Enjoy the Holidays by Keeping PACE

by Penney Cowan, Executive Director, ACPA

Every year as the holidays come along, do you promise yourself that you’re going to be more organized, more in control, and not wear yourself down so that you can actually enjoy the season? Well, that is what I find myself thinking as the days get shorter and I gear up for the holidays.

The problem for so many of us is that we tend to get caught up in the moment, the excitement, and the expectations of events that we forget to stop and listen to our bodies. The lists get longer, time grows shorter, and energy levels diminish. We are determined to get everything done even, as the saying goes, “if it kills me.”

However, our bodies are much smarter than we realize, if only we would pause and listen to them. As you work your way down that holiday to-do list, it is easy to miss the cues from your body; the little “ouch!” that you ignore over and over again. Even with your body whispering “Slow down and PACE yourself,” it is easy believe you can do just a little bit more.

That word, PACE, falls on deaf ears. Instead of doing what we know we should do—prioritize and work within our limitations—we forge ahead with a new sense of urgency to make the most of our good days. We push until we hear the screaming pain that stops us cold. And the next day our bodies speak volumes to us, starting as we try to get out of bed. Once the pain makes its presence known, we know we won’t do much of anything for the next day or two. So, we fall behind on our to-do list. We can only hope another good day comes along soon so we can catch up.

This is what happens when we ignore our need to PACE. We know that pacing is the key to successfully completing tasks. Yet, the idea of actually practicing pacing seems so elusive. Perhaps the following will help you as you and your family keep PACE this holiday season.

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Creating New Holiday Traditions
Pacing and Preparation Help Make the Season Special

by Erin Hart

Holidays can be fun times—full of joy and laughter, family and food. For many, they foster a spirit of giving and goodwill.

But for those with chronic pain, the holidays can be a time of stress and pain—especially for those who try to do too much, all at once, without asking for help. Fatigue and emotional upheavals ensue—and holiday joy disappears.

But it doesn’t have to be that way, as these three women have discovered. With the right mix of delegation, prioritization, and healthy habits, the holidays can be a happy time, even if in a different way.

A Season of Regret
For Mariann Farrell, the holidays have always been a special time of year to spend with friends, immediate and extended family—and revel in the happiness that the season brings.

But in 1984 and 1985, it was more of a time of depression and regret.

In a span of 13 months, she was involved in two car accidents, which left her with severe back and leg pain. At the time, her children, Erin and Cullen, were 10 and 15, respectively—old enough to understand that something was wrong with their then-38-year-old mom, but not mature enough to grasp the depth of her ailments.

“I was depressed. I had to give up my career, church choir, and teaching piano lessons. And I surely couldn’t be the wife and mom I wanted to be,” said Farrell, 67, of Pittsburgh, Pa. “My life was upside down. My poor husband didn’t know what hit him. He had to go to work, cook, clean, and take care of the kids. And my kids? They couldn’t understand why I couldn’t get out of bed and do things with them, or why the doctor just couldn’t ‘fix’ me.”

And if that wasn’t bad enough, the holidays rolled in—and the regrets abounded. Farrell recalls that the first Christmas after her accidents, Cullen was singing in an evening choral solo program at school. She had a bad pain day, and opted instead to stay home and rest. When her son came home that night, he sat on the side of her bed to share details of the evening. The guilt of missing the program overwhelmed her heart.

“Even though I did not feel well, I don’t know why I just didn’t get out of bed and go see him perform,” she said. “Looking back, I don’t think I knew how to deal with my pain—or how to do things despite my pain.”

She wasn’t able to take her kids to Christmas activities or shop for gifts. At one point, tired of missing out, Farrell forced herself through the motions—shopping, baking, decorating—and paid for it with a long, painful recovery period.

Pacing Pays Dividends
Several years later, Farrell said she realized she had to find a better way to manage her pain and mind/body connection so that she could continue to create positive memories with her children. She connected with a Pittsburgh-area pain management program, as well as an ACPA support group. The tools she has gained over the years are priceless—and come into play frequently around the holiday season.

She relies on her housekeeper to help with the cleaning, and her husband Bob pitches in with the cooking and decorating. Although they do venture out to shop for gifts for brief periods, the bulk of it is completed via home shopping TV networks or the Internet. The annual Farrell Christmas letter and cards are started in November. Bob Farrell wraps Christmas presents as soon as they are purchased. And holiday meals are a family team effort.

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“T’m fortunate that my family understands that ‘this is how it has to be,’” said Farrell. “Some women and men think that they have to do the whole show at Christmas, and reality is—they don’t.”

