



CHRONICLE

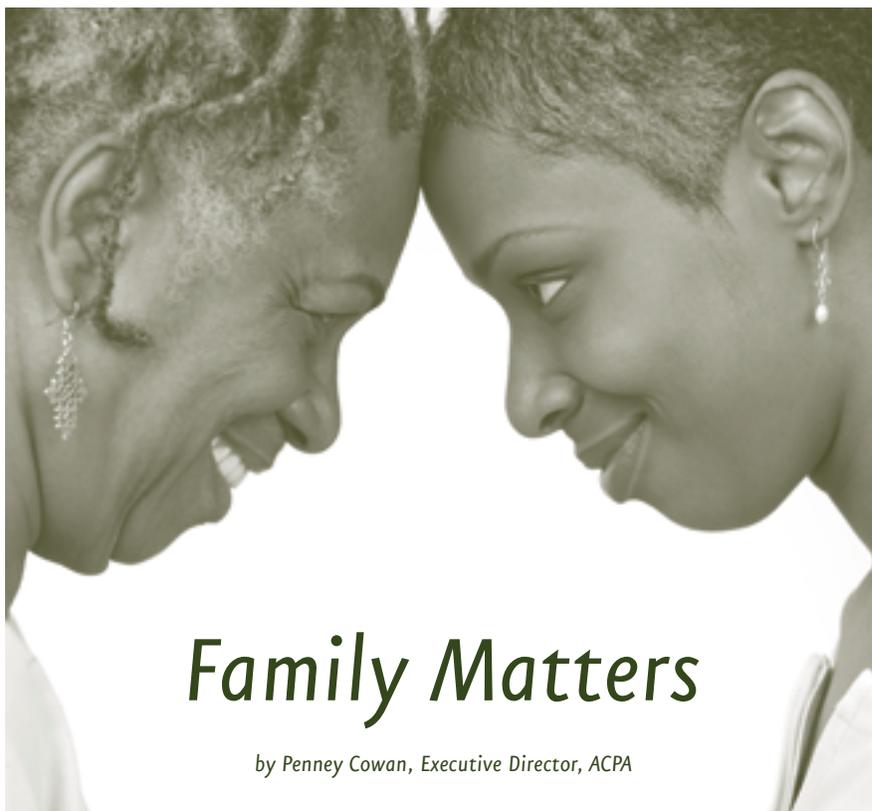


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Family Matters

by Penney Cowan, Executive Director, ACPA

For many of us, living with chronic pain can seem like an impossible burden. Pain can take away our identity, our sense of worth, and our ability to function. Pain also takes away many of our friends and coworkers who don't seem to understand the impact that pain has on our lives. Perhaps we may not always realize the tremendous impact it has on our family.

People with pain become consumed with their pain and trying to achieve some sense of a "normal" lifestyle. In such a state, they don't see the effect pain has on everyone they live with. Pain also takes its toll on their family members' abilities to carry out their

own "normal" routines. Their own relationships with friends and coworkers become strained, and friendships can disappear. The whole family has lost its freedom to live the life they knew and loved.

What the person with pain may not see are family members struggling to go to work or school, and also trying to do the simple tasks that the person with pain can no longer do. These might be things like preparing meals, doing laundry, cutting the grass, taking out the trash, doing the shopping, or taking care of the children.

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Love and Compassion Bring Joy to Lives with Chronic Pain

by Erin Hart

Individuals living with chronic pain sometimes feel alone—or believe that no one in their lives truly understands how each day can be a struggle. Fortunately, love and compassion can make all the difference, as these two facilitators share.

Reflections and Acceptance

There are times when Tara White, 56, of Roseville, California, reflects on the last decade of her life. She had married again—this time to a wonderful man named Jim. And she was working in a job she loved as a registered nurse.

