



Review

REFLEX SYMPATHETIC DYSTROPHY SYNDROME ASSOCIATION

IN THIS ISSUE:

- 1 Sustaining Our Mission
- 2 News from the Patient Representative
- 3 RSDSA to Fund a New Opportunity in Clinical Research for CRPS Care
- 4 RSDSA News
- 5 Sammie Barrett Rocks!
- 7 Shock and Awe: New Therapy Helping Patients with Chronic Pain
- 11 Imaging Neuroinflammation— An Important Advance for Pain Medicine
- 14 Donations



Events such as the Achilles Walk support all three arms of our mission—creating awareness, offering support for those with the syndrome, and raising funds for research.

Sustaining Our Mission

By James W. Broatch, MSW, Executive Director

THE REFLEX SYMPATHETIC DYSTROPHY Syndrome Association (RSDSA) was founded in 1984 by Audrey Thomas and Frank and Roe Davis to create awareness of the syndrome, offer support to patients, and raise funds for research.

Today we honor that mission and have expanded it to include support by educating not only those afflicted with the syndrome, but their families, friends, insurance and health care providers on the disabling pain CRPS causes. We encourage individuals with CRPS to offer each other emotional support within affiliate

groups and RSDSA supports research into the cause and cure of CRPS.

From the beginning, the three parts of our mission have been equally important. Since 1992, RSDSA has funded \$1,423,354 in 23 fellowships and grants, all of which in one way or another have moved this community forward in understanding the pathophysiology and potential treatment options for people with CRPS. Two years ago, we established a patient registry and commenced a 20-year study which will examine how CRPS affects individuals' health over time. In

(Continued on page 3)

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

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CRPS 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) 337.22 – 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 Members:



News From the Patient Representative

By Mary Beth Kenny Ludington

Hi, everybody!

By the time you read this, summer will be in full swing, and the Achilles Walk for Hope and Possibility will be over. I wish each of you could participate in it, as it is such an emotional and uplifting experience. There are times throughout the year when I, who work from home with the RSDSA, feel as though I am operating in a vacuum. Achilles gives me the opportunity to interact with so many others who experience the same kinds of things that each of us does every day. The feeling of community is incredibly powerful.

Unfortunately, on the other end of the spectrum, we all know how isolating pain can be. That is why it is so important that we become “ambassadors of awareness,” and help spread the word about RSD/CRPS. I’m sure almost every person reading this newsletter has been contacted by a friend or relative and asked to speak to someone else dealing with RSD/CRPS. When I speak with others, I invariably tell them how grateful I was when I first contacted RSDSA years ago. It felt so comforting, so validating to have a knowledgeable, sympathetic place to turn for information and support. I wasn’t alone, I wasn’t crazy

(well, my family might debate that point!) because there was an entire organization devoted to MY disease! The first time I got the newsletter, I practically cried! Now, because of the donations we have received, and because of the way the organization has grown, we have an enormous amount of material we can provide to those with RSD/CRPS and to their families when they make that same all-important first call.

I am proud to volunteer with RSDSA because I know that, in the words of our President Paul Charlesworth, “we do a lot with a little;” in fact, 93 cents of every dollar we spend goes directly towards programs and services. Since 1992, we have funded over \$1.3 million in fellowships and grants. An example of the type of project RSDSA has funded with your help is explained in this edition of the newsletter. It contains a story about research at Beth Israel Hospital on a noninvasive therapy called transcranial direct current stimulation. This is a new technology with exciting potential to help those who have not responded to conventional therapies.

The future looks bright when we remember that together we can make a difference! ■

(Continued from page 1)

recent years, we have been disappointed by the number and quality of research applications submitted for our consideration. Our Board decided after consultations with our Scientific Advisory Committee (SAC) to be a catalyst and foster interest into new areas which we believe hold special promise for people with CRPS and a number of other neuroinflammatory diseases.

We have reached out to other patient advocacy organizations and begun to sponsor a series of international translational research workshops. In October 2010, RSDSA sponsored Activated Glia: Targets for the Treatment of Neuropathic Pain, which brought together key researchers, clinicians, and patient advocacy groups to discuss the role of activated glia in the neuronal mechanisms of chronic pain. The second workshop will be held in October 2011 on Imaging Neuroinflammation and Neuropathic Pain. Representatives from The National Fibromyalgia Association, The TMJ Association, Interstitial Cystitis Association, , The Facial Pain Association, The American RSDHope Group, and the National Spasmodic Torticollis Associations are attending. The outcomes of these workshops have the potential to change the way that clinicians and researchers think about CPRS and may move us forward to finding better treatments, better insurance coverage for our constituents and ultimately, a cure. Concurrently, with the input from our SAC, RSDSA is investigating other promising areas of research.

We are guided by a stellar SAC that understands better than anyone the complexity of the syndrome. Because research is a central component to our mission, we have chosen to fund the work that others will not. A perfect example is The multi-centre international

(Continued on page 6)



RSDSA's support of this research may appear to be an extraordinary event, but perhaps not. Let me explain.