“At my ACPA group, I talk a lot about pacing and modifying traditions for the holidays. Women worry that the holiday
won’t be the same if they don’t make the eight different kinds of cookies that grandma made. Men [with chronic pain] think they still have to get up on the roof and hang the lights.

“I share with them that the holidays won’t be less meaningful if they can’t do all the things they used to. Ask for help from family members or grandchildren or approach the decorating and traditions in a different way.”

Living by What she Teaches
And Farrell practices what she preaches. She doesn’t decorate, cook, or shop as much as she used to because she has realized that there is far greater value in spending time with her family in a semi pain-free state. Instead of gifts, she might offer her grown children an evening of babysitting so they can go out with their spouses. And she makes sure to modify her sweet intake so that she can continue a 30-year tradition of afternoon tea and cakes with the women in her family at a Pittsburgh hotel.

“I used to be filled with such fear because I couldn’t do the same kind of Christmas holiday that everyone remembers from before my accidents,” said Farrell. “But I’ve resigned myself to the fact that it’s more important for me to focus on my family and our time together than stressing over the perfect holiday. For me, stress only equals more pain.”

A Good Life Turned Upside Down
Up until 2006, Lorainne Brutsman of Boise, Idaho, was living the life she had always wanted. After completing a master’s degree in organizational management, she was working as a small business consultant and was completely supporting herself. She had just purchased her first income property and had two healthy, grown children that she adored. In that same year, what she thought was a recurring, persistent bout with the flu was diagnosed as fibromyalgia and rheumatoid arthritis.

It took Brutsman, now 49, several years to figure out that her chronic pain was here to stay. And that instead of waiting around to return to the life she once had, she needed to excise herself from the victim mentality and use her mind to cope with the disease. She, like so many others with chronic pain, has had to learn the fine arts of pacing, forgiveness, and understanding. And all three come into play during the holiday season.

Holiday Heartache
As much as Brutsman enjoys the holiday season with her children, grandchildren, and siblings—and would never wish this time away—she has found that extended family members (and sometimes close ones) aren’t as understanding as they could be. She recalled one Thanksgiving where everyone but her father avoided her.

“My cousin had prepared a big Thanksgiving dinner, and as bad as I felt that day, I pushed myself to get up and go,” she said. “During dinner, family members ignored me or kept their distance—instead of offering their help. I was in so much pain that day I cried—cried because of being ostracized and cried because of the way I felt.

“Some time after that day, I saw pictures of myself. I looked like death warmed over. I saw myself as others saw me that day, and I vowed I would never do that again. I will not push myself to do things or go places when I don’t feel well.”

Learning to Set Limits
One of the ways that Brutsman has learned to make the holidays more bearable is by pacing herself. You won’t find her shopping with the masses on Black Friday. Instead, she purchases gifts throughout the year during short outings to stores—or at yard sales. She sets a three-hour-per-day time limit for holiday-related activities—whether that be for decorating, crafts (a favorite family holiday tradition), cooking, or informal gatherings. She delegates tasks or asks for help. And she has learned to say no to invitations—something that not everyone understands, especially this time of year.

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“People who have been told ‘I can’t’ or ‘no’ enough times eventually stop asking,” Brutsman said. “I found this in my own family. They just don’t ask me to attend anymore. It’s harsh, but I’ve learned to exercise forgiveness and understanding. I try to put myself in their shoes: they likely believe that by not asking me, I won’t be upset that I have to say no. I know deep down they aren’t trying to punish me or hurt me.”

**Crafting Family Time Around Pain**

Her greatest joys during the holiday season are her children and grandchildren. Misty, her daughter, lives in Oklahoma City with three kids—ages almost 14, 8, and 6. Her son Chance and his two children, ages 6 and 4, live nearby. She tries to alternate holidays with them—although that act, as with all others in her life, depends on the severity of her chronic pain. Last year’s Christmas trip to Oklahoma City required a month-long recovery.

“When I arrived, my daughter and my grandchildren didn’t know how to act around me on my bad days,” Brutsman said. “My daughter is always on the go—and I’m not. They couldn’t understand why I slept a lot. But after a while, they all learned more about my pain and the limitations it causes in my life. I felt my pain put a negative spin on that holiday, but the positive that came out of it was a greater understanding.”

When she spends holidays with Chance, she has presents delivered to his house ahead of time so she doesn’t have to carry heavy packages. They’ll have a traditional Christmas dinner—but it may not be on Christmas; it might be in February, as it was this year. Everyone, including the grandchildren, has learned to adapt to her situation. They relish the togetherness, no matter what time of year they get together.

