assess each activity or event I plan to participate in, mapping out the closest routes, shopping in stores that have seating areas, and overall trying to minimize the amount of

discomfort I will be experiencing. Living with chronic pain has taught me to better balance my life and choose the activities that are most important to me.

Because I do not walk with a cane or a walker, most people do not see my pain or my disability. Their comments can sometimes create feelings of guilt and even self doubt. Now I take the time to educate people about conditions that are not always apparent to the naked eye. Chronic pain has taught me to put myself above other people's opinions and to accept myself for who I am.

About six months ago, I decided to leave my job. It was a very difficult decision that has given me extra time to care for myself but left me isolated from people. Still, it became very clear to me that it is much better to keep as active as I can, get a new vision for my life, and stay connected to people. Another lesson: I am not my job or what I do. I am not even my body. I am a person who is trying to re-create a balanced, happy life in spite of my physical disability.

Though I have tried physical therapy, massage, acupuncture, Rolfing, lumbar injections, medications, chiropractic manipulation, homeopathy, and yoga, I have tried to stay open to new advances in medicine and never give up hope. Someday, a new procedure might help my condition. This is pain's ongoing lesson of hope and perseverance.

About two years ago, I started a support group for people living with chronic pain and it has truly changed my life for the better by connecting me with people who understand. We listen and support each other because we know the challenges that each of us faces every day and share the common experience of living with chronic pain. In our support group, I can take what I have learned and pass it to someone else. If I help one individual learn to better cope with chronic pain then I have made a difference.

Pat facilitates the Morris County, N.J., Chapter of the ACPA, creates guided imagery and relaxation CDs to reduce pain and hopes to teach coping strategies for people living with chronic pain.

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The Voices of People with Pain.

In this issue of *Chronicle*, we opened our pages up to our readers. Eight ACPA members were kind enough to share their stories. "Voices of People with Pain" tells of the lessons learned, the challenges conquered, and the perspective gained by living with chronic pain.

Special thanks to Linda Balanesi, Andrea M. Bowen, Marg Hall, Theresa McConville, Pat Merritt, Sally Price, Georgia Short, and Jonathan Van Ee. Other essays that we received may appear in future issues.

What Living with Pain Has Taught Me

by Theresa McConville, Mount Vernon, Washington

Pain taught me that it comes in a variety of ways and in varying degrees of intensity.

Pain medications don't always work to relieve all of the pain the way we expect they will. And sometimes doctors refuse to treat our pain with stronger pain medications for fear of making addicts out of us. Pain has taught me that patience and compliance with doctor's orders can win respect and the meds I need to survive.

My pain is associated with multiple back surgeries. The last surgery in 1998 was to repair a Meningocele and left me paralyzed and in constant pain. I've been diagnosed with spinal adhesive arachnoiditis, cauda equina syndrome, shunt dependent, degenerative disc disease, and arthritis.

Pain has taught me that not all friendships survive under the weight of chronic pain. Family members aren't immune either. I guess people in pain all the time are a drag to be around.

"Stress reduction also eases pain, so I journal, read, paint, sculpt, design, and live beneath my financial means. I've also learned the value of play and the usefulness of body movement."

Volunteering and living proactively eases pain by helping me to get outside of myself and to feel more in control of my life. The Internet is a fabulous venue for socializing with people who are busy coping with their own pain.

It can also be a valuable tool to find books and tools that can make life easier.



Stress reduction also eases pain, so I journal, read, paint, sculpt, design, and live beneath my financial means. I've also learned the value of play and the usefulness of body movement.

Pain taught me to research, acquire, and then actually use every assistive device I could find. My strategy is to know my pain and my options so that I can take full advantage of the good days.

I have learned to use the cornerstone of my pain management system—my adjustable bed. It adjusts to various positions and has a heating feature, but the best aspect for me has to be the alternating pressure pad. A powerful air pump fills and empties rows of baffles that keep the mat moving underneath. This prevents the pain of pressure points and bedsores. I can't sleep on anything else. I use a power wheelchair inside and out, but my bed is where I

go to rejuvenate and ease the pain of being up and about.

I share my life with dogs. I enjoy training and can really use a well-trained service dog to help me to get outside in all kinds of weather at any time of day. My dog reconnects me to nature, allays any fears I may have had about being alone, and widens my social world.

Pain has taught me to go inside myself to feed my soul and live in hope with a positive mental attitude.

