



# Review

REFLEX SYMPATHETIC DYSTROPHY SYNDROME ASSOCIATION

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*This newsletter is not intended to provide advice on personal medical matters, or to substitute for consultation with a physician.*



*Team RSDSA, led by Karen McManus, at the Lake Hollingsworth Walk-a-thon in Lakeland, Florida.*

## A Paradigm Shift

*By James W. Broatch, MSW, Executive Director*

For several years, the official RSDSA t-shirt read, "If Hell were a medical condition it would look like RSD." We felt that it truly represented the plight of our members and that it would at least draw attention to the devastating effects of the syndrome. This year, buoyed by several positive events, we redesigned the shirt with the tag line, "Take Flight with Hope," using artwork by Elisabeth McBride, one of our long-time members. Therefore, "from hell to hope" has become our new mantra.

in New York's Central Park to take part in the Achilles Walk for Hope & Possibility. By participating in the walk, individuals chose to make a difference in their own life and in other lives impacted by CRPS.

We were a sea of green t-shirts. Team RSDSA, three times larger than last year, outnumbered all the other teams. Most people did the 2-mile loop, either unaided, with canes, or in wheelchairs. There were smiles and laughter and even, in some cases, tears. Success is a powerful and emotional experience.

On Sunday June 22, 180 individuals from across the United States gathered

*(Continued on page 3)*

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RSD has been assigned the code number 337.2. It has been classified into four categories:

- (1) 337.20 – unspecified site
- (2) 337.29 – other specified site
- (3) 337.21 – upper extremity
- (4) 337 – lower extremity

**How to give to RSDSA through the United Way**

RSDSA is a partner in the combined Federal campaign. Our designation number is #11045.



Working to raise awareness of reflex sympathetic dystrophy syndrome (RSD) and complex regional pain syndrome (CRPS) since 1984.

**Corporate Sponsors:**



## News From the Patient Representative

*By Mary Beth Kenny Ludington*

ALTHOUGH THE YEAR IS LITTLE MORE than half over, a lot has already happened at RSDSA! By the time you receive this, the Achilles Walk will already have taken place. Registration was at an all time high for this event, with Team RSDSA accounting for over half the entries in the entire race! The money we receive from Achilles helps support our research initiatives; last year alone we funded over \$140,000 in research—the most ever!

We are grateful to everyone who responded to our online surveys. The information we gleaned from your responses will allow health care providers to better treat their CRPS patients. In fact, the journal *Regional Anesthesia* recently announced that they will publish the results of our first survey, thereby enabling us to reach a wide audience of physicians who specialize in pain management.

One extremely hopeful result we received from both surveys was your response to the question regarding remission. 17% of those responding attested to the fact that they had experienced remission of their symptoms at some point during the course of their disease. More importantly, nearly all (83%) of those who had been in remission were STILL in remission! We have asked

Dr. Srinvasa Raja of Johns Hopkins, who administered the survey, to try to obtain more information about that amazing statistic for us.

Soon we intend to launch a study on the long-term health effects of CRPS under the direction of Dr. Peter Moskovitz. Anyone who has suffered with CRPS can confirm that pain, while perhaps the most obvious and troubling symptom, is certainly not the only one we experience. No one has ever attempted to catalog this constellation of symptoms and the aggregate effect on an individual's general health before. Generously funded by the Brodsky Foundation, it is an exciting and ambitious undertaking, and we will welcome your input when it gets underway.

Finally, in the end of April, the Board of Directors met in Washington, DC. Among the items on the agenda were: a discussion on how to position CRPS as a women's health concern, how RSDSA might interface with the VA in dealing with returning vets who have neuropathic pain, and how we might be able to utilize the services of a professional fundraiser, Kim Kaiser, the consultant who advised us to "Take pride in who you are!" I think that's pretty good advice for all of us! ■

(Continued from page 1)

On Saturday June 28, Karen McManus organized a walk-a-thon in Lakeland, Florida. Approximately 30 participants walked a 2-mile loop around scenic Lake Hollingsworth, and raised more than \$2,000 For RSDSA.

Go to our website and click on our slideshow to view our Heroes. Feel our hope. I urge you to join us next year in Central Park, in Lakeland, or to participate in other special events to raise money for the hope and the possibility of a cure. We will help you organize an event in your community to raise funds and promote awareness of this poorly understood and under recognized syndrome.

Once in a while we receive queries from our members about how much of the funds raised actually go to research. For events like the Achilles Walk, RSDSA can take up to 10% to cover costs, such

as publicity, the t-shirts, etc., which means that 90% of your contributions actually fund research projects. Last year, thanks to events like the Achilles and others held during the year, RSDSA was able to invest more than \$145,000 in research grants, our largest expenditure ever in a single year.

The Achilles Walk is just one event. All across our nation individuals with CRPS and their caregivers are choosing to make a difference. Colleen Bartman of RSD in Motion of Ohio organized a walk-a-thon and raised more than \$1,000 for CRPS research. Renee Uitto of Ashland, Wisconsin, and her family and friends walked in the driving rain to raise \$1,000. Troy Walker invited his neighbors and friends to his annual Kentucky Derby barbecue and raised \$1,000. Kim Vosse and Stephanie Lewis of the C.M. McGee Middle School in Berlin, Connecticut wrote two eloquent essays on living with CRPS and \$200 was donated to RSDSA. The Drakes of Pequannock, New Jersey,

raised \$800 by organizing a dress-down day at their school. Individuals are getting involved on many levels.

