CPA is all about reaching out to others with information, understanding, and support. It was born in 1979, at a time when I had never been more hopeless and helpless. I thought it might be my last year on this earth, but it turned out to be one of the most amazing years of my life. On Halloween 1979, I entered a pain management program at the Cleveland Clinic, believing this would be my final failure. What I could not know was that seven weeks later I would emerge as a fully intact person with all the hopes and dreams I had before the pain restored to me. During those seven weeks—with a great deal of effort on my part and that of the staff—it was able to make the transition from patient to person.

I can remember meeting Dr. Ed Covington, director of the pain management program, for the first time. He did not hesitate when he said that he could help me live with the pain. I did not believe him and only agreed to go through the program as a way of proving to my husband that there was no hope for me.

Needless to say, I was wrong. There was hope for me. And I had not completely given up or I never would have survived the program. But it took a combination of my efforts, support from a medical team that gave me exactly what I needed, and knowing that there were other people that were on the same journey as I was. While I was very hopeful when I left the pain program as a person, there were also very troubling thoughts going through my mind. First, would I be able to maintain what I had accomplished while in the pain program? Second, how could I share what I had learned? It was just too good to keep to myself. I now knew that there were others like myself who, because of their pain, isolated themselves from the world, draining any chance for hope. I needed to let them know they weren’t alone and there was hope for a better tomorrow.

During those weeks, one of my most profound experiences was to meet other people who also found their lives out of control because of their pain. I really thought I was the only one in the world battling the pain and isolation. In many ways they validated me by simply being there, looking “normal” and yet talking of the loss and suffering they had endured since pain came into their lives. I knew that I was not alone.

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They were white boxes tied with red ribbons, and they held the most precious gift you can give to someone who has chronic pain. “It’s something we hang onto desperately here,” Brenda Hendricks told her ACPA group of The Villages, Florida, as they gathered for a holiday season dinner. “I put the word ‘hope’ in the boxes for us. If you lose hope, you’ve lost it all. Sometimes we do lose hope, but we get it back.”

The gift-giving was symbolic of what Brenda sees as the most important thing her support group offers to people with pain. “Hope what we give when we reach out to others, our 10th step on the road from patient to person. It’s what we receive as we share with others. Reaching out is as necessary to the person who is a veteran in living with pain as it is for the person just learning to live with pain. It’s an underlying theme as we share the lessons of the other nine steps that urge us to accept, get involved, set priorities, have realistic goals, know basic rights, recognize emotions, practice relaxation, exercise, and review our outlook.

We give hope to one another each time we listen attentively or share in a group, as well as each time we visit, make an encouraging phone call or write a note, ... We also spread hope when we let our public leaders and our medical professionals know of the needs of people in pain.

Sharing Knowledge, Anger, and Pain

Ask Brenda. Though she spent 20 years as a nurse and nurse practitioner, it took three back injuries and as many surgeries to learn that even though she was a nurse, she didn’t know much about chronic pain. She had to study ACPA materials to learn that chronic pain needs to be treated differently than acute pain and that the patient has to get involved.

Leading a support group, Brenda sees new people come in “so mad and so angry.” She remembers how she felt stuck in anger for so long when she was in the early stages of adjustment to persistent pain. So she lets the person talk, all the time praying that her own pain won’t flare up. As she listens to the fury, she reminds herself to step back and not take it personally.

A Safe Place to Talk

Sometimes reaching out is letting a person be silent. Many new people come to a group not wanting to talk right away. “First we make them feel comfortable,” says ACPA group leader/staff nurse Joe Menios of Harrison Township, Michigan. “They don’t need to talk if they don’t want to.” Instead, they listen to others and are assured of the strict confidentiality rules of the group.

To show new members that group is a safe place to talk, ACPA leader Skot Stribolt of Chico, California, says he often begins by talking about himself: how a fall as a teenager started a lifetime of back pain, exacerbated by neck pain from a car accident when he was 21 years old.

But all these leaders have endured and are still enduring. This makes them care about other people in pain, and reach out to help. As Skot says, “Heroes aren’t born, they’re cornered.”