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Overcoming Chronic Pain

by Jonathan Van Ee, San Jose, California

I was 30 years old when the pain started and was working in a law firm. I have since read that stress-related chronic pain conditions afflict people in their 30s and 40s who are in some of the busiest and most stressful times of their lives.

Right before the holidays started, all my billable hours had to be entered into the law firm's database. This was a huge task. I typed fast for about two hours.

That's when the pain started and it did not go away. Thereafter, the backs of my fingers ached every time I typed. After about two months, I booked an appointment with a doctor.

That doctor told me my condition was not at all serious and would definitely get better over time. He diagnosed me with tendonitis, saying the tendons in my fingers were sore from overuse.

But, neither the anti-inflammatory medication nor icing my hands seemed to help.

My condition improved a little and stabilized. At least I was not getting worse. For the next two years I would live with the same continuous dull pain in my fingers. Then, it started getting worse. Much, much worse.

I saw a number of specialists and physical therapists, read books, researched the Internet extensively, spoke with many people about my pain, and stopped typing completely. But my condition deteriorated to the point where I effectively stopped using my hands. My legal career, art hobby, and pretty well my entire life came to a halt.

Eventually I attended a repetitive stress injury support group in San Francisco. There, a group of panelists repeated that that your mind can play an important role in causing pain.

"When I refocused my mind, my pain immediately started to lift."

To cure the pain, they said, you must make your mind change how it interprets pain.

That approach made a lot of sense to me, because I had started to question whether my pain was really the result of a problem with the tendons in my fingers. When I would sit in front of a computer my hands would be in pain. But, if I sat on a couch, I wouldn't necessarily feel the same level of pain. That made absolutely no sense to me and my doctors and therapists couldn't offer an explanation either.

I came to believe that my mind was causing the pain and that I must treat my condition by pushing through the pain. After reading up on this approach, I uncovered a number of notable facts. One Harvard student indicated there is no evidence (none!) that there is anything wrong with the tendons of people who have been diagnosed with tendonitis caused by repetitive stress injuries (like me).

When I refocused my mind, my pain immediately started to lift. Now I can feel only the memory of pain in the tendons of my fingers. They feel like a muscle sprained some time ago.

Doctors who employ the mind-is-body approach believe that it works not only for tendonitis, but also for back pain, (which is where the approach actually started) headaches, fibromyalgia, and much more.

I have often wondered why I didn't improve sooner. Here is what I've learned.

1. I didn't question my own mind. If I had questioned the strength of my mind the same way I questioned the strength of the tendons in my fingers, I would have conquered the pain sooner.
2. Doctors who depend on referrals for business are reluctant to even mention that pain is caused by the mind. (At the onset of my pain, I probably would also have been offended.) Doctors and physical therapists do not use the mind-is-body approach because it is not in their financial interest to cure chronic pain patients. Cured clients cease to be clients.

The numerous success stories that I heard were the most powerful force in my trying this approach.

More details on Jonathan VanEe's story are at www.mindisbody.com. View his artwork at www.jonathanvanee.com.



painting by Jonathan Van Ee

Chronic Pain 101

by Andrea M. Bowen, Maine

Apparently the sign-up sheet for the short course on pain was full. So began my studies as a lifelong learner—with chronic pain as my teacher. Plenty of lessons along with never-ending tests became the norm and remain so to this day. Thirty-four years is a long time to be in this course but the daily lessons and accumulated knowledge continue to have an impact on my life and change the way I view the world.



To survive the journey I instinctively began living a day at a time; actually, a doctor's appointment at a time. Life and pain merged into one. I lost my "life" to pain for a long time. I pretended to be retired at 23 and vowed to work longer when older. I never imagined an entire life with pain and kept thinking the pain would disappear with each surgery on my spine.

Living a day at a time kept me going even through my darkest days. It remains a very useful life strategy.

The pain taught me that my pain experience is my own, affected by my personality, my upbringing, and my emotional wounds. I empathize with

your pain, but mine is mine and yours is yours. Most folks experience pain as an acute episode. They may stub a toe or jam a finger in a door. Their reaction may be huge. After all, this may be the worst pain they have ever felt. For each of us the reference point is different. Pain tells me to remember this wisdom and be empathic to others' experience with pain.

Hunting for control was, for me, the kiss of death for a happy life.

Pain keeps me honest. Cheating has no place when it comes to the issue of control. The quest to control the pain lasted many, many years and guided my decision-making around treatment choices.

