rsdsa
community update

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UP COMING CONFERENCE
Denver, Colorado

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Neridronate Clinical Trial

To inquire about your participation or to determine whether a clinical trial site is nearby, you may visit www.studycrpsnow.com.

COVER STORY

JOIN RSDSA *in* *Denver!*

On Sunday, June 14, RSDSA and a cast of amazing speakers will head to Denver for The Integrated Solutions to CRPS Conference. We created this conference for people just like you!

Individuals with CRPS, friends, family, and caregivers of the CRPS community are urged to attend and hear from caring doctors like Dr. Pradeep Chopra and Linda Watkins, PhD., a world renown expert on microglia activation and neuropathic pain, and inspirational CRPS warrior, Sharon Weiner. The RSDSA, along with the help from generous sponsors, has assembled a friendly forum where you and experts in the CRPS field will spend the day sharing valuable information and exploring new solutions to help manage CRPS. You will have the opportunity to talk to and network with others who experience what you do, day after day. Also, please join us on Saturday night, June 13, 2015 to register and network between 5:30 - 7:30 PM at the Doubletree by Hilton Denver - Stapleton North located at 4040 Quebec Street. We hope you will enjoy the light reception and an opportunity to meet your fellow attendees!

One of the attendees at a past conference wrote us, Both George and I were able to compare my present treatment to that recommended by your speakers. It was definitely an 'eye opener' in the best sense of the word."

Register today at **http://events.r20.constantcontact.com/register/event?oeidk=a07eaf3rhud50653382&llr=dhaazxbab** ■

FEATURE STORY

Neridronate Clinical Trial

To inquire about your participation or to determine whether a clinical trial site is nearby, you may visit **www.studycrpsnow.com**.

The trial medication is neridronate which belongs to the bisphosphonate class. Pharmaceutical attention became focused on neridronate after a very successful trial in Italy was published in Rheumatology: **rsds.org/wp-content/uploads/2015/02/rheumatology-kes312%20full.pdf**

Individuals with CRPS Type 2 are excluded from the trial. The distinction between CRPS Type 1 and Type 2 is that individuals are diagnosed with CRPS Type 2 when specific nerve damage can be detected.

Bisphosphonates have been used to treat CRPS for years overseas and also in the US. Some doctors who are familiar with bisphosphonates have used these in CRPS. Just visit PubMed: **www.ncbi.nlm.nih.gov** pubmed and query bisphosphonates for CRPS and you will see 31 citations dating back to 2009. PubMed is a great website to bookmark for future scientific and clinical web searches.

Currently, two other pharmaceutical corporations are applying for FDA approval to sponsor a clinical trial in CRPS. It's an exciting time for all individuals affected by CRPS. Stay tuned!

To learn about this trial and other clinical trials for CRPS, please visit, **ClinicalTrials.gov**■

Non-stop, unbearable pain could be a medical condition called Complex Regional Pain Syndrome (CRPS). Learn more about a new clinical trial we're conducting to evaluate an investigational treatment.

While there are no approved treatments for pain associated with CRPS, doctors and researchers are working to find pain relief treatment options. Currently, local doctors are conducting a clinical trial of a trial pain medication for people diagnosed with CRPS-I.

They want to evaluate the safety and effectiveness of this trial medication, which is administered by a series of infusions.

To pre-qualify for this trial, you must:

- Be between 18 and 80 years of age
- Have a medical diagnosis of CRPS-I
- Be receiving stable treatment for CRPS-I for at least 1 month prior to the trial

The trial doctor will review other eligibility criteria with you. All trial-related visits, tests, and medications will be provided to you at no cost. In addition, reimbursement for trial-related time and travel may be provided.

To learn more about this trial, please call
888-641-4961,
visit www.studyCRPSnow.com

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HEALTH AND WELLNESS

The RSDSA Wants You To Join Us In New York

Last year, hundreds of people from all over the world joined the RSDSA as we walked through Central Park in New York City. People from all walks of life were brought together and demonstrated the unity of the RSD/CRPS community. This was all made possible by Achilles International. This year, on June 28, we will be bringing the community together again for the 13th Annual Achilles Walk for Hope and Possibility.

The RSDSA is looking for people with RSD/CRPS, their caretakers, family, friends, and general supporters to participate in this year's walk. Much more than just a walk or a fundraiser, this is the chance to help people connect. Everyone has a chance to tell someone their story and in return, they get to hear stories similar to theirs. Swapping stories has led to unbreakable bonds between walkers and hope that, together, we can all make a difference in the world of RSD/CRPS.

"We are so excited to be back at Achilles this year! We are so grateful they continue to put on an amazing event. Having the RSDSA participate in this event is incredible. Not only does it help raise awareness and hope, but it also helps the people with RSD/CRPS and their caretakers and loved ones meet people that they can relate to," Samantha Barrett, intern for the RSDSA said, "It is incredible to see everyone come together for such an important cause."