He has the compassion to help people better communicate with their doctors and even goes with them to their appointments. “It’s an emotional time to go to a doctor, they’re scared, and afraid they will get confused,” he says.

Skot tells of how exciting it is when his whole group shows empathy and gets involved in helping someone. Recently, a young person in severe pain from spinal stenosis and migraine headaches came to the group. “It sort of lit a fire among us and we all got into research to try to help. It was really a joyful thing for us,” Skot says.

Benefiting from Involvement

Joe agrees that when the members of the group get involved, everyone benefits. “It’s so important in a support group that everyone participate,” he says. Joe and his co-leader Ed Krappmann both have fibromyalgia and help each other, especially when one of them experiences the confusion of “fibro fog” while leading the group.

Though people in pain may feel an initial urge to pull away from people, the benefits of reaching out are many. The obvious one is an improved perspective of your own situation. “Saddest of the sad” is what Skot calls people who truly are devastated by their injury or pain. “People who have lost it all—jobs, medical coverage, home, family security, and money—are left living with chronic pain on public assistance. To me these people are the real victims of chronic pain. They can’t enjoy the things we do because they don’t have any money.”

Joe says the most important thing he does to keep his perspective in line is doing what he can to help others who are worse off. “Things like taking them for doctor appointments, picking up a prescription, or just calling to see how they are and chatting for a while. This allows me to be aware of how blessed I am to be able to give them a hand. It also gives me a sense of worth and well-being,” he says.

Brenda is currently dealing with pain flare-up and a malfunction in her implanted spinal stimulator, which had previously helped her quite a bit. While deciding with her doctor on their next move, she’s dealing with the increased pain by decreasing her activity. But she’s also reaching out to her group so she can keep her focus off herself. “It gives me a purpose,” she says. “It is something I know the good Lord wants me to do. You just feel so useless if you can’t do something on this earth other than take up space.”

Fortunately for people living with chronic pain, Brenda, Joe, Skot and many others continue to reach out and offer hope to those around them, while at the same time finding purpose and hope for themselves.
If you have suffered from sleep disturbances and wonder if you should be worried, ask yourself: How long has it been going on? Does it interfere with your daily functioning? We've all had an occasional bad night, when we can't stop our mind from racing, or we're sick with a cold or have some aches and pains. This occasional insomnia is annoying but not too serious, and usually lasts no more than a few nights, or, at most, a few weeks. This "acute" insomnia is self-limiting and effectively treated by making some changes in your lifestyle. If need be you can try over-the-counter (OTC) medications.

CIRCADIAN RHYTHM

Circadian rhythm is the innate fluctuation of physiological functions, including sleep and waking, tied to the 24 hour day-night cycle. Melatonin is a natural hormone produced by the pineal gland that has a role in circadian rhythm control. Melatonin may be helpful for reducing symptoms of jet lag, but there is minimal evidence of efficacy for insomnia. It appears to be safe for short-term use, but long-term safety is unknown.

L-TRYPTOPHAN

L-tryptophan is sometimes used as a hypnotic. There is little evidence that it works for insomnia, however, and there are possible toxic interactions with some psychiatric medications.

BENZODIAZEPINES

Pharmacologic treatment for insomnia is commonly used for insomnia. There is, however, no good evidence that these are effective for insomnia, and there is minimal evidence of efficacy for insomnia. It appears to be safe for short-term use, but long-term safety is unknown.

Nonbenzodiazepine hypnotics are a new class of hypnotics. As a class, these medications generally have shorter half-lives than their benzodiazepine predecessors, which mean they have greater effects on sleep onset than on sleep maintenance. They also cause only minimal morning sedation and other daytime impairments. Nonbenzodiazepine hypnotics also may have less potential for abuse than benzodiazepine hypnotics, although further research is needed. Research into the effects of nonbenzodiazepine hypnotics also may have less potential for abuse than benzodiazepine hypnotics, although further research is needed. However, there are many simple steps you can take to create an environment conducive to sleep and improve your sleep habits. Treat your bedroom and your bed as a special place to rest. Don't use your bed for work or eating; you do not spend the time in your bed, you do not feel refreshed physically, and your sleep patterns are disrupted. Your pain is worsened by both the physical and emotional consequences of lack of restful sleep.

