Since no one person with pain is exactly like any other, you might expect that your experience at the clinic or emergency room would be different from the person sitting next to you. But when these differences result in a doctor not accepting your report of pain, providing insufficient treatment for pain, or refusing to treat your pain, there is cause for concern.

So what does it really mean when we talk about disparities in care?

It could mean that minorities are treated differently, receive less care, and have less access. It can also mean that those who can pay for their treatments have more access to a higher quality of care.

Does it perhaps mean that our veterans, those who served our country with honor and gave us with the freedom we cherish, do not receive timely and perhaps adequate care? Or maybe women are treated differently than men, older people differently than young ones?

Could it be those who are incarcerated have minimal access to the same quality of care the rest of society has? Or perhaps it is those who work in the fields and ranches—giving us the food we eat and take for granted—are never really considered when we think about quality health care for all.

Making Decisions Based on First Impressions

There are studies that demonstrate marked differences in treatment in emergency rooms when the person treated is man vs. a women, a Caucasian vs. an ethnic or racial minority. We don’t need studies to guess that those who can easily get to top city hospitals will get different care than those who live in rural areas.
Making Pain Visible: Avoiding Disparities in Treatment

by Alison Conte, Editor, ACPA Chronicle

Since each person with chronic pain is an individual and has his or her own special circumstances, we wouldn’t expect to receive identical care for pain. But you wouldn’t expect your treatment to be less comprehensive just because you are African-American, female, or of Latin heritage. Unfortunately, this is often the case.

The Institute of Medicine (IOM) report, Relieving Pain in America (June 2011), noted that disparities in pain treatment are one of the barriers to receiving adequate pain care in the U.S.

The report found that “most studies that have evaluated the potential for disparities in pain treatment on the basis of racial or ethnic differences have found them” (2–9) and that “undertreatment of pain among racial and ethnic minorities exists for a wide range of settings and types of illness or injury” (2–11). These studies have revealed that pain treatment can differ for the same symptoms depending on the person’s race, ethnic background, age, gender, and economic level and that “cultural perspectives strongly influence reports of pain in general.”

The IOM suggested that health care professionals need additional training to “address gaps in knowledge and competencies related to pain assessment and management, cultural attitudes about pain, negative and ill-informed attitudes about people with pain, and stereotyping and biases that contribute to disparities in pain care.”

Professionals in the Pain and Disparities Special Interest Group of the American Pain Society (www.ampainsoc.org/ membership/sig/sites/disparity/) are currently working to promote advocacy, education, policies, programs, and research to eliminate the unequal burden of pain among racial and ethnic minorities and underserved populations in order to optimize the quality of life for all persons with pain.

But people with pain can also help to end disparities. By participating in their treatment plan and pain management, they can improve the way they communicate about their pain, so that doctors and health care providers don’t make erroneous assumptions based on their own bias or past experiences. By treating each person with pain as a person—not a stereotype—they can fully understand the effects of pain—beyond the 1 to 10 pain scale—and treat accordingly.

CONTINUED ON PAGE 3...
Ethnic minorities with visible injuries (like a broken bone) seem to incur fewer disparities in the ED than those with non-visible pain (such as abdominal and back pain.) “We would expect that the more obvious pain is, the less likely it is that other factors would influence the pain management,” said Dr. Todd. “There is more disparity if it is less objective.”

Though most ED doctors ask about pain as the fifth vital sign and use the 1 to 10 pain scale to evaluate pain, it remains a very personal experience, requiring intense communication.

Studies show that the traits of the doctor and the person with pain influence how they will interact. This includes their gender, age, education, ethnicity, economic status, and healthcare literacy. Younger people are more vocal and expect to receive more satisfaction from their healthcare providers. Older people complain less about symptoms that are actually quite burdensome.

**People with Pain Must Do Their Part**

Disparities in care could be diminished by educating people on how to explain their pain to a nurse. “The nurse often has a closer relationship to patients and this might be an easier way to get the message across,” he said. “Some people are intimidated by their doctors.”

“People must be taught that it is OK to talk about pain, and that it will not threaten their relationship with their doctor,” he said. He explained that oncology patients are reluctant to discuss pain with their oncologists for fear that it is an indication that cancer treatment is not working. “They don’t want their cancer to get worse, so that don’t admit that their pain is getting worse,” he said.