Since its founding in 1984, RSDSA's mission has included advocating for understanding CRPS and supporting people with the syndrome—individually, in their communities and across the country. RSDSA provides access to information and services to patients, their families and friends, their doctors, and to the medical and health care community at large.

RSDSA to Fund a New Opportunity in Clinical Research for CRPS Care

RSDSA'S BOARD OF DIRECTORS UNANIMOUSLY elected to fund a 2½ year clinical research project: A multi-centre international study exploring the patients' definition of recovery from CRPS. The principal investigator is Professor Candy McCabe, PhD, of the Royal National Hospital for Rheumatic Diseases in Bath, England. Her distinguished consortium of clinical scientists includes Andreas Goebel, PhD; Nicholas Shenker, PhD; and Richard Haigh, PhD; also of the United Kingdom; Johan Marinus, PhD and Roberto S.G.M. Perez, PhD of the Netherlands; Florian Brunner, PhD, of Switzerland; Professor Frank Birklein, MD, and Christian Maihöfner, MD, PhD, of Germany; and Professor Troels Jensen, MD, DMSc, of Denmark.

This research project holds the promise of setting the standard for outcomes measurement of clinical research trials of treatments for CRPS I into the future. It will also establish collaborative relationships among clinicians and scientists around the world. In some ways,

RSDSA also raises funds for these services and for innovative research that has the ultimate goal of finding a cure for CRPS, and short of that, treatments that relieve the suffering caused by the disease.

RSDSA's research mission has three parts. The first seeks new and improved diagnostic methods to identify CRPS faster and with greater accuracy (better sensitivity and better specificity). The second seeks to understand the mechanism of the disease that is CRPS: What is the cause? Why do some people get it and others do not? Why do some people recover and others do not? The third research mission of RSDSA seeks effective and safe treatments for CRPS. An overview of research projects that RSDSA has funded in these three areas is available at RSDSA's web site (www.rsd.org/research.html).

Recently RSDSA worked with respected clinicians, notably among them Norman

(Continued on page 6)



Caption

MEET MARY FIORE

WE WANT YOU TO MEET MARY FIORE, whose daughter, Anna, has CRPS. Mary will be working with RSDSA part-time to help us promote greater awareness of CRPS, raise funds to provide more support to people with CRPS and their caregivers, initiate educational programs, and to raise funds for our international translational research conferences, the development of more effective treatments, and eventually a cure.

To contact Mary, please call toll-free, 877-662-7737 and we'll get you in touch with her.



Caption

HELP RSDSA RAISE MORE THAN \$130,000 BY AUGUST 27

SUE PINKHAM AND THE MOTHERS AGAINST Chronic Pain have been angels to RSDSA. Last year, Sue and her strong team raised more than \$4,000 by selling 25%-off coupons to Macy's for \$5. It is a wonderful way to say thank you to a neighbor, to a friend who has been there for you, or to a family member. Or to give yourself a treat!

5,234 individuals receive this newsletter from RSDSA. Imagine if each one of you chose to sell just five tickets: $5,234 \times \$25 = \$130,850$. Imagine.

The coupons are only \$5 and the entire \$5 will benefit research and awareness programs for RSDSA.

The tickets can be used in Macy's Stores nationwide and to make purchases on-line.

You receive 25% off all day on regular, sale and clearance items including home on August 27.

I believe it is possible. Join us to make it a reality.

To participate, please call Sue Pinkham at 781-771-2095 or send an e-mail to suepinkham@comcast.net.



Sue Pinkham with Karen Richards at the Macy's Shop for a Cause Day

Thank you to all who participated in the *Achilles Walk for Hope & Possibility* on June 26! The next issue will feature photos of the walk. In the meantime, check out the video on the RSDSA home page (www.rsd.org).

WHILE MOST TYPICAL HIGH SCHOOL STUDENTS were busy changing their Facebook profile pic and tweeting about the latest smartphone app, Sammie Barrett was busy producing a live rock concert—but not just any rock concert. Sammie created Rock for RSD to promote awareness of and raise funds for RSDSA.

A devoted dancer for over 12 years, Sammie was in eighth grade when she sprained her ankle in ballet class. When

therapists ever. She helped me get strong and understood what was going on.” Over time, Sammie was functioning with an occasional flareup here and there, but suddenly out of nowhere, she was stricken with a setback.

One January morning, Sammie literally couldn’t get out of bed. The pain had spread up from her ankle to her midback on her left side. “It was worse than the original accident.”

are not mentally prepared.” Her doctor wanted to admit her for further evaluation. They left Boston and looked for a different solution.

Sammie and her mom turned to Sue Pinkham, one of the founders of Mothers Against Chronic Pain, located outside of Boston. Sue’s daughter, Jodie, also suffers from CRPS. “Sue was instrumental in connecting me with Dr. Pradeep Chopra. Had it not been for Sue, I would probably



Sammie Barrett Rocks!