Energetic individuals, such as Bea Danko of Streator, Illinois, Bob Harris of Akron, Ohio and Bruce Shapiro of Ocean, New Jersey, are contacting their legislators to pass CRPS Education and Research bills in their states.

Every day I'm amazed by the courage of individuals with CRPS who are heroically transforming themselves from victims to individuals who choose to live their lives as fully as possible, regardless of their pain, mobility issues, and losses—individuals who are working despite their debilitating pain, volunteering to help others, attending school, caring for their family, or just deciding to walk or swim to maintain or improve their mobility, despite the pain.

Take flight with hope. We are making a difference. ■

## Join RSDSA

### PEOPLE WHO JOIN RSDSA ARE NOT CONTENT

to be victims, but take an active role in our goals of education, awareness, and research. Our members are people like you—patients, family and friends, healthcare professionals, attorneys, and business people who understand the devastating effects of CRPS and want to make a difference. Your RSDSA membership is important. There is power in numbers and we would like to see our membership, currently more than 7,000, double so that when we talk to the legislature, the pharmaceutical companies, and medical associations, our voice is strong and our message is clear.

As a member, you have a forum to communicate your concerns, share your experiences, and learn about the most recent advances in treatment and research. Fill out the membership application and join today!

### YES! I would like to be a member and support RSDSA

- Patient (US) \$20       Patient (outside US) \$25  
 Can't afford membership       Additional donation

NAME .....

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CITY ..... STATE ..... ZIP .....

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- Please send me information on starting a support group.

For credit card orders, please complete:

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**Please make check or money order in \$US payable to RSDSA. Mail your check with this form to:**  
RSDSA, 99 Cherry Street, PO Box 502, Milford, CT, 06460





# Mailbag

Mr. Broatch,

When we spoke on the phone, you stated that you would publish an alternative point of view. Here is the first one:

I take issue with the fact that the focus of this publication, and of the entire field of study, has shifted to *pain* and *pain management*. Even the name of the diagnosis has been changed to reflect this shift in focus, and the research is following in that direction.

**THE PEOPLE LIKE MYSELF WHO DID NOT FINISH THE QUESTIONNAIRE MAY HAVE BEEN PHYSICALLY UNABLE TO PROCEED; BUT THERE IS NO BASIS FOR THAT GUESS.**

We have been told repeatedly that “pain” is whatever we perceive it to be, and the “scale of 0 to 10” is also whatever we perceive it to be. We’re also told that “10” on this scale is supposed to represent the upper limits of what the individual can imagine the worst possible pain to be.

This amounts to a subjective evaluation of an undefined quantity (“pain”) constrained by the limits of each one’s

imagination, measured on a scale of each one’s own construction. Please note that the “scale” does not allow for what comes after the body has reached its tolerance level, *e.g.* numbness, dissociation, hallucinations, altered or loss of consciousness, etc. This “0 to 10 scale” concepts acceptable for conveying an individual’s tolerance and general comfort level, and may have nursing applications. However, it is not objective, and is therefore unfit for use in scientific research into post-traumatic autonomic dysregulation/dysfunction (*i.e.* CRPS) itself. CRPS is mind-bendingly painful, but it is a lot more than that. Pain is only a dialect of the language of sensation

with which the body communicates; it is not the primary problem.

I had hopes that the Johns Hopkins research project would help to define the condition and better describe it by asking questions of the vast pool of research subjects: us, the patients. There is some information that cannot be gotten from controlled experiments with lab animals. I had looked forward to participating in

the Johns Hopkins study because I have had CRPS twice, and half of my life has been commandeered by this experience.

I tried to complete the survey. I couldn’t. The questions constrained the possible answers either to what the researchers presume they already know or (I suspect) to what the researchers assume that some other ‘authority’ knows. The questions presupposed that CRPS is about pain; that it happens only once; that it occurs in one or more of four limbs; and that it is a linear experience characterized by intense pain. Those are just a few of the constraints.

The people like myself who did not finish the questionnaire may have been physically unable to proceed; but there is no basis for that guess. It is just as likely that they were stopped by the same stumbling blocks that stopped me. There was no allowance for alternative answers. Those who did complete the study could only follow where they were led. The moment they reached a question that could not be answered within the constraints, they were prevented by the survey programming from going any further.

I don’t know what such a lapse is called in the field of scientific research. It is a kind of leap-frog over the discovery process that would be a significant oversight even in a high school term paper. In learning about the unknown, it is wise to ask about what you do not know. Asking a question and begging the question are not the same thing and do not achieve the same results. It’s impossible to learn anything new without first acknowledging, “I don’t know.”

I would love to participate in a research program that allows some latitude for the actual experience of CRPS patients, including those for whom pain is neither the only nor even the dominant problem, those who have had CRPS for a very long time, and those who have had it more than once. Studies in such a program should compare and evaluate the diagnostic criteria, methodology, and symptoms used in diagnosing the different patients participating. They should study the medications, supplements, therapies, and other treatment regimens that they have used. They should explore the cardiovascular, gastrointestinal, and other major systemic malfunctions that *the patients* associate with their CRPS.

