



CHRONICLE



Through 30 Years Our Mission Remains the Same

by Penney Cowan, Executive Director, ACPA



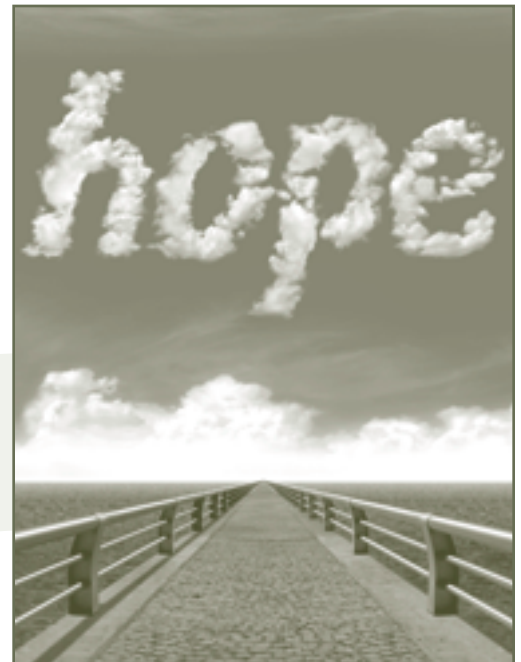
In 1980, we started the American Chronic Pain Association in reaction to a bleak realization: too many people believe that they are the only person in the world who is forced to live with pain. As each day passes, these individuals lose any sense of hope for the future.

They needed to know that they were not alone, that there were others who would support and believe in them. Equally important, they needed to know that if they were willing to take an active role in their health care, they might just be able to regain their lives.

The fact remains that people with pain deserve to have their pain taken seriously and to be treated with respect. For more than 30 years, the ACPA has helped people with pain to understand in the simplest terms a very complex problem: how to live with chronic pain.

The ACPA continues to empower people with pain so they no longer feel hopeless when they look at their lives. **The ACPA has a twofold mission:**

- * *To facilitate peer support and education for individuals with chronic pain and their families so that these individuals may live more fully in spite of their pain.*
- * *To raise awareness about issues of living with chronic pain among members of the health care community, policy makers, and the public at large.*



To fulfill this mission, we needed to make people with pain aware of their rights and responsibilities. Access to appropriate medical care for their pain is a right of all people. But even with the best medical care, many people will still have some level of pain that they will have to live with. We teach that living well with chronic pain is possible. But to live well in spite of pain, individuals must participate in their care plan, leave behind the passive role of “patient,” and re-establish an identity as a person.

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The ACPA and How it Grew

by Alison J. Conte

In 1980, when Penney Cowan started a support group for people with chronic pain, her mission was to help those people understand that they were not alone, and that there were ways to improve their quality of life in spite of the pain.

She acted from experience. In 1979, after six years of chronic, debilitating pain, Penney was diagnosed with Fibromyalgia (then called fibrositis).

“It took me six years to get a diagnosis and my reaction was, ‘OK. Fix it.’ But there is no miracle cure. The fear of pain, not knowing when the pain is going to strike, is what most limits the quality of life,” Penney said.

Soon after the diagnosis, on October 31, 1979, she reluctantly entered a pain management program at the Cleveland Clinic under the direction of Dr. Edward Covington. “I went there to fail,” said Penney. “For seven weeks I struggled. I was stubborn; a really tough nut.”

But Penney eventually opened up to the realization that she was not the only person who felt isolated and alone because of pain.

Learning to Live with Pain

Dr. Ed Covington recalled thinking of Penney as one of the most stubborn people he ever worked with. “After a time, I realized that what I was

confronting was actually perseverance. Whatever she tackles, she is doggedly determined to carry it out. This is remarkably inspirational, especially to people who are tempted to give up,” he said.

In the program, Penney learned to take greater responsibility for her recovery, understand the emotional aspects of pain, exercise to recondition her muscles, examine priorities, and set reasonable goals. She learned to distract her mind from the pain through biofeedback. “The brain can’t focus on two things at once. If I’m concentrating on something else, I’m not feeling the pain,” she said.

“The skills I learned have become so ingrained that I no longer get up in the morning and think about taking one step at a time. It’s all second nature now,” Penney said. “But it took a lot of work, time, and commitment to move my mindset from ‘disabled patient’ to ‘functioning person.’”

After six weeks, on December 14, 1979, she left the pain management program as a person. “There was still pain, but I was functional. I had my life back,” she said.

Let’s Get Together

“I started the support group to reinforce and maintain my own wellness skills and get over my fear that I couldn’t make them work outside a controlled environment. I wanted to share these



skills so I was not all alone trying to make them work,” she said.

