The ACPA Mission:

To fulfill your aspira-
tions, through the
flexibility and inde-
dependence of your
individual pain,
and the public
whole.

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2005

Caring for Your Emotional Health
by Patricia Conlin, Executive Director, ACPA

The personal and social impact of chronic pain can be overwhelming. While we may try to cope with our pain in a variety of ways, we also need to recognize the emotional effects of chronic pain.

Most of us are familiar with the effects of emotions: strong feelings of joy, sorrow, reverence, hate, or love that can come over us without warning, without warning, and sometimes, with negative consequences.

At some point in our search for relief from chronic pain, we have all heard the words: “It’s all in your head.” There is some degree of truth to this statement. However, the mind-body connection is not a simple issue that can be explained away by psychological factors. We are people with real feelings, though we may be ill-equipped to recognize these emotions during times of physical distress. We need to understand the direct effect emotions have on our pain levels and on our ability to cope. At the same time we need to understand how pain affects our emotions during these stressful times.

If we examine what Dr. Bernie Siegel, well-known author of Love, Medicine & Miracles, has to say, we might begin to understand the depth to which our emotions affect our well-being. He says:

“...it personally feel that we do have biological ‘live and die’ mechanisms within us. Other doctors' scientific research and my own day-to-day clinical experience have convinced me that the state of the mind changes the state of the body by working through the central nervous system, the endocrine system, and the immune system. Peace of mind sends the body a ‘live’ message, while depression, fear, and unresolved conflict give it a ‘die’ message.”

So perhaps, if we can control or at least recognize emotions, we will gain some power over the way our bodies respond to physical pain. Our emotions certainly play a role in how we respond to long-term or chronic illness. Emotions can be very difficult for those in pain to cope with. In the book Mind! Body Medicine, authors Daniel Goleman and Joel Gurin write about the emotional connection to pain control:

“Thoughts and emotions can directly influence physiological responses, including muscle tension, blood flow, and level of brain chemicals that play important role in the production of pain.”

CONTINUED ON PAGE 5.

Happy Anniversary!
The ACPA is 25 years old!
Help us celebrate at our
members’ meeting in Lake Tahoe.
See page 10 for details.
**Taking Action Helps Defeat Negative Emotions**

**STEP SIX**

After years of dealing with arthritis pain and fibromyalgia, Nancy Fortner has become an expert in turning negative emotions into positive ones. Instead of looking for or expecting big changes in her life, she has learned to congratulate herself on the small victories.

When she feels angry or frustrated about her physical limitations, Nancy focuses on aspects of her life where she has taken control and made her life easier. “It takes discipline,” says the 60-year-old Rio Vista, California resident, “but it pays off.”

Nancy recalls when she began a computerized sign business in order to help her husband take an early retirement. “I soon realized I had been in total denial about my illness,” she says, noting that severe increased symptoms forced her to give up the business. “I felt guilty about it,” says Nancy, “but instead of blaming myself for no longer doing it, I started congratulating myself for having done it at all.”

Another time the mounting clutter in her home discouraged her from inviting friends over, increasing the social isolation that often occurs with chronic pain. She says, “I was blaming myself and saying, ‘Oh, you’re just lazy.”

Instead of dwelling on negative emotions, Nancy searched for one small area she could improve, and found her bathroom vanity.

“In a moment of insight I realized I don’t use these things every day,” she says, and resolved to keep the vanity clear. Feeling encouraged by that success, she slowly worked through the whole house, gradually disposing of things she didn’t use daily. She disciplined herself to keep the areas clear of clutter, and adopted nearer habits, such as sorting the mail right away. In time, she had an organized house, a happier husband, and a solution to what seemed an overwhelming problem.

“I congratulated myself because these are household chores I’m still able to do; chores I don’t have to ask my husband to take over for me,” she says. “It does much to improve my mood—and his too—to come home to a clean house every day.”

Reaching out to other people is another wonderful antidote to a depressed mood. When she wasn’t able to get out to meetings of the various ACRA groups she had started, Nancy found help from online support groups. She is currently a trained moderator for courses offered on the CFIDS/ Fibromyalgia Self-Help website (www.cfidsselfhelp.org).