By Beth Meadows

x-rays and other tests revealed no physical evidence for her excruciating pain, it took six doctors and four months to reach a diagnosis of CRPS. It was a long process, and even her own pediatrician couldn’t believe it was true.

Sammie and her mom quickly realized that the process of finding the “right” doctor and physical therapist were far more challenging than producing a live rock concert.

Over the next three years, Sammie would finally discover a doctor who knew how to treat her condition and a physical therapist (PT) who understood the program. She would see Moira Slyne Vayda, formerly of Braintree Rehabilitation, four times a week. Sammie remarks that Vayda was “one of the most amazing physical

Sammie returned to the hospital where CRPS was originally diagnosed, but they had closed her case. Knowing that she was in a wheel chair and in a lot of pain, they claimed that they would admit her in as an emergency case, but Sammie’s “emergency case” took three months to get an appointment.

Once Sammie was in the hospital, a newly assigned physical therapist who was not familiar with Sammie’s case grabbed her ankle and twisted it without warning, sending Sammie back into the wheelchair for three months. Meanwhile, two other PTs told Sammie to “tough it out” and warned “there would be a lot more than that,” and even went as far as to accuse her of faking it because she couldn’t be in that much pain.

Sammie’s screaming and her mother’s screaming led to statements like “You

still be waiting to see a doctor,” Sammie asserts. Dr. Chopra, director of the Interventional Pain Management Center of Rhode Island, brought Sammie right in and broke through her pain within a week using a low dose ketamine treatment called troches (pronounced trO-keys), which are small throat lozenges that dissolve between the cheek and the gum over a period of 20 to 30 minutes. “I call them my RSD inhalers,” said Sammie. “They work fast and keep the pain at bay.” She also takes Lyrica daily.

On her 18th birthday, on April 28, Sammie could walk again, thanks to Dr. Chopra.

You would never guess there had been any frustration from this positively spirited young woman. Even though Sammie was confined to a wheelchair for months, she stayed focused organizing the next

(Continued from page 3)

study exploring the patients' definition of recovery from CRPS described by Peter Moskovitz, MD, on page X. Another is the article on transcranial direct current stimulation (tDCS), studied by Richard Cruciani et al in Beth Israel in New York which is demonstrating positive outcomes for people with CRPS. You can read that story on page X.

In addition, read the interview with Mark Cooper, PhD, who is chairing the series of translational research workshops that are funded by the RSDSA. This research, according to Dr. Cooper, "is the future of medicine."

A few words about the other equally important arms of our mission— education, awareness and support. The RSDSA has developed educational programs and materials to help educate healthcare providers about CRPS. We have conducted five national conferences for health care practitioners and patients; on our website we house a PowerPoint® slide program for health care professionals; and we exhibit at national pain association meeting. The only way we will ever overcome the under - diagnosis and delayed diagnosis and poor treatments, is by promoting much greater awareness. We have produced a 1-minute public service announcement, Are you in constant pain? This is also the reason why we are completing a video to educate physical and occupational therapists, often at the center of CRPS professional care giving, on better and more effective techniques for CRPS patients.

While we work to find a cure, a critical part of our mission is to offer hope for everyone who calls our offices, visits our website, or joins our organization. With RSDSA, they are no longer fighting the battle alone. Often over the past years, providing direct to people with CRPS has been very direct and

(Continued on page 13)

concert — sending letters to corporations like Pepsi, which was one of the sponsors of this year's Rock for RSD. She spent numerous hours writing press releases, contacting bands through YouTube and other social media sites, and designing a FaceBook Fan Page for RSD.

This remarkably talented 18-year-old, who comes from a family of musicians, was asked how she came up with the idea for Rock for RSD. Sammie replied, "I've always been a lover of music." One day, while in marketing class, Sammie was faced with a new class assignment; to create a marketing campaign. She cleverly turned a classroom assignment and her own life experience into a very successful event to help find a cure and promote awareness for RSD.

For the past three years, Sammie, with the help of the Plymouth community and sponsors, has raised roughly \$2500 for the RSDSA each year.

Since Sammie started producing the Rock for RSD concerts, several of her schoolmates have also developed RSD and they have expressed their gratitude to Sammie.

(Continued from page 3)

Harden, MD, and Steven Bruehl, PhD, to refine the diagnostic criteria for CRPS. RSDSA supported the basic science leadership of Anne Louise Oaklander, MD, PhD. On the tireless initiative of Mark Cooper, PhD, RSDSA sponsored a translational workshop on the basic science of neuroinflammation and glial activation www.rds.org/glial_workshop/glial_conference_summary.html.

Another workshop on the objective imaging of neuroinflammation will take place in October, 2011. Nonetheless, taking new knowledge from the laboratory to the clinic where it can be of service to real people in pain is difficult. RSDSA sought well-designed, innovative clinical

The most recent show was held on May 14, with nine bands from Boston to Cape Cod all performing for the cause. Joe Goldberg, manager of Memorial Hall, who has donated the venue for the past three years told the Plymouth Patch, "My passion for live music and her desire to spread the word about RSD seemed to fit together naturally."