The Sleep Problem in Society

Approximately one-third of adults in the U.S. report difficulty sleeping, and 10 to 15 percent have the clinical disorder of insomnia. Among primary care patients, approximately half have sleep difficulties, which are often undetected by health professionals.

Practice Good Sleep Habits

There are some simple things you can do to achieve better sleep:

• Don’t watch a scary or action movie (or the evening news) just before bedtime.
• Avoid caffeine, alcohol, nicotine, and other sleep-disturbing chemicals in the evening and before bedtime.
• Exercise regularly, but not too close to bedtime.
• Get up at the same time every day, regardless of when you go to sleep.
• Make sure your bed frame and mattress are supportive and comfortable. They may need replacing.
• Try meditation and relaxation therapy (progressive muscle relaxation, visual imagery, etc.) to reduce physiologic arousal.
• Drink soothing warm milk or herbal or decaffeinated tea.
• Block out light with room darkening window shades or an eye mask.
• Resolve emotional stress issues before bedtime.
• L-tryptophan-rich foods such as turkey or pasta can be eaten in the evening. Other tryptophan-rich foods include cottage cheese and nuts.

Recent scientific studies confirm that practicing good sleep hygiene is as or more effective than pharmacologic treatment in improving the quality and quantity of sleep. The importance of appropriate recognition of and treatment for chronic insomnia was recently documented in a published statement from the National Institutes of Health (NIH).

The Stages of Normal Sleep

When you sleep, it starts with a light sleep where your muscles relax and your brain waves are irregular and rapid. Your brain waves then become larger, with bursts of electrical activity. Next you move into deep sleep, in which the brain produces large, slow waves (sometimes called “delta” or slow-wave sleep).

After an hour or so, you shift into a highly active stage characterized by rapid eye movements, hence the name REM sleep. Paradoxically, even though your brain waves pattern is almost the same as when you are awake, it is this stage in which you are least likely to be awakened by external stimuli. You’re in the dreaming stage, which occurs several times across the course of the night.

About 75 percent of your night is spent in non-REM sleep and about 25 percent is spent dreaming. REM periods tend to become longer and more plentiful as the night continues.

Pain-Related Medical Sleep Disorders

Some medications prescribed for chronic pain may disrupt the normal sleep cycle. Some may be activating and make quality sleep difficult. Substances like caffeine, theophylline, and other stimulants, steroids, antihypertensives, and antidepressants can cause insomnia.

People who snore or have sleep apnea (periods when they stop breathing while asleep) are likely to have fitful, low-quality sleep. They half-wake several times a night and wake up unfreshened.

Obesity can cause or worsen sleep apnea, an important factor in people with chronic pain who have a tendency to gain weight due to decreased activity. In addition, the use of certain medications and even depression can disrupt dietary habits.

When you don’t sleep, you don’t feel refreshed physically, mentally, or emotionally, but there are also significant negative consequences. Inadequate or poor sleep can result in fatigue, irritability, impaired alertness, and less cognitive ability. This can cause more mistakes and less productivity at home and on the job, increasing errors and accidents. All of these factors may lead to increased pain for the person with a chronic pain problem.

Approved Sleep Medications

The U.S. Food and Drug Administration approved benzodiazepine and nonbenzodiazepine hypnotics for the treatment of insomnia. They are approved only for short-term use and side effects can include next-day impairments, such as morning sedation, cognitive impairment, and poor motor coordination.

Nonbenzodiazepine hypnotics are a new class of hypnotics. As a class, these medications generally have shorter half-lives than their benzodiazepine predecessors, which mean they have greater effects on sleep onset than on sleep maintenance. They also cause only minimal morning sedation and other daytime impairments. Nonbenzodiazepine hypnotics also may have less potential for abuse than benzodiazepine hypnotics, although further research is needed. Some of the antidepressants are sedating and are prescribed for insomnia. The low cost of antidepressant medications along with unrestricted long-term use and minimal abuse potential may have lead to greater use of these medications for insomnia.

Over-the-counter (OTC) medications like antihistamines are commonly used for insomnia. There is, however, no good evidence that these are effective for insomnia, and there are effects can include next-day impairments, such as morning sedation, cognitive impairment, and poor motor coordination.