"Living a day at a time kept me going even through my darkest days. It remains a very useful life strategy."

Through trial and error (many, many errors), I discovered control to be an illusion. The only part of the pain experience I can control is my reaction to pain, not the pain itself. By responding to pain through my

smorgasbord of pain management strategies, I move from victim to victor and survive the everydayness of the pain.

I had heard the saying, "grieve the loss" and was clueless as to what it meant. Pain taught me that to live the life I have now, I must give up the one I thought I had. The roller-coaster of grief over what I can no longer do or aspire to, and the acceptance of my pain and what I can do and can aspire to, continues, but the ups and downs are less severe. Acceptance is deepening and self care is growing. Doing what I can to keep my body and mind in good condition is getting easier.

The lifelong course continues with these sage lessons learned:

- ❖ Take life a day at a time
- ❖ Have empathy for others' pain without comparing it to my own
- ❖ Beware of the need to control
- ❖ Respond rather than react to pain (response requires thought and choice)
- ❖ Accept the pain

And just when I think I'm doing really well, another pop quiz is given and I learn the lessons over again. These lessons provide me a hopeful and happy life.

Andrea M. Bowen is the author of "The Art of Living with Chronic Pain" available on www.pookapub.com.

Going to Hell and Back

by Marg Hall, Lake Tahoe, California

Chronic back pain has changed my life. Since 2003 I have been to countless doctors in search of an accurate diagnosis and effective treatment. It has meant that at age 59, I am currently unable to work and unable to make even the simplest of commitments. I think of the last few years as a trip into the “underworld.” My friends, family, and co-workers, to some degree, have been forced to go along with me on this journey.

I can no longer travel in the ways I did when I was younger, but I have been traveling in a spiritual sense. Like the Greek mythical maiden Persephone, who in one instant lost the ground beneath her feet and was swept by Hades into hell, I have had to suddenly confront dramatic changes.

Facing pain and disability brought with it anxiety, fear, and depression. I felt as if the gods and goddesses had thrown me to the ground and held me there until I cried “Uncle!” My life was way out of control. At one point I was told I probably had ovarian cancer (I don’t) and felt relief as well as terror, that an end was in sight.

“I learned to see chronic pain as simply another challenge to my nerdy, engineering self. I could still do a lot; I just had to figure out how to do things differently. My motto became, ‘Adapt. Don’t Fight.’”

Two books helped me learn to live a deeper, fuller, more accepting life. I recommend them to my fellow travelers. The first is *Close to the Bone: Life Threatening Illness and the Search for Meaning* by Jean Shinoda Bolen, M.D. Although written for those confronting cancer, AIDS, and other terminal illnesses, this book is still filled with helpful wisdom for those of us grappling with life-altering disabilities like chronic pain. I have rediscovered my contemplative side. I find great joy in reading, meditation, and quiet observation of the mysteries of the natural world. I now have a deeper pagan spirituality and a vast new reservoir of compassion for those in our society who are disabled, sick, or just simply underdogs.

The second book that helped me is *Moving Violations* by John Hockenberry. The author is a former NPR reporter who has traveled the world in his wheelchair. When an auto

accident left him paralyzed at age 19, he found himself with a radically different body and set of challenges. This is the story of his personal transformation, of his very unique take on world events and the world of disability, told with an amazing sense of humor and creativity. By reading this book I learned to see chronic pain as simply another challenge to my nerdy, engineering self. I could still do a lot; I just had to figure out how to do things differently. My motto became, “Adapt. Don’t Fight.”

This vision came to me to give me comfort. I was climbing up glacier point at Yosemite (I like to hike) and this trail, of necessity, involves scores of switchbacks to accommodate a 3,000 foot climb. The switchbacks are simply the means to arrive at the top: adaptive devices, as it were. Looking back, the hike isn’t about the switchbacks; it’s about the overall journey. What does it matter how I get there as long as I find some joy in getting there? So, as an example, since sitting is often painful, I made a bed in my car so that whenever the pain got too much I could pull over and lie down. My inflatable camping mat is like a switchback that gives me more mobility. I carry it everywhere.

I’ve learned that having chronic pain and discovering methods to cope with this particular disability is a lot like a journey to hell and back, and a bit like going on a steep hike. We get to travel as much as the other guy—we just do it a little differently and get to see a lot of things that other folks might miss.