Sue Pinkham adds, "Sammie is an incredible young woman who has worked extremely hard raising awareness of RSD/CRPS and raising money to help researchers find a treatment and/or CURE for RSD/CRPS. Her Rock for RSD concerts are amazing."

On June 4, 2011, Sammie graduated on from Plymouth South High with a standing ovation as she WALKED across the stage.

Looking ahead, Sammie continues to find a way to promote awareness and raise funds for a cure and has already begun working with Sue Pinkham on a concert in Rhode Island this fall.

We salute Sammie Barrett for her huge contribution to RSDSA, and we offer our continued support to her and her family. Rock On! ■

research proposals, but few emerged that were worthy of support – until now.

As the sole funding agent for this project, RSDSA and its Scientific Advisory Committee has the opportunity to monitor and counsel the research process and build cooperative relationships for future research efforts. All parties benefit, not the least being people with CRPS and their loved ones. As Humphrey Bogart said in "Casablanca" (in the person of Rick Blain), "Maybe not today, maybe not tomorrow, but soon..." Prof. McCabe's research opens a new opportunity in clinical research for CRPS care. It is an extraordinary event, and perhaps not. It's just good scientists doing good science. That, in part, is what RSDSA is for. ■

A NEW NONINVASIVE THERAPY CALLED transcranial direct current stimulation (tDCS) is sending shockwaves through the medical community and creating awe-inspiring results among patients with chronic pain. This non-pharmacological procedure passes a low-amplitude electric current through the skull to the brain. The current acts as a dampening agent, quieting parts of the brain that have become overactive and responsible for pain.

At the Institute for Noninvasive Brain Stimulation of New York (INBSNY; part of the Beth Israel Medical Center in New York City), a group of researchers and clinicians are exploring the power of electricity to improve pain. Dr. Ricardo Cruciani and Dr. Helena Knotkova, along with a team of colleagues and international collaborators, are using electrical currents to soothe overexcited pathways in the brain to bring about pain relief. Patients with chronic pain develop pathological changes in the excitability of the somatosensory and motor cortices. These regions of the brain process input from areas sensitive to touch, and they plan and execute movement. Normalizing the excitability in these regions can induce pain relief. It is speculated that the low-amplitude current used in tDCS therapy tempers neuronal excitability and modulates the firing rates of individual neurons.

Scientists have been experimenting with electrical stimulation of the brain for over a century; however, there has been a resurgence of interest in this technique during the past decade. In addition to pain



Shock and Awe: New Therapy Helping Patients with Chronic Pain

By Stefani Kronk

management, researchers are investigating the use of tDCS in myriad and diverse situations, such as improving math, verbal, and motor skills, and enhancing physical performance, as well as alleviating depression. Although the concept of using electricity to modulate brain activity is not new, recent advances in identifying the area of the brain that requires stimulation and the optimal placements of electrodes have yielded improved results.

Dr. Cruciani and his colleagues administer tDCS treatments in 20-minute sessions on five consecutive days. While the patient sits comfortably in a chair, two 2x2 inch electrodes are placed directly on a specific area of the scalp, and a current is passed through the skull to the brain. The procedure is painless, although some patients note a tingling, itching, or burning sensation on the skin under the electrodes. With five quick sessions totaling two hours of noninvasive, painless treatment, patients who have been suffering chronic pain for decades are experiencing remarkable results. On average, 66 percent to 70 percent of patients receiving tDCS therapy show a reduction in pain. For those who respond, pain is reduced for one to 16 weeks, with most patients having their symptoms alleviated for six to eight weeks. Eventually, the effects of tDCS fade and pain levels gradually increase.

Move over Medicine—A New Way to Combat Chronic Pain

“The beauty of tDCS is that it’s very simple, it’s noninvasive, and it seems to help certain types of chronic pain,” Cruciani says. If the research continues to show success, the team at

INBSNY hopes that tDCS will become an integral component in the pain treatment armamentarium. Dr. Cruciani and his colleagues are focusing their research on patients with chronic pain who do not respond to conventional therapies. “These patients are the ones we are most interested in because they are the hardest to treat, and therefore are the ones who are in the most despair. And we need more effective tools to treat them,” says Cruciani.

Although medication is the standard of care for treating pain patients, and Dr. Cruciani, who in addition to a medical degree holds a PhD in pharmacology, appreciates the contributions pharmaceutical agents have made to pain management, he also recognizes the drawbacks. “Pharmacology can be powerful and extremely helpful for patients with pain, but it is not the only answer,” Cruciani states. He believes the inherent complexity of medications can cause unforeseen complications. “When

you give a medication to a patient, the drug travels through the entire body. Why expose the entire body to chemicals when we don’t know what the long-term effect might be?” he reasons. “Ideally, we should be targeting the area of the brain where we think the problem is,” he concludes. Because numerous pathways are engaged to perceive pain and these pathways are

interrelated, Cruciani explains, chemically altering the activities of one channel through medication might cause unwanted effects or compensation in another.