Then, chronic pain hit—first in her hands, elbow, and ankles. After having wrist and elbow surgery, Tara was diagnosed as having complex regional pain syndrome (CRPS). Although she returned to work for six months, her pain continued to worsen, which meant she had to give up her career. A few years later, more nerve compression and several surgeries on her left ankle followed. The emotions were overwhelming.

“I went back and forth through all of the stages of grief,” Tara said. “My life had changed drastically. And I also felt incredible guilt from not being able to contribute to our family, especially financially. I had worked full time since I was 16 years old. But eventually, I accepted that this was my new life and I could enjoy being home and being a wife.”

What eventually helped Tara hone in on the positives was Jim’s support. From day one, he’s accompanied her to doctor’s appointments, pre-op, and surgical procedures. She refers to him as the “single most important part of her recovery—the real deal.” He wouldn’t be anywhere else, although there are times when he feels powerless.

“Tara is tough and sometimes goes until she hits the wall,” Jim said, “even though she knows there are consequences. But I try to support in her any way that I can—by helping around the house or recognizing what she needs in the moment (such as a hot pack or encouragement to sit and rest). But sometimes, I can only help so much. Medication can only help so much. That’s the powerlessness of the disease that she has and it makes it hard for the caregiver. But, as long as I can give something, then I feel like I am contributing.”

Giving Back to Others

Another rung in Tara’s support ladder has been the ACPA. For the last five years, she has facilitated the Sacramento support group. She also writes book reviews that are published in *The Chronicle*. A self-proclaimed “giver,” Tara offers guidance and lessons learned from her own pain journey in the hopes that others can live fulfilling lives.

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Tara and Jim White

*Amanda Vandervort with
her husband Steve and
daughter Jessica*

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One topic that generates significant conversation at the support group is how important a strong support system is—to both ease the physical burden and lighten the emotional baggage.

“Having someone to help allows us to better pace ourselves so that we can continue to enjoy life,” Tara said. “I see a mix in our groups of people with supportive and non-supportive spouses. Especially for the latter, I give them literature that they can share with their significant others. This includes a description of what chronic pain is and how it can affect someone. I also suggest ways to respond when someone says ‘you look fine. How can you be in pain?’ We also talk about how to involve our spouses or support person—and the types of things we can say or ways in which we can show our appreciation.”

Breaks for Appreciation, Activities, and Blessings

Showing appreciation can help strengthen the family bond. Once a week, Tara and Jim cook a big meal together. Tara also likes to sneak a chocolate bar into Jim’s lunch, make him a special dessert, or stop by his work and leave a note in his truck.

They also make a point to take a break from all things chronic pain. Before they met in 2002, Tara and Jim were both outdoor enthusiasts—Tara with hiking and cycling, and Jim with skiing, kayaking, and mountain biking. Seeking to compromise, they began cycling together. Once Tara’s wrist and arm pain made the sport difficult, she and Jim began tandem cycling. He sits in the lead spot and she behind him, with her arms supported on a special arm rest that Jim designed. They compete in cycling events several times a year in California, and have taken three trips with 19 other tandem couples to Europe to bike through the countryside.

Although Jim doesn’t have an outside caregiver support system, he has a lot of first-hand experience that he’s eager to share with others in his situation.

“I think when you encounter another family going through this, your first reflex is to say ‘Oh, it’ll get better.’ But sometimes it doesn’t. I think the most important thing I’ve learned is good communication. Tara has been my best teacher—both in helping to care for her and in interacting with others in our situation. And if I don’t know what to do, then I know she’ll tell me what she needs.”

If anything, Tara’s chronic pain has only strengthened the couple’s bond. And if the roles were reversed, there’s no other place she’d be than at Jim’s side.



“Marriage is a team effort,” Tara said, “and we are best friends. We didn’t know at the beginning that life would take this turn. If Jim became ill or incapacitated, I would be right by his side taking care of him. We’ve learned together as we’ve gone along, and we feel incredibly blessed.”