CONTINUED ON PAGE 4...
When a personal physician is seen as a lifeline, we may not want to convey a negative situation. If people went to the doctor's office looking their worst, instead of their best, it would be easy for the staff to see the impact that constant pain has on their ability to sleep well, shower, and dress each day. But people will dress nicely and get their hair done to go to their family physician. They want to be a “good patient,” following instructions without complaining and making good progress, he explained.

“So we disguise our pain and fear expressing our needs,” Dr. Todd said. “But in the emergency department we can’t help but admit that things aren’t going too well. You have to admit the level of symptoms that brought you to the ED.”

**Shrinking the Pain Scale**

Living with pain all the time shrinks the pain scale, according to Dr. Todd. If one lives with a pain level of 6, and goes to the emergency department when it spikes to 8 or 9, it is very different from the person in the ED to whom 3 or 4 is too painful to tolerate.

“You have to explain what this pain level means to you, discussing that you can’t do what you usually do, and the impact it has on your life,” he said. “You have to go beyond the raw number and make your pain visible to the health care provider, make it meaningful.”

Several ACPA communication tools focus on this need, and can enhance communications. (See page 3.)

People who live with pain must also increase their health care literacy in order to understand what their doctors are recommending for treatment. This includes the importance of exercise and relaxation, when and how to take medication, what side effects should be reported, and how to store, protect, and dispose of medication.

“Every person needs adequate follow-up, warnings, and information about the risks involved in treatment,” he said. At the hospital, it can be difficult to assess a person’s level of healthcare literacy, if they have someone to help them at home, or if they have transportation or housing issues.

“Everything we do is based on our understanding of the person’s situation and it helps if people with pain can adequately convey that,” he said, adding that cultural competence, social justice, and equity are gaining prominence in medical school curricula.

**Practice in Support Groups**

Pain support groups are a good place to practice communicating about pain. People can share notes about what has worked for them in confronting disparities in care and demanding that their basic rights be respected. Support groups also provide the social interaction that is necessary for good mental and physical health.

“When you reduce social isolation, you also reduce depression, grief, and stress, all of which contribute to pain. People who talk with and reach out to others function at a higher level and gain greater satisfaction from life,” said Dr. Todd.
Rising Above Disparities to Get the Help You Need

by Erin Kelly

At some point in their lives, most people with pain have difficulty getting appropriate care—usually because resources are unavailable or because insurance coverage is insufficient. But in some cases, we are denied care because of who we are, what we look like, or other circumstances beyond our control.

Drew Bufalini, an ACPA facilitator in Rochester Hills, Michigan, has first-hand experience with the effect prejudice can have on medical treatment. “When I first experienced my pain problem I didn’t know what to do except to go to the emergency room,” he says.

But he found that some emergency department staff tended to suspect that patients complaining of pain are faking symptoms to obtain narcotics illegally. “They try to wait you out,” he says, and in fact, it was quite some time before he was able to get help. “If they make you wait long enough, most people will just leave.”

It was frustrating, but he knew he had to advocate for himself. “You have to fight to get them to believe you,” he says. “I had no idea what was happening to my body, or if it was all in my head, but in no way was I at the hospital for drugs. I certainly didn’t want to be there.”

Prompting a Positive Response

Although being denied care based on a stereotype can be frustrating, there are positive ways to deal with the situation. “Storming out of the emergency room is probably the worst thing you can do,” Bufalini says. Even when you are upset, it’s important to be polite to the doctors and nurses who care for you. “They say you catch more flies with honey than you do with vinegar,” he says, “Although when you think about it, who wants flies?” he jokes.

A good working relationship with your medical team is the ideal, but even in non-ideal situations your behavior influences your care. “I’ve seen people in hospitals treat the nurses like their butlers,” Bufalini says. “That’s not going to get you the kind of sympathy you need when you’re having a bad day.” He also points out that people’s expectations can be too high. “We think that doctors have a magic wand to make us better, but they don’t.”

If we get angry when doctors can’t live up to our unrealistic expectations, those feelings will influence our behavior. Advocating for yourself is important, but lashing out emotionally is counterproductive. “You wouldn’t treat a fry cook at McDonald’s the same way I’ve seen some people talk to their doctors,” Bufalini says.