The first groups, promoted through her church bulletin, were called Support Can Be Beautiful. Within a year, Penney was traveling among seven groups to teach pain management.

“We were different from other support groups in that we didn’t talk about medications or symptoms or doctors. We shared the skills that would change attitudes, help each of us to set priorities, and reach our goal: a return to a functional life.”

Forming the Board

In 1982, Penney was running Support Can Be Beautiful from the basement of her home in Monroeville, Pennsylvania, near Pittsburgh.

With seven support groups, Penney felt she had reached her limit, but was convinced that more had to be done. A new acquaintance, Chuck Lidz, encouraged her to structure her organization, train facilitators, register as a non-profit corporation, and establish a board and

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1980~1985

1980

Penney Cowan starts two pain support groups near Pittsburgh.

1982

ACPA’s Board of Directors formed.

March 3, 1983

ACPA formally gains non-profit status.

1984

ACPA presentation at the Fourth World Congress on Pain.

By 1985

21 support groups in five states. Family support groups and hospital visitation programs established.

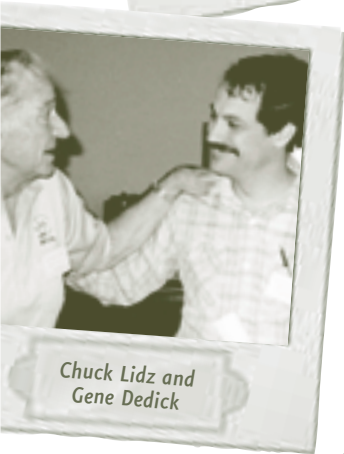


Angela Maher



Dennis Turk

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Chuck Lidz and Gene Dedick

bylaws. “Penney found me when she was seeking an expert in self-help groups,” Chuck Lidz said. “Her earnestness was so compelling. She was without cynicism.”

“I never expected to see her again, but two months

later she had registered the American Chronic Pain Association. She came back and asked me to be on the board,” Chuck said.

“What is always impressive about Penney is that it is hard to turn her down,” Chuck said. He in turn recruited Angela Maher, Jim Kuhn, Nicole Kelly, and Joe Baim. Joe Baim, PhD is a management consultant who served for 20 years, with several terms as president.

“Chuck brought people to the board who cared for each other, who were passionately committed to the mission,” Joe said.

Penney also asked Ed Covington to join the board but he was hesitant because he was still her doctor. “After a year, Penney fired me as her doctor. She valued me more as a board member. So I drove to Monroeville every three months, and got speeding tickets on the way back to Cleveland,” Ed said.

Decisions, Debate, and Discussion

The board was formed in 1982. Two years later there were 21 support groups in five states.

“Chuck and I rarely agreed on anything except the mission. ACPA was a part of our lives. All of us were passionately committed to it,” Joe said. “Chuck supported Penney in her writing, until he got Nicole to do it.”

Nicole Kelly joined the board in 1983, bringing expertise in writing and public relations. She helped ACPA use the media to reach more people with pain and edited manuals, guidebooks, and *The Chronicle* newsletter.

Nicole is still on the board today, working on the website, videos, and new print materials and also helping Penney speak for people with pain in public and government forums.

Joe remembered that, “Nicole was extraordinarily committed. And when Ed Covington could break away from his work in Cleveland, he would join us. Ed is the world’s most empathetic human being, but he could also be tough minded when the situation called for rigor and discipline.”

Ed Covington was very involved for 10 years, giving Penney support and promoting the ACPA not only to people with pain but also to pain specialists. “I edited the book that Penney wrote, *Patient to Person*, about 40 times,” he said, “or so it seemed.”

“The early meetings were around Penney’s dining room table in her Monroeville home,” Joe said. Jane Colborn, the first board secretary, recalled that the meetings always included Penney’s excellent home-baked cookies.

“Penney told everyone they would only need to meet four times a year, but the committees met once or twice a month. It was a real working board, not a governing board,” said Jane.

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1986 ~ 1990

Over five years, 44 support groups grew to 409 in four countries.

Membership dues initiated.

June 1990

National office moved to Rocklin, CA.

The ACPA Chronicle and first video created.

First conference for ACPA leaders.

Penney Cowan awarded The Jefferson Medal by the American Institute for Public Service.



1989 Retreat

The ACPA and How It Grew

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“The meetings were long. Joe and Chuck were the best of friends who took opposite sides. They argued constantly and lovingly,” Jane said. “Nobody ever left angry.”

Joe described Jane, who was secretary for 22 years, as sane, solid, and steady, making real contributions. “Chuck was always positive, though at the time I called him overly optimistic. My contribution was paranoia,” said Joe, who fought for insurance, disclaimer language, and standards for facilitators.