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Valerian is derived from the valeriana plant root and thought to promote sleep, but there is no proven benefit for insomnia. It is unregulated and possibly associated with liver damage. Other herbal products are sometimes used for insomnia, but there are no data supporting their efficacy and there are similar concerns about safety and drug interactions.

However, there are many simple steps you can take to create an environment conducive to sleep and improve your sleep habits. Treat your bedroom and your bed as a special place to rest. Don’t use your bed for work or eating so that you associate it only with sleep.

Talk to your doctor if you have a sleep problem or ask to be evaluated by a sleep specialist. He or she will help you decide if you are on too many medications—or even the wrong medications—and if some are the problem. Insomnia or poor sleep hygiene is a common problem for society and especially problematic for persons with chronic pain.

Don’t ignore it, as proper and effective treatment may result in better health and reduced chronic pain.

People often use alcohol to reduce sleep-onset latency (the time period between lights out and falling asleep). Although alcohol helps you fall asleep faster, it also causes poorer quality sleep and nighttime awakening and is clearly not appropriate for some with a risk for substance abuse. Some medications used for pain can cause liver damage when used in conjunction with alcohol.

Some Sleep Aids Still Unproven

Circadian rhythm is the innate fluctuation of physiological functions, including sleep and waking, tied to the 24 hour day-night cycle. Melatonin is a natural hormone produced by the pineal gland that has a role in circadian rhythm control. Melatonin may be helpful for reducing symptoms of jet lag, but there is minimal evidence of efficacy for insomnia. It appears to be safe for short-term use, but long-term safety is unknown.

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Don’t ignore it, as proper and effective treatment may result in better health and reduced chronic pain.

Recent scientific studies confirm that practicing good sleep hygiene is as or more effective than pharmacologic treatment in improving the quality and quantity of sleep. The importance of appropriate recognition of and treatment for chronic insomnia was recently documented in a published statement from the National Institutes of Health (NIH). State-of-the-Science Conference on the Manifestations and Management of Chronic Insomnia in Adults. It is available at: http://consensus.nih.gov/2005/2005InsomniaSOS026html.htm.
Persons with chronic pain are frequently treated in the emergency department (ED). If you are one of them, you may know what that experience is like. After conducting a survey on this subject on our Website, the ACPA found that many people were dissatisfied with their visit to the ED. During September and October 2005, the ACPA Website surveyed 248 individuals who went to their local hospital emergency departments for pain relief. Ninety percent of respondents were white, 80 percent were female, and 84 percent were insured. Forty-four percent had visited an ED three or more times within the past year.

When asked why they visited the ED, 88 percent indicated that their pain was out of control. More than half, 54 percent, stated they had contacted their personal physician for pain relief prior to their ED visit. A minority of respondents (16 percent) said their doctor told them to go to the ED, while 19 percent said their doctor would no longer treat them. In 30 percent of these instances, respondents felt that their physicians were afraid to treat them because of the high doses of analgesics required and for 34 percent, physicians had told them they had “done all they could.”

On arrival in the ED, 96 percent reported severe pain intensity (NRS 7 or greater). Seventy percent expected to be offered something for pain relief within 30 minutes of ED arrival while 58 percent expected to experience pain relief within 30 minutes. However, expectations weren’t matched by the results. In fact, 64 percent waited longer than one hour to be seen and 43 percent waited longer than two hours to receive analgesics. Only 44 percent of respondents felt they were treated with dignity and respect by the ED staff and just 22 percent stated they were satisfied with their treatment.

In terms of pain management, 47 percent rated their ED visit as “poor,” “terrible,” or “the worst experience of my life.” Patients felt that the ED staff needed to improve the way they cared for patients, to be more sensitive and reassuring, and provide patients with choices. (This last area was cited most often.)

“This preliminary survey highlights the many challenges faced by those seeking relief from chronic pain and a marked mismatch between patient expectations and the ED treatment of pain,” said ACPA board member Dr. Knox Todd. “ACPA clearly has an opportunity to increase understanding among emergency department physicians so they can better treat people with pain.”