Overcoming Societal Prejudices

Some people have trouble establishing relationships with healthcare providers because of who they are. Because of societal biases, some medical professionals will ignore elderly people or disabled people—even addressing a younger companion or caregiver instead of talking to the person directly.

Evelyn Cooper, a support group member in Ocean Park, Maine, is in her early 70s and sometimes takes her daughter to medical appointments as a back-up listener. However, she avoids the experience of having doctors “talk around” her because she always makes sure her doctors know she is in charge. “When you go to a new specialist, introduce yourself at the beginning and make it clear what kind of person you are,” Cooper says. “Participate in the discussion and ask questions.”

Bufalini also has evidence that your insurance status can make a big difference in how you are treated. “I have a friend who went to the same pain clinic for years,” he explains, “But when he switched from private disability insurance to Medicaid, the quality of his care took a nose dive.” Although he was seeing the same physician, after the insurance switch the doctor’s visits were shorter and the team seemed to put less effort into focusing on his problems.

Cooper says that her insurance status hasn’t affected the quality of care she receives, but it does determine the amount. “I went to a pain clinic when I lived in Colorado,” she says, “and while I was there they treated me exactly like any other patient.” But Colorado Medicaid would only pay for a few visits, she points out.
Other health problems, especially behavioral health issues, can interfere with proper pain care. Says Bufalini, “If someone has issues like alcoholism or drug abuse, their other problems aren’t taken seriously. Doctors won’t prescribe strong pain medications because it’s risky, but at the same time they frequently don’t steer people toward help for the alcohol problem.”

Of course, often chronic pain diagnoses are difficult to ascertain. Bufalini says that many pain-causing syndromes are not taken seriously by the medical community. Fibromyalgia, chronic fatigue syndrome, and other conditions are not easy to definitively diagnose. “It’s like a diagnosis given in lieu of a diagnosis,” once most other causes are ruled out, says Bufalini.

Cooper also has struggled with imprecise diagnoses and their effects on the medical community. “I haven’t got a diagnosis yet. All I know is that I have nerve pain caused by the accidents I was in.” She says that doctors aren’t always comfortable confronting problems that they don’t know how to fix.

Really? You Don’t Look Sick.

Also, Cooper’s problems can’t be seen on an x-ray and she doesn’t usually look sick. “I walk with a cane, but otherwise I look normal—a lot of us do,” she points out. She thinks that physicians sometimes don’t take her complaints seriously because of how well she seems. “You have to advocate for yourself, but if you find someone who doesn’t seem to pay attention, well, you just don’t go back to that one!” she says.

“You have to advocate for yourself, but if you find someone who doesn’t seem to pay attention, well, you just don’t go back to that one!”
Bufalini believes that the basic approach to medicine needs to change for chronic pain treatment to improve. “The paradigm is wrong. Doctors feel they need to have a diagnosis to know how to treat someone. I lived in pain for seven years and didn’t have a diagnosis until two years ago.” He also believes that some physicians have a “drug bias.” They tend to prescribe medication quickly, before considering alternative therapies, which, depending on the person, isn’t always the best route.

Cooper agrees that physicians can be too eager to treat with pills. “I went to one physician who asked me about my problems and sat there with the prescription pad in her hand. I left there with five prescriptions and I don’t think she paid attention at all to what I was saying. I’m not a drug person and I’d rather try other treatments first,” she explains. Cooper has been helped by acupuncture and chiropractic treatments, and has recently started physical therapy, although she has had difficulty with insurance that limits the number of physical therapy visits.

Cooper also has done her own research into home remedies. She swears by certain spices, like ginger tea and flourless chocolate brownies with cayenne, which she says reduce her pain and help her digestion.

The future of health care is always uncertain. Will improved access to care mean better treatment for even imprecise pain diagnoses or will increased specialization lead to longer wait times even for well-accepted treatments? Cooper and Bufalini weren’t making any predictions. But no matter what the future holds, patients will always need to be their own advocates with healthcare providers. We must all use our coping skills to get the treatment we need, the best overall healthcare we can find, and manage life with chronic pain.

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**Confronting Disparities in Pain Care**

CONTINUED FROM PAGE 1...

Should the color of our skin, the type of work that we do, the area we live in, our ability to pay, or even our gender impact our treatment? Standing on the outside looking in, we would answer, “Absolutely not.” After all, “you should never judge a book by its cover.”