A Retreat in the Mountains

The first facilitator training retreat, in 1989, brought together people who hadn’t been out of their homes in years. “People came who couldn’t sit for very long because of their pain,” Jane said. “Those who drove a long way had to stop often to get out and stretch. But they were so proud and happy that they made it.”

During the first few retreats, Ed remembered being surrounded by whiners. “They had to tell me all about their

symptoms, pills, and problems,” he said. “But as the yearly retreats went on they talked less about their medical conditions and more about what they had learned and shared about managing pain. It was obvious that they’d succeeded in shedding the patient, and had become the people they used to be.”

The workshops focused on improving support group meetings and encouraging interaction among members. Ed and other professionals lectured about depression, medication, and pain psychology.

Jane, now age 90, noted changing attitudes about pain. “When I was in the hospital in the early 1960s, I wasn’t treated for post-operative pain. But when I was there in the late 1990s, both the nurses and doctors asked about my pain and gave me medication. I like to think the ACPA has had something to do with that.”

Other early board members were Angela Maher, MBA, CCM who made major contributions to budgeting and

policy with her steady judgment. Darlene Lovasik, RN, MN also played a substantial role, serving several terms as president. They both contributed to *Patient to Person*. Angela was also an editor of *Staying Well*.

The ACPA thrived through the early days due to Penney’s dynamic passion, Ed’s empathy, Jane’s steadiness, Chuck’s positive outlook, Nicole’s energy, and Joe’s thoughtful caution. Along with other devoted board members, this foundation of leadership allowed the ACPA to move forward—still garage based—but into the national arena of health care and pain awareness.

ACPA on the National Stage

For years, the ACPA operated on a shoestring, funded at first by Penney’s husband Scott, and later by a few small donations.

“H.J. Heinz Foundation gave us our first big grant, \$17,500,” Penney recalled. “It was the first grant request I ever wrote. We got a computer, stamps, our first official stationery, and a phone.

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1991~1995

1991

526 support groups in 49 states, Europe, and Russia.

1994

Presented Chronic Pain as Stigma to American Pain Society.

1995

830 support groups, expanded to England, Mexico, Scotland, and Ireland.

National Office Resource Line created to help callers. ACPA Professional Advisory Board formed. ACPA Workbook II, Maintaining Your Wellness developed. ACPA Workbook for Family Members published. Materials translated into Spanish and Russian.

Donna A.K. Kalauokalani



Darlene Lovasik



Maggie Chesnut,
coordinator of ACPA's
Growing Pains



Claire
Patterson



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We printed real pamphlets and did mailings.”

“Obtaining funding on a larger scale was one of our ongoing struggles. Foundations want to see formal structure, but that can get in the way of spontaneity and the ability to respond to emerging needs. Another option was support from the pharmaceutical firms, which have a specific interest in supporting the organization. These factors can be very influential,” Chuck said.

It is now clear that potential funders valued ACPA’s independence. “Our credibility has made us attractive to pharmaceutical firms that are seeking a partner for non-branded educational programs and public awareness campaigns,” Nicole noted. “We stay close to the consumers so we understand their needs. And no one is better than Penney at developing creative, effective ways to meet these needs.” In 1984 at the Fourth World Congress on Pain in Seattle, organized by the International Association of the Study

of Pain (IASP), Darlene Lovasik did a presentation about the ACPA. “Because of that we were contacted for a radio interview and word started to spread,” Penney said.

“We did an interview with *Prevention Magazine*, and all of a sudden there were hundreds of calls a day, even without a toll-free line,” Penney said. “For many people actually talking to someone who believed them was transformative. But I encouraged them to go further, join one of our support groups, or start a new one,” she said. “During the Gulf War I was amazed by the soldiers who wrote to the ACPA, very concerned about the people they left behind, their family members in pain.”

To Reach Out, To Find Funding

By 1991 there were 526 ACPA groups in 49 states, Canada, Australia, New Zealand, and Russia.

“Penney lived on the phone, and sent materials to people, urging them to start support groups,” Ed said. “There were some brochures in doctors’ offices, and

word spread through annual meetings of the American Pain Society and the American Academy of Pain Medicine. Then, all of a sudden, there were groups in Albuquerque and Moscow.”

“In a support group people can learn to verbalize what they are going through, understand their conditions, and use their coping skills. The other group members provide emotional support,” Penney said.

Ed agreed. “Support groups are actually curative and can benefit people with pain even if they don’t get medical treatment. They can vastly improve the quality of daily life.”

Manuals and Newsletters

A donation from Blue Cross in 1987 allowed ACPA to print *Patient to Person, First Steps*, also known as the red book. The second manual, *Staying Well, Advanced Pain Management for ACPA Members*, published in 1994, was known as the blue book.

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1996~2000

Reflections of You *designed*. ACPA *Growing Pains* started for young adults.