Dr. Todd will present these results at the 25th annual meeting of the American Pain Society meeting in May 2006, as “Pain in the Emergency Department: An Online Survey of Patient Experience.”

When Pain is an Emergency

Medical Updates

Learning More about Medicare D

As of January 1 the new Medicare part D took effect. Under the new plan, Medicare will offer insurance coverage for prescription drugs through its own plans and other health plans. This coverage will typically pay over half of your drug costs next year for a monthly premium. May 15, 2006, is the last day to join a plan offering coverage for 2006.

Many people are having trouble understanding and using Medicare D. Some states are helping residents pay for prescriptions because of glitches in the new federal drug benefit. More information is available at www.medicare.gov. A link entitled “Want to Learn More About the New Medicare Prescription Drug Coverage?” provides good, basic information. There is also a link to a Formulary (Drug) Finder, which lets you enter the drugs you use to find out which plans in an area have formularies that cover these drugs. This could be helpful for our ACPA members who take special medications to help them cope with pain. Contact 1-800-MEDICARE or www.eldercare.gov to find out about local counseling and assistance available in your area.

For a review of the steps you can take if your drug isn’t covered by a drug prescription plan, see our Medication Coverage Fact Sheet at www.healthassistancepartnership.org or www.theacpa.org.

NIH Researches Pain

The National Institute of Health (NIH) Pain Research Consortium was established in 1996 to fulfill the need for coordination across the many NIH institutes and centers that have programs and activities addressing pain. Several recent Pain Consortium initiatives are designed to close gaps in the research portfolio, advance pain research through advances in technologies and knowledge, and improve pain management.

The latest report from the NIH Pain Research Consortium is available at www.nih.gov/about/centers/od/oba/news/press-releases/051208.html. It is a document that provides hope, because it addresses many areas involving pain that need the kind of research NIH can provide. You can also link to it from our website at www.theacpa.org.

Meds Card Update

The 2006 Supplement updating “ACPA Medications & Chronic Pain” is now available at www.theacpa.org.

Here’s a handy way to keep track of your medications and communicate with your doctors. Clip out and fill in this MedCard from ACPA and keep it in your wallet. You can order additional copies at www.theacpa.org or call 1-800-533-3231.
Many people have problems with housecleaning and the control of clutter. Chronic illness can make this task even harder. Once a home reaches a certain stage of disarray, it can seem hopeless. Living this way contributes to emotional distress and social isolation. However, I have also learned that living in and welcoming guests into a clean and orderly house helps me feel better about my life.

As my health declined over the years, my ability to do housework gradually decreased. At first I tried to enlist help from my family for some of the chores around the house. Then I hired a housekeeper to come in once a week. Even with that, clutter still kept building up and eventually the cleaning person quit.

Now I clean in small stages. Rather than soldier on with a project until it is completed or I collapse, I stop when I am tired and rest. I even rest before I get tired.

My first step was to get medical help for my various ailments: sleep apnea, hypothyroidism, arthritis, asthma, allergies, and fibromyalgia. By improving my health, I got more sleep, had more energy, and gained better mental focus.

Steps to a Better Life
To get from chaos to comfort, I learned to identify small practical steps that I could take and then made sure to do them one at a time.

Moving Day
About a year ago, my husband and I faced a big challenge: moving to a smaller home. I had already been doing a lot of thinking about what was important to me and what things like family and friends, not possessions. So in preparation for the move, we divested ourselves of over half of our “stuff.”

These “things” that we owned were not enriching our lives. Instead, they were making housekeeping difficult and could keep us from moving to smaller and more practical quarters. My first step was to make a list of the possessions that I was sure I wanted to keep—items I loved and used regularly.

Now I ruthless pruned away what I did not need or want. I called in relatives, charities, collectibles dealers, and junk haulers to take things away. We didn’t worry about the value of selling these items; it was more important to be free of them.

In our new home, we have hired a cleaning service and also a gardening service. We had to face the reality of my illness and recognize that we needed the help. So we pinched our budget elsewhere. Looked at from a certain standpoint, household help is a medical necessity.