Finding Strength and Answers

For most of her life, Amanda Vandervort, 36, of Des Plaines, Illinois, has lived with chronic pain—something that took two decades to diagnose.

At age 10, Amanda began experiencing fibromyalgia pain, but doctors insisted she was having growing pains. Then she was told the pain was a result of a back injury she suffered in January 1999. It wasn’t until she was 29 years old that someone “finally told me I wasn’t crazy,” she said.

It was then that her new husband Steve suggested the pain she was having was likely caused by fibromyalgia. Steve’s former mother-in-law had lived with the condition, so he instantly recognized the symptoms. He introduced Amanda to a doctor who immediately gave her the diagnosis she had been seeking for so long.

“With this diagnosis, I learned that 95 percent of those living with fibro can trace it back to a traumatic event,” Amanda said. “When I was 9 years old, my mom had a hysterectomy and because of complications, lost her leg to gangrene. On top of that, my family was so engaged in trying to figure out what was going on with my mom that no one really paid attention to what was happening with me. It wasn’t accepted in the 80s that this could happen to kids. So I guess you could say I’m lucky. I’ve had it so long that I quickly found ways of coping.”

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“When you have chronic pain, it’s important to cultivate relationships and create an organic support system. The ‘village’ is our family. We have so many people in our lives now that will help whenever and however we need it, at a moment’s notice.”



“I feel a ton of guilt that I can’t be a mom to Jessica in the ways I had envisioned,” Amanda said. “I can’t discipline her and put her in time out when she acts out. I can’t take her to Disney—something I know she’d love to do. But I do what I can to find the workarounds that make everyone happy.

“On my good days, we wake up in the morning and review our favorite activities list and select one to do together. We love going to the zoo and talking about all of the animals. Or we bake together. On bad days, we have a movie day, where she gets to pick the movie. On those days, I do my best to point and explain, and she seems to understand.”

And with the right individuals, understanding can flow. Amanda said she’s grateful for the Chicago area support group she belongs to, as well as the Des Plaines group she facilitates. In fact, one lady from Des Plaines has a child with issues similar to those that Jessica faces, so she shares her lessons learned with Amanda.

Caregiver Challenges

Husband Steve, who works full time during the day, hits the ground running when he walks in the door each afternoon. He handles the housework, fixes dinner, and takes over parenting duties with Jessica. He also lends a ready ear to Amanda if she needs to vent about her day.

Steve admits that although he does as much as he can for Amanda and Jessica, he finds it very stressful. Couple time is rare, save for an annual no-kids outing to the Renaissance Fair. Chunks of “me time” to disengage and play video games are precious and few.

As much as Steve appreciates all of the help that he and Amanda have received from friends and family, he advises anyone else embarking on this journey to fully evaluate the commitment level that a life with chronic pain dictates.

“This life can be very debilitating and limiting—especially for the person living with chronic pain,” Steve said. “We can’t go places, do certain activities as a family, or just be a couple. And it’s very hard for a caregiver to have downtime because you are so focused on the other person.

“But if you care about this person and are willing to go through this life with them, then that is what you will do. Because the rewards are that this person will be there for you, no matter what you face, because of all the things you do for them.”

Love and Compassion Bring Joy to Lives with Chronic Pain

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Relying on the Village

Although her health issues have broadened over the years, and coping has become more of a challenge some days, Amanda is deeply thankful that she has so many people in her life who are willing to help. Steve has been her rock from day one. Within six months of meeting her, he decided they should move in together so he could help care for her. The ladies in the Vandervorts’ church are quick to answer if Amanda rings them for help in taking care of her 4-year-old daughter Jessica. Both Amanda’s dad and father-in-law have also lent their assistance.

“When you have chronic pain, it’s important to cultivate relationships and create an organic support system. The ‘village’ is our family,” Amanda said. “We have so many people in our lives now that will help whenever and however we need it, at a moment’s notice.”