1996

Website launched.

Volunteers convert *Chronicle* to audio tapes. Kits for Wellness released. First public service announcement spurs more media coverage.

2000

ACPA groups now include British West Indies and Saudi Arabia.



Colette Inomata with Dan and Kim Galia



The Arlington chapter discusses questions for ABC News medical experts.



PARTNERS for UNDERSTANDING PAIN

The ACPA and How It Grew

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The *ACPA Medication Supplement*, now called the *Consumer Guide to Pain Medication & Treatment*, was first published in 2000. Dr. Ed Covington edited the first version, a job that was taken over by Dr. Steven Feinberg, pain specialist and rehabilitation physician in Palo Alto, California. For the last 10 years, Steven has been senior author and has written and updated the *Consumer Guide* every year. Board member Dr. David Provenzano now serves as co-author.

“We started the *Medication Supplement* so that people with chronic pain could be well informed about their treatments, medications, and options,” Penney said.

“I started writing for the *Chronicle* in 2000, and then began editing and writing the *Consumer Guide*,” Steven said. “It started out as a little project and became a big project. Over the years, I’ve put in a zillion hours writing for the *Consumer Guide* and *Chronicle*.”

The 2010 edition is 80 pages long and covers the full range of possible treatments for pain, from opioids and antidepressants, to magnet therapy, and

hyperbaric chambers. Herbal medicines and behavioral therapies are also covered.

Other *ACPA publications* include the *Facilitator Guide* for group leaders, a *Workbook for Family Members*, a *Regional Director’s Manual*, and an annual *Coping Calendar*. The *ACPA Chronicle* began publishing as a quarterly newsletter in 1983.

“We often require families of patients in our pain rehabilitation program to purchase the *Family Workbook*,” Ed noted. “They often feel that every strategy they’ve tried to help their loved one either failed or made them worse. The book is very enlightening, gives them direction without blame. It’s worth hours of counseling.”

Joining the Pain Community

In 1990, Penney, her family, and the ACPA moved to Rocklin, California. Through a grant from the Mayday Fund in the late 1990s, the ACPA hired its first part-time employee.

By 1996, there were 830 groups in all 50 states, Canada, Australia, England, Mexico, Scotland, Ireland, New Zealand,

and Russia. Penney had begun attending more national and international meetings. “Penney was always a great speaker. She was credible in a way that let her connect with audiences,” Chuck said. On this topic, Penney commented, “Leading ACPA gave me confidence. With all I have been through with my pain, nothing fazed me.”

In 2001, ACPA received seed money from Purdue Pharma to promote September as Pain Awareness Month and form *Partners for Understanding Pain*, which would go on to undertake legislative action like the Pain Care Policy Act. It brought together 80 organizations to ensure the messages of Partners were carried through both the professional and public communities. Because of the efforts of the ACPA and Partners for Understanding Pain, September is now recognized as pain awareness month.

Out of the Garage, Into the World

In 2005, the ACPA moved out of Penney’s garage, stayed three years in its first office, and then moved to a larger, 2,000 square-foot space.

Working alongside Penney in the office is Joni Armstrong, who has been ACPA

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2001~2005

First Consumer Guide to Medications and Treatments. Quality of Life Scale, Pain Log, and CARE Card created.

Launched *Partners for Understanding Pain*, with 80 organizations. Pharmacists’ and nurses’ tool kits developed. PA Governor declares September Pain Awareness Month. It Takes Nerve campaign (nerve pain education) launched.

2005

First office space leased. Support groups now include Wales, India, and Jordan.



ACPA regional directors met in Chicago in 2008.



Penney's husband, Scott Cowan and his mother, Kathleen Cowan



Bob and Marianne Farrell



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office manager since March 13, 2006. Kim Galia, Outreach Coordinator, started June 7, 2010 as the liaison for facilitators and support groups. "That's our office staff," said Joni. "We do have an IT person who works closely with us as needed, and a network of freelancers and production people who have worked with us for years and understand our mission. And, we have lots of volunteers who come in to help us assemble mailings and literature."

"In the last ten years, we've just exploded with materials, as we try to help people with communication CARE cards and tool kits," said Penney. The CARE Card for pharmacists and the Tool Kit for nurses were part of the Partners for Understanding Pain CARE Campaigns. In 2006, a Tool Kit was devoted to addressing the issue of pain in older adults.

The ACPA website became a new way to share news, calls to action, and research studies, as well as resources—like the *Fibro Person*, videos, and an online relaxation session. "But the web can only go so far," said Penney. "It is not a substitute for a social network.

People with pain need to fight isolation and depression. They need to get out of the house and connect with others in person."