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Pain as Companion and Teacher

by Sally Price, Newport News, Virginia

When I think of what pain has taught me, I have to go back to my old diary entries, where I recorded those first lessons.

5/8/00: “Bad pain day yesterday and today. Finally got to sleep Sunday morning around 4:30 a.m. Up today at 7:20 a.m. to wash hair and dress so can lie down by 8:10 a.m. so can pick Nan up at 9 a.m. for Sunday School at 9:15 a.m. Nan has to get up at 6 a.m. to be ready, for she has to spend one hour sitting hooked up to oxygen. We all have our hardships. So I dragged through day yesterday with increased pain and tiredness, didn’t go to church musical because knew I hurt too much and wouldn’t be able to see any of it for lying down in pew.”

1/26/02: “I don’t feel like I have to please everyone as much. I feel more my own person. If someone doesn’t like me, too bad. I’ve discovered that a voice I kept hearing in my head—making me feel responsible for everyone and everything around me—is not God but is a lie I can reject, without guilt!”

5/20/05: “I hate this pain, this control on my life. Why Lord, why do I have to deal with this? It is on my heels constantly like a yipping dog, constantly pulling me down like gravity.”

After reviewing my recent diaries, I then read some entries from the 1950s when I was a teenager.

3/27/58: “I got mad at Joanie. She told me it was all my fault that Milton stopped liking me because I told her I didn’t like him one day. He calls me his ex-girlfriend. At lunchtime I was feeling lonely and unwanted.”



“Sometimes when I have a tendency to blame everything on my pain, I have to remember that I would have had problems from life and aging whether I had chronic pain or not.”

In my teenage days I had no pain, but I still had problems and emotional ups and downs. Sometimes when I have a tendency to blame everything on my pain, I have to remember that I would have had problems from life and aging whether I had chronic pain or not.

Today I live more comfortably than I have in the nearly 28 years I have had persistent low back pain. What has helped? A pain pump implanted six years ago has reduced the intensity of the pain. Through the ACPA I learned to manage my pain by accepting my limitations (the hardest step), realizing the part my emotions play in my pain, and keeping a grateful attitude by focusing on what I can do rather than what I can’t. I also grow in my faith in Jesus so I don’t feel sorry for myself, and reach out to others with as much laughter as I can muster.

I also recommend two books that were helpful in dealing with my perfectionism and physical pain: *Seduced by Success* and *Harvest from the Pain*.

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Finding Hope in a Life of Pain

by Georgia A. Short, Oregon

My life of pain began in the early 1970s after a house-related accident. The pain went down my neck into my shoulders, down my arm, and into my fingertips. I couldn't eat for a week because of the jaw pain. We didn't have money to treat it, so the pain remains much the same today.

In my 40s I developed endometriosis, which doubled me over often due to the severity of the pain. After four to five years of this, I had a hysterectomy, but there were complications. I was in the hospital eight days and almost died.

Later, I developed Lyme disease. Aside from my regular pain, I had to wrap my knees to walk and went to our county fair in a wheelchair. I was left with arthritis in both knees, going to the emergency room for the pain. By this time I was diagnosed with myofascial syndrome and fibromyalgia.

The pain was advanced at this time at all points. I don't have flare-ups because I have the pain 24/7.

Two years ago I had a fall and have gone through excruciating pain in my sacrum and both buttocks. I also had a bi-level cervical fusion. There were so many bone spurs the doctor spent an extra hour removing them. My neck still hurts, pain that will wax and wane as it heals.

At this point, with pain medication not working and my weight dropping dangerously, I didn't want to live and was losing my battle with despair. I had set a date and method to take my own life.

I picked up the phone and started saying my goodbyes. When she heard from me, my sister drove up from California even though we had been estranged for six years. She took me to my daughter's home and they pampered me for a



"Our plans are to try to get a fixer-upper sailboat and go to the South Pacific to help others."

week. I gained some weight, but most of all they gave me hope.

Each day something happens and I think, "I would have missed this." I just met a girl who is in the Israeli army for whom I now pray. I talk to my sister several times a week. I just had a wonderful Christmas with my daughter and four grandchildren.

Our plans are to try to get a fixer-upper sailboat and go to the South Pacific to help others. While we are on the dock we are reaching out to others. Many are hurting and I honestly care and listen much more than I did before. I can honestly say, "I know how you feel."

No longer do I feel useless. I have even been able to start water exercise in a pool again. For those of you who may be feeling that there is no hope, I pray this story encourages you. Feel free to contact me (through the ACPA headquarters office).