This complex cause/effect relationship is difficult to keep in balance. “For successful pain management, one needs to block or stimulate an enormous number of pathways, simultaneously. All these pathways converge in the same area of the brain—the sensory motor cortex. If we can modulate that area, we can potentially see positive results,” says Cruciani. The logic behind tDCS is to go right to the source of pain perception rather than modify one piece of a very large, complex, and intertwined puzzle. “By targeting neurons in a particular part of the brain and modulating their excitability, there is the potential to obtain the same results as using multiple drugs simultaneously,” he says.

The Best of Both Worlds

Dr. Cruciani’s research background allows him to explore different hypotheses for pain management. “We are also looking for new avenues to explore and fresh ways to look at things. We are constantly doing. I think it’s because that’s the way we’ve been trained. We are always looking for answers for the problems that patients have,” he says. Not only is Dr. Cruciani satisfied by the scientific pursuit for answers, the human component is a large

“Pharmacology can be powerful and extremely helpful for patients with pain, but it is not the only answer,” Cruciani states.

driver in his tenacity. “It makes me feel good when someone else feels good. I like that,” he explains.

After working in research for 15 years, Dr. Cruciani decided that, in addition to basic science, he wanted to see patients and conduct clinical research as well. He credits patient contact for enhancing his creativity and problem-solving skills, and ultimately, the research conducted by the team. “A combination of research along with direct patient care gives you a certain edge. You are thinking about the patients all the time,” he says. By becoming involved with patients and seeing the adverse effect of pain on their daily activities, Dr. Cruciani resolutely conducts his research. “You see the suffering, the disappointment, and the side effects. It gets you going; you are constantly thinking, ‘what can I do for

this patient that might be different or that might not otherwise be available,’” he explains.

Thomas Tobin from Staten Island, New York is one of the patients with chronic pain Dr. Cruciani speaks about. A former New York City police detective, Tobin was diagnosed with CRPS (complex regional pain syndrome) one year after surgery to treat a leg injury. Like many people suffering from CRPS, Tobin’s

life was altered dramatically as a result of the constant, intense pain. He went from living an active, energetic life to being unable to work and isolated from mainstream activities because of the effects of CRPS. Although Tobin takes up to 35 pills a day to keep the pain at bay, it remains largely uncontrolled. Tobin’s lack of relief and the side effects from the medications keep him searching for alternate pain management therapies.

Patient 001

Dr. Cruciani, who has several years of experience in electrophysiology, became motivated by the preliminary results of tDCS research conducted in Germany in the early 1990s. He reasoned tDCS could become a viable option for pain management. With his interest piqued, Dr. Cruciani and a colleague at the National Institutes of Health began collaborating to further investigate the potential of tDCS.

“At the time we became interested, there were not that many people working with tDCS for pain management,” Cruciani says. For four years, Dr. Cruciani and his colleagues analyzed tDCS while simultaneously obtaining funding for larger scale research. Dr. Cruciani and Dr. Knotkova opened the INBSNY

in 2008, one year after the first trial that investigated the potential of tDCS showed promise in 2007. Dr. Cruciani's initial research was partially funded by the Reflex Sympathetic Dystrophy Syndrome Association (RSDSA) which awarded him with the Rachel Tobias Pain Research Young Investigator Award in 2007. This award is granted annually to

a postdoctoral fellow or resident with an interest in CRPS research. This award helped Dr. Cruciani fund the two-phase pilot study focused on relieving neuropathic pain in patients with CRPS.

The results of this study have been the catalyst for future work by the ISBSNY. James Broatch, Executive Director for the RSDSA, was pleased the association's grants committee chose to fund this innovative project as Dr. Cruciani started researching the use of tDCS in CRPS. "We hope this technology will be widely available for CRPS patients and others suffering from chronic pain syndromes," states Broatch. For his first trial,

Dr. Cruciani enrolled one of his patients, Thomas Tobin, "I was patient 001; it's not quite like being "Agent 007," but it was something really big to me," he says with a chuckle. Tobin wasn't hesitant about starting with this new experimental therapy. "Because Dr. Cruciani is my regular doctor and we have a good relationship, I trust him completely. Plus, if it hurts badly enough, you'll try anything to make the pain go away, even if it seems unbelievable," states Tobin. The day after his third 20-minute session, Tobin woke up and immediately knew

something was different. "It took a second to realize what it was. For the first time since 1998, I was virtually pain free. I hadn't experienced that in nine years. I couldn't believe it," he says. When Tobin returned the following day for his fourth session, he related his experience to Dr. Cruciani in an emotional event. "I'm crying, my wife is crying, Dr. Cruciani is

The day after his third 20-minute session, Tobin woke up and immediately knew something was different. "It took a second to realize what it was. For the first time since 1998, I was virtually pain free. I hadn't experienced that in nine years. I couldn't believe it," he says.

crying," Tobin recalls. "I was so happy—not only for myself but for Dr. Cruciani. This treatment was working—for both of us," he says.