Getting to People Sooner

"Throughout it all, there was never any indication that Penney had chronic pain, except for an occasional furrowed brow. She had the same endless energy as she has now," Joe said. "She is dynamic and charismatic and committed; but what is so rare is that she does it without ego, totally sincere."

"She was self conscious and faltering when she started, but Penney has developed into an articulate, international spokesperson for the needs of those with chronic pain," said Ed. "For more than 30 years she worked 80 hours a week, most of the time without a salary or paid assistants. She is the soul of ACPA."

"When people with pain hit bottom, they come to us," said Penney. "If we can get to people sooner, they will suffer less and not fall as far. When they find us they may start learning

to become an active participant rather than a passive patient, and live a higher quality of life," Penney said.

"So often they experience that 'Aha!' moment. They realize that their real goal is to reduce the sense of suffering and get back to the things that matter most. I often hear, 'Why didn't someone tell me that this was the way to navigate the maze of pain?'"

This is what the last 30 years have been about: sharing the ACPA message that Penney repeats every day. "You may not be able to make it go away, but you can have a full life while living with pain."

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2006 ~ 2010



Fibromyalgia project with web resources and five-city tour.
Emergency Department Survey research; In Case of Emergency materials.
Lower Back Pain Practice Guidelines created.
Tool Kit for Older Adults added to Partners Tool Kits.

It Takes Nerve tools, Nerve Central Station, added to website.
Pilot project with Kaiser Permanente for staff education.
AGrABILITY presentations in 10 rural communities.

Changing Lives for 30 Years

by Erin Kelly



The ACPA started because of one woman’s journey to wellness. But in its 30 years, it has changed many lives and grown into a well-known source of help for individuals and professionals. *ACPA Chronicle* talked to some long-time ACPA members about the changes they’ve seen in their lives and in ACPA.

Decades of Personal Growth

Although most people who become involved with the ACPA want to learn pain management skills, long-term members find there’s much more to gain from being involved in the organization.

Judy Gober, a facilitator in eastern Pennsylvania, got involved with the ACPA in the early 90s after she realized that she could not go back to work after surgery. “I had coped with pain for many years, but then it took over my life,” she says. “Penney was the first person I talked to who knew what that was like.”

After 15 years as a group facilitator, Gober was managing her life well. Then a few years ago, her luck changed drastically.

“I thought going on disability would be the biggest change I had to cope with in my life, but I was wrong,” says Gober. Shortly after moving back to her hometown, her husband was diagnosed with cancer, and she cared for him until his death a year later. “I had learned to pace myself and take rests, but it was very difficult not to give in to that impulse to keep going,” she explains. “I had to say to him, no, you’ll have a nurse tonight because I have to rest.”

Then, just weeks after her husband died, the brother Gober had relied on passed away unexpectedly. She was scrambling to figure out how to restructure her life until her son and his young family agreed to move into her home.

“I kept saying that I’d lost my caregiver when my husband died, but I realized that I’m my primary caregiver,” Gober says. “I have the tools I need to adjust to a total life change—and I know I can do it, because I did it before!”

Penny Rickhoff, ACPA’s regional director for Arizona, also is grateful for the changes ACPA has made in her life since she got involved in 1993. “Other than my grandchildren, the best things that have happened to me in the last 15 years were tai chi and the ACPA,” Rickhoff says.

“ACPA group members have become my lifelong friends,” says Rickhoff. She says that people in ACPA groups seem to make personal connections, unlike people in other support groups she’s attended.

Facilitating a group that meets in the evening helped Rickhoff learn to accommodate other social activities, even though her pain is worse at night. “Going to group meetings twice a month gave me the confidence to tackle other evening activities. I don’t worry that I won’t be able to drive home afterward.”

Rickhoff is also able to share her expertise with others far and near. “I’ve had opportunities I never would have had without ACPA,” she says. Rickhoff was involved in a legislative task force on pain medication, and in 2005 she spoke at the annual meeting of the American Pharmacists Association about the human side of pain management. “It was so exciting to have the opportunity to educate people in that professional environment,” she says. “I felt that they really valued what I had to say.”

Rickhoff is a local resource too. “A doctor from a small hospital called me up and asked if I knew how to keep back patients out of his ER,” Rickhoff says. She and her group had discussed a technique to avoid emergency department visits by planning ahead with your doctor to prescribe fast-acting pain medication in case of flare-ups. “I told him to send them to the ACPA and have them learn to talk to their doctors.”

Because of her ACPA work, Rickhoff was even featured in a 2005 *Time Magazine* article about chronic pain. “They ran a picture of me doing tai chi in my garden,” she says. “I heard from people I hadn’t talked to in years!”

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PAUL O'NEILL, TRIBUNE
EXERCISE: Penny Rickhoff, foreground, and others take a class in tai chi at the Via Linda Senior Center in Scottsdale.