We may not know what CRPS is, what causes it, or how to cure it; but asking the questions, gathering the hard facts and looking at what *is* is always a good opening move.

I do appreciate the considerable efforts of everyone at the RSDSA and of everyone who is working on this knotty problem. I am, therefore, loath to find fault. I would refrain from any criticism were it not that the incidence of CRPS is increasing, that autonomic dysregulation is becoming more common, that it is afflicting children, and that we will be having many more war-related cases of CRPS in the very near future.

Sincerely,

Judith O'Halloran-Rosen

AS A MOTHER OF A 12-YEAR-OLD AFFLICTED with CRPS, I've found mirror therapy to be our saving grace. The pain docs and PTs I know and have worked with haven't been aware of this therapy. The PTs have been excited to hear about it.

We all know that CRPS is a problem with the central nervous system—after a surgery or injury, the brain began sending pain signals to an immobile limb, trying to get it to answer back. This is in the same category as phantom limb pain and post-stroke pain. The central nervous system needs a chance to be rewired. Anesthesiologists (pain doctors) are very frustrated by it. There was a big “what do we do with CRPS?” conference in LA a year ago.

My daughter's CRPS started after an ankle sprain in a soccer game last fall. Nothing would touch it, until I learned that mirror therapy can be effective for phantom limb pain. We tried it. It successfully “tricked” her brain into “seeing” her completely disabled foot as a working foot. After one session (and an evening of watching funny movies), she went from terrible pain and no blood circulation to “that's ticklish” when it was time for PT. We've used mirror therapy twice since then when she's had recurrences with the smallest of injuries (it hit hard and fast last week, but the mirror shut it down again).

Don't be fooled by her quick recovery—her brain is young and plastic, and she'd only had the syndrome for 4 to 6 weeks. Studies describe using this therapy for

weeks before getting results. But hey—it's free, easy to do, and low-risk!

For more information, search on “mirror therapy” on the net. For studies and case descriptions, search on PubMed (<http://www.pubmed.gov>).

Here's a quick “how-to” mirror therapy example:

For a foot, sit with a mirror between the “good” and “bad” feet. The mirror needs to be big enough that you can look down and see a full reflection of the “good” foot and lower leg. The “bad” foot is fully hidden behind the mirror. We picked one up at a thrift store that was tall enough that it could lean against her knee on her “bad” side.

Move the “good” foot. Keep it moving. Watch it intently as it moves. Do this for several minutes at a time. Meanwhile, the “bad” foot moves with it. (In pain-free people, keeping the hidden limb still while moving the reflected limb has been shown to confuse the brain and cause tingling and pain. So make every effort to move it.) In my daughter's case, she couldn't move the “bad” foot, so we had her picture it moving in her mind.

We also make a point of never using “bad” or “good” foot with her, since that kind of “factoring out” of the injured foot is what contributed to the CNS dysfunction in the first place. Instead, we've had her name each foot as though they are puppies she dearly loves! ■

—Kathe Gallagher, MSW

AT THE AGE OF 11, MY DAUGHTER'S SIXTH grade classmates created the "Alli's a Faker Club," which was obviously not a school-sanctioned club. Struggling with undiagnosed CRPS pain in her ankle, she would attend school either limping, on two crutches, in a wheelchair, with the aid of one crutch, or walking just fine

Your child might also be eligible under the current special education law known as Individuals with Disabilities Education Act (IDEA 2004). According to the National Dissemination Center for Children with Disabilities (NICHCY) "IDEA is our nation's special education law. It guides how states and school districts

sickle cell anemia; and (b) adversely affects a child's educational performance."

Although CRPS is not specifically listed, it could qualify as a chronic health problem and may adversely affect educational performance. Educators will be keenly looking for the "adversely affects performance" component. Whether it is a 504 plan or an IEP under IDEA, there are laws that provide special help for your CRPS child.

You have the right to request an initial evaluation of your child (504 or Special Education), which must be conducted within established timelines. The evaluation determines if there is a disability present and to learn in detail about any specific needs of the student. The determination of whether a student has a substantially-limiting impairment is made on an individual basis. Such an evaluation can, and should, include input from your medical team.