Nancy is not one to sit and stew in her emotions. She looks for solutions.

When learning to use a C-PAP (Continuous Positive Airways Pressure) machine for her sleep apnea, she became intensely frustrated, so went to a psychologist for help with her emotional state.

When she encountered stiff joints after sitting, a solution came to her at a concert. She felt much better after “swaying to the music.” So now when sitting for a prolonged time she tries to move slightly, “like rocking a baby,” she says.

“I praised myself for coming up with another idea for handling my pain,” Nancy has learned how to take control of the little things she can control and not get hung up in big solutions. “When you have a chronic illness, you’re not going to make it all better.”

Another little thing that has been a big help is to rest before she gets tired, something that most persons with fibromyalgia don’t do. “Usually they push themselves until it’s too late and they get a flare,” she says. (For more information, go to “My Secret Weapon: Pre-Emptive Rest” by Bruce Campbell on www.cfidsselfhelp.org).

Nancy says her biggest obstacle to dealing with her feelings was born her belief in the “shoulds.” “I was a very conscientious, hard-working person. I had to learn that a job that wasn’t done perfectly was still valuable,” she says. “I also had to learn to delegate, and that if others didn’t do it my way, that’s still okay.”

Nancy focuses on the benefits of chronic pain, like finding pleasure in a quadruple rainbow or her two dogs. “People think it’s amazing to see me in an electric scooter with two dogs on leashes,” she says with a hearty laugh.

Her pain has helped her be more aware of other people, she says. “Dealing with suffering has made me feel more a part of the human race. It helps me if I think, ‘How would I feel toward someone in the same situation as me?’ I would be very sympathetic. So why don’t I do the same with myself?”

How we handle our feelings about having chronic pain centers on one thing, says Nancy. “We have a choice. Either we look at ourselves as a victim or as someone facing a challenge.” Doing the latter makes all the difference.

Turning Negatives into Positives

Keeping on top of negative emotions so they don’t overtake us is especially important for people with chronic pain. If stressful feelings aren’t dealt with, they can increase our pain, and decrease our ability to manage the pain. As Nancy says, “Everything is interactive. If I have bad pain it tends to bring my emotions down, and it works the other way too.”

Her daily strategy is to find interesting things to do, “so I don’t think about the pain,” she says. A creative person, she turned to painting and pottery making when she had to give up her teaching job. When the osteoarthritis in her knees made it too hard to stand at an easel or sit at a potter’s wheel, she started making jewelry from semi-precious stones, a hobby she continues today.

When her circumstances changed, Nancy didn’t bemoan the fact that she could no longer do something she loved. Instead, she would congratulate herself on finding something she still could do. It made a lot of difference in her moods, she says.

Nancy is familiar with the damaging effects of negative emotions from her childhood. “I had a lot of anger. My parents divorced, my mother died, and each sibling was adopted by different relatives, and raised separately. There were other events that came up later in my life. I realized this anger was doing me harm. It was zapping my energy,” she says.

When she realized that holding onto anger was only hurting her, she was able to release it. Living in the present also helps to deal with pain and fear.

“I realize there’s nothing I can do, so I redirect (myself) to today,” she says. “If we live in the past or are always looking at the future, we’re missing what we have, and that’s the present.”

**Alternate Ways to Deal with Pain**

Meditation also helps Nancy deal with her emotions and pain. She says, “I meditate two times a day for 15 minutes with my eyes closed. I try not to think of anything. I sort of blank out and go in a state of deep relaxation.”

Getting regular gentle exercise also helps, Nancy says. She swims laps and does aqua aerobics several times a week. “If I start feeling my mood kind of low, I start moving my muscles in some way,” she says, recalling how taking long walks helped her through the intense grief of losing her sister.

Living in the present also helps to deal with pain and fear.
To Move Ahead in Life, Confront Emotions

by Sally Price

If you don’t deal with your feelings, you can’t deal with your pain.

Brenda Hendricks, 52, of The Villages, Florida, has learned that lesson well and others to see the connection between their emotions and their pain.

“When I was first diagnosed with chronic pain, I didn’t want to accept it. I shoved the anger down and got depressed, because of the grief and loss. I didn’t want to deal with the fact I was going to have chronic pain the rest of my life,” Brenda says. “It took years before I could.”