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Changes at ACPA

And the ACPA has developed over the years too. Says Gober, “We have so many more resource materials available now, and not just for people with pain but for caregivers and spouses. We’re continuously adding resources, branching out, and covering more areas.”

Life has changed for the facilitators, who now have a full-time outreach coordinator to support them. “In the early days, when we needed something we went directly to Penney,” Rickhoff says. Although it was nice to be able to get an answer straight from the source, Penney wasn’t always available. The outreach coordinator focuses on helping support groups.

ACPA has also taken advantage of the Internet’s growth over the past three decades. “It’s so much easier for people to access information online,” Gober says, “and we can keep in contact with people from all over the world by e-mail.”

ACPA’s network of facilitators has expanded since the early days. “At the yearly retreat now we have more and more people coming from all across the U.S.—and from Canada and other countries too,” says Gober. She appreciates hearing stories from people who live in diverse environments. “When a facilitator from northern California tells a story about the resources they have, you think about how you can get your town to catch up,” Gober says. “When you talk to someone from rural Idaho and learn they have a choice of one or two doctors, you realize that you could be taking better advantage of the great providers you have in your area.”

Facilitators still have yearly gatherings, but the meetings have gone from small retreats to conferences in more comfortable facilities. “In the early days, we slept on cots,” remembers Gober, adding that it was worth it to be able to share ideas with colleagues in person. Rickhoff agrees. “We could talk

personally about how to handle group issues, and learned what other groups were doing for fun—social outings, and projects for charities,” Rickhoff says. “It really keeps you from burning out.”

Changes in the Health Care Environment

ACPA members have also witnessed changes in medicine over the last 30 years. “More doctors are recommending alternative treatments, like acupuncture, which they didn’t offer 15 years ago,” says Rickhoff.

Awareness of chronic pain has increased dramatically in since 1980, and the ACPA is now a recognized name in the health care community. “It used to be that if you went to talk to a physician group or people at a healthcare facility you had to do a sales job,” Gober says, “but now if you say you’re with the ACPA people know what you’re talking about.” The ACPA website, handout literature, television PSAs, and speaking engagements have helped get the word out.

Although Rickhoff believes that doctors are still overly reluctant to prescribe opioid medications for chronic pain, she says that doctors now see the value of self-help. “If you let your doctor know that you are exercising, going to a support group, and looking into other treatments, I think they are sometimes more open to prescribing pain medications,” she says.

Rickhoff also points out that a growing numbers of doctors are specializing in pain management. “What a change that is from 15 years ago when you were lucky to find one!” she says.

In 30 years, the ACPA has helped change how we view and treat chronic pain, and worked to support more and more people. But perhaps most significant is how ACPA has helped produce small and large triumphs in the individual lives of people with pain.

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Looking Back and Looking Forward

by David Provenzano, MD
President, Board of Directors, ACPA

Since 1980, the American Chronic Pain Association (ACPA) has offered peer support and education in pain management skills to individuals with pain, their family members, and health care professionals.

When I first became involved with the ACPA four years ago as a busy clinician, I joined with the knowledge that for many individuals suffering from chronic pain there is—unfortunately—no cure. These individuals therefore have a huge unmet need for a set of “tools” that will allow them to continue to function. They need to prosper, participate in their desired activities of daily living, and educate themselves on available treatment options so they can make shared decisions with their healthcare providers, and find enjoyment in their lives—while living in chronic pain. The ACPA’s goal is to meet this need.

Recently, the board reviewed ACPA’s historical timeline. I was truly amazed with the accomplishments of the organization over the last 30 years. Initially, in 1980, there were two support groups in Pennsylvania and by 1994 there were support groups in all 50 U.S. states and eight other countries. In 2000, there was a total of 856 chapters.

The educational library of the ACPA has also continued to grow, offering the annual *Consumer Guide to Medication and Treatment* (both written and video formats), the Facilitator Training Video, and the Coping Skills Calendar. We have also developed and provided tools to assist members in effectively communicating with their healthcare professional such as the doctor’s visit follow-up sheet, CARE card, Quality of Life Function scale, and Living Better with Pain log.

As technology has advanced so has the ACPA. We now offer a new, top-quality website and we also reach out through Facebook. These accomplishments would not be possible without significant contributions of the ACPA members, facilitators, Board of Directors, and Advisory Board.

So where will the ACPA be in the next 30 years? The answer to this question really depends on the desires and needs of the members. But here is the direction we are heading in today.

Currently, we are working on developing additional high quality educational materials that offer unbiased information

on available treatments for effective pain management. Projects slated for 2010 include a medication safety video and a video on understanding medical devices like the spinal cord stimulator, intrathecal pump, and transcutaneous electrical nerve stimulation device.