School personnel will have valid input regarding the educational aspects, but

## Does Your Child's School Have a "Faker's Club"? The CRPS Student's Rights

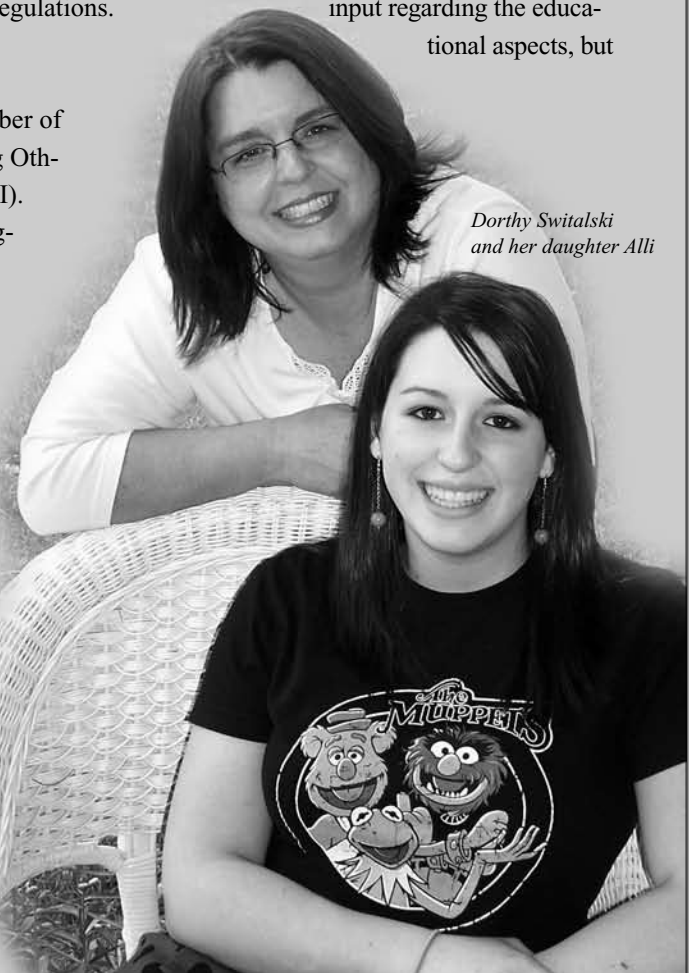
By Dorothy Switalski

This varied from day to day, depending on the amount of assistance she needed to walk. Her classmates came to the likely conclusion that she must be faking. After all, who uses crutches one day, walks the next, and comes to school in a wheelchair the next? It just didn't make sense...she must be faking. The cruel, taunting whispers in the middle school hall confirmed that they doubted her pain. Eight months later, the CRPS diagnosis came and things began to change, especially the atmosphere at school.

Students with CRPS have unique challenges when it comes to education, and may qualify for special services, including those under a 504 plan. Section 504 is part of the anti-discrimination law known as the Americans with Disabilities Act (ADA). According to the United States Department of Education (USDOE), students qualify for Section 504 protection "who have a physical or mental impairment that substantially limits one or more major life activities." The eligibility process should be in place for each local school district, and you should contact an administrator for assistance.

provide special education and related services." An Individualized Education Plan (IEP) is developed in accordance with IDEA law, and your state's special education rules and regulations.

Special education has a number of eligible categories, including Otherwise Health Impaired (OHI). The criteria for an OHI designation is "Limited strength, vitality, or alertness, including a heightened alertness to environmental stimuli, that results in limited alertness with respect to the educational environment, that (a) is due to chronic or acute health problems *such as* asthma, attention deficit disorder or attention deficit hyperactivity disorder, diabetes, epilepsy, a heart condition, hemophilia, lead poisoning, leukemia, nephritis, rheumatic fever, and



Dorothy Switalski and her daughter Alli

your child's medical team (e.g., physician, pain specialist, physical therapist, psychologist) should provide documentation regarding the diagnosis and your child's health history. As you know, CRPS is not easily diagnosed by those in the medical field and is often not a visible syndrome, making it even more difficult for educators to understand. Providing detailed information about CRPS to school personnel is crucial as part of the initial evaluation.

Once at the evaluation meeting, one of your questions should be "What are WE going to do to help my child?" It is very important that everyone involved is part of the team, which is sometimes easier said than done. Nevertheless, approach the meeting optimistically with an expectation that your child's needs *will* be met. If the evaluation team comes to a conclusion you disagree with, you have the right to proceed in accordance with both 504 regulations and special education rules. Requesting an evaluation is the first step to getting your child the help he or she needs and deserves.

Once the need for special services is established, it is especially important for schools to understand that the needs of CRPS students change from day to day, sometimes from hour to hour. To that end one should be aware that CRPS may adversely affect a child's education when:

- Regular attendance is not possible (this is a biggie)
- Pain distracts a student from concentrating
- School personnel don't "believe" their pain
- They miss instruction and are expected to teach themselves
- They are expected to always be doing "make-up" work (a perpetual state of being behind is not good)
- Participation in gym class is not possible
- They are singled out from other students or by other students

- Social interaction is limited
- Cooperative learning is limited
- Vision is compromised

Flexibility in the 504 or IEP plan regarding accommodations and modifications is essential. Accommodations can be made to allow the student to complete the regular curriculum. Modifications differ from accommodations in that the regular curriculum is changed or modified to meet the needs of the student. Even secretaries, playground aides, and cafeteria workers should be informed of special circumstances, as they will also be dealing with your child. Accommodations can include:

- Access to a teacher consultant
- Absences are not counted against them
- Additional tutoring and/or instruction is provided
- Homebound instruction when needed
- Teacher-generated notes will be provided
- Laptop for use when writing is an issue
- Extended deadlines for assignments
- Additional time allowed for test taking
- Alternative assessment options (oral, project based, demonstration)
- Extra set of books for home use so carrying a heavy backpack is not needed
- Books on tape if vision is an issue
- Changing classes when other students are not in the halls to avoid bumping
- Use of the elevator
- Being allowed to call home when needed without question
- Being allowed to go to the nurse's office without question
- Being allowed to choose to go outside or stay in during recess
- Being allowed to make their own decision regarding gym participation
- Class lectures are video taped for student to view at home
- Class materials are available on Blackboard (online)
- Flexible schedule (no first hour, allowed to arrive late)
- If feeling better later in the day, allowed to participate in extracurricular activi-

ties, even on days when they have missed part or all of class.