On some low-energy days it seems like all I accomplish is keeping things in their proper places. But that is an important part of housekeeping. Also, I congratulate myself for my efforts and for what I accomplish. I have learned to focus on the huge effort I make each day, not what I should do or would do if I were healthy.
The Ten Steps

**STEP 1: Accept the Pain**
Learn all you can about your physical condition. Understand that there may be no current cure and accept that you will need to deal with the fact of pain in your life.

**STEP 2: Get Involved**
Take an active role in your own recovery. Follow your doctor’s advice and ask what you can do to move from a passive role into one of partnership in your own health care.

**STEP 3: Learn to Set Priorities**
Look beyond your pain to the things that are important in your life. List the things that you would like to do. Setting priorities can help you find a starting point to lead you back into a more active life.

**STEP 4: Set Realistic Goals**
We all walk before we run. Set goals that are within your power to accomplish or break a larger goal down into manageable steps. And take time to enjoy your successes.

**STEP 5: Know Your Basic Rights**
We all have basic rights: to be treated with respect, to say no without guilt, to do less than humanly possible, to make mistakes, and to not need to justify your decisions with words or pain.

**STEP 6: Recognize Emotions**
Your body and mind are one. Emotions directly affect your physical well-being. By acknowledging and dealing with your feelings, you can reduce stress and decrease the pain you feel.

**STEP 7: Learn to Relax**
Pain increases in times of stress. Relaxation exercises are one way of reclaiming control of your body. Deep breathing, visualization, and other relaxation techniques can help you to better manage the pain you live with.

**STEP 8: Exercise**
Many people with chronic pain fear exercise. But unused muscles feel more pain than toned flexible ones. With your doctor’s guidance, a modest exercise program that you can do safely. As you build strength, your pain can decrease. You’ll feel better about yourself, too.

**STEP 9: See the Total Picture**
As you follow these steps, you will see that pain does not need to be the center of your life. You can choose to focus on your abilities, not your disabilities. You can grow stronger in your belief that you can live a normal life in spite of chronic pain.

**STEP 10: Reach Out**
Once you have begun to find ways to manage your chronic pain problem, reach out and share what you know. Living with chronic pain is an ongoing learning experience. We all support and learn from each other.

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Making a Difference: John and Susan Gold

**by Sally Price**

Allowing others to help us can be a challenging aspect of living with chronic pain. Like Susan Gold of Saco, Maine, many of us would prefer to be independent. But when Sue’s husband, John, took over the household chores in a matter-of-fact way, she nominated him for an award.

Last November, John won the annual Endo Pharmaceuticals “Making a Difference” Award in the caregiver category. “I was quite touched that Sue felt that strongly that she would nominate me,” John said.

In her nomination, Sue wrote: “Two years after John and I were married, pain in my knees and shoulder became so severe I couldn’t sleep for more than three hours at a time. Eventually, I was diagnosed with rheumatoid arthritis.

“Through it all, John has been an exceptionally compassionate and loving caregiver, in all meanings of that word. He built a platform for our bed, making it easier for me to get in and out. He took over the household chores, so I could use whatever energy I had to devote to family and my work as a self-employed writer/publisher.

“He cared for my 12-year-old son, listening, guiding, and playing with him, and his friends even when I couldn’t. John doesn’t see himself as a hero, saying ‘I always expected I would share jobs with my wife. I’d like to think I’m her partner and I help whenever I’m needed to.’

“Understanding how important it was to me to keep working (not only to preserve my self-worth but to take my mind off pain), he rearranged his schedule to work part-time with me. He drove me to our shared office and served as officemate, and helpmate. Later, he built an addition to our house and set up a home office for me.

“With gentle humor, he keeps me on track. He is by my side for medical appointments, tests, and even surgery when allowed. Perhaps most important, he encourages me in all I do. When I started the ACFA pain support group 12 years ago, he cheered me on when I got discouraged. He created the group’s website, cooks for our annual barbecues, and talks to callers needing help. Without him, there would be no group. He’s my hero.”

John doesn’t see himself as a hero, saying “I always expected I would share jobs with my wife. I’d like to think I’m her partner and I help whenever I’m needed to.”