Brenda worked through her emotions with a counselor. “I think she gave me permission to sit there and sob, to let it all out. After awhile you have to stop bawling and say, ‘I’m not going to do this anymore. I have to get on with life.’

Before the therapy helped her overcome her stubbornness, Brenda thought negatively. “I didn’t want to admit my body had changed. I always thought it could be fixed.”

Accepting Pain and Anger

Brenda has had daily, persistent pain for over seven years. It’s mostly in her legs, caused by nerve damage and degenerative disc disease, followed by three back surgeries. Constant driving as a nurse practitioner in a health department may have also contributed to her condition.

As a result, friends and coworkers were afraid to see her. Anger settled in. “I felt I had lost my health and my friends. I didn’t know if I was going to have an income,” she says.

Once she faced her anger, she opened the door to acceptance and peace. Today, as an ACPA facilitator, she sees many people who are stuck in the anger stage. “All they want to do is hammer the doctors. They don’t want to learn to get past the anger, but until they do, they can’t move on,” she says.

Emotions like anger, depression, grief, fear, guilt, and frustration can increase a person’s pain. “If I don’t keep my stress level down, I can’t deal with the pain,” she says. To control her stress, Brenda practices her activity and is assertive, rather than passive or aggressive with others. She accepts that she can’t change people who are in denial about her pain and controls her need for perfection.

Identifying the Cause of Emotions

Brenda recalls feeling guilty because she felt she should be cooking meals. When she understood her guilt, she could accept the fact that she couldn’t stand long enough to cook and that her husband really enjoyed cooking.

Depression poses particular problems for those experiencing continuous pain. As Brenda says, “A lot of us with chronic pain have depression because our serotonin (those feel-good chemicals produced by the brain) levels drop and we can’t always exercise to keep them up. Some people really need to stay on an antidepressant.”

Fear is another strong emotion for those who live with unpredictable days and an uncertain future. Brenda deals with fear by thinking, “I have lived through flare-ups before and they may have lasted two days or three months. I can live with whatever comes down the pike.” She then takes any precaution she can, for instance, making her house more accessible.

Positive emotions now dominate Brenda’s life. She moved to Florida two years ago and, although she misses her grandkids back in Kentucky, the warmer weather and sunny days have lessened her pain. She also received a spinal cord stimulator implant several years ago.

Once Brenda faced her anger, she opened the door to acceptance and peace.

As facilitator of an ACPA group, Brenda enjoys finding good speakers and helping members deal positively with pain’s problems. She’s looking forward to the goal-setting section of the manual and is planning a personal goal to give up sugar in an attempt to reduce pain.

Brenda accepts the reality of chronic pain in her life with pragmatic determination and courage. When she says, “These things happen. Nothing is going to change it. We just have to learn to live with it,” she exhibits a triumphant sense of moving forward with her life.

And the most important thing she’s talking on that journey is hope. “I haven’t given up hope that I can continue to live and have quality of life,” she says.

Caring for Your Emotional Health

As we look at the steps we use to move from patient to person, it is important not to neglect our emotional well-being. I have heard many people in pain say, “It’s hard to know who I am anymore.” People who used to be content with their lives have found that fighting pain has made them short-tempered, lacking their normal get-up-and-go, and often angry with the people they care about. What we don’t yet realize is that our physical feelings have a direct effect on us emotionally. To begin the journey to wellness we must realize this and take the time to treat our emotional well-being as well as our physical health.

Pain is experienced in both your body and your mind. You cannot try to manage them separately if you want to regain control of your life. These are several chapters in your ACPA workbooks on recognizing and managing emotions as well as dealing with depression. I encourage you to review them.

“Keep in mind that we cannot control what we feel emotionally. Situations we experience create emotional reactions, sometimes happy, sometimes not. The best we can do is to recognize that an unwanted emotional state may be connected to something physical, deal with it the best we can, and if necessary, seek help, so that we can continue moving forward in the recovery process.”