Fitting Children into this Life

Amanda wishes she was able to fully raise her daughter Jessica, who has attention deficit hyperactivity disorder (ADHD) tendencies and oppositional defiant disorder (ODD). Add those two diagnoses to the general rigors of daily life with a preschooler, and living as a person with chronic pain becomes even more challenging.

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New ACPA Video Reveals the Critical Role of Family Life

When families feel chronic pain, everyone in their family feels the consequences. Spouses, children, siblings, parents and others are all affected when chronic pain affects their loved ones. They are also affected by the restrictions that chronic pain imposes on work, chores, fun, finances, employment, energy levels, attitude, sleep, and mood.

In the end, many family members suffer from all the side effects of a life with pain—everything but the pain itself.

The ACPA has a new three-part video, *Family Matters*, which discusses the issues loved ones face. It offers suggestions for keeping the whole family happier and more functional when chronic pain is an unwelcome guest in your home. You can view it at www.theacpa.org/family-matters.

The ACPA has tools and techniques for people with pain, as well as their family members and caretakers. These practices help them accept that pain has become a part of their lives, but also to know that they are not alone. You and your loved ones can rebuild life as a family, even with chronic pain.



Helping Children Cope with Change

Children see and hear more than we think they do. Their lives are changed if a parent is incapacitated. If we don't explain what has happened, they may be confused and blame themselves for a parent's pain.

This is why it is important to tell children what chronic pain means, and that you love them as much as you did before. Otherwise, they can become frightened, overwhelmed, withdrawn, and depressed.

The experts in the Family Matters video explain that family members are often confused and hurt when pain comes into their lives. Some of the issues that cause misunderstandings are:

- * The fluctuations of chronic pain: person is fine one day and disabled the next.
- * The inability of being able to plan for and enjoy a social life.
- * Irritability, stress, anger, guilt, or blame.
- * The burden of responsibility or the need to constantly rely on a caretaker.
- * Friends who don't understand that everyone is affected by pain.

It is equally important to tell children about the limits that pain may put on activities. Though it may be tempting to ask children to do more around the house, you should let them live their own lives as much as possible.

We must also remind them that they are not alone. Children and teens may be helped by sharing their feelings on the ACPA interactive website, Growing Pains, at www.growingpains.org.

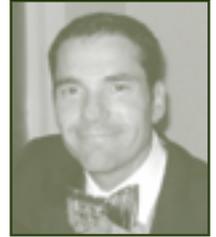
Caring for the Caretakers

Caretakers are also burdened by pain. Without any time to themselves, the caretaking family member can feel confined and depressed. They may be a target of anger from the person with pain and have few chances to pursue the activities they once enjoyed.

Couples should work together as a team to set goals. You can investigate better ways to manage pain. You can learn to say no when demands are too difficult, and learn to ask for help from others. You can both benefit from relaxation techniques or exercise.

Better pain management will allow the person with pain to be more independent, and let the caretakers do less around the house—even resume forgotten hobbies.

When your family works together to accept the pain as a new reality, you can deal with the feelings that arise from it. Together you can manage the pain and find pleasure in family life. | TOP |



Board Member Profile: Chris Duncan

by Alison J. Conte, Editor, The Chronicle

These articles are intended to give members more insight into the interests and contributions of ACPA board members.

Chris Duncan has always been interested in personal health and fitness. A dedicated runner, he completes three marathons a year and often places among the top 10 competitors in his age group.

His passion meshes well with his 20-year career in healthcare marketing, where he is often involved teaching others how to maintain better health. This work in patient advocacy and healthcare literacy led to his appreciation of the American Chronic Pain Association (ACPA). In 2014, he agreed to join the board of directors.

He had crossed paths with ACPA Executive Director Penney Cowan at a number of the medical and pain management association meetings. “I was working at Ligand Pharmaceuticals in 2005, introducing a pain medication. Penney and I worked together on a project that both Ligand and the ACPA supported.”