Jessica Begley of Texas says: "The Achilles Walk was the first RSDSA event I attended after going into remission… It was an amazing sight to see pain survivors sharing their stories and their hope for a brighter future! It was an honor to walk among my fellow pain warriors." Kerry Hussey of Massachusetts had a similar experience: "This walk is a great way to bring people together and connect people from around the country and even around the world for a day. Those connections can last for years after!"

RSDSA hopes to inspire the RSD/ CRPS community by instilling a sense of inclusiveness in our participants and to inspire them through the comradery and spectacular support displayed throughout the day. Every person matters, whether they personally have RSD/CRPS or if they support someone with RSD/CRPS. As we all arrive at the finish line, we have achieved a common goal.

RSDSA looks forward to working with Achilles International in 2015 for the 13th annual Walk for Hope & Possibility. To register, please visit **http://rsds.org/event/achilles-2015-walk-for-hope/** ■

A WALK FOR A BETTER TOMORROW
Watch an engaging, inspiring film of the 2013 RSDSA Team fundraising and awareness walk in Central Park on June 30, 2013.

RSDSA COMMUNITY NEWS

The Cynthia Penaskovic Memorial Fund

Pain is a more terrible lord of mankind than even death himself. - ALBERT SCHWEITZER.

Too often, life changes on a dime as my pastor frequently tells our congregation. Just ask any person suffering with CRPS when they developed CRPS/RSD and they can immediately relate the date and time. So it was with Cynthia Penaskovic, a vibrant naval pediatric flight nurse who developed CRPS/RSDS 25-years ago after a car accident in southern California. Her doctors at Scripps Torrey Pines in San Diego called it "one of the worse cases of widespread RSDS they had even seen."

Joan Penaskovic, Cynthia's sister spoke of her subsequent "solitary life spent creating exquisite beaded art which she often donated, until she could no longer hold the threads. She was blessed with extraordinary grace and courage, providing loving support for her widowed mom, family and friends, when she was the one in dire need." Sadly, Cynthia lost her 23-year-old battle with CRPS in November 2013.

Joan Penaskovic and Veronica Meyers, Cynthia's mother wrote to RSDSA to inquire about establishing a *Cynthia Penaskovic Memorial Fund.* Cynthia envisioned a fund that would "serve as a lightning rod for CRPS/CRPS Research Only so that "no one would ever suffer the way I did.' The RSDSA Board of Directors unanimously accepted a generous donation to establish *The Cynthia Penaskovic Memorial Fund.* It was stipulated that the funds would be donated to promising laboratories and scientists through fellowships and grants targeting research for a cure.

Serendipitously their gift arrived at the right time. RSDSA has recently established an International Research Consortium with the goal of linking laboratories worldwide to foster greater collaboration amongst scientists researching CRPS; thus producing more robust studies leading to better treatments and hopefully a cure.

Joan Penaskovic asked us to encourage the CRPS community to join in this effort. Her simple plea is, "Do not let Cynthia's suffering be in vain. It was her last wish to help drive funding for Research and with your help we can cure RSDS/CRPS. Donate now."

C. Everett Koop, former Surgeon General of the United States cautioned us that the treatments of today cannot be the treatments of tomorrow." Consider that the National Institutes of Health only invests less than one percent of research dollars into pain research. It is up to us.

To donate to *The Cynthia Penaskovic Memorial Fund,* visit **rsds.org/donate/** and give generously in Cynthia's memory (make sure that you write in memory of Cynthia in the box on PayPal's second page) or in the memo line of your check. Thank you for your generosity. ■

RSDSA COMMUNITY NEWS

Chuck Hood

Chef extraordinaire

Chuck Hood was diagnosed with CRPS in April 2014 after a crush injury to his left upper extremity at work. While growing up in the San Francisco Bay Area, Chuck was blessed to have been exposed to many diverse cultural styles of foods.

He first worked in a family-operated pizza restaurant during high school and developed the love of cooking while eating his parents' fabulous home-cooked meals. Although trained as a paramedic, Chuck decided to make a career change and followed his heart into the culinary industry. He mentored under many great chefs e.g., Rob Oset with Darden Restaurants doing Caribbean-style cooking in Las Vegas, Nevada which led to a position as a culinary trainer in Miami, Florida.

Chuck discovered his real calling in the food industry when he was hired by Centerplate, a Sports and Entertainment Catering Service where he wrote his own menus and prepared meals for the sports media covering games as well as pre and post-game meals for players of both the Colorado Rockies and the visiting teams. After two seasons, he followed a coworker across town to the Denver Broncos, handling menu development for