Emotions that are ignored or denied can put a substantial roadblock on the path to wellness. If you think you need help to better understand what you are feeling, ask your health care provider for a referral to a psychologist or psychiatrist. These mental health professionals will help you work your way through your emotions.

Our emotional well-being has a direct effect on the outcome of our distress. If we can’t recognize emotions, then we cannot change them and we are missing an important component in the transition from a patient to a person.

Learning to live well in spite of chronic pain is a process. The ACPA’s Ten Steps from Patient to Person outlines skills and attitudes that can help you make the journey. Visit the ACPA online at www.chronicpain.org to learn about all of the Ten Steps. To learn more about emotions, consider the list of books on page 12.
Can Music Lessen Chronic Pain?
Research study finds listening to music can help

Scientists and music lovers have long believed that music influences our body and mind, but its specific contribution to pain relief is still open to debate. Katherine Livesidge, a postgraduate student at the University of Edinburgh, worked with ACRA members to investigate how listening to daily music could affect chronic pain.

Her research considered the way pain travels through the central nervous system and that both psychological and physiological factors probably contribute to changes in pain levels. She also wanted to know how the insistence of pain demands our attention and inhibits our abilities to think and reason.

Because the auditory and nervous systems are connected in the brain, using one system may limit the function of the other; that is, music listening can limit or even override your ability to process pain signals.

The study's goal was to learn the impact of music listening on:
- Actual and perceived pain
- Anxiety and depression
- Information processing (thinking) as a result of pain

Two men and 28 women between ages of 23 and 70 completed the experiment. They included 13 chronic pain patients, and 16 people who do not have pain as a control group. Many were recruited through the ACRA. Participants listened to 15 minutes of jazz music everyday for 28 days, and kept a record of their pain levels and other changes on a computer.

How do you feel?
The results showed that there were short-term benefits from listening to music, but music listening did not lessen pain, anxiety or depression cumulatively across the course of the study, by the day or week. For a short time after listening, participants said they felt better. Daily music listening did improve muscle aches, sleeping patterns, reduced muscle cementation, regulated heart-rates, reduced headaches, and enabled participants to 'block' their pain. Music listening made participants more positive and gave them a new perspective, improving their sense of well-being, control over treatment, and pain levels.

As with pain-killing drugs, music listening benefits are short term and time limited, but they are evident. As anyone who has heard too many Christmas carols knows, the beneficial effects increase as listeners become familiar with the music, but then decrease with over-familiarity.

The study also found that mental processing may be hindered by chronic pain even after pain relief. Music listening allowed participants to reorient their thoughts and divert their attention from their pain.

Livesidge suggests that people with pain can use and enjoy music. Here are some other tips:
- Continuity is more effective, so keep listening on daily basis.
- Choose music with a slow tempo, as this mirrors the resting pulse rate and maximizes your physiological response to the sound.
- Choose one piece of music, and use it as long as you keep liking it. You will reap more benefits as you become more familiar with it.

For the entire study, contact Katherine Livesidge, (K.A.Livesidge@sms.ed.ac.uk)

School Nurses Treating More Kids with Migraines

Though some kids may fake a headache to avoid a test, many young students suffer from frequent migraine headaches. The American Council for Headache Education (ACHE) has a new website—www.ache.org/kids—alerts adults to warning signs and ways to help.

Migraine headaches are more common in school-age children than many believe. A recent survey by ACHE revealed that school nurses see more than ten students a month for headaches, many of which may be migraine.

In fact, 4 to 5 percent of children, some as young as 7 years old, suffer from migraine. The numbers increase after puberty, with 10 percent reporting migraines by late adolescence. And yet, many teachers and parents don’t believe children when they say they have a headache.

Brenda Jowers, RN, a school nurse at University School of Nashville in Tennessee sees about eight students a day complaining of headaches. “I check to see if their eyes hurt, if they see flashes of light, or feel nauseated,” she said. If students report having these migraine symptoms, I make sure that their parents know.”

While some students are highly competitive and get headaches as a result of stress, many are under a doctor’s care for migraine.

“People need to understand there’s a huge difference in the amount of pain with a migraine,” said Jack Hicks, a high school senior who has had migraine headaches since sixth grade. “It’s incapacitating. Often you really can’t function in school.”