Yet, every day we all seem to make decisions based on what we see at hand instead of waiting to learn the full story. It is difficult for most of us to get past our first impressions; to let go of things we’ve heard or prejudices too often passed down from parent to child. We can’t help but be influenced by environment, culture, and life experiences.

If you think about it, aren’t all of us affected by disparities to some degree? This is especially true for those of us who live with pain. While we know there are disparities in health care today, it is just a little bit more difficult for a person with pain to be fully validated when it comes to ongoing care.

**Don’t Let Disparities Hurt You**

Keep in mind that pain is invisible and there is no way for others to really know how much pain we experience. You will have to make it very clear to your health care providers if you hope to avoid under treatment based on your circumstances.

Disparities in care mean something different to each person, depending on who you are, where you live, and your way of life. When it comes to health care, I think anyone who shares in the care and treatment people with pain needs blinders all around and a real sense of compassion.

In this issue, we will examine disparities in care from the perspectives of doctors, researchers, support group facilitators, and people with pain. We will also share some ideas on how you can improve communications to diminish the chances of disparities affecting your own treatment program.
Handcrafted Medicine Bags Serve as Creative Distraction from Chronic Pain

by Tara White, RN

Continuing the traditions of his Cherokee Indian ancestors has given a California man, Ralph King, a creative focus for his life and a distraction from his chronic pain.

Ralph is not only creative and optimistic, he has a wonderful attitude that spreads to anyone within hearing distance. Very knowledgeable and interesting to talk to, Ralph also lives with chronic pain, which began when both of his ankles were badly damaged in a car accident and later developed into painful degenerative arthritis. Ultimately, both joints were fused with screws, not only making it difficult to walk, but quite painful as well.

Ralph is a member of the ACPA Sacramento/Citrus Heights Chronic Pain Support Group in California. The group’s leader, Mary Shumate, says that Ralph has been attending meetings for over a year. “He’s an amazing man, positive and appreciative of our group,” said Shumate.

One way Ralph deals with his pain is by keeping his mind occupied in other ways, including creating leather medicine bags in the Native American style.

Half Cherokee Indian by heritage and a retired farrier by trade, Ralph decided he wanted to use his creative talents to give him peace of mind. A former neighbor of his, Palou De Santoes, was trained in Italy as a leather smith. Ralph asked if he would teach him how to make a medicine bag. De Santoes gave him a scrap of deerskin and told him to cut it out himself, and he would show him how to sew it up. “I developed an imagination to do it,” said Ralph.

Since then, he has created his own lacework and after meticulous research, developed his own line of traditional American Indian bags. He notes that one of his sources for traditional details came from a Navajo Indian woman by the name of Helen who works at the Indian Museum by Sutter’s Fort.

Beginning with a traditional medicine bag, Ralph has gradually increased the size of his bags to include a Shaman’s bag, a flute bag, and a basic tote bag to be worn over the shoulder. All his bags are made of buckskin, rather than leather, which is the traditional way. All have custom lacing, hand braiding, and fringe and are closed with deer antler buttons. The finished products are truly beautiful works of art.

Ralph explained that the medicine bag is meant to be worn around the neck for protection. It can hold things such sage, which was burned for purification with the smoke traveling to the Creator, an arrowhead for strength, or other items specific to the wearer. The Shaman’s bag would carry medicine, a pipe, and tobacco. The Flute bag is meant to carry a Native American flute carved out of cedar wood.

The basic tote bags come in various sizes and shapes, with traditional beadwork and fringe. To keep the bags as authentic as possible, he only uses natural items such as agate and bone beads. Native American Indians used every part of the deer they hunted for meat, using the bones for tools and antlers for buttons.

Ralph gets a great deal of satisfaction from doing this work, an excellent example of the value of distraction as a helpful chronic pain coping tool. Soft-spoken and humble, this man inspires all of us who manage chronic pain. He also donates time to feed the homeless as a way to give back to others.

Anyone interested in purchasing one of Ralph’s traditional, handcrafted buckskin American Indian bags, can contact him at 916-920-0151. Prices vary as the bags are all very different.
To Find Your Way, Help Others Find Their Way

by Jani Larsen, National Veterans Coordinator for ACPA and VIP

When the doctors told me there was nothing more they could do for my pain, it was the saddest day in my life. We have cures for certain cancers, and physicians can actually operate on a human brain, but there is no cure for pain?