“The fact is, I’m living in chronic pain, and I have to adjust my life to accommodate this,” said Brutsman. “As a chronic pain sufferer, I would never want the holidays to not exist. But I can’t just forget I have chronic pain because it’s the holidays.

“The adjustments I make allow me to have the holidays in my own way—on my terms and in a way that benefits me. It may sound selfish to some, but that approach has allowed me to be more forgiving and accepting—and stops me from wishing my life was the way it used to be.”

**Creating New Holiday Traditions**

Pacing and Preparation Help Make the Season Special

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Rachel Grimes (right) with her mother Becky Parish

**An Unexpected Gift**

Sometimes, the best gifts come in small packages. Or in Rachel Grimes’s situation, without any package at all.

Ten years ago at age 19, Rachel Grimes was living the typical freshman college life—going to classes, hanging out with friends, exploring, enjoying outdoor sports, and planning for her future.

However, in January 2004, a snowboarding accident resulted in multiple back breaks. Over the next 10 years, she underwent seven surgeries and procedures to help heal her back—all of which were accompanied by heavy narcotic pain medications. In 2009, after struggling for nearly five years to manage her condition and the resulting damaged psyche, she opted (with a physician’s permission) to stop taking her pain meds. Said Grimes, “It’s been the greatest gift I’ve ever given myself.”

**From Pretending to Prospering**

While day-to-day activities were rough for Grimes, the first Christmas after her accident was the worst. Grimes found herself pretending to be someone she wasn’t. She plastered a smile on her face—but she felt cold and distant. She smiled and laughed—perhaps a little too much. And though no one really questioned her, Grimes says she knew her family and friends understood that something wasn’t right.

As difficult as that holiday was, it made her realize she had to change and take some positive action. She began researching natural pain management, positive thinking, willpower, and how to prioritize what truly matters in life. After she stopped taking her pain meds five years ago, she is a different person today.

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“Through hard work, I learned to embrace my pain and other medical problems as my best friends—instead of demons I was trying to fight,” Grimes said. “I learned to give my body the love, rest, attention, and nutrition it needs. I empower myself by believing that I have the power to cope and manage my pain, naturally.”

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Expressing her Reality
With this change in perspective, she said, daily situations became easier. She figured out a way to reach out to the friends and family who had withdrawn during her dark times. And she figured out how to better manage the weeks and months leading up to holidays and family gatherings so that she can actually enjoy them without pretending.

“I follow ACPA’s 10 steps—some of which include setting priorities, not overcommitting yourself, and finding time to rest and relax,” she said. “Although for me there are still family members and friends who will never understand, I do my best to express my reality with as many people as I can. If I can’t come to them, perhaps they can visit with me. Not everyone will understand. But it’s always nice to have someone on ‘my team’ at these holiday gatherings, so I can just look across the room to that person and know I’m not alone.”

The Mother-Daughter Connection
Grimes’s advocate during holiday gatherings is her mom. With just a look, the two can communicate about how Grimes is feeling in any particular moment. Her mom always makes sure she is comfortable—ensuring an open seat on the couch or placing a cushion on a chair. Her mom, she said, possesses the perfect combination of awareness and sensitivity.

She has also learned to pace herself. As a teenager, she might have eagerly embraced shopping on Black Friday. As an adult with chronic pain, she shops all year long. As she finds gifts, she places them in a box for safekeeping. As a kid, she always enjoyed helping her mom cook and bake for the holidays. She still does—but in a modified way. Grimes handles most of the prep work in a seated position, while mom does the heavy lifting of pots and pans, and anything else that requires standing.

Blessed and Grateful
Holiday party invitations typically fill her inbox and, sometimes, she has to decline. Dinner plans may have to be rescheduled or plans modified so that her friends can come to her. And for the most part, Grimes’s family and friends understand, because she has explained her limitations.

Still, sometimes she experiences the emotional tug of “what life should be like.”

“Christmas is supposed to be laughter, union, and celebration, but for me, it is also sadness,” Grimes said. “We as people expect certain outcomes for our lives, and I am furthest from what I ever imagined for myself. I’m sad because of my reality; sad because my body is sick and always hurting; sad because I can’t work full-time; sad because I can’t purchase the gifts I would like to for loved ones; and sad because I don’t have the resources or life I thought I would have.

“But, I remember that sadness is always neighbored by happiness, so it’s a nice juxtaposition. Even though this life, and my holidays, are not what I expected they’d be, I’m still beyond blessed and grateful, and proud to be me despite my chronic pain.”
There is a kind of a hypnosis that sweeps America as we get closer to Christmas, Hanukah, and Kwanzaa. People find themselves thinking thoughts like: “What am I going to get my sisters? How can I afford it? I don’t feel like getting them that.” and “Who should I ask to the party?”