When rheumatoid arthritis first struck Sue, they had to give up the recreational hiking, mountain climbing, and snow skiing they loved. She continued to work, but turned everything in the home over to John. “It was hard because she was in a lot of pain and we couldn’t figure out what was causing it,” John says.

Now that Sue has a diagnosis and a medication that helps control her symptoms, John does fewer household chores. They work together and have resumed walking, cycling, and canoeing. They also share activities with Sue’s ACFA support group.

“I realize there are people out there in constant pain who go about their lives and do good things,” he says. “It really impresses me that they’re a fun group of people.”

In the 15 years John worked as a news reporter, he received various awards but, he adds, “Nothing quite as significant as this.”

Sue found that learning to depend on John, and he on her, has strengthened their bond. The way he went about helping was the key. “He helped me by doing it matter-of-factly. He didn’t hold it over me or treat me like an imbecile. He just did it,” she said.

The Endo Pharmaceuticals “Making a Difference” Award is given annually to recognize exceptional work of a person who has chronic pain, of a pain management professional, or of a caregiver or family member helping to ease a loved one’s pain.

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ACPA Update

New ACPA Groups
Welcome to our new members!

- Tracy Zuckerman, Wood, RI
- Scott Donny, Danville, IL
- Debra Tyler, Elizabethown, KY
- Andy Walker, Rhode Island, KY
- Rose Smalley, Sioux Falls, SD
- Stid Chamberlyne, Orange, VA

In Appreciation: Our Professional Advisory Committee
On behalf of the board, I’d like to thank the members of our Professional Advisory Committee, who guide us with their expert opinions and help to support our work on behalf of people with pain. This group of stellar professionals includes:

- Dennis Turk, PhD
- University of Washington
- Susan P. Buckelew, PhD
- University of Missouri Medical School
- Daniel B. Carr, MD
- New England Medical Center
- Stanley L. Chapman, PhD
- Center for Pain Medicine Emory Clinic
- Colleen Dunswordy, MD
- UPMC Pain Medicine Program, Pittsburgh
- David J. Haddox, DDS, MD, FAAPM
- Purdue Pharma L.P.
- Robert D. Kerns, PhD
- University of Washington
- Mark P. Jensen, PhD
- Brigham and Women’s Hospital
- Greg Middeke, MD
- VA Medical Center, West Haven, CT
- John D. Loeser, MD
- University of Washington
- Judith A. Paice, RN, PhD
- Neuroscience Institute, Chicago
- Rowland G. Hazard, MD
- Spine Institute of New England
- Jerome Schofferman, MD
- Spine Center, Daly City, CA
- Melissa Wolfe, MS, PT, ATC
- University of Knoxville

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

In Appreciation: Our Professional Advisory Committee

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Truck Focus: Dr. Jennifer Christian

Jennifer Christian, MD, MPH, joined the ACPA Board of Directors in 2009, bringing along her experience as a doctor teaching doctors about managing and preventing disability.

Dr. Christian had worked in occupational health for many years in a variety of settings—in industry for large private employers, in public health, in a solo medical practice, in 3,000 doctor HMO’s, in managed care companies, and with workers’ compensation insurers. In all these settings, she has worked to reduce the amount of needless work disability caused by medical conditions.

Today she is President and Chief Medical Officer of her own company, Weylity Corp., in Wayland, Massachusetts, which provides training and consulting services to employers, insurers, healthcare providers, and managed care companies.

Weylity focuses on the gaps between the parties that create a lot of needless work disability and job loss—the intersection of medicine, the workplace, and human behavior. “We shift the focus away from the question ‘does this period of absence qualify for benefits?’ and towards the question ‘can this work disability be prevented?’” says Dr. Christian.

Jennifer Christian, MD, MPH, joined the ACPA Board of Directors in 2009, bringing along her experience as a doctor teaching doctors about managing and preventing disability.

“We encourage the parties to look for a way to prevent disability,” she says. “Although pain is often the stated cause for absence from work, sometimes it is disabling only because the person thinks it is.”

Dr. Christian finds she has many professional interests that coincide with ACPA’s mission, including a long, professional acquaintance with board member Dr. Steve Feinberg.