Who do you turn to? What is your next step? It is human nature to want to move forward and to fight whatever is uncomfortable in our bodies, but if the doctors cannot help, who can?

I find that whenever I do not understand something, research is the key. After researching pain—and more specifically “pain management”—I found the ACPA.

When I found ACPA, I found that other people were going through—or had conquered—the same issues I was facing. By attending a meeting I found a brotherhood, a sisterhood, a kinship; an amazing place to share stories and find answers.

That is when I decided I would like to help others and, in turn, help myself through difficult times.

Reaching out to others is one of the ten steps in managing pain and moving from patient to person. By helping others through their journeys, we are finding our own way. I cannot begin to tell you what a remarkable journey the past eight years have been with the ACPA.

Watching others find alternatives to suffering, and learn about themselves as they work through the adversity, has been a great experience. Learning ways to cope with the pain has increased the quality of my life and I feel stronger every day.

Increase the Quality of your Life

Helping others is the most meaningful and worthwhile practice you can have in life. Watching others grow and become stronger through learning the ten steps from patient to person is a rewarding experience.

You can start by helping the Veterans In Pain program. We need veterans who want to help veterans and in turn help themselves through difficult times. We are best at understanding what our fellow service members are enduring. Through that understanding comes compassion and compassion is the driving force in helping others.

I know what it takes to make it through a day when you live with pain, how the pain drains you, and the numbness you feel inside. It’s as if you are operating on autopilot. I know it seems daunting to schedule a two-hour group meeting twice a month when you have no idea how you will feel, or if you’ll even have the strength to leave your home that day. To commit to others when you cannot find the strength to commit yourself is a quite a challenge.

I had to pretend to pull it together to get through my first two meetings. After that, I eagerly anticipated attending the next meetings. Everyone wanted to help and the ACPA facilitators guide was easy to follow. Once I had others involved, it took little time to prepare for a group.

I have just a few goals in life, but being involved in the ACPA makes each day worthwhile. It has become an honor to assist our nation’s warriors and help them help themselves through these difficult times.

It would also be our honor to work with you and build the VIP program into something we can all be proud of. Email me today at VIP@theacpa.org for information on becoming a VIP facilitator and helping Veterans In Pain.

Medical Symposium on the Problems of the Veteran

The Cyril H. Wecht Institute of Forensic Science and Law, will present its 12th Annual Conference, “Post-Combat Problems in the 21st Century: Medical, Legal, and Societal Considerations” on November 8 and 9, 2012, at Duquesne University, Pittsburgh, Pennsylvania. From the diagnosis and treatment of traumatic brain injuries to Post-Traumatic Stress Disorder and chronic pain, the challenges of American military veterans in 2012 are legion. This conference will convene experts in psychology, DNA analysis, anthropology, occupational therapy, domestic abuse, and criminal law. Visit www.duq.edu/forensics for details and registration.
New ACPA Survey Highlights Significant Misperceptions about Diabetic Peripheral Neuropathy and Prompts Development of the Maze of Pain

A recent survey by the American Chronic Pain Association in collaboration with Pfizer Inc. has spurred the development of several new tools to help people with diabetes that experience diabetic nerve pain (pain from Diabetic Peripheral Neuropathy or painful DPN).

The survey compared how healthcare providers perceive the pain associated with DPN to the awareness level of persons with DPN.

Nearly one in five of the estimated 26 million Americans with diabetes experience painful DPN. Despite its prevalence, this survey of 1,004 people with DPN symptoms and 500 healthcare providers demonstrates major misconceptions and a significant lack of awareness surrounding diabetic nerve pain.

The results showed that:

* More than eight in 10 (83 percent) people with DPN symptoms report experiencing painful symptoms; however, on average, HCPs estimate that fewer than half (41 percent) of their patients with DPN experience pain.

* Three-quarters of respondents (77 percent) report their DPN symptoms impact daily activities; conversely, on average, HCPs estimate that only 38 percent of their patients with DPN suffer daily limitations, half the amount reported by patients in the survey.