Or maybe it’s just this: “I’m going to be alone again.”

For those of us with chronic pain, we likely will feel somewhat alone. And our thoughts are different from other people’s. Ours run like this: “How long can I sit at the big dinner without flaring up? What do I do when the pain hits a ‘7’? Will I have to see Dr. Smith again? Do I have enough meds?” and so on.

Perhaps the best question is: How are we supposed to survive this extra holiday stress and why do we do it?

Even in the most loving of families, we may experience stressful holidays, largely because of our unrealistic expectations. So temper your expectations, put your health first, and do what you really want to do.

Create Realistic Expectations

The perfect Norman Rockwell-type holiday season is a myth. In one poll, only one in three Americans said they really enjoyed going home for the holidays. So, if you are not happy about visiting family, you are not alone. If possible, stay somewhere other than your parents’ house. Then, let go of the ideal images and try these ideas to get through the visit.

**Sensibly restrict yourself in what you do and say.** You’ll have to live with the consequences of your actions and inactions, so don’t do or say what you’ll later regret. That includes overeating, excess drinking, or speaking impulsively without thinking it through first.

**Plan to do specific things with family members.** We get into trouble when we sit in the house and hang out. By doing something together, you let the activity be the focus. Go to a favorite restaurant, attend a holiday play, or pitch in with chores.

**As long as it doesn’t offend anyone, humor can be your best friend.** Silly holiday movies can bring perspective; check out *Home for the Holidays*, *National Lampoon’s Christmas Vacation*, *How the Grinch Stole Christmas* or *A Christmas Story*. Play videos of your favorite stand-up comedian.

**Have an ally.** Recruit a friend, support group member, or therapist who is aware of your real feelings about visiting your family. See if they can meet up with you during the visit or be available by phone if you need a reality check.

**Limit your shopping.** Don’t try to win people with the perfect present. It’s not a successful tactic for winning love that lasts. The things that matter most are not things. They are the quality of how we experience and live in each moment with ourselves and others. Love is most easily found in small, intimate exchanges.

**Learn to say “no.”** Don’t take on more than you can handle with holiday gatherings. You don’t need to do it all. Ask for help before you need it.

**Self-Care is Crucial**

As with the oxygen masks in an airplane, care for yourself first; only then will you have something to give to others.

**Honor your personal needs.** If you need alone time, take it. Watch for signs of anxiety and body signals. Are you eating and drinking too much? Withdrawn? Claustrophobic? Fidgety? What message is your body sending you? Tune in to these signals and change your environment. Take a drive or a nap.

**Pacing is essential.** If you feel yourself getting stressed or abused, take a break. You can simply excuse yourself to the bathroom, take a walk, or listen to music. Give yourself the option to arrive late and leave early. You’re dealing with pain and you don’t need an excuse.

**Use every relaxation technique you can.** One of the best is taking three deep breaths with especially long, slow exhales.
Maintain your normal routines as much as possible. Get plenty of sleep, as a lack of sleep can negatively affect your emotions, coping management, and attitude. Take time to maintain your usual exercise program, too.

**Self-Talk is Dangerous**

Steer away from your negative thought patterns. Don’t think too much about the could-haves, should-haves, can’t-haves of your life. Thoughts about how unfair life is, comparing yourself to others, or comparing your current life to your past life just generate toxic messages of self-loathing. If you find yourself straying in this direction, turn it around.

- Distract yourself. Say over and over in your mind, “Maybe it’s ok, maybe it’s ok.”
- Sing a song, pray, notice your breath patterns, busy yourself (wash dishes or do crossword puzzles).
- Say to yourself, “That’s not totally true!”
- Try anything to silence and not believe your inner critic.

You can choose to turn away from those thoughts because they are not the whole truth. Despite your pain, you have something you can be grateful for. Count your blessings, starting with, “I’m not homeless, in jail, in the hospital, or where I was 10 years ago.”

**To heck with what they think.** You are the only one you have to live with, so do what will make YOU feel good in the long run.

**Keep Conversation Light**

Don’t take unthinking behaviors personally. Most people are on “automatic” and aren’t considering how their conversation is affecting you. They would do the same things with anyone else who was in your role.

Don’t try to convince anyone of anything. Release the need to be right. Let them have their perceptions even if they’re inaccurate. You know what your truth is and that’s what’s important.

Just listen. If it has been a long time since you were together with these people, just listen as if you are a stranger from another country with curiosity about who these people are. If they ask, tell them the facts of your life in the best way you know how. Be ready to roll with the punches if things go wrong.