Some ways to recognize a headache as a migraine include:
- Awaking from sleep due to a headache
- Worsening or more frequent headaches
- Early morning vomiting without nausea
- Fever or a stiff neck

ACHE has information on its website to help teachers, nurses, and parents identify and treat migrane and chronic headaches in children. To prevent headaches, children should try: getting enough sleep, drinking enough fluids, avoiding foods that trigger headaches, eating a balanced diet, and managing stress.

Jaw Muscle Pain?
Volunteers Needed for TMJ Research

Researchers at Johns Hopkins School of Medicine and the University of Maryland are looking for people with jaw muscle pain from temporomandibular joint disorders (TMJ/TMD). Volunteers are needed for a research study to investigate sleep, pain sensitivity, and symptoms related to TMJ/TMD.

You must be between 18 and 65 years old and have had muscle pain for six months or longer. Participation involves a dental evaluation for TMJ/TMD, completing interviews and questionnaires, two overnight sleep studies at Johns Hopkins, completing sensory testing procedures, and six brief telephone interviews over three months.

Compensation can be up to $450. Upon completion, participants are eligible for one free behavioral medicine consultations for sleep problems, pain, or stress management. Michael T. Smith, Ph.D. is the principle investigator and the study is funded by the National Institutes of Health.

For information, please call 410-614-3596 and ask about the TMJ Sleep Study.

The ACRA and Clinical Trials: From time to time the ACRA is asked to post notifications of clinical trials on our website. To communicate these studies, the ACRA does not endorse or approve the study, its methodology, or the institution conducting the trial, nor do we make any promises as to the outcome for any individual. The decision to participate in such studies should be a matter of personal medical consultation with the individual patient’s doctor.
Neuropathic Pain Network Offers Help on the Web

The Neuropathic Pain Network’s (NPN) new website will provide support to the more than 16 million people with neuropathic (nerve) pain. The site, www.NeuropathicPainNetwork.org, gives up-to-date information in English, French, German, and Spanish.

The mission of the NPN is to help people with neuropathic pain better cope with their pain, obtain the best treatment, and improve the quality of their lives. The new site educates the public about the signs and symptoms of neuropathic pain and identifies ways to treat the condition. Neuropathic pain results from an injury or disease of the nervous system. It is characterized by a burning, tingling, and/or shock-like sensation. Some people with neuropathic pain find even the touch of clothing on skin intolerable. Nerve pain is often under-diagnosed and under-treated. The 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. The development of the web site was funded by an unrestricted grant from Pfizer Inc.

Diseases in the Shadows

Three serious “diseases in the shadows” deserve increased federal research funding, according to the Alliance for Aging Research in Washington, D.C. These chronic conditions—urticaria incon tinence, chronic obstructive pulmonary disease (COPD), and age-related macular degeneration (AMD)—deserve increased funding because they affect a growing number of people.

Incontinence, COPD, and AMD collectively affect at least 48.3 million Americans, yet the National Institutes of Health spend only 0.3 percent of its $27.9 billion budget (FY2004) on these conditions—far less than the portion devoted to cancer and asthma. Alliance Executive Director Daniel Perry and a panel of medical experts urged support for increased funding at a recent Capitol Hill briefing.

For example, NIH spends $2.25 million on incontinence research, a disease that afflicts 25 million Americans but remains largely hidden because many sufferers are too embarrassed to talk about it or seek treatment. Surveys show COPD affects 14 million Americans who have emphysema, chronic bronchitis and other conditions characterized by obstructed airflow to and from the lungs.

Age-related Macular Degeneration (AMD) is the leading cause of legal blindness in people over age 50.

Ways to Explain Migraines

“Understanding in a Box” is a free tool kit for friends and family of migraine sufferers. It can be ordered by calling 866-519-0300 or visiting www.migrainerelief.com, sponsored by Pfizer Pharmaceuticals. The kit includes a children’s book, “Mama Lion’s Migraine” to help children under stand about migraines and how they can help. It also has three pocket-sized tip sheets and a booklet with facts about migraines and treatment information.

Other resources include a video offered by Ortho McNeil Pharmaceutical. You can also get updated information on migraine prevention and pain relief medications at their website, www.orthoMcNeil.com.