They stayed in touch because Chris liked how the ACPA helped people with pain. “As a board member, I want to use my marketing experience to help get the word out, to bring people to the resources that the ACPA has to offer,” he said.

Chris grew up in Phoenix, Arizona and holds a B.A. in business from the University of Arizona and a M.B.A. from the University of Redlands, California. He has been married for 20 years and has three sons.

Chris’ responsibility in the pharmaceutical and biotech industries has been in various therapeutic areas, including pain management. Most recently he was executive director, marketing and product strategy, at Nektar Therapeutics. Prior to Nektar, Chris was at Zogenix, Amylin Pharmaceuticals, Ligand Pharmaceuticals, Vical, and Schering Plough. Today he is a business development consultant with BelHealth Investment Partners, working in specialty pharmacy, pharmacogenetics, toxicology, and data analytics.

Chris helped many of these firms bring medications through the commercialization phase, prior to FDA approval. This process prepared drugs for the commercial market. At other times, he led sales, marketing, and business operations. “It was a diabetes drug program that initially brought me into the patient mindset. I was focusing on patient education and it opened my eyes to the need for health literacy. So many people don’t understand how their medications work. Without that knowledge, compliance and follow-up fall by the wayside,” he said.

“As a board member, I want to use my marketing experience to help get the word out, to bring people to the resources that the ACPA has to offer.”

Understanding the patient perspective became even more important in the 1990s, when regulations changed to allow direct-to-consumer promotion. “We no longer had the physician as intermediary,” Chris said. “Now people were coming to clinicians with information they found on the Internet about drugs they wanted to try.”

“Today, people are more engaged in their healthcare. They have plenty of opportunities to learn how to take care of themselves,” he said.

Yet, Chris realizes that information alone won’t make people with chronic conditions follow the rules. “Many of them aren’t motivated to follow their doctors’ directions for diet, exercise, or medication. This could be due to their background, education, societal pressures, finances, or access to care,” he said.

Recently, Chris has been reaching out to community health organizations. “This is one way to get people to be proactive about their pain and their health,” he added. “Connecting with others can be a motivating force.”

“The ACPA does a lot of good through the high quality information and tools we make available,” Chris said. “We’ve invested time and effort to develop great tools to manage pain. These tools help people to track their progress and talk with their doctor. We want to get these tools scientifically validated so more institutions will use them.”

“In the pharmaceutical industry, we know that patients need to stay on their medication and pay attention to their orders. But you can’t count on a pill to fix everything.

“This is why the industry partners and funds organizations like the ACPA. People with pain also need that side of a treatment plan—the stretches and meditation and positive attitude—that the ACPA promotes. It’s the yin and yang of pharma,” he said.

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ACPA Updates

Navigating the Maze of Pain

The ACPA is partnering with the American Pain Society to present “[Navigating the Maze of Pain](#).”

This event is from 1 to 4 p.m. on May 13, at the Palm Springs Convention Center in Room Smoketree AB. The location is 277 N. Avenida Caballeros, Palm Springs, California.

Members from both organizations will present information about self-management of pain, as well as the communication skills that people with pain need to know. The program is for people with pain and those who care for them. You can learn how to navigate the maze and find strategies for getting life back on track. Registration is required. Please call 1-800-533-3231 to register.

Pharmacy Students Raise Awareness of Chronic Pain

The University of Florida College of Pharmacy held a volleyball tournament to raise awareness and money for chronic pain management. It was sponsored by two organizations on campus: the American Pharmacists Association Academy of Student Pharmacists and the Florida Society of Health System Pharmacists. We greatly appreciate the \$210 that they raised and donated to the ACPA.

New Pain Management Group Advocates for Responsible Medication Use

The [Alliance for Balanced Pain Management \(AfBPM\)](#) was launched in November 2014 to ensure people with pain can get the care they need from all medical and social providers. They support appropriate access to integrated pain management programs and responsible use of prescription pain medicines. AfBPM will reinforce awareness of how to use, store, and dispose of prescription medications to reduce abuse, misuse, and diversion.