Ask nonjudgmental questions. Forget about old assumptions and expectations. If relatives treat you as if you are still 10 years old, don’t respond as a 10 year old might. As best you can, just observe neutrally, as if they were clouds floating by.

Deal with the holidays one day at a time, and go for progress, not perfection.

Don’t fall back on out-of-date emotional reactions that belonged to your younger self. Instead, believe in your breath, body, and the simple things: the laws of gravity, $1 + 3 = 4$, rocks are hard, water is wet, and you can’t make your family change.

**Prepare neutral responses.** Let sleeping dogs lie. Don’t try to fix the past. Instead say things such as, “I wouldn’t say that.” “I can’t imagine what I was thinking back then.” "I wonder how it came to be that we see things differently."

**Stay in the here and now, or in good memories.** Let go of past hurts and wounds as best as you can. But make apologies when necessary. Forgive yourself and others, for any ways that you’ve blown it.

**Start New Holiday Traditions**

Choose to be with people who support you, as often as possible. Hold and/or attend several small events that include different people whose company you enjoy. Or mingle with strangers and leave relatives out altogether. Do not feel obligated to celebrate all the traditional holidays if they don’t make you happy. One family of mixed religion has only one annual holiday celebration they call “Hanumasgiving.”

You might choose to gather those people who are most supportive of your needs as a “family of choice.” Twelve-step meetings during holidays are one good alternative, such as Al-Anon, Adult Children of Alcoholics/ACA, Overeaters Anonymous, or AA, even if you’re not an alcoholic. (You could also meet up with members of your ACPA support group.)

So deal with holidays one day at a time, and go for progress, not perfection. Keep it simple and easy. When in doubt, leave it out. Instead of things, strive for health, safety, connections, peace, and serenity. Let live, let go and let be as best you can.

Charles Horowitz, Ph.D. is a counselor in Boulder, Colorado, who has specialized in treatment of people with chronic illnesses for the past 15 years. He entered into this specialty by successfully researching and working with his own chronic pain ailment, which was the result of a 1984 accident. He facilitates an ACPA Support Group and is a Board Member of NAMI, the National Alliance on Mental Illness, Boulder Chapter.
What Does Pain Have to do with Cold or Flu?

As cold and flu season approaches, you may find yourself in the local pharmacy searching for an over-the-counter (OTC) medicine to help relieve cold and flu symptoms. If you are already taking medicine to treat pain symptoms, remember that many of your trusted medicines for both pain and cold and flu could contain the most common drug ingredient in America: acetaminophen.

Acetaminophen is safe and effective when used as directed, but taking more than directed is an overdose and can lead to liver damage.

Acetaminophen is found in more than 600 OTC and prescription medicines, including pain relievers, fever reducers, and sleep aids, as well as many cough, cold, and flu medicines. Throughout the year—and especially during cold and flu season—always double check your medicine labels to avoid doubling up on medicines containing acetaminophen.

The ACPA has partnered with the Acetaminophen Awareness Coalition, which formed the Know Your Dose campaign to educate patients and consumers on the safe use of medicines containing acetaminophen. Follow these four simple steps to use acetaminophen safely:

1. Always read and follow the medicine label.

2. Know if medicines contain acetaminophen, which is in bold type or highlighted in the “active ingredients” section of OTC medicine labels and sometimes listed as “APAP” or “acetam” on prescription labels.

3. Never take two medicines that contain acetaminophen at the same time.

4. Ask your healthcare provider or a pharmacist if you have questions about dosing instructions or medicines that contain acetaminophen.

Visit [www.KnowYourDose.org](http://www.KnowYourDose.org) for a list of some common medicines containing acetaminophen and a new infographic for the chronic pain community. Don’t forget to follow the campaign on Twitter @KnowYourDose for health tips during cold and flu season.
Computer Scientists in Spain Test How Music in the Brain Heals Pain

by Alison Conte

A CPA is aiding cutting-edge music therapy research by computer scientists at the University of Malaga in Spain. Our members are testing music compositions created by computers and delivered anywhere through an Android phone app to determine if the music can aid relaxation and minimize feelings of pain.

Professor Francisco J. Vico leads a research group focused on Artificial Intelligence in the School of Computer Science at the University of Malaga in Spain. His research in Melomics music technology has resulted in computers that compose professional music with no human intervention.

“Melomics” combines the terms “melody” and “genomics.” Genomics is the discipline of sequencing, assembling, and analyzing all of an organism’s genetic material—its genome. Melomics, then, is an algorithm that fiddles with genome-like data structures to produce plausible music compositions.