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Pain Teaches Appreciation of Courage, Everyday Joys

by Linda Balanesi, San Mateo, California

Chronic pain entered my life 11 years ago, following a serious illness. Like most of us with chronic pain, I attempt to minimize the impact of it and find joy and fulfillment in everyday life.

I learned to trust my own knowledge and experience. Following my own research, I recognized that I must develop my own plan of care. Healthcare providers do not have all the answers. They are people, and for some, pain management was not included in their education. Also, preconceived ideas are hard to dispel.

I recognize the key importance of sound nutrition, exercise, and regular hours of sleep. I have learned that I need to pace myself, allow myself to change my mind, or say "no." So I work and play within my own parameters. I give myself permission to take a sick day when symptoms escalate, even when I would rather not.

I found that a pet is a wonderful therapist. As long as she feels safe and her needs are met, she does not care whether I have health issues. Her honest, non-judgmental behavior allows me to be myself. Her presence assists me in releasing worries at bedtime and encourages me to be more active during the day.

I have come to recognize the courageous among us. It is courageous to meet personal, family, and community obligations while dealing with ongoing, painful conditions. This recognition has brought me another gift, patience.

My daily experience with pain has value to others. This is somewhat comforting to me. I can enlighten other healthcare professionals. There have been instances when my recognition of a patient's chronic pain has yielded positive results. And my peers know that pain is of key importance to me. We had a poster presentation and pain symposium this September.



I have great appreciation for things others take for granted. I feel a sense of accomplishment in completing simple tasks: grocery shopping, washing clothes, cleaning my apartment, traveling to doctor's appointments, and such. I love the warmth of the sun, delight in the antics of the hummingbirds, and find joy in patio gardening.

Although I would love to be free of this pain it is unlikely I ever will. I don't have to like it but what is, is.

Lesson of Living with Pain CONTINUED FROM PAGE 1...

I am in control because I understand that there will be times when I may not be able to do as much as I would like, but that these times will pass.

Pain may always be a part of my life, but each day I remind myself that in spite of the pain I still have the ability to live as I choose. I don't allow the fear that pain may restrict me to prevent me from making plans to live my life.

Fear is the controlling factor for so many of us. Though the pain can stop us in our tracks, if we can conquer the fear, somehow we can enjoy those good days more and get through the most

difficult days with less stress . . . and fear.

There are many lessons to be learned when life is challenged by pain. These lessons are an ongoing reminder that we need to:

- * Focus on our abilities, not our disabilities
- * Concentrate on things that we can control
- * Exercise every day
- * Live by the motto: "Don't sweat the small stuff and it's all small stuff."
- * Listen to our bodies and know when to stop
- * Keep our inner child alive through play

* Maintain our right to do less than humanly possible.

These are but a few of the lessons that I have learned along my journey from patient to person. Amazingly, no matter how far you travel in your journey, there is always something to learn.

"If we can conquer the fear, somehow we can enjoy those good days more and get through the most difficult days with less stress."

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Successful Clinical Trials - A Team Effort

by Donald Manning, Medical Affairs, Celgene Corporation and Department of Anesthesiology and Pain Management, University of Virginia; and Alyse Cooper and Elisabeth Kurkimilis, Medical Affairs, Celgene Corporation

The development of new, safe, and effective therapies for pain relief requires careful study in human volunteer participants. People who are interested in participating in clinical trials of new therapies should carefully consider many factors.

What is a Clinical Trial?

A clinical trial is a carefully controlled study conducted in participants who volunteer to test the safety and effectiveness of new drugs, medical devices, or techniques. Studies of drugs and devices are controlled by the United States Food and Drug Administration (FDA), and form the basis of drug and device approvals in our country. Without the completion of high-quality, accurate clinical trials and subsequent approval of new treatments, medical science and the high level of healthcare we have come to know would be impossible to maintain.

Pharmaceutical/biotechnology companies, professional organizations, or government agencies typically conduct clinical trials, however, trials which are considered to be exploratory in nature could also be organized and run by individual physicians or investigators. In this article we will concentrate on trials of new drugs.

A clinical trial is assigned a phase number based on the type of question(s) the study hopes to answer. In **Phase I** studies, researchers test a new drug or treatment among 20 to 80 healthy volunteers or in some cases, patients, for the first time. These early studies determine a safe dose range, look at side effects associated with increasing the dose of the drug, help to gain some early evidence of effectiveness, and examine how the body breaks down, absorbs, and eliminates the compound.