Since beginning tDCS therapy, Tobin has significantly cut down his use of rescue medication for breakthrough pain. Before a session, he needs up to 15 pills a day to keep his pain in check. By the fourth day of treatment that number is usually cut in half, by the fifth even lower, and the week following treatment, just a few doses are needed. "To me, that's proof positive.

There is no question—I know tDCS is working," says Tobin.

Ongoing Research

Currently one of the questions Dr. Cruciani is trying to answer is what types of pain have the most favorable response to tDCS. On average, approximately 60 percent of patients respond to therapy; however,

Cruciani and his colleagues believe that percentage will increase when the appropriate pain types are identified. A nonrandomized, open-label study currently underway at INBSNY has enrolled more than 100 patients suffering from a variety of conditions ranging, from neuropathic pain in cancer patients, to neuropathic pain after surgery, in an effort to gather data about the types of chronic pain that respond to tDCS therapy. Results from this simple study will allow Dr. Cruciani to create a more refined protocol to further investigate the efficacy, side effects, and tolerability of tDCS in the pain types that showed earlier promise.

In addition to identifying the types of pain in which tDCS can be most beneficial, Dr. Cruciani and his colleagues are exploring

the potential confounding effects of pain medication on tDCS. "At this time, we don't know if some of these medications might impair or even potentiate the effects of this procedure," says Cruciani. This complicated issue is yet another area of investigation for the team, and data will be forthcoming.

For Tobin, the benefits of being a trial participant extend beyond obtaining statistical data and take on a higher meaning. "Participating in these trials gives me a sense of empowerment. . .

like I'm not just taking it. I'm being proactive and actively fighting this disease," he explains. In addition, Tobin finds satisfaction in helping Dr. Cruciani with his research. "I volunteer for every study Dr. Cruciani conducts. It is a way to help them and give back in an effort to acknowledge how much they've helped me," he says. Tobin understands that every protocol might not be beneficial for him, but knows that the information gathered will ultimately be useful. "Even though it might not benefit me directly, with the results of the research, I will be able to help others down the road," he states. Tobin also encourages other people suffering from chronic pain to participate in trials conducted by the INBSNY. "If people don't participate, we won't know the answers," he says.

Dr. Cruciani and his colleagues are enthusiastic about the findings of their research and are currently in the process of obtaining additional funding. "Unfortunately, we have more questions than we have the ability to answer at this point," he admits. Although he feels that most researchers are experiencing the effects of the slower economy as it relates to grant money, he underscores the importance of continued funding to support ongoing tDCS research.

The Future of tDCS

Dr. Cruciani admits that he and his colleagues are still in the very early stages of understanding the potential for this technology. "The more we learn, the more questions we have. Then you realize how far behind you are from where you would like to be," he relates. Rather than being discouraged by the amount yet to be understood, Cruciani is enthusiastic about the possibilities of tDCS. "If you compare where we are now, we are no question in the infancy of this treatment. But you have to look at it in perspective. I look at this as just

the beginning, and I am excited," he states. Dr. Cruciani believes this therapy will help patients with multiple types of chronic pain. And by combining tDCS with pharmacology and other treatments, he hopes the benefits can be extended to keep pain in check for at least a year.

Tobin, who averages three months between sessions, recently went five months without treatment, the longest he has experienced a reduction in pain since starting tDCS therapy almost four years ago. When Tobin's pain gradually returns to pretreatment levels, he returns for another series of tDCS therapy. Like other patients, Tobin hasn't experienced desensitization to this therapy and continues to experience pain relief with each treatment regimen. For Dr. Cruciani, this is one of the advantages of tDCS. With typical pharmacologic options, patients can build up tolerance for medication, requiring more and more medication—and therefore experiencing more side effects—to enjoy the same level of pain suppression.

Dr. Cruciani and his colleagues are collecting data to determine the long-term effects of tDCS. Tobin estimates that he has gone through almost 20 rounds of tDCS therapy comprising

five sessions each. To date, after approximately 100 treatments, he has experienced no drawbacks. "The only side effect I've had is some mild tingling during the session and being a bit tired afterwards, but that's it. And trust me, that's worth it," Tobin says. Currently, Dr. Cruciani and his colleagues are imposing a three-week waiting period between treatments because there is no safety data on more frequent use. However, Dr. Cruciani points that there is no indication that more frequent use is harmful, but no data yet exist to support a more aggressive treatment schedule.