AfBPM is composed of 22 organizations. The steering committee is made up of representatives from the Alliance for Patient Access, the American Cancer Society, the ACPA, Mallinckrodt Pharmaceuticals, the Partnership for Drug-Free Kids, and The Gerontological Society of America.

Zumbathon™ Charity Event Benefits ACPA

The ACPA received a \$400 donation from a group of licensed Zumba® fitness instructors based in the eastern Bay Area of northern California. The group consists of members of the official Licensed Zumba Instructors Network, who meet several times a year at “jam sessions” to exchange choreography ideas for their Zumba Fitness classes, sharpen their skills, and network with fellow instructors.

One of the instructors, Robin Cranford, decided to hold a charity Zumba class, also known as a “Zumbathon”, for Invisible Illness Awareness Week, Sept. 8 to 14, 2014 ([invisibleillnessweek.com](#)). She reached out to other members of the group, specifically those who live with or advocate for invisible illnesses themselves or among their families. One instructor, Jennifer Cifuentes-Rojas, nearly moved to tears, jumped on board right away. Cifuentes-Rojas has fibromyalgia, and Cranford’s daughter has Crohn’s disease, two conditions without obvious symptoms.

“When you are involved in the fitness world,” Cifuentes-Rojas said, “you seem to be strong and healthy, which many of us

are. However, in the midst of our fitness careers, some of us also struggle in silence, as do so many in our society. Other people don’t guess you have an illness. We wanted to increase awareness and compassion for those with invisible illnesses.”

Seven instructors participated the 90-minute Zumbathon Charity Event on Sept. 13, 2014, including one of their local Zumba Jammers™—a Zumba choreography expert—who helped create fliers and t-shirts. Their theme, “Shining on the Outside,” was inspired by a song by emerging artist Iris Downey, who generously gave the ladies permission to use her song as their cool-down track.

About 100 people joined the class, giving their entrance fee and other donations to charity. One hundred percent of the money collected was split evenly among five charitable organizations. These were selected by the participating instructors based on the invisible illnesses for which they advocate.

For her portion, Cifuentes-Rojas researched organizations related to invisible illness and was pleased to “stumble on” the ACPA. “I loved the website, which was up to date and filled with resources,” she said. “And when I called, I got a live person on the first call. We are happy to donate some of our proceeds to such a great group.” | TOP |



Book Review

Living Abled & Healthy: Your Guide to Injury & Illness Recovery

written by Christopher R. Brigham, MD with Henry Bennett

Review by Tara White, RN

Living Abled and Healthy is a comprehensive resource guide with a focus on ability rather than disability.

Each of us has things we can do to improve our lives, our attitudes, and our perspectives toward our individual illness or injury. Wherever we are in our journey, we each need to become and remain our own advocates in the vast healthcare system. This includes managing our families, our work or compensation systems, our physicians, and the vast array of alternative therapies available to us. We must also seek out good nutrition and healthy exercise.

Although this may seem overwhelming, Dr. Brigham uses the word “abled” to define us as capable of successfully living healthy and productive lives whether or not we still have our ‘full range’ of abilities.” The author offers valuable information based on his experience as an internationally recognized preventative and occupational physician. This is accomplished through thorough explanations, his many resources, and his website: www.livingabled.com.

He lists several important principles that are discussed at length and can apply to all of us:

- * Taking control of our life and health
- * Staying positive
- * Partnering with quality healthcare providers practicing evidence-based and data-driven medicine
- * Approaching health problems from a “biopsychosocial” perspective
- * Weighing the risks and benefits of tests and treatments
- * Focusing on a healthy mind, body, and spirit
- * Choosing healthy habits, exercise, and diet
- * Continuing with our jobs, if at all possible

Dr. Brigham points out that healthcare in the United States is a reactionary system, focused on treating the ill and injured. This is not likely to change easily, but we all still have choices.