After the successful completion of Phase I studies, **Phase II** studies are conducted. These typically involve a larger number of people (100 to 300) who have the condition for which the drug was developed. They look at the safety and potential efficacy of the drug. Because of the exploratory and early nature of these trials, investigators place significant restrictions on the type of participants in the study to give the greatest chance of seeing an effect of the drug without the interference of other medical conditions or treatments.

Large **Phase III** trials are conducted once a drug has been determined to be safe and effective. These trials are designed to confirm the efficacy of the study drug in a broader

population—one that is more representative of the people who will eventually use the drug. As these trials are considered critical for drug approval, strict protocol adherence is required in order to comply with government regulations and guidelines. These trials, which can involve thousands of people, test the study drug against the best standard therapy used for the treatment of the disease under study. Many times, if there is no other standard therapy, the study drug is compared to a placebo (sugar pill) rather than another active treatment.

Results from Phase III studies evaluate the overall risk-benefit ratio (effectiveness of the drug compared to potential side effects caused by the drug) and provide information which is used by the manufacturer in the package insert and labeling. After drug approval, **Phase IV** post-marketing studies are conducted. These studies typically provide additional information regarding the safety, benefits, and optimal use of the drug. Trials in this phase usually have the least restrictions on participant entry.

Seeking Answers

Participants in pain therapy trials should seek and be comfortable with answers to these questions before agreeing to enter a trial.

Do I qualify for this study?

Study protocols contain information regarding the requirements needed for a participant to enroll. These “inclusion” and “exclusion” criteria are based on such factors as age, gender, type/stage of disease, medical history, medications being taken, laboratory values, etc. These criteria help to ensure 1) the safety of the participants and 2) that the study objectives are fully met. Based on these criteria, the Clinical Investigator will determine if you are eligible to participate in the study.

What happens if I have a pain flare or pain due to an event or trauma not associated with the condition being studied? What “rescue” medications, if any, will I be permitted to use?

Many studies include provisions for the use of additional pain medication in the event of a pain flare or trauma of some type. Because additional pain medication can have an impact on the ability to assess the effectiveness of the study medication, the protocol may limit the number of times a rescue medication may be taken and/or when the medication may be taken during the study. The names of permissible rescue medications may also be indicated in the protocol.

Will I be allowed to change the study drug dose in the event I experience an adverse event?

The protocol will specify under what conditions study drug dosage changes will be permitted. In cases where the study objective is to determine how high a drug dose can be tolerated, participants may be required to discontinue from the study in the event a study drug dosage decrease is required.

Will I be allowed to continue on my current pain medication?

Studies of pain therapies are frequently complex due to the nature of pain. Many times, it is difficult to design studies for pain indications due to the number of pain-relief medications the participant is already taking. Some studies, for example, will ask participants to continue taking their pain-relief medications with no variation in dosing allowed; others will ask participants to discontinue all of their current pain-relief medication and wait for the pain to worsen (called a “flare” design).

Are all of the study drugs “active” or is there a possibility I could receive a placebo?

Many pain studies are designed to permit the continuation of current pain medication(s), especially if there is a possibility that a participant could receive a placebo. This helps to ensure, from an ethical perspective, that pain levels of participants receiving placebos will, we hope, at least remain stable and not increase in intensity. Some studies are also designed with an additional continuation phase that ensures receipt of an active study drug for all participants, once the initial portion of the study has been completed.

How much work and time commitment is required of me?

The informed consent document, which you sign prior to study participation, contains specific information regarding how frequently you will need to return for study visits and the type of assessments (questionnaires, laboratory work, etc.) that will be completed at each visit. If you have any questions or concerns regarding the study requirements, you should not hesitate to ask the Clinical Investigator or study coordinator prior to agreeing to participate in the study.

Will I be able to return for an “unscheduled” study visit if I have a problem?

Yes. The safety of study participants is the first concern in clinical studies. If you have a problem during the course of the study and your physician feels it is necessary for you to return to the office, he/she will conduct an extra study visit to ensure your well-being.

Will I know the outcome of this study?