“We are hopeful that our campaign, Diabetic Nerve Pain: Starting the Dialogue, will not only shed light on the symptoms and impact of DPN, but also provide a sense of hope so that individuals will be able to better manage their diabetic nerve pain. It is important to have meaningful conversations with healthcare providers to talk about managing pain symptoms,” said Penney Cowan, executive director of ACPA.

Because communication is a key component in any medical treatment, the ACPA has developed tools to clearly identify symptoms, what it feels like, and the level of discomfort. Through the ACPA’s Maze of Pain, people with painful DPN can find solutions to the confusing maze that can characterize dealing with chronic pain. “As they begin to work their way through, what they know as a tangled maze of endless paths and dead ends becomes a route to regaining control over their life while keeping pain in its place,” said Cowan.

The “Maze” will guide the individual through different paths that offer various resources.

* **DPN Pain Map:** Clearly identify where you experience pain with an easy-to-use tool that can be printed and shared with your healthcare providers.

* **Conversation Guide:** A conversation guide that helps you to talk with your doctor about the nerve pain that you experience, the impact it has on daily functioning, and the factors in life that affect your level of pain and quality of life.

* **Manage It:** Tools that will help you to take an active role in managing the discomfort and daily activities caused by painful DPN. You will learn how to:
  * Set priorities and realistic goals that are within your ability;
  * Become empowered through learning and understanding your basic rights;
  * Listen to your body and tell it how you want it to feel;
  * Manage the impact your emotions have on your ability to manage pain; and
  * Manage the roles that you, your family and friends, and healthcare providers have in managing your diabetes and DPN each day.

You will be able to explore the Maze of Pain on the ACPA website, when it is completed during fall 2012.
ACPA Updates

Combined Federal Campaign
The American Chronic Pain Association has been accepted by the U.S. Office of Personnel Management for inclusion in the fall 2012 Combined Federal Campaign as a member of Health & Medical Research Charities of America.

If you work for the Federal Government and would like to designate the ACPA for a contribution, please contact us at 1-800-533-3231, or acpa@pacbell.net to find out the CFC number. This is only valid for CFC members.

Arthritis Foundation Recommends Physical Activity
A new report from the Arthritis Foundation, Environmental and Policy Strategies to Increase Physical Activity among Adults with Arthritis, states that physical activity is essential in managing pain and function and improving daily life for those with arthritis.

The American Chronic Pain Association is one of many organizations that are partnering with the Arthritis Foundation to help propel implementation of this new initiative. You can learn more and get involved at www.arthritis.org/physical-activity.

People living with arthritis have disease-specific barriers to being physically active including pain, fear of making their arthritis worse, lack of knowledge about the best type and amount of exercise, and fear of injury. However, physical activity has been proven to help decrease pain, delay the onset of disability, improve physical functioning and independence, and enhance mood and quality of life for adults with arthritis.

As the nation’s most common cause of disability, arthritis affects 50 million adults in the United States—more than 20 percent of the adult population.

And this number is expected to grow as the population of older Americans and number of obese Americans continues to increase.

Along with decreasing pain, physical activity can delay the start of disability, improve muscle strength, mobility, mood, and independence, and enhance quality of life. High rates of arthritis among people with other chronic diseases—such as diabetes, heart disease, and obesity—for which physical activity are important, increases the value of physical activity as a tool for managing arthritis. Yet, adults with arthritis are less likely to be physically activity than are those without arthritis, according to the Centers for Disease Control and Prevention (CDC).

The new report is a comprehensive resource that calls on organizations in six sectors to help make it safe, accessible, and convenient for adults with arthritis to be physically active, and meet the goals of the National Physical Activity Plan. Among those who can help in this effort are leaders in community and public health; healthcare; transportation, land use and community design; business and industry; parks, recreation, fitness, and sport facilities; and the mass media.

Arthritis Survey Online
The ACPA wants to gain a better understanding about people who live with arthritis and what they do for relief of the pain and discomfort. In addition, we would like to know the impact it has on daily life and where to look for more information about managing this condition.

This survey for people with arthritis will take no more than ten minutes to complete. Your responses will be combined with all others and we will not share any of the information you provide with anyone or identify you in any way to others. You can go to www.theacpa.org to take the survey.

September is Pain Awareness Month.
See our website for related news.

Welcome to our new groups and facilitators.