Melomics started as a technology for music composition, developed by Professor Vico in 2009. The current project aims to modify this technology to provide adaptive computer-composed music for music therapy.

The results from this melomics research project will help develop effective, high-tech mental health tools to help self-manage a wide number of conditions. Named Empathetic Music Therapy (eMT), this complex technology is designed for 21st century music therapy and is ready to be put to work after four years of development and testing.

eMT uses an artificial musician to play music that relates to the listener’s current emotional and physiological state. Monitoring and feedback are done via a smartphone that is connected to AI algorithms in the cloud. (Cloud computing involves a large number of computers connected through a network or storage through virtual servers.)

Music requirements were specified by music psychologists. Based on these, a super computer created the actual music content, which finally was supervised by professional musicians. The goal is to make it as distracting, relaxing, activating, or engaging as possible, so that the right music can be used at the right time. It provides interactive music therapy using the smartphone as a sentient computer that can sense a person’s physiological or emotional state. It will then deliver music that positively affects that state in real time, helping users to manage sleep and reduce pain perception.

At night, the mobile app will detect the subject’s movements while in bed, estimating the state of consciousness by actigraphy, and play the appropriate music to increase relaxation that leads to sleep. During the day, the app will receive the feedback of the patient’s subjective perception of pain (the visual numeric scale for pain will be used), modulating music to induce distraction or relaxation, depending on the input.

ACPA Involved in Testing

With the cooperation of the ACPA, the researchers intend to eventually involve thousands of people in a clinical trial. It will test eMT in the self-management of chronic pain through music, as an inexpensive, effective, and easy-to-use tool.

In October, six ACPA members tested the music for 14 days using a mobile app to facilitate delivery of the music for personalized music therapy for pain management.

Because music is well known as a way to relax and manage chronic pain, this research will evaluate the efficacy of an eMT service as a cognitive, active strategy for chronic pain self-management. It could be developed as a tool for people to easily and effectively manage their pain through music on a daily basis.

“We are doing a test of the project with six members,” said Penney Cowan, executive director of the ACPA. “Later, we will look at the results and then, if necessary, the team will make any changes it feels are necessary before launching the app. We are working on this because we realize the importance of using music in pain management.”

Anyone who is interested can participate by downloading the Android version of this app at empatheticmusic.org.

In order to carry out the trial, the app will prompt the participant to complete a brief survey on his or her personal and medical status. After this, the app collects usage data that will be processed to learn how pain perception and sleep disorders evolve as the user engages the app. The test is varied out in an ambulatory way, without medical personnel or clinical controls. This makes it important to have a large sample, gathering usage data for thousands of participants, which will compensate for the use of minimal controls.

**ACPA Updates**

**Happy Anniversary to Growing Pains**

GrowingPains.org, ACPA’s interactive social website, is one year old!

Our “baby” was launched in late 2012, an outgrowth of the Growing Pains online support group for youth with chronic pain and illness. GrowingPains.org offers many interactive features. Users can make their own avatar, upload pictures and video, write their own private or public pain logs, add WordLeefs, answer questions, explore innumerable resources, and have online discussions with others.

We know young people with chronic pain face challenges at school, with siblings and friends, in participating in extracurricular activities, and communicating with healthcare providers. In an open and safe manner, Growing Pains allows users to connect with others who understand what it’s like to live with chronic pain.

Growing Pains offers a new section just for parents—designed to help them understand how this kind of online support group can help their children move toward a better life, physically and emotionally. The site has experienced moderators, and each child’s privacy will always be protected.

Several features have developed from user experiences over the last year. GrowingPains.org now has scrolling updates that will allow users to see each other’s activity as it happens. The demo video is now easier to find and the site navigation has been consolidated. The changes are meant to connect users more closely and build a sense of community.

**Volunteers for ACPA**

Thirty employees from the software company Oracle, Rocklin, California, volunteered at ACPA headquarters on Oct. 14, 2013. They helped us by stuffing envelopes, folding papers, and assembling packets of materials. Oracle has been coordinating the volunteer program for 10 years and we thank them for their generosity and service.

**Runner Makes Donation**

Many thanks to Amanda Ryan, 24, of Boston, who ran her first half marathon on Sept. 8, 2013, in Chicago, and raised more than $1,193 for the ACPA in connection with her race.

She set up a website to collect donations from friends, family, and co-workers. Her employer, Bank of America Merrill Lynch, has offered to match part of the gift, which will bring the total close to $2,000.

“My sister has fibromyalgia,” Amanda said, “So I wanted a cause that would support research and services to help people like her. When I contacted the ACPA, they were very personally interested. I felt that they that cared about people and would be a good charity to support.”