As Dr. Brigham writes: “We need to understand that health and other challenges are simply part of life. Attitudes shape lives, create meaning, and define destinies. Being resilient and claiming empowerment can make all the difference. Passiveness limits our opportunities and gives to others what should be our control.”

What will help us make the right choices and stick with them? Dr. Brigham believes that our history, our present, our beliefs, the ability to express gratitude, take responsibility, become resilient, manage stress appropriately, nurture relationships, and have healthy goals is the way to go. What goes on in our minds significantly affects what happens in our bodies and can vastly improve our lives. Each of these concepts is discussed in full and in an easy-to-understand format.

Another very helpful area of the book includes definitions of various disability terms and medical claims. The author states we must be cautious about accepting diagnostic labels. We must educate ourselves about what our doctors recommend, especially when it involves invasive procedures and surgeries.

He also writes that our perceptions of injury or illness often offer a better prediction of our recovery than objective measurements taken by our doctors. When we are more positive about our future, we are more likely to have better functional outcomes.

Also very helpful are his discussions of the various compensation systems and how they function, the many alternative therapies available today, and excellent information about drugs and all that is involved once prescription therapy has begun. Additionally, there is an excellent list of resources, including advocacy groups such as the ACPA.

I strongly believe this book is a necessary addition to any self-help library. It is definitely written from a physician’s point of view but in a very easy-to-understand manner. I believe the biggest takeaway from this book is this: Every new day offers us the chance to recreate ourselves, to stay open to the moment. When we are not who we were, we can become who we will be. We need never see ourselves as “disabled,” only “differently abled.” We can focus on what we can become. We can learn from others who fully embrace life despite what some might see as impossible barriers.

Living Abled & Healthy: Your Guide to Injury & Illness Recovery, by Christopher R. Brigham, MD with Henry Bennett. Healthy Living Publishing, 198 pages, ISBN # 978-0-9634454-2-1; www.livingabled.com

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Book Review

The Burning Truth: Complex Regional Pain Syndrome

written by Wendy Weckstein

Review by Tara White, RN

I was very excited to read this book and find another outstanding true story about Complex Regional Pain Syndrome (CRPS). This is one of the best I have read. Despite having CRPS myself and having read extensively on the topic, I learned a great deal from this book.

Sadly, though, this is another case of waiting years for the right diagnosis and treatment. There can never be enough attempts to get the information out there so that no one has to wait for a diagnosis while living with debilitating pain.

Wendy Weckstein is a physical therapist with a master's in teaching. Her husband is a child psychiatrist. Their son, Devin, age 13 and just beginning eighth grade, had hopped onto his older brother Ethan's shoulders to cheer for Ethan's high school football team. Unfortunately, at one point Devin fell to the hard earth, landing on his tailbone. He was sore but it took a few days for the family to realize this was much worse than it appeared. He exhibited burning pain down his right leg to the point where he could no longer even put weight on it.

The next two years changed the whole family's life. Even though they are medical professionals, they were given the same "it can't be that bad" or "perhaps it's all in his head" wild goose chase that so many of us have experienced. It is only by gut instinct and chance recommendations that they finally get headed in the right direction.

They dealt with 15 doctors, 12 painful surgical procedures, 14 disabling medication trials, controversial and dangerous treatments, and four weeks in intensive care as they pooled all their resources in a desperate attempt to control Devin's suffering.

Weckstein defines CRPS as is "a rare neurological disorder characterized by intense and persistent burning, stabbing, or aching pain, extreme sensitivity to touch, swollen extremities that are exceedingly hot or cold, and often skin, nail, and bone changes. The debilitating disorder often confines its victims to wheelchairs, crutches, or bed rest if proper treatment isn't forthcoming."