The Link Between Grief and Pain

This article is based on a talk by Sharon Michael, LSW, to the Chronic Pain Support Group in Old Orchard Beach, Maine and an subsequent discussion by group members. I facilitate the group, which has been meeting since 1993.

Those of us who live with chronic pain are all too familiar with the five stages of grief described by Elizabeth Kubler Ross in her groundbreaking work On Death and Dying. The loved one we grieve for, however, is not another person; rather, it is a part of ourselves.

We suffer many losses when chronic pain robs us of the life we once knew. Many of us have been forced to abandon careers, homes, friendships, and even marriages as pain caused us to change our activities and our relationships.

Not everyone goes through every stage of grief. Some people spend little time on one stage but get stuck for ages on another stage. Understanding how we grieve can help you learn to let go and follow life’s journey.

Stage One: Denial

Your first response to living with chronic pain may be denial. Whether it’s been six weeks or six years, we deny that the pain will continue on, thinking, “This isn’t happening to me.” While denial cushions the initial shock of your diagnosis, it makes it more difficult to recognize and cope with the pain.

Discussing the diagnosis (or the symptoms) and studying the facts of your disease or condition, will help you gradually come to the realization that the pain is part of your life.

Stage Two: Anger

Why did this have to happen to me? You may feel angry at the injustice of being struck with pain. You may be angry with others who don’t have chronic pain or don’t understand its effects. If the pain is the result of an accident, you may be mad at the responsible person. Anger and envy erupt as you watch others do the things you used to be able to do, frustrated as the pain continues month after month.

Getting angry is normal and it will help you push through to self-realization. But venting anger by attacking others could damage relationships that may be vital to you. You need a safe way to express your anger. Sharing thoughts and honest feelings with a support group or a sympathetic listener is the best way to get through this stage.

Stage Three: Bargaining

If you let them, the “if onlys” can take over your life. “If only I didn’t have pain, I would ... If only there was a cure, I could ...”. Bargaining with God, with ourselves, and with our doctors is another normal stop along the way to acceptance.

The only problem is that it doesn’t work. At some point, you have to put aside the “if onlys,” acknowledge what is, rather than what could have been, and move on.

Stage Four: Depression

Depression, sadness, hopelessness, frustration, bitterness, and self-pity; almost everyone who lives with chronic pain experiences these feelings. But they don’t have to overwhelm you. Crying can help you heal your bruised and battered emotions. Talking about your losses to understanding friends is another way of coping.

If depression lasts more than two weeks, seek medical help. Medication and psychotherapy can help depression.

Stage Five: Acceptance

Finally comes acceptance. You don’t have to give up on finding a cure someday, but you do have to accept your life as it is, with pain and limitations. Once you accept that, you can get on with your life and start forming and achieving your own personal goals.

Nancy, a member of our chronic pain support group, says, “Lupus lives with me; I don’t live with lupus.” She accepts the limitations that lupus has put on her, but she also makes the most of the life she does have. That includes volunteering for several organizations and—on her worst days—putting on makeup to hide the pain.

When you finally accept that the pain is not going away, you can plan strategies to cope with it and live your life fully.

By Susan Bailey Gold
The ACPA is kicking off our 25th year with lots of exciting events. Here’s a quick summary.

**Partners and the Pain Care Policy Act**
Penney Cushen and other representatives of Partners for Understanding Pain met with Congressman Mike Rogers of Michigan to discuss the reintroduction of his National Pain Care Policy bill in 2003. This bill would enhance pain education for new physicians, create a center for pain study in NIH, and launch a national pain awareness effort, among other initiatives. At the September Partners meetings, passage of this bill was adopted as a key goal for 2005. Watch for news about how ACPA members and friends can support this bill in the months ahead.

**Retreat Planning**
ACPA is planning a special event to mark our 25th Anniversary—a members’ meeting in Lake Tahoe, Nevada, Sunday, June 12 through Wednesday, June 15. We will celebrate 25 years of building Pathways Through Pain with presentations on improving relationships with health care providers, dealing with pain in the workplace, family and intimate issues, and social and recreational challenges. In addition, we will have activities designed for the needs both the novice in pain management and those “old hands” who can benefit from advanced pain management skills.