Once a study has been completed and the data has been analyzed, results can be made available to participants. Each investigator will receive data only on his/her patients. In addition, the results of the studies will, in general, be

Your Rights in a Clinical Trial

The FDA has established regulations and guidelines under which clinical trials must be conducted. All participants in studies are free to give consent and are guaranteed certain rights. These might include the right to know exactly what will happen to you; what other treatment choices are available to you; the right to ask questions prior, during, and after participation in a trial; and the right to leave the trial at any time by withdrawing your consent.

Here are some questions that study participants should always ask.

- ✧ What is the purpose of the study?
- ✧ Has this treatment been studied before?
- ✧ How long will my participation last?
- ✧ Are special procedures required (such as a hospital stay, or specialized tests)?
- ✧ What are the possible risks and benefits?
- ✧ Who do I contact with any questions or concerns?
- ✧ Will my insurance or I be required to pay for any of the treatment?
- ✧ Will I be reimbursed for travel-related expenses relating to my study participation?
- ✧ What long-term care is part of the study?
- ✧ Who will be in charge of my care?
- ✧ Will I be compensated if I am injured during the trial due to treatment?

published following the analysis and interpretation of the complete set of data. As studies may continue for years, however, participants must understand that information regarding the outcome of the study may not be available until long after their participation has been completed.

Your Responsibilities

Part two of this article will address the responsibilities of the study participants, the study sponsor, and the study site personnel to ensure successful, high-quality clinical trials.

Additional information regarding clinical trials may be found on the following websites:

- www.cisr.org
- www.diahome.org
- www.clinicaltrials.gov
- www.centerwatch.com
- www.cancer.gov
- www.clinicaltrials.com
- <http://clinicalstudies.info.nih.gov/>

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ACPA Update

New ACPA Groups

Welcome to our new groups and facilitators.

Chris Clark
Florence, AL

Kevin Miller
Chandler, AZ

Margaret Hall
North Tahoe/Truckee, CA

Kay Sorrell
Ft. Lauderdale, FL

Nicholas Martin
Lansing, MI

Bill Kunert
Rolla, MO

Cherith Hamilton
Wings of Grace
Bozeman, MT

Patricia Santoro
Warren and Morris
counties, NJ

Rex Marshall
Uniontown, OH

Michael Scott
Yakima, WA

Michael Hutchison
Milwaukee, WI

Roger Mai
Milwaukee, WI

David Bailey
Milwaukee, WI

Robert Felder
Nashotah, WI

Medications Supplement Online

The new ACPA Medications & Chronic Pain 2007 Supplement is now available at www.theacpa.org. Updated yearly by Dr. Steven D. Feinberg, the supplement was originally written by Dr. Edward C. Covington.

A valuable source of information about pain medications, it includes web links for certain medications and relevant Internet sites of interest. Generic names are primarily listed with brand names in parentheses.

The supplement deals only with medications and does not mention the many other important treatment approaches to chronic pain. It is not meant to serve as medical advice for your condition or your specific medication needs. Remember that the best source of information about your health and medication needs is an open dialogue with your treating doctor.

Visit our New Web Site

The ACPA has a new and better Web site, made possible through an unrestricted educational grant from Purdue Pharma. The new site is easier to use, with a search function. It also has a calendar of events and easy access to copies of the *Chronicle*. We hope visitors will come back often to check out the changing news and features, read weekly tips for those who live with pain, and respond to the interactive poll. The new site has an online store which makes it easy to order brochures, manuals, CDs, and even t-shirts.

New Facilitators Newsletter

ACPA facilitators can stock up on tips, good advice, and useful information through the new ACPA Facilitators Newsletter.

Kristianne Sunde, Facilitator Resource Coordinator for the ACPA, has just published the first issue, which is available to any facilitator. The six-page newsletter covers how to plan support group meetings

and find a location to meet. Another article reviews how people with chronic pain can benefit from reasonable expectations and pacing their activities.

To get a copy of the newsletter or to make comments and suggestions, please contact Kristi at acpagroups@pacbell.net or phone the ACPA at (800) 533-3231.

APS Names Centers Of Excellence

One of the ACPA's Partners for Understanding Pain, the American Pain Society (APS), is honoring the country's outstanding pain care programs by naming Clinical Centers of Excellence in Pain Management. This awards program recognizes forward-thinking teams of health-care professionals who are addressing the critical needs in pain management on the local level.

"This furthers our strategic goal to advocate and promote the benefits of multidisciplinary pain management programs," said APS President Judith Paice, RN, PhD. APS asserts that a successful pain management program requires a team of health care professionals who understand the complex mix of clinical, psychological, social, and emotional variables that affect people with pain.