Modifications can include:

- Exemption from Physical Education
- Not being required to make up "bell-work"
  - o Expected to complete coursework and master class objectives, standards and benchmarks just not the busy work, especially after an extended absence.
- Graded on completed work only
- Adjusted curriculum when appropriate

Please know that this is by no means a complete list. Also, the accommodations/modifications made for one CRPS student will be very different than for the next, depending on current symptoms and may change often.

Since my daughter's diagnosis in 2004, I have been very pleased with our school district's efforts to accommodate her ever changing needs. I know others have not been as fortunate, and have struggled to get their school to listen, understand, and provide needed assistance. In an attempt to help her teachers understand, I hold what I've coined "CRPS 101" at the beginning of each school year. The principal calls a meeting with all of her teachers, the special education teacher consultant and himself. I share with them her journey since CRPS; what she has been through, what could lie ahead, and what her current needs are. This has proven to be a wonderful tool and a way to get everyone on board and working as a team. Shortly after her diagnosis, I printed the RSDSA flyer *Helping Children/Youth with CRPS Succeed in School* and discussed it with the school counselor. We made the decision to share information about CRPS with her sixth grade classmates. On the same day each sixth grade teacher shared the following information with their class.

*(Continued on page 10)*



# Come to Phoenix in October for the RSDSA Annual Conference!

*New Perspectives on CRPS: Research, Diagnosis, Treatment*

On October 3 and 4, 2008, RSDSA will be holding a two-day conference in Phoenix, Arizona, entitled 'New Perspectives on CRPS: Research, Diagnosis, Treatment.' Working in conjunction with the RSD Care and Share Support Group of Phoenix, Arizona, we will have day-long sessions for both medical professionals and the lay community.

## CONFERENCE AGENDA

**Patient Day:**  
October 3, 2008

**Professional Audience:**  
October 4, 2008

**Welcome**  
*James W. Broatch, MSW, Executive Director, RSDSA*

**CRPS: Where are we today?**  
[What do we know and what do we think we know?]  
*Anne Louise Oaklander, MD, PhD*

**Differential Diagnosis and Treatment of Comorbidities**  
*Bradley S. Galer, MD*

**Interventional Therapies**  
*Joshua P. Prager, MD, MS*

**Psychiatric Pain Management Treatment for CRPS**  
*Sarah M. Whitman, MD*

**Treatment Options for the PT and OT**  
*Melanie E. Swan, OTR/L*

**Question and Answer Session**

## FACULTY



**Bradley S. Galer, MD**  
*Vice President of Nuvo Research, Inc.*

**Anne Louise Oaklander, MD, PhD**

*Associate Professor of Neurology at Harvard Medical School, and Assistant in Neuropathology at Massachusetts General Hospital*



**Joshua P. Prager, MD, MS**  
*Director of the Center for the Rehabilitation of Pain Syndromes (CRPS) at the Departments of Internal Medicine and Anesthesiology, David Geffen School of Medicine at UCLA*

**Melanie Swan, OTR/L**  
*Occupational therapist and the former Clinical Manager of the Rehabilitation Institute of Chicago Chronic Pain Care Center*



**Sarah M. Whitman, MD**  
*Psychiatrist and host of HowToCope-WithPain.org website and blog*

For updates on the conference, visit our website at [www.rsd.org](http://www.rsd.org). ■

**Y**ou only have to talk to Vicky Jerdee for 30 seconds or so and her Arkansas accent gives away her rural roots and her no-nonsense approach to problem solving. Talk to her for more than that, however, and you tap into her passion for helping people with pain find their collective voice and their demand to be heard. As a key player in the RSD Care and Share Support Group and trained as one of the Power Over Pain Action Network's spokespersons, Vicky spends a good part of her time trying to solve the problem of the overall lack of awareness of CRPS among the medical and lay communities.

Having worked as an RN for 21 years before she developed CRPS, Vicky was no stranger to the medical environment. She worked in many different departments, including the open heart unit, cardiac catheterization lab, endoscopy, emergency department, recovery room, research, so she did the whole gamut.

She also is no stranger to hard work. "I grew up in Arkansas on a cotton farm. I worked on the farm in the summer and the winter I would get up in the cotton trailer and pack up the cotton. It was a hard job, but it taught me the meaning of a dollar," she says.

Unlike many patients who can remember the exact trauma that led to CRPS, the cause of Vicky's syndrome is still vague. "In 2003, I developed CRPS symptoms when I was working as a manager of the endoscopy department. We don't know what caused it. They think I was exposed to a virus or bacteria that got into my spine, which caused my CRPS and degeneration in the lumbar area. It affected me from the waist-down, and, after an 18-month period without insurance, has now spread to my right arm," she explains. Vicky was diagnosed with fibromyalgia



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## Interview with Vicky Jerdee, RN

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in 1997, but it was under control when she developed CRPS.