We are partnering with organizations such as the Department of Veteran Affairs and Kaiser Permanente to assist in the development of peer support groups. Furthermore, we will continue to attend legislative and government events to make sure that the voice of the individual with chronic pain is heard as decisions are made with regards to pain care on Capitol Hill. We welcome any ideas from members on future areas of development. The message delivered by Penney Cowan, the Board of Directors, and the members of the ACPA is always this: an individual suffering from chronic pain must leave the role of a passive “patient” and become a person again. We will continue to spread this idea for many more years with everyone’s assistance.

As a healthcare professional, I have personally seen how the ACPA helps with so many unmet needs in the area of chronic pain management. Please continue to partner with us in making sure that the voice of individuals with chronic pain is always heard around the globe.

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An individual suffering from chronic pain must leave the role of a passive “patient” and become a person again.



Our Mission Remains the Same

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A Positive Attitude

Throughout these three decades, ACPA support groups have never focused on physical pain, but on helping members develop a positive attitude and an enhanced perception of control. ACPA group members learn to become independent people whose pain is kept in a proper perspective.

The group does not replace, but rather enhances, traditional medical treatment. Support groups work with the medical community to help members take more responsibility for their own recoveries. We encourage them to become an active part of the treatment team and be well-informed consumers.

Today, the ACPA is still focused on the needs of the person with pain. It has stayed true to its mission of providing peer support and teaching coping skills to each person who asks for our help.

Our programs and services provide encouragement and information to people with pain and their families so they can regain control of their lives.

The most important contribution the ACPA gives each member is a sense that someone cares. The powerful statement—"you are not alone"—welcomes each new member and allows a special connection to occur within the ACPA group.

As we continue the mission that we began in 1980, we know that future efforts will provide more ways to enable people with pain to improve the quality of their lives and reduce their sense of suffering. These may be delivered through written materials, support groups, Web pages or something brand new. As long as there are people who are told to learn to live with chronic pain, there will be a need for the services provided by the ACPA.

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*Become an active part of the treatment team.
You are not alone.*

ACPA Updates

VA Recognizes Milwaukee Facilitators

The Department of Veterans Affairs (VA) presented a Patient Recognition Award to Roger Mai, Dave Bailey, and Michael Hutchison on May 24, 2010. The three men lead an ACPA support group in Milwaukee, Wisconsin that is affiliated with the VA there.

Jill S. Klayman, PhD, head of the Milwaukee VA pain management program, presented the award. It stated that Dave, Michael, and Roger, after making the difficult journey from patient to person, wanted to help others find their way to a good life despite chronic pain.

“Their experience has led them to become peer facilitators of an ACPA support group. Under their direction, this group meets monthly at our medical center and is available for anyone who wants to learn to deal with pain in a positive way,” the award stated.

During the past year, Dave, Michael, and Roger have engaged in outreach at various education fairs for VA staff and veterans. They have received additional training from the ACPA and the VA so they can effectively channel resources. Their support group is now part of a pilot project looking at a more formal partnership between the VA and the ACPA nationally.

The recognition text continued, “However, these three men have accomplished something far more important than developing a peer-facilitated chronic pain support group... Despite significant pain and disability, they have created lives with meaning, purpose, and value, and that deserves some recognition!”

ACPA Facilitator Focuses on Veterans

Jani Larsen served in the military from 1983 to 1986 in Panama and Honduras during the Contra/Sandinista war. She received an honorable discharge.

“I was a Military Police person, performing patrol duties and ensuring physical security with a top-secret security clearance,” she said. In 1985, while running with both hands full, Jani tried to jump over a small stream. She fell backward and used her elbow to brace herself. “I dislocated my right elbow and when it was reset the doctors told me I had minor nerve damage,” she said.

Ten years later, experiencing tingling and numbness in two fingers, she sought out a neurologist and began a long journey of pain.

“In 1998 there were few pain clinics and no one who really knew how to treat pain in Madison, Wisconsin. As a human resources executive, I spent most of my time typing notes, documents, and research on the computer. This exacerbated the nerve pain in my right arm,” she said.

When told she should leave her career to avoid more pain, Jani was devastated. After years of classes to advance her career—while caring for a child as a single mother—the thought of giving it all up was a complete shock.

“Now I was being told that all that hard work, the work that was my identity, was no longer needed. Who was I if not that strong, independent person I had grown to be?” she recalled. “This was a REAL identity crisis! You work so hard to become identified by your career, and it is all taken away in a matter of months!”



Fortunately, Jani found and joined the ACPA in 2004. “I would not have my identity back if it were not for the things I have learned through ACPA. Once you join ACPA it seems you are constantly evolving to become a different, better person than who you were.”