The team at INBSNY can see enormous potential for tDCS and hope it will become a commonplace tool for patients suffering from certain types of chronic pain. Because the apparatus to administer tDCS therapy is relatively simple, Dr. Cruciani is hopeful that this device can be made readily available for patients. "Our goal is that patients will be able to conduct these sessions at home with a simple device," Cruciani says. "We are really excited about this and we are very hopeful this therapy is going to make a significant difference in the lives of many patients in the future," he concludes. ■



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IN OCTOBER, RSDSA WILL HOST A translational research workshop on Imaging Neuroinflammation and Neuropathic Pain, which will be chaired by Mark Cooper, PhD, University of Washington; and Vince Clark, PhD and Erin Milligan, PhD, both from the University of New Mexico in Albuquerque. This invitation-only workshop will bring together basic researchers, clinicians, and biomedical representatives to examine neuroimaging methods, and to further investigate neuroinflammation as a cause of neuropathic pain and associated co-morbidities. It will also help accelerate the development of imaging methods to diagnose neuroinflammation, and to follow the timecourse of neuroinflammatory diseases, as they respond to medical treatments. Dr. Cooper, a member of RSDSA's Board of Directors and of the Scientific Advisory Committee (SAC), talked with us about the importance of the new imaging technologies, and their implications for people with CRPS.



include the release of neurotrophins and cytokines. At the same time, white blood cells are often attracted to the injury site. In animals, and in humans, researchers can label white blood cells with magnetic nanoparticles and then image them infiltrating into injured nerves, or into injured brain tissue using magnetic resonance imaging (MRI). Positron Emission Tomography (PET) and Single Photon Emission Computed Tomography (SPECT) can be used to image the activation of microglia, resident immune cells in the nervous system. These are key cellular markers of neuroinflammatory processes. Imaging sites of activated

microglia and infiltrating leukocytes in the nervous system is a huge step for pain medicine.

RR: Why?

Dr. Cooper: Before this, doctors didn't have ways of seeing what activated microglia and infiltrating leukocytes were doing in the live human nervous system. Nanoparticle-enhanced MRI imaging is rapidly expanding in clinical research. The possibility of applying this technology to neuropathic pain diagnosis is on the near horizon.

Imaging Neuroinflammation— An Important Advance for Pain Medicine Talking with Mark Cooper, PhD

By Debra Nelson-Hogan

to be published in The Pain Practitioner

RR: So how does this research change the way we look at CRPS?

Dr Cooper: The scientific and medical communities have concluded that neuropathic pain is frequently a neuroinflammatory disorder. Around 2000, Donald Manning, MD, PhD [a member of the RSDSA Board and SAC] emphasized that RSDSA should be looking at activated glia as a possible cause of CRPS. This has become a central focus for RSDSA, and was the topic of our first translational research conference last October. ([http://](http://www.aapainmanage.org/literature/PainPrac.php)

<http://www.aapainmanage.org/literature/PainPrac.php>

www.rsdas.org/glia_workshop/glia_workshop.html)

RR: Can you explain how glial cells work?

Dr. Cooper: When the nervous system gets injured, chemical signals are sent out from injured neurons, which activate neighboring glial cells. In response, neighboring glial cells are triggered to produce neuroprotective reactions, which

RR: So this has real practical applications.

Dr. Cooper: Absolutely. With this knowledge, doctors can make a variety of informed decisions. For example, once a medical team identifies sites of neuroinflammation, they can decide how to treat it. One option is to calm the neuroinflammation down with drugs

aimed at activated glia, and therefore relieve one presumed cause for the pain. An alternative option is for doctors to treat the disrupted neurophysiology of the chronic pain patient by having the patient engage in physical therapy. Glial attenuators, however, open many important opportunities for the treatment of chronic pain. Consider for a moment, the treatment of high fever. Fever is a normal defense process to help eliminate infections. However, if the fever becomes too high, it can cause brain damage, or even kill a patient. In the late 1800s, Aspirin was considered to be a wonder drug because it could calm fever-generating mechanisms. Physicians could suddenly control a life-threatening condition using an anti-inflammatory therapy. We are arriving at the same point with neuroinflammation. Glial attenuators have the potential of calming a key cellular generator of neuropathic pain – activated glia. However, to develop better glial attenuators, doctors and researchers will need to be able to see what is going on in the inflamed human nervous system, using new advances in cellular and molecular imaging.

RR: You are looking at CRPS on the cellular level then, not just the nerves?

Dr Cooper: Yes. Glial cell-neuron conversations are an important type of information processing that is taking place within the nervous system. In a chronic pain state that is produced by neuroinflammation, some neurons are being triggered into a survival mode because of signals sent to them by neighboring activated glial cells. During this period of social disruption, the neurons don't process information normally. Consider this analogy. When data processing centers within a city or country start to malfunction, what happens? The whole economy can begin to collapse. Some processes are driven into overdrive, and other processes just don't happen. You see that with

CRPS, perhaps more than with any other neuropathic pain disorder. Data processing disruptions can potentially occur in almost every data processing center of the nervous system. Abnormal, and sometime extreme, changes occur in target organs as a result.