ACPA members are often advocates for sound pain care in their communities. To support them in this role, we hope to offer communication and media training. This interactive learning experience will show members how to be stronger voices for people with pain, even if they never face a TV camera.

And, as always, the event will be a way to reconnect with old friends, make new ones, and have fun among those who share your challenges and your triumphs. Space is limited, so complete and send the registration form on page 11 soon!

**First Steps Manual Now in Chinese!**
We are pleased to announce that our basic pain management skills manual is now available in Chinese, thanks to the volunteer efforts of Su Yin-Ying of the Tai-Tock Seng Rehabilitation Center in Singapore.

**Thanks for Visiting**
Visit our ACPA website, www.theacpa.org, once again topped one million in December. Our goal is more than numbers, however. We want the site to offer real help, information, and community to those who visit there. Please let us know if you have any ideas for improvements and additions to the site.

**Annual Giving: Why We Still Need You**
In late December, you received the ACPA’s annual request for contributions. It was a time marked by great need here and overseas, where millions of people still face the devastation of the tsunami. Nevertheless, we hope you will include the ACPA in your charitable giving this year.

In less dramatic ways, pain also devastates lives. Your tax-deductible contribution to the ACPA can help ensure that there will be someone there when individuals in pain reach out for help. When you support the ACPA, we can continue a wide variety of efforts to speak out for people who live with pain.

**Board Member Profile: Dr. Todd Knox**
This is the first of a series of articles intended to give readers more insight into the interests and contributions of ACPA board members.

Dr. Todd, MD, MPH, joined the board of the ACPA in October of 2004. Dr. Todd is on the faculty of the Department of Emergency Medicine at Beth Israel Medical Center in New York, where he directs the newly established Pain and Emergency Medicine Institute.

“More than 40 percent of people who go to an emergency department do so because of pain. Forty percent of the time, they have conditions resulting in chronic pain,” said Dr. Todd. “Given the prevalence of pain in our emergency departments, I feel it is important that clinicians become involved with groups such as ACPA, both to learn more from the ACPA membership and to communicate ACPA members’ needs to our specialty colleagues.”

Dr. Todd is interested in researching pain management, health disparities, injury control, and health services. He has studied ethnic disparities in analytic use in the emergency department setting and is a founding member of the American Pain Society’s Special Interest Group on Health Disparities. Dr. Todd serves as principal investiga-
tor and project director for the Pain and Emergency Medicine Initiative for the American College of Emergency Physicians. His publications have appeared in the New England Journal of Medicine, JAMA, and Annals of Emergency Medicine, among others.

He says the ACPA does a wonderful job of educating its members, adding, “We need to extend this reach to the people we serve in the emergency department. In addition, the influence of ACPA members on federal legislation related to healthcare access is enormously important.”

Dr. Todd received his undergraduate degree from the University of Texas at Austin in 1998 and received his MD from the University of Texas Southwestern Medical Center at Dallas in 1998.

He received his Masters in Public Health in Epidemiology from the UCLA School of Public Health in 1999.

“Health care providers have learned more about pain over the past several years, partly as a result of the public’s call for better care,” says Dr. Todd. “We have a long way to go before this knowledge is translated into daily practice.”

**Pathways Through Pain: Celebrating 25 Years**
Do your efforts in managing your pain need a boost? You are not alone! Get some support, advice, and ideas from others who understand your situation at the ACPA annual retreat for members and facilitators.

Join us at beautiful, secluded Zephyr Point, Lake Tahoe, Nevada, from Sunday evening, June 12 through Wednesday morning, June 15. (For details on the program, see the article on page 10.) Don’t miss the dinner cruise on the lake on Tuesday night! The total cost is $280 per person (double occupancy) and $380 per person (single occupancy), which includes room and meals. Transportation is not included and must be arranged on your own. There is a hotel shuttle from the airport in Reno, Nevada. See www.zephyrpoint.org for scenic views and details.