**Live from New York**

The ACPA opioid safety public service announcement is now live on the big screen in Times Square. This ten-second version of our PSA reminds people who use opioids to store them securely, dispose of them properly, and NEVER share them. It will run through January 5, the height of the holiday travel season.

Funding for this opportunity came from a bequest from an anonymous donor. We are very grateful to her for making this outreach possible.
Southern Maine Support Group Celebrates 20 Years

The Chronic Pain Support Group of Southern Maine has been helping members live a good life despite pain for 20 years. The group celebrated this achievement and its motto—“Pain is inevitable, misery is optional”—at a 20th anniversary gala party at the University of New England’s (UNE) Biddeford campus on September 9, 2013.

The group had its first meeting in August 1993 in the Saco/Biddeford region of Maine. Susan Gold of Saco founded the group and facilitated meetings for 15 years. Ernest Merritt, also of Saco, took over as group leader in 2008 and continues to serve as facilitator. The group is sponsored by the Arthritis Foundation and is a member of the ACPA.

At the anniversary dinner, Gold recalled how the support group and its members helped her recapture her life after she had struggled for several years with chronic pain caused by rheumatoid arthritis. As she stated in the gala program, “The link to others who understood allowed me to take that first step toward rejecting misery, accepting my new life—pain and all—and grabbing all the joy I could every day.”

At the party, Merritt, the current facilitator, said the group helped him cope with a back injury and the challenges of chronic pain.

Shirley Gagne and Rose Spulick, both of Biddeford and co-facilitators of the group in past years, talked about their pain journeys and the support they had received from group members. Nancy Kelley of Old Orchard Beach told of her long odyssey with chronic pain, and the group’s encouragement and understanding during hard times.

Lindsay St. Louis, a UNE student who has worked with the group for the past year, was honored for her contributions. Margaret Duffy, associate vice president of public health and advocacy for the Arthritis Foundation, presented a certificate of appreciation to mark the 20th anniversary.

Participants viewed the “Portraits of Pain” video, featuring interviews with several local people who live with chronic pain. Both Merritt and Gold appear in the video, which was originally presented at UNE’s “The Science of Pain and the Art of Healing” symposium in April 2013.

Edward Bilsky, Ph.D., director of UNE’s Center for Excellence in the Neurosciences and vice president for Research and Scholarship, spoke on “Outside Looking In—How Education, Research, and Community Activism Can Reduce Pain and Suffering.” He noted that while researchers cannot directly experience what people with pain go through, they can help others—including healthcare providers—understand pain better and can work toward easing pain for those who live with it every day.

For support group topics or for more information, visit the group’s website at www.painsupportgroup.org or call Evelyn at (207) 937-5020 or Jane at (207) 934-4189 or e-mail supportgroup@gwi.net.
Letter to the Editor

Dear Penney,


I applaud your write up of his motivational and heroic work as well as the broader theme of the importance of engaging in the arts as a vehicle for pain management [September issue of The Chronicle, http://www.theacpa.org/Chronicle].

As a past chapter leader and current hotline nexus for the ACPA in New York City/Westchester County, I can personally attest to the therapeutic value of art as another modality in chronic pain management. When engaged in my creative passions, photography and writing, I am blissfully unaware of my nemesis (low back pain).

I agree that it is not a question of whether it is perfect or not. The very act of producing something artistically your own in spite of one’s personal challenge is a tremendous boost to personal self-esteem. This is a commodity very difficult to come by in the daily struggle to feel a sense of accomplishment when so many doors are slammed shut to pain sufferers!

Even if one can only approach art therapy as a passive participant—an observer of painting, sculpture or as a listener to music—there is still that sense of being involved in the passion of life. That in itself is a victory over pain!

May this issue present all individuals who deal with chronic pain with another tool to use in becoming a person rather than a patient.

Jerry Becker
Bronxville, New York Chapter
New York City, Westchester County

Enjoy the Holidays by Keeping PACE

CONTINUED FROM PAGE 1...

Let us take a closer look at the word PACE

- Prioritize
- Action
- Comfort
- Enjoy

Prioritize: Before you begin to tackle your long to-do list, take a moment to ask yourself what is the most important task to complete first. You might want to refer to the chapter on priorities in the ACPA Workbook Manual (pp. 10-15). Take a few minutes to reacquaint yourself with identifying and listing your priorities. If you can assign relative importance to the things you want to accomplish, you will have that all-important feeling of control over your life.