Like many people with CRPS, her diagnosis took a while and her personal loss has been significant. "It was almost a year to the very day of the initial onset before I was diagnosed with CRPS. I had gone through four neurologists, four rheumatologists, and three primary care physicians before I got to pain management," she explains. "When I initially got sick, my employer was not supportive; I lost my home and everything. My kids—a son who is now 18 and a daughter who is now 20—went to live with their dad and a friend took me in.

### Advocacy and Legislative Work

Once diagnosed, Vicky became an advocate for the better diagnosis and treatment for people who have CRPS. "In Phoenix, it tends to be that the pain management doctors are the ones diagnosing CRPS, and not neurologists; we see very few neurologists in this area who even know

about CRPS. In Tucson, doctors even have signs in their windows saying that they won't take pain patients—there is a huge need for education and awareness of chronic pain in this area," she explains. She channels her advocacy energy through her involvement with several groups, including The Power Over Pain (POP) Action Network—a grassroots network of volunteers who are people with pain, caregivers, and healthcare providers. Sponsored by the American Pain Foundation, POP works with other advocates, professionals, and organizations to improve pain care in America.

"Through the Power Over Pain Action Network, I host seminars on chronic pain where we discuss, among other chronic pain issues, how to manage patient expectations, how to keep a pain diary, and review the pain patient's bill of rights. We also distribute information on the undertreatment of pain and teach them to be their own pain patient advocates," Vicky says.

She is also a mentor for American RSDHope and the RSD Care and Share Support Group in Phoenix, Arizona. "I educate new members on their rights and give them the opportunity to ask questions and become involved. I became active with RSD Care and Share in 2005. RSD Care and Share hosts a pain expo every year. Vicky also works with the Arizona Pain Initiative in Phoenix and the Southern Arizona Initiative in Tucson on advocacy and legislative efforts and is working on a CRPS education and awareness bill for Arizona. "Being involved politically like this, you can see how legislation really moves things forward for pain patients. We're currently looking for cosponsors for the Arizona CRPS Education and Awareness Bill, but issues within the state budget are preventing the bill from moving forward," she adds. ■

**Q:** *The skin on my foot is thickening and my nails are brittle and cracking severely. I believe that I may lose some of my nails if I can't treat them or care for them properly.*

**Are there any special tips for foot and nail care for those with CRPS?**

taking this vitamin daily for a couple of months. If this fails, there are also some topical nail moisturizers and nail strengtheners that can be applied to the nails. One such product is Elon® Nail Conditioner, available online at <http://www.ilovemynails.com>.

## CLINICAL Q&A: Foot and Nail Care for Those with CRPS?

*By Elliot Udell, DPM*

**A:** There are many conditions that can cause nails to become brittle and to crack. Two that come to mind immediately are fungal toe nails and vitamin deficiencies, but there are others. CRPS can cause nail problems, since it sometimes affects the circulation in the toes. I recommend that you see a podiatrist and have him or her evaluate the circulation in your toes. The podiatrist can then take a portion of the affected toe nail and send it to a laboratory. We have very sophisticated laboratory techniques today and fungi in nails can be seen through microscopic analyses.

If the test, however, comes back negative, you might want to try taking an over-the-counter vitamin called biotin. One company markets it as Appearex®. Many people suffering from brittle nails report gratifying results after

The bottom line, however, is that if you are having problems with your toe nails, a thorough podiatric examination is a worthwhile investment. Potential problems can often be averted by catching them early, before they become big problems. ■

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*Dr. Elliot Udell specializes in pain management of the foot and ankle, and is in practice in Hicksville, New York. He is currently president of the American Society of Podiatric Medicine and is on the board of the American Society of Podiatric Dermatology, and board certified in Podiatric Primary Care as well as Pain Management. He lectures at medical seminars throughout the US and Europe. Dr. Udell can be reached at Suite 206, 120 Bethpage Road, Hicksville, NY 11801, Tel: (516) 935-1113, E-mail: [Elliotu@aol.com](mailto:Elliotu@aol.com).*

*(continued from page 7)*

- It's called Complex Regional Pain Syndrome.
- CRPS is very painful (imagine putting your hand on a hot burner and not being able to remove it).
- CRPS symptoms can vary from day to day.
- CRPS can cause sensitivity to touch (be cautious about bumping).
- You cannot catch CRPS from another person.

Later that day, I received an e-mail from one of her teachers. After their discussion, she asked her students "Is there anything you can do now to help Alli?" One boy raised his hand and replied "Apologize." From that point on the "Alli's a Faker Club" ceased to exist.

The ultimate goal is to be sure your child's needs are addressed. When parents and school districts work cooperatively, it is the student who benefits. Oftentimes, providing knowledge and awareness about CRPS are the keys to success.

For further information, visit:

US Department of Education, Office of Civil Rights <http://www.ed.gov/about/offices/list/ocr/504faq.html>

National Dissemination Center for Children with Disabilities (NICHCY) <http://www.nichcy.org/idea.htm> ■

RSDSA has published a brochure called *Helping Children/Youth with RSD/CRPS Succeed in School*. You can find it on our website at [http://www.rds.org/4/resources/pdf/helping\\_children.pdf](http://www.rds.org/4/resources/pdf/helping_children.pdf).