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Books referenced in Recognizing Emotions, the article on page one, are: Love, Medicine of Miracles, Lessons Learned About Self-Healing From a Surgeon’s Experience With Exceptional Patients by Bernie S. Siegel, M.D., Harper Perennial, 1996; and Mind Body Medicine by Daniel Goleman and Joel Stein, Consumer Reports Books, 1993.

Here are some other books that may be helpful:


There are many misunderstandings about anger, such as “it is always good for you to express your anger,” and “suppressing anger is always unhealthy.” Not so, says Ms. Tavris. She explains anger from the point of view of anatomy, gender, stress, marriage, and personal behavior. She also suggests strategies for living with anger and getting beyond anger.

**The Angry Book** by Theodore I. Rubin.

Dr. Rubin lets us know we all get angry because we are all human. Various types of anger require various appropriate responses. Anger that is not handled constructively can lead to further problems.


This is the story of how Cousins rallied all his inner resources and used humor and laughter to overcome what was supposed to be an incurable disease.


If chronic pain is holding you back from a positive, rewarding life, this book can show you how to identify what is important to you and how to find all of your options.

**Healthy Pleasures** by Robert Ornstein, Ph.D., and David Sobel, M.D.

The authors, a brain researcher and an expert in preventive medicine, show how simple pleasures—a hug, a movie, a bubble bath, and an occasional hot fudge sundae—have a positive effect on our ability to ward off disease.


With easy-to-understand explanations and plenty of reassurance, Borysenko describes how to evoke the relaxation response, a state of mind and body that helps the body overcome the physical and emotional effects of stress.

**Simplify Your Life: 100 Ways to Slow Down and Enjoy the Things That Really Matter** by Elaine St. James, Hyperion, 1994.

Since much of pain management is about simplifying our lives, this is a handy little book. St. James shows how to identify priorities and act accordingly. The essays are short and to the point, as are her other books on similar topics.

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**Reading About Emotions**

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**The Fibromyalgia Syndrome**

*A Clinical Case Definition for Practitioners*

Edited by L. Jon Russell, M.D., Ph.D.

Reviewed by Kathy Lyons

This wonderful book is the answer for many doctors and patients alike. If you have ever tried researching fibromyalgia for your own edification or to inform a physician, you probably encountered much misinformation. Even some quite reputable sources are less than up to date, or base their understanding on personal experience rather than solid research. In this book, L. Jon Russell, a world-renowned fibromyalgia researcher and editor of the Journal of Musculoskeletal Pain, has done a great job of separating the wheat from the chaff.

As a consensus document compiled by a panel of experts, this book represents the first major guideline for practitioners since the American College of Rheumatology classification criteria for Fibromyalgia syndrome was devised in 1990. Written by physicians for physicians, it is well documented and footnoted, with studies rated by their adherence to high standards.

Patients should keep in mind that this is not an easy-to-read patient handbook, but it is not totally unintelligible to a layperson, either. One can grasp most of the salient points, especially with a medical dictionary at hand. Secondly, and this is the big bonus, a doctor is so much more likely to accept this information than facts an article from the Internet, a magazine, or even most books. If you have fibromyalgia, you should have *The Fibromyalgia Syndrome*.

Order online at www.harvardhealth.com/stores/product.asp?b=int542.

**My Battle with the Beast**

*By Tino Amarei*

Reviewed by Kathy Lyons

The subtitle, “One Woman’s Inspiring Journey with Complex Regional Pain Syndrome” does a good job of summing up this self-published book. CRPS, which is also called causalgia and reflex sympathetic dystrophy, is a chronic nerve disorder that usually occurs at the site of an injury to the arms or legs.

In Tino Amarei’s case, it was a “beast that came in the night.” A young wife and mother of two young children, she awoke one October morning in 1998 in excruciating pain and unable to walk.

Four years and 16 doctors later, she was finally diagnosed and treated correctly. It is a situation that we hear about all too often, and it is even more frustrating in the case of CRPS, where early treatment can result in remission, but delay can lead to progression and irreversible changes in bone and muscle. Tino’s story is about pain and fear, but more importantly, it is about hope, perseverance, family, and community, which she lived through.

To order, send $47.95 plus $4.99 shipping and handling, along with your name and address to: “My Battle with the Beast” Order, POB 96, Round and Ready, CA 95679.

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