Cindy Langr
Saint Paul, MN

Joanne Yeager
Bedford/Cleveland, OH

Michael Lucas
Harrisburg, PA
NIH selects 11 Centers of Excellence in Pain Education

The National Institutes of Health Pain Consortium has selected 11 health professional schools as designated Centers of Excellence in Pain Education (CoEPEs). The CoEPEs will act as hubs for the development, evaluation, and distribution of pain management curriculum resources for medical, dental, nursing, and pharmacy schools to enhance and improve how health care professionals are taught about pain and its treatment. Twenty institutes, centers, and offices at NIH are involved in the consortium.

“Virtually all health professionals are called upon to help patients suffering from pain,” said NIH Director Francis S. Collins, M.D., Ph.D. “These new centers will translate current research findings about pain management to fill what have been recognized as gaps in curricula so clinicians in all fields can work with their patients to make better and safer choices about pain treatment.”

A list of the new Centers of Excellence in Pain Education can be found at http://painconsortium.nih.gov/centers-of-excellence-in-pain-education.html

Interagency Pain Research Coordinating Committee

More than 100 million Americans suffer from migraines, arthritis, and other chronic pain conditions with an annual economic toll of nearly $600 billion in medical bills and lost productivity.

To help address the national problem of chronic pain, Congress directed the U.S. Department of Health and Human Services, through the Affordable Care Act, to create the new Interagency Pain Research Coordinating Committee made up of national experts in pain research and patient care. Its members, announced by the National Institutes of Health, are biomedical researchers, representatives from nonprofit public advocacy organizations, and representatives of seven federal government organizations, including non-federal researchers, physicians from Harvard Medical School, the American Cancer Society, and Stanford University School of Medicine.

The committee will work to identify critical gaps in basic and clinical research on the symptoms, causes and treatment of pain and will recommend federal research programs in these areas.

The focus will be to coordinate pain research activities across the federal government with the goals of stimulating pain research collaboration, fully leveraging the government resources dedicated to supporting pain research, and providing an important avenue for public involvement. The committee will explore public-private partnerships to broaden collaborative, cross-cutting research, and consider best practices in disseminating information about pain to public and professional audiences.

“Pain is a universal condition, a serious and costly public health issue, and a challenge for family, friends, and health care providers,” says Story Landis, Ph.D., director of NIH’s National Institute of Neurological Disorders and Stroke (NINDS) and the committee chair. “This committee will play an important role working with federal agencies spearheading pain research. I am pleased that its membership reflects a great depth and wide range of both scientific expertise and effective public advocacy.”

For more information, visit www.ninds.nih.gov/news_and_events/news_articles/InteragencyPainResearchCoordinatingCommitteeannounced.htm

Migraines, Strokes may be Linked to Childhood Adversity

Migraines, strokes, and other inflammatory diseases suffered by some adult women may be linked to adverse experiences that occurred during childhood, says a new study co-authored by a Ball State University researcher.

A study of 140 women between the ages of 18 and 50 found a strong correlation between incidents of childhood adversity and migraines, chronic daily headaches, and inflammation that leads to strokes, said Jagdish Khubchandani, a community health education professor in Ball State’s Department of Physiology and Health Science and a faculty fellow with the university’s Global Health Institute.

The study found:

- About 79 percent of women with migraines reported suffering adversity during childhood as compared to 21 percent of the headache-free.
- Participants reporting continuous headaches had an adversity score of 3.24 while participants without headaches had a significantly lower adversity score of 1.53.
- Participants reporting frequent migraines were more likely to identify themselves as lower income and less educated. They were smokers with higher body mass indexes and hypertension.
- Participants with adverse childhood experiences were more likely to report chronic daily headaches and have increased blood levels of markers for stroke and blood clotting.

More information can be found at Ball State University News Center, www.bsu.edu/news/article/0,1370,7273-850-65668,00.html
Book Reviews

How to Get a Good Night’s Sleep: 75 Natural Sleep Prescriptions
written by Norman Ford

Review by Tara White, RN

Just about everyone in my ACPA group has complained about not being able to sleep well. As a matter of fact, insomnia has become a legitimate and very common medical issue. At times I have felt as though I was the Insomniac Queen of the Universe and that was before my pain problems began!

I have read a great deal on the subject and, despite the original 1994 publishing date, I feel this book still has a great deal of very useful and legitimate advice to offer. It is also quite comprehensive and covers just about every conceivable reason for not sleeping.