LIFE IS FULL OF ITS BUMPS AND BRUISES. Who among us does not have a knee or elbow scar from a fall off a bike? I remember a phase where I must have fallen every few weeks running on a sidewalk, with a scarred up knee to show for it.

The healing response from these sorts of injuries usually occurs in a predictable sequence. First, the tissues respond with inflammation that can last anywhere from 7 to 14 days. The increased circulation caused by inflammation brings in a flood of specialized cells to clear out wound debris. The next phase, fibroplasia, lasts for 7 to 10 days, and may overlap part of the inflammatory response. Fibroplasia is critical for establishing the presence of cells that begin to produce the foundation for new tissues. The final phase, remodeling, can last for weeks as tissues mature and regain their strength.<sup>1</sup>

This is not the case when complex regional pain syndrome (CRPS) is involved, since nerves misfire and normal healing processes that are necessary do not occur. Although one study of 1,006 patients found that less than 7% of people with CRPS are affected by chronic open wounds<sup>2</sup>, this small percentage does not diminish the importance of addressing this issue. When left untreated or treated insufficiently, the wound can rapidly move to an infected state that jeopardizes the rest of the limb. Yet, because of the small proportion of people with both CRPS and chronic open wounds, there is very little literature to guide clinicians in the best practice.

Looking closer at issues that complicate skin integrity, vascular changes are the ones most reported, and the most problematic. Vascular changes have

shown varying relationships between changes in the sympathetic nervous system and temperature differences.<sup>3</sup> By assessing skin samples, others have noted changes in nerve innervation of hair follicles, sweat glands, and blood vessels.<sup>4</sup>

For those who have issues at the skin surface, chronic edema is frequently encountered. Using the same population as



## Wounds that Won't Heal

By Anita L. Davis,  
PT, MSM, CA-AAPM, CEAS

previously mentioned, 40% of those with complications presented with infection, 35% with ulcers and 36% chronic edema. Chronic edema has been consistently linked to further development of infection and additional complications. In the general population, edema can be managed with compression garments or other mechanical compression treatment, but with CRPS, this treatment is frequently intolerable without additional pain interventions.

Therefore, other strategies are employed, which can include lumbar sympathecto-

my, sympathetic blocks, or other similar treatments that have not only provided a degree of pain relief, but also assisted in healing the lesions.<sup>4,5</sup> Some have even resorted to indwelling epidurals to provide a tolerance for mechanical compression to aid in healing.<sup>6,7</sup> In addition, hyperbaric oxygen has been used in wound treatment.<sup>8</sup> Although research is still in progress, some results are promising. None of the studies, however, involved the wounds of those with CRPS.<sup>8,9</sup>

Aggressive treatment may also include surgical reconstruction to aid in arterial blood flow. This even has its challenges in those not affected with CRPS.<sup>10</sup> As with any surgical intervention, the surgery itself can pose a risk of increased pain for those with CRPS. It is estimated that 6% to 10% of patients with CRPS will require surgery on the affected extremity for various reasons.<sup>11</sup> If provided with appropriate interventions, the probability of negative consequences can diminish. The recurrence rate of those receiving a stellate ganglion block with a surgical procedure was only 10%. This was also seen in those with intraoperative intravenous

regional anesthesia using clonidine and lidocaine. The intravenous anesthesia was felt to be superior, given the inherent difficulty and complications with a stellate ganglion block.<sup>11</sup>

Other skin conditions include ulcers, bullae and other types of wound formation. Infection is a frequent complication of any skin lesion. Typically infections are addressed with antibiotics. However, topical treatments and oral antibiotics have been minimally effective in those with CRPS.<sup>7</sup> Laan et al noted treatments

such as intramuscular long-acting penicillin injections, intravenous mannitol infusion and intravenous penicillin.<sup>2</sup> When infection repetitively develops in wounds of those with CRPS, antibiotics are frequently ineffective. Reasons for resistance to healing with conventional methods include impaired oxygen consumption and vascular abnormalities that affect blood flow in the extremities.<sup>2,3,7</sup>

With such difficulty in successful healing of wounds in individuals with CRPS, prevention is a critical component. There are generally recognized factors that one can control to minimize the potential of skin lesions. These include abstinence from cigarette smoking, clean hygiene, healthy eating habits, and exercise as able and proactively manage diabetes if present.<sup>12</sup>

Despite these basic efforts, wounds may still appear. The specific etiology of these wounds has not yet been identified to help determine the best course for prevention. Therefore, when such wounds present themselves on those with CRPS, immediate attention by a healthcare provider is recommended. Having a vascular surgeon involved may be necessary to provide good wound care and comprehensive treatment once infected wounds begin to appear. ■

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## A Patient Perspective on Chronic Wounds

WILSON H. HULLEY, RSDSA BOARD Vice President (Communication, Disability and Advocacy) has spent the last 10 months suffering wounds that have not healed properly. He says, "RSD creates a unique healing environment. The skin's sensitivity creates a horrific problem. Normally, if a person has a wound you might put ointment and a bandage on it and allow it to heal. With the pain associated with CRPS this isn't always possible."