Action: Once you have determined the order in which you want to approach your holiday to-do list, you need to take action. Your actions have a direct impact on how you manage your pain from day to day. You must make sure that your actions are within your limits. And, before engaging in any physical activity—from wrapping presents to unloading the dishwasher—it is a good idea to do a few warm-up stretches to guard against injury.

Comfort: Consider how to maximize the comfort of both your body and your mind. Before beginning a task, ask yourself if it is within your limits to complete. Is it something that you can do by yourself or will you need help? Can you do it in the time available? If it does take longer than anticipated, have you given yourself time to rest throughout the task? Your physical comfort should be considered when preparing your list of priorities.

Enjoy: Is this task one you will truly enjoy? Is your heart set on accomplishing this thing? Do you believe it is important for you to do? Consider carefully how it will affect the end result, or if you are doing it because others expect you to.

I realize that some work is no fun, but simply needs to be done, and we do it because it is part of our job. However some tasks are simply no longer within our abilities, are really not that important, or will not enhance our lives. These we should place at the end of our list, or eliminate them altogether.

The ACPA hopes that you will be able to PACE your activities this holiday season and take time to enjoy yourself.

From all of us, Happy Holidays and the very best for the New Year!
Book Review

Battle for Grace: A Memoir of Pain, Redemption and Impossible Love
written by Cynthia Toussaint with Linden Gross and John Garrett
Review by Tara White, RN

This book is about courage under fire, the fire of Reflex Sympathetic Dystrophy (RSD), now called Complex Regional Pain Syndrome (CRPS). It is a book about survival and fighting the medical system that wronged you. It is also a book about not giving up, even after 30 years of chronic pain that would leave most people without hope or inspiration. Instead, the author, Cynthia Toussaint, founded For Grace, an organization devoted to ensuring the ethical and equal treatment of all women in pain.

I first learned of Toussaint’s story many years ago, drawn to her because I, too, have CRPS. It keeps me from working as a nurse, although I am much less affected than she. Her story captivated me and I have followed her cause, helping with letters to congressmen as needed and reading her book as soon as I heard about it.

I found this book to be a deeply honest, no-holds-barred story of a life stolen by pain. As Toussaint and her life partner John Garrett say, it was a “journey that healed and lifted us into a peace and consciousness we never thought possible.” In a brutally truthful way, they write about how, together, they forged a way ahead, using “the transformative power of suffering.”

The book shares their experiences, beginning with Toussaint’s career as a professional ballerina and a seemingly minor injury that, rather than healing, worsened, producing agonizing pain. Then multiple doctors and misdiagnoses led them through a maze of more suffering, relationship-challenging emotions, and scary, isolating dead ends. Although she made many mistakes along the way, Toussaint not only takes responsibility for them, she also explains how they helped her to rediscover her true self. One of my favorite passages is this: “I don’t believe in regret because we make the best decisions we can each moment of our lives.”

With time and tenacity, Toussaint learned to become her own healthcare advocate. With the help of her family, she was able to pick her own battles, make her own decisions, battle breast cancer, and begin a new career as an advocate for other women in chronic pain.

The book also tells how her caregiver Garrett realized for himself how devastating all of this was for his precious Cynthia. He states: “Most people, myself included, haven’t experienced what it’s like to know something in your body can betray you at any moment. If you’re able bodied, you take things for granted, like having legs strong enough to support you. Or that your nerves will send healthy messages to your body instead of sending constant waves of pain.” His journey is interwoven through the book concurrently with hers so the reader experiences both perspectives of their lives as they unfold.

Both of them must come to terms with the tragic fact that because she had been misdiagnosed and told “everything was in her head,” Toussaint gains only partial remission. “It is awareness, along with early intervention, that is the difference between a life saved or a life ravaged by RSD.”

To help others, she embarks on a campaign to raise awareness and make legislative changes in support of the pain community. Together, they have accomplished a tremendous amount. In Garrett’s words: “No one should ever have to live through what we’ve experienced. This is our ‘dream of never again’.”

This is a book for anyone who has had chronic pain misdiagnosed, been maligned by the healthcare system, or has struggled with lack of support or the disbelief of others. Both Toussaint and Garrett open their hearts and expose their deepest feelings in their struggle for survival. For this reason alone, this book deserves to be read.

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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The ACPA is a peer support organization: we help each other learn to live fully in spite of chronic pain. Your 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 Dawn Marie Schuetz**
Given by John Schuetz

**In Memory of Veda Wells**
Given by the ACPA

Veda Wells is survived by her husband, Ernest Wells; her father, George Riolo; her six children, Andrea, Robert, Julia, Donnie, Kristopher, and Kelli; and 14 grandchildren. Veda was the U.S. Postal Service mail carrier for the ACPA and a friend for four years.

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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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