Although this book does not focus on a person in pain per se, it does stress the tremendous importance of sleep and the serious effects of not getting enough. For example, the author states that “a chronic sleep deficit of 30 to 90 minutes a night swiftly suppresses our immunity and intensifies risk of almost any illness and disease.” He states that sleep deprivation can make you feel as if you are “living in a fog with your focus frayed.” When you add chronic pain and pain medications to the equation, all of these problems are exacerbated.

Moreover, for many of us, the same bedtime ritual that normally signals our brain that it is time to go to sleep can also become an insomnia routine. When nightly pain is added to all our other life stressors, our “fight or flight” response is always simmering. This must be reversed to eliminate insomnia. It is essential to have several natural remedies available to help us to relax the body and mind and get to sleep. This is exactly what this book offers.

The author stresses that you must first talk to your physician to rule out any health issues that are affecting sleep, such as sleep apnea, snoring, and weight loss. Improper diet, frequent napping, and stimulants are other sleep-destroying habits. He focuses on discovering the specific root issue of your insomnia, such as trouble getting to sleep due to chronic worry, waking up several times a night, or waking up too early and not being able to get back to sleep.

For solutions, he covers guided imagery and breathing techniques and shows how to defuse anxiety, worry, anger, and fear. Seventy-five easy to follow “Sleep Rxs” are offered to help us get the wonderful, rejuvenating sleep we so badly need.


Recipes for Repair: A Lyme Disease Cookbook
by Gail and Laura Piazza

Review by Claudia Welch, Harbor City, CA Facilitator

Recipes for Repair: A Lyme Disease Cookbook is a guide to following the Lyme Inflammation Diet® developed by Dr. Kenneth B. Singleton, MD, MPH., including recipes and a diet plan.

Though complicated, this book has been well thought out and is very inviting. Because some ingredients may be obscure, you will have to wind your way through the Lyme Inflammation Diet (LID) Food Glossary for clarification and directions on how to make things like Ghee (a clarified butter).

Part I covers the very complicated process of understanding chronic inflammation, toxins, and enzymes; defining the phases of the diet; dealing with sugar cravings (which is important because “discontinuing the use of all sugar is essential for recovery from chronic inflammation”); detoxification; consideration for problem headaches; and organic vs. conventional foods. The instruction on how to read nutritional labels was helpful. I used it with my ACPA group. The self-assessment tool was informative. Just this first part could be overwhelming, especially to someone who is newly diagnosed.

Part II, “Getting Started”, contains cooking rules and methods, equipment needed, the LID glossary, (containing definitions of ingredients used) and the types of food that would be eaten, including but not limited to, grains, nuts, legumes, and fats.

In Part III we finally get to the recipes, but we don’t really get to the “root” of the diet (no pun intended) as we are just in the first phase. (There is a list of foods that can be eaten during each phase.) I did learn that “fruit consumption should be modified while using antibiotics.” The Phase I recipes alternated between simple and complicated, so easy is a possibility.

Phase II is the “reentry phase” during which you can add more foods, but only after the three weeks of Phase I. Again, this was too rigid for me.

I would recommend it only to the most serious person determined to make an abrupt change in their lifestyle. The reader must be prepared for their dietary habits of a lifetime to change completely, unless their philosophy has been parallel all along. This includes the way you shop, think, cook, and eat.

The knowledge contained in this book and the program outlined is very concise. If one is determined to address the diagnosis using food, this is a formidable resource.

Thank You!

Since 1980, the American Chronic Pain Association has provided people who must live with daily pain a means to help themselves to a richer, fuller life. We are grateful to have the support of these corporate sponsors for our mission:

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Thanks to these corporations for grants that enable ACPA to fund special projects:

**Purdue** provided an in-kind service by printing 1,000 of the ACPA workbooks: From Patient to Person: First Steps

Development of the ACPA website was made possible through an unrestricted educational grant from Medtronic Foundation and Purdue Pharma.

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

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Tributes

**In Memory of Kate Brown**
Survived by husband Larry Brown

Given by
John and Donna Gerlaugh
Terri Christian

**In Memory of Our Aunt Dorothy Folden**

Given by
Dave Helgerson, Darla Helgerson and Dawn Helgerson Zavadil

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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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