She would like to see ACPA focus on making sure that doctors know about ACPA, and encouraging them to use resources such as ACPA’s education materials with their patients. Overall, her goal is to strengthen ACPA’s outreach to providers and to increase referrals to and participation in ACPA programs.

Dr. Christian earned her MD and Masters in Public Health from the University of Washington in Seattle. In the late 80s and 90s she worked in Anchorage, Alaska, both for the city health department and in private practice in Occupational Medicine. She was the Alaska State Medical Association’s Physician of the Year in 1992. Today, she is a member of the American College of Occupational and Environmental Medicine and chairs the Work Fitness & Disability Section as well as the Stay-at-Work and Return-to-Work Process Improvement Committee.

“People will voluntarily restrict their activities because of pain. They sometimes think that an activity causes pain, when in fact their pain increases for other reasons. So they stop that activity, and then another one, and then another one. Soon, they are avoiding most everything. Science (and the experience of successful ACPA members) shows that the best treatment for chronic pain is staying active, not withdrawing from activities,” she says.

Dr. Christian has recently been learning about the challenge of living with chronic pain through her mother-in-law, who has metastatic cancer. Dr. Christian herself is coping with plantar fascitis, an inflammatory condition that causes intense heel pain. She says, “I think compassion is more authentic when you are touched by a problem yourself.”

“ACPA is a practical, consumer-driven empowerment organization. I am personally aligned with the self-determined view that ACPA espouses with its members in an intelligent way,” she says. “I totally support the view that the point is to have a good life with chronic pain, rather than give up your life in order to avoid pain.”

Tribute for Shirley T.

Shirley Thompson, a long time ACPA member, passed away in January 2006. Shirley had been part of the ACPA since the beginning, attending the second group that started in Pittsburgh. She became Regional Director for the Pittsburgh area in 1985 and provided support and understanding to all those who reached out to her. She will be deeply missed, but she has touched thousands of people in a positive way over the past 25 years with the ACPA. We extend our deepest sympathies to her friends and family.
Facilitator’s Forum
by Mariann Farrell, Facilitator of the Pittsburgh Area ACPA Support Group

For the 15 years that I’ve been a member of the ACPA, it has been a major force in my progress in moving from patient to person. Penney Cowan, ACPA director, first encouraged me to become the facilitator of the Pittsburgh area support group. I always thought Penney spent most of her time in California, attending to ACPA affairs and answering the phone. Boy, was I wrong!

You see, I was recently asked to attend the ACPA Board of Directors meeting in Pittsburgh. I was honored to attend this meeting as local facilitator, and was one of the few non-board members there.

What a diverse group of people we have on our board. In meeting them, I had a chance to see what skills and personalities each brings to the table. They are from many different cities of the country and many are not in the health care profession, as I had imagined. We have a computer whiz, a photographer, an insurance specialist, our director of program services, along with many others, and, of course, Penney. Each offered insightful input as well as great suggestions for future projects.

The offerings on our ACPA Website were discussed at length, including changes for the future. I suspect that many of us, myself included, aren’t “on the Web.” I ask family members to download information from our ACPA Website for me. This way I’m kept informed on the latest news.

Penney spoke about grant monies received for ACPA program development and outreach projects for our membership, as well as the new Live Better with Pain Log (in its final stages of development). I think this log book will help us—and our doctors—keep track of and manage our daily pain levels.

It became very clear to me that Penney is no stay-at-home gal. For the board meeting, she flew into Pittsburgh from Scotland, where she had attended a conference concerning chronic pain. She frequently flies to many cities in the U.S. and around the world to get the ACPA’s message out to people in the health field and other public forums.

To sum up my experience, I am deeply appreciative and pleased with what our board of directors does for us. I’d like to publicly thank them for their commitment and hard work on behalf of the ACPA facilitators and members.

Thanks to:
Purdue Pharma
for providing printing for the ACPA MedCard
Ligand Pharmaceuticals Inc.
Organon USA Inc
for supporting the Live Better With Pain log book
The Medtronic Foundation Patient Link Grant
for translations of From Patient to Person

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.

WeCPA 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:

To Donate to The ACPA:

We welcome gifts in any amount:
Supporting Contributor Up to $25
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$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.

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