"CRPS often begins after a relatively minor injury to a limb or nerve. The pain becomes horrific. Its victims have described it as a burning fire that never goes out, a barbed wire wrapped

around their skin, or a knife stabbing them repeatedly, 24 hours a day. It develops when the nerves begin to misfire and continue to send pain signals to the brain even after the original injury has healed," she writes.

As Mrs. Weckstein states "a mother's worst nightmare is watching her child suffer." This book is based largely on a journal she kept during this time. It eloquently describes her "personal anguish" as being "nearly overwhelming" and paralyzing as she watched her son's condition deteriorate.

On top of all this, she had to maintain her new business, marriage, keep her two other children's lives as normal as possible, as well as manage Devin's missed school work.

Approximately 50,000 people are affected by CRPS each year in the United States, mostly adult women. But children as young as three have been diagnosed. Unfortunately, few physicians know about the disorder, and many don't believe it is real.

Finally, after two years, an acquaintance of an old friend led them to the Children's Hospital of Philadelphia (CHOP). The program entails an intense amount of painful physical therapy and occupational therapy with rigorous desensitization, up to six hours a day, until this reflex normalizes.

It wasn't easy for Devin, but he was determined that he was going to get his life back. Despite his Mom's correct belief and insistence on physical therapy, it was a combination of factors that did the trick.

Thank goodness for this family's courage and determination. Thank goodness the author kept a journal to help her deal with this increasingly horrifying experience. While she does credit the wonderful Reflex Sympathetic Dystrophy Association (www.rsds.org), important information about CHOP was buried under a link rather than a cover story.

Mrs. Weckstein includes a detailed Pediatric CRPS Family Resource Guide and a section of photos of Devin's journey. She is extremely motivated to help other parents and prevent what happened to her precious child. Thank goodness for her!

The Burning Truth: The Inspirational True Story of One Mother's Search for the Answer to Her Teenage Son's Painful and Highly Misunderstood Neurological Disorder, Complex Regional Pain Syndrome (CRPS), by Wendy Weckstein. Abbott Press, 197 pages, \$15.99. ISBN: 978-1-4582-0219-2; www.wendyweckstein.com

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Family Matters

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Children Feel at Fault

The burden of pain is not just on the adult members of the family, but the children as well. Children can misinterpret what is being said. They may hear their parents argue and think that it is because of something they did or said. They can feel insecure because there is no one to nurture them and take care of them as they use to. They become afraid, and their behavior may change for the worse.

It is difficult to watch a parent who is ill and not able to fulfill his or her accustomed role. So it is critical that parents talk to their children; let them know it is not their fault that mom or dad is hurting. Parents must find new ways to spend time with their children, even if they are less active, even if it is just to sit and talk.

Pain is a family matter and it takes open communication, understanding, support, and an infinite amount of patience.

The ACPA has a new video focused on the family. In this three-part video, we look at the impact that pain has on the family, the children, and the feelings created by the pain. You will see and hear what families struggle with to keep the family whole. And you will hear suggestions to help families cope with chronic pain together.

This *Family Matters* video was honored by the 2014 Telly Awards, an organization that recognizes outstanding online video content.

Take a few minutes to explore a wonderful new addition to the ACPA video library. You can find the videos at www.theacpa.org/family-matters.

Family does matter!

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Welcome to our new groups and facilitators.

Sue Ellen S. Johnson
Sacramento/Carmichael, CA

Tracey Lynn Chester
San Diego, CA

Jane H. McGarity
Ormond Beach, FL

Linda Kyvik
Satellite Beach, FL

Cynthia Erickson
Saint Peters, MO

Bonnie J. McLoud
Palmer, MA

Sandy Dresser
Rockford, MN

Roy J. Waymire
Olive Branch, MS

Dorothy Oberman
New York, NY

Sheila D. Perkins
Toledo, OH

Tomas Albergo
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For contact information for any support group facilitator, please call 800-533-3231.

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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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