Any multidisciplinary program within the U.S. that provides direct patient care and is primarily focused on the treatment of pain was eligible to apply. Nominations for 2006 closed in January 2007. APS will present this prestigious recognition during the Society's annual scientific meeting in Washington, D.C., May 2 to 5, 2007.

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Board Member Profile: Donna A. K. Kalauokalani



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

The newest member of the ACPA board of directors is Donna A. K. Kalauokalani, MD, MPH, Assistant Professor, Department of Anesthesiology and Pain Medicine at the University of California, Davis School of Medicine. She is also Director of Health Outcomes Research in the Division of Pain Medicine there.

Dr. Kalauokalani was asked to join the ACPA board in 2006, after meeting Penney Cowan at a conference at UC Davis. "Not many organizations represent the patient's voice," said Dr. Kalauokalani. The ACPA and its partners and activities do a good job of that and should continue to seek opportunities to do so. I look forward to incorporating more ACPA materials in my health services research and academic activities."

Born in Honolulu, Hawaii, Dr. Kalauokalani found that specializing in pain was a natural fit with her native culture. "When I was in medical school in the late 1990's pain management was just coming together as a field," she said. "But alternative medicine felt natural. It was part of my upbringing."

She specialized in anesthesiology, but "every turn I made was bringing me closer to pain management," she said. She asked her fellowship director Dr. John Loeser, professor of neurosurgery at University of Washington, "How do we evaluate what we are doing to manage pain in an evidence-based fashion?"

At his suggestion, she pursued that question in her studies, training as a

Fellow of the Robert Wood Johnson Clinical Scholars Program at the University of Washington, from 1997 to 1999, where she also obtained her master's degree in public health.

Dr. Kalauokalani specializes in anesthesiology, pain management, and preventive medicine. She splits her time between research and patient care and is currently involved in three interesting projects. One of them is an American Cancer Society-funded study, which examines how a patient coaching intervention can help patients with cancer pain work with their doctors, gain more control over their pain, and be better advocates for their own health.

"Not many organizations represent the patient's voice. The ACPA and its partners and activities do a good job of that and should continue to seek opportunities to do so."

In Dr. Kalauokalani's second project, through the Agency for Healthcare Research and Quality, she is studying racial and ethnic disparities in treating occupational low back pain.

She is also leading a program development project focused on improving the quality and value of pain care in prisons. "We don't often consider how chronic pain intersects with mental illness and drug abuse, but for the prison population, that is a common problem," she said.

"I enjoy the research, inquiring and investigating from a health services perspective to determine what is an

adequate standard for patient care—and how we improve access to good care."

Though she interacts with many people with chronic pain in her research and as a consultant, Dr. Kalauokalani has also had personal experience with pain. A bout with sciatica a few years ago made it very hard to sleep, drive, or sit. "It's tough to be the patient," she said. "It took a lot of time, effort, and physical therapy to get back to my normal functioning."

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The Chronicle is published quarterly by the American Chronic Pain Association.

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

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**In Memory of
RALPH ZAPPALA**

Given by
Richard and Susan Hanson

**A Salute to our Very Best:
DALE GENOVA STRICKLAND**

This lovely, talented and so humorous and wonderful lady left us this past December 14, 2006. Oh! How we all miss her and how we miss those monthly newsletters she created—so colorful and so unique, which she mailed to each of us.

Dale was with our group from its inception, November 1994. And from that date on, she continually and unselfishly supported and encouraged her fellow ACPA members, even though she herself was suffering immensely. Through it all, our Dale was a loving wife and cherished family member.

Most of all, Dale was fun. Dale was funny! She made all of us laugh! And Dale loved us, each and every one of us. We were all her sisters (and a brother).

Our hats are off to you, our dearest one.
God bless your sweetest heart.

With all of our love,
"The Aloha Group," Fort Lauderdale, Florida

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CEPHALON

for a grant to conduct our survey *Understanding Pain in the Emergency Department*

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.

We welcome gifts in any amount:

Supporting Contributor	Up to \$25
Sustaining Contributor	\$25 to \$50
Patron	\$50 to \$100
Hero	\$100 to \$250
Champion	\$250 to \$500
Angel	Over \$500

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:

Become a member of ACPA. A \$25 donation to the ACPA entitles you to membership through Dec. 31, 2007. You'll receive a membership card and a 10 percent discount on all ACPA materials or products.

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