“By helping veterans and those facilitating veterans’ groups, I feel my life has been given new meaning and there is something I can do to make a difference. I want to help individuals fight through the battle of pain and come out victorious,” Jani said. “I know it can be done—I am just about there!”

Jani Larsen, Regional Director in Madison, Wisconsin, is ACPA’s new VA coordinator. She will work with facilitators who are planning or maintaining a VA group. These groups meet in, or are run by, a VA Hospital or vet’s center. In addition to fostering education in pain management skills, Jani will be offering guidance on how to navigate the VA system.

Facilitators and prospective group members should contact Jani through ACPA headquarters at 1-800-533-3231 or ACPA@pacbell.net.

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Thank You!

Please join us in welcoming our regional directors.

Ernie Merritt

Regional Director for Maine

Max Sokolnicki

Regional Director for Michigan, Illinois, and Florida

Jani Larsen

Regional Director for Wisconsin, also our new National Veterans Coordinator



Welcome to our new groups and facilitators.

Sue Ellen Houston

Susanville, CA (Reno, NV)

Michael Wofford

Susanville, CA

Kimberley Grant

Buellton, CA

Leimomi Yates

Honolulu, HI

Sandra Scott

Robbins, NC

Donna Haase

Harrisburg, PA

Hima Dalal

Lexington, SC

Terry Witty

New Port Richey, FL

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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Forest Laboratories for the Fibromyalgia Web-based interactive person

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Tributes

IN MEMORY OF

FRANCIS STEINBERG

MOTHER OF CINDY STEINBERG

ACPA REGIONAL DIRECTOR FOR

MASSACHUSETTS

Given by Marilyn Zieve

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.

Please send inquiries to:

The ACPA
P.O. Box 850
Rocklin, CA 95677

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Board Member Profile: Edward Covington, MD



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

Dr. Edward Covington is a founding member of the board of directors of the ACPA board and has continued to participate for 29 years. Dr. Covington is the Director of the Neurological Center for Pain in the Neurological Institute at the Cleveland Clinic Foundation. He developed the Cleveland Clinic's chronic pain rehabilitation program for functional restoration of patients with chronic non-cancer pain unresponsive to medical/surgical treatments.

This was the program Penney Cowan went to in 1979. It taught her the pain reduction, physical rehabilitation, and psychological coping skills that allowed her to return to a functional life and inspired her to begin support groups for people with chronic pain.

When she organized the American Chronic Pain Association, she asked Dr. Covington to join the board of directors.

Dr. Covington works extensively in the areas of pain rehabilitation and pharmacological management of pain. He is a frequent speaker on pain-related topics and has published articles on the physiology of pain, the psychology of pain, and pain treatment issues.

"Many things destroy the lives of people with chronic pain," he said. "They use all their strength and resources to try to find a cure, and only get more demoralized. What we share through the ACPA is that there isn't a cure, but

that life can be good despite the pain." "Just because there is no hope for a cure, it doesn't mean life is hopeless," he said. "People need to learn to put their resources to other pursuits; to having a job, a social life, a better quality life."

"Almost everyone who comes to our pain clinic wants pain relief as their primary goal, but we are surprised to find that often the ones who are most grateful are those whose pain is changed minimally, but who leave with an improved quality of life," he said.

Just because there is no hope for a cure, it doesn't mean life is hopeless.

Dr. Covington described studies that compared patients who have treatment to "get the pain fixed" and those that "learn how to make the best of it." The researchers find that the second group—people who have taken control of their pain—feel better and have greater function.

He said this is why "Take an active role in your own recovery" is one of the ACPA's Ten Steps. "It is so important because it helps people with pain look at how they feel and function. It helps a lot," he said.

"People with pain feel alone and different. Their chronic pain is not visible and other people don't understand it. I've had patients who've gotten cancer and found it easier than having chronic pain, because other people can grasp the problem," he said.

In ACPA support groups, people with pain meet people who understand. As Dr. Covington said, "What you learn best is what you have to teach. Doing for others helps you.

In his work, he has reviewed research studies that looked at patients who were treated with nerve blocks for pain compared to those who participated in pain rehabilitation programs. "Those in rehab were more in control, had greater well-being, and felt that the future was in their control," he said.

"Professional pain treatment providers are devoted to making 'patients' better. They are medical professionals and want to fix these people. The ACPA is different because we are focused on giving them an internal locus of control. And that can lead to a good life."

Reared in Tennessee, Dr. Covington has been a Cleveland resident for over 30 years. He earned his medical degree from the University of Tennessee and completed an internship at the Baptist Memorial Hospital in Memphis, Tennessee and his residency training at the Mayo Clinic in Rochester, Minnesota. He is a past president of the American Academy of Pain Medicine and serves on the American Board of Pain Medicine.

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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.