Wilson's wound started as a blister and went from there. "It ulcerated and my podiatrist didn't like the way it was looking. It kept getting worse. It is a nightmare; I've tried acupuncture, muscle stimulation and nothing cures it." He has worked with a podiatrist to manage the wounds, and has had some success with bacitracin—an antibiotic ointment available over the counter. Since his feet are affected, he also makes his own bandages using sterile adhesive pads (he uses Tefla® type pad) and self-binding non-adhesive tape. He suggests that individuals with wounds, particularly on their feet, try different products until they find the one that works the best. It may not cure, but might comfort." In addition, Wilson tries to wear sandals whenever possible and changes his socks up to five times a day in order to keep his feet as dry as possible.

**Q: Dear Jeanne,**

**Can I do volunteer work without jeopardizing my disability benefits?**

**Bored at home,  
Sarah**

will justify canceling your claim. It's not about right or wrong; it's about money. There are many cases where claimants' benefits have been wrongly cancelled for doing minor activities that were well within their stated limitations. Should your benefits be cancelled, you will need

provider and report you as a case of insurance fraud. (All benefit providers have fraud hotlines.)

In the absence of legal protections, do what you can to avoid the *appearance* of fraud. Choose volunteer work that is

## Q&A: Disability Issues

By Jeanne Lazo

This column is by the author of *Persistence is Power*.

Disclaimer: This column provides general information and is not intended to provide specific advice on medical or legal matters, nor should it substitute for consultation with doctors, attorneys, or human resources/benefits experts.

**A: Dear Sarah,**

Unfortunately, there are no laws that guarantee people with disabilities the right to do volunteer work. My answer depends on the type of benefits you are receiving.

You probably would not be jeopardizing Social Security benefits (SSDI or SSI), because Social Security does not have resources to investigate the majority of claimants. Still, you should avoid doing any work you claimed you could not do because of your disability. For example, if a back injury caused your disability, and you claimed you could not lift more than five pounds, avoid volunteer work that involves lifting more than five pounds. Or if you claimed you could not work full-time, do not do volunteer work on a full-time basis.

In the case of disability insurance or workers' compensation benefits, I advise caution. Both types of benefit providers *do* have the resources to investigate claimants and both have strong financial incentives to look for any evidence that

IT'S NOT  
ABOUT  
RIGHT OR  
WRONG;  
IT'S ABOUT  
MONEY.

to hire an attorney, usually at your own expense, and fight, sometimes for years, to reinstate your claim.

Other than an investigation, how else might your benefit provider find out that you are working as volunteer? Someone who observes you working as a volunteer could contact your benefit

well within the limits of your disability and ask for help with any tasks that are outside of your limits.

Doing volunteer work from home could be the perfect option. You could do much to help others within the privacy of your home.

If you want to try volunteer work as a first step in a return-to-work strategy, consider discussing your plans with your benefit provider, but, again, use caution before you open this can of worms. Even a simple inquiry can raise a red flag and spark an investigation if you are receiving disability insurance or worker's compensation benefits.

—Jeanne

.....  
*Jeanne Lazo coauthored Persistence is Power! A Real-World Guide for the Newly Disabled Employee. You may send questions to her at [jeannelazo@aol.com](mailto:jeannelazo@aol.com). ■*



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## 2008 CALENDAR OF EVENTS

**SEPTEMBER 13, 2008, 9:30 A.M.**

### **2008 WALK FOR AWARENESS AND A CURE**

Cleary Lake Regional Park,  
Prior Lake, MN

Join the Minnesota RSDS Coalition at their annual fundraising walk to raise funds for CRPS research and educational initiatives, and a celebratory pot-luck picnic immediately after. Please visit the website (<http://www.rsdsminn.org/48.html>) for updates. If you are interested in volunteering this year's Walk, please e-mail [walk@rsdsminn.org](mailto:walk@rsdsminn.org).

**OCTOBER 3-4, 2008**

### **NEW PERSPECTIVES ON CRPS: RESEARCH, DIAGNOSIS, TREATMENT RSDSA ANNUAL CONFERENCE**

Phoenix, AZ

Speakers include Anne Louise Oaklander, MD, PhD, Joshua P. Prager, MD, MS, Bradley S. Galer, MD, Sarah Whitman, MD, and Melanie E. Swan, OTR/L. Free to RSDSA Members.

**NOVEMBER 12, 2008**

### **2008 BOUNTY OF HOPE. DINNER AND SILENT AUCTION**

Union League Club, 38 E 37th St.,  
New York, NY

The Bounty of Hope is RSDSA's flagship fundraising event that enables us to fund

research and launch awareness projects for physicians, nurses, rehabilitation professionals, parents, teachers, people with CRPS, and the general public.

**DECEMBER 7, 2008**

### **2ND ANNUAL USC QUENCH THE FIRE 5K RUN & WALK**

The proceeds from the USC Quench the Fire Run/Walk will help in raising awareness of neuropathic and other chronic pain conditions such as Complex Regional Pain Syndrome (CRPS), and support the USC Pain Center. The funds will be directed for clinical research and trials, patient education, and community outreach events.



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