To understand the physiological context of neuroinflammation, it is useful to think about cellular interactions in terms of cellular sociology, particularly when it comes to the dynamics of wound repair. Injury to the nervous system stimulates microglia to transition from a surveillance mode into a highly neuroprotective mode. Microglia are like the National Guard being mobilized in a community during a natural disaster. Using microscopy, you can see what these activated microglia are doing—they surround injured neurons, providing chemical signals to keep the neurons alive, while the microglia are looking for pathogens because of the injury. The microglia are also there to destroy the bodies of dying neurons. They have to clean up the cellular debris of the injury. Imaging what's going on in these neuroinflammatory states, and understanding the local cellular sociology in these locations, is where the basic researchers are headed. To understand persistent neuroinflammation, researchers are hoping to determine which molecules activate specific cellular behaviors. This type of inquiry is where new pharmacological therapeutics are likely to come from.

Physicians are able to look at the behavior of the whole organism, i.e. the whole person, but they are often limited to looking at external signs and talking with the patient about how he or she feels in response to various stimuli. In the clinic, doctors can't often see the sources of neuroinflammatory pain, they must infer it using reasoning. That's why there is a need for better diagnostic imaging tools, to find out about the cellular and molecular levels. From ongoing research on neuroinflammation, there

is an exponential growth in information about these dynamics. The exciting thing is that imaging technologies are being rapidly developed to visualize molecular and cellular behaviors that underlie the neuroinflammatory process. These imaging technologies will help transform pain medicine. At the October workshop, some of the world's leading experts on neuroinflammation and neuroimaging will gather to exchange information, and hopefully form new collaborations. Clinicians at the workshop should be able to form novel partnerships with very talented neuroinflammation researchers. These types of interactions what the FasterCures Foundation, a Medical Action Tank, calls "partnering for cures."

RSDSA's goal is not only to make this happen in the CRPS community, but to foster partnerships between other groups to make neuroimaging advances happen faster for all neuroinflammatory and neuropathic pain disorders. That is the motivation behind forming an International Neuroinflammation Knowledge Consortium - to foster new collaborations between basic researchers, patient advocacy groups, the biomedical industry, as well as clinicians working on neuroinflammatory disorders.

Imaging neuroinflammation can help in the study and treatment of many neurological disorders--ALS, Alzheimer's Disease, Autism, Multiple Sclerosis, Parkinson's Disease. The CRPS community is not in this alone. We are utilizing a vast amount of knowledge that has been generated from all of these communities. That's why RSDSA is gathering people who are associated with over 40 different patients organizations and medical research foundations, who are concerned with neuroinflammatory and/or autoimmune disorders.

These workshops are extremely useful because they allow RSDSA to interface with all of these other organizations and to be able to synthesize and project this

(Continued from page 6)

very personal. Thousands have called or e-mailed our office seeking help. We get calls looking for guidance on locating medical practitioners with competence in treating this terrible syndrome. We get calls from those desperate and destitute, alienated from families and barely hanging on to their will to live. We get these phone communications and often respond to them at all times of the day and night. Our responders include our entire volunteer and paid staff and our hard-working Board of Directors, particularly the three Board members with CRPS and the three Board members that have or had family members with the syndrome. We know how severe the problems can be with many aspects of CRPS. With RSDSA, they are no longer fighting the battle alone.

Please look to our website and future newsletters for updates on progress towards fulfillment of our mission. We are extremely grateful for all of your help in meeting our mission. ■

knowledge to key stakeholder communities including patient organizations, compensation organizations, government officials, and physicians. It is a very important to get expert pain practitioners, with their extensive clinical experience, to interact closely with basic researchers. This is the “bench-to bedside-and back” concept in action. RSDSA’s private and corporate sponsors are generously supporting this effort.

RR: How does the neuroimaging of neuroinflammation translate from the research bench to the office visit?

Dr Cooper: There are two steps. One is to get research from the bench into clinical research. Then one needs to take these technologies from clinical research into clinical practice. Those two goals are central to what the Imaging Neuroinflammation and Neuropathic Pain meeting is about. We are bringing in people who have new technologies developed from basic research, like Dr. Ralph James, an Associate Director of the Brookhaven National Laboratories. Dr. James’ laboratory has developed a SPECT gamma ray camera

for screening prostate cancer. At RSDSA’s first translational research workshop in Chicago last year we learned about these type of gamma cameras from Dr. Richard Banati (Univ. Sydney). We then contacted Dr. James and asked him to consider repurposing the camera for neurological disorders, specifically to look at neuroinflammation in the spinal cord. Dr. James is now working on this with Dr. Erin Milligan and her collaborators at the University of New Mexico, to see if this is possible. I think that this is a very important outcome from the Activated Glia workshop that we held last October. It is also an excellent example of how quickly translational research workshops can help foster new partnerships, and move knowledge from the bench into clinically relevant research. By forming a network of partners, the RSDSA/CRPS community is gaining tremendous intellectual resources, as well as sharing the knowledge that we have accumulated about CRPS. This is how our organization can help catalyze advances for many neuroinflammatory disorders, including CRPS. ■

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 6,000, 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!

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To learn more about this opportunity, please call Jim Broatch at 877-662-7737 or send an e-mail to jwbroatch@rdsd.org.

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Our members are people like you—patients, family and friends, healthcare professionals, attorneys, and businesspeople who understand the devastating effects of CRPS and want to make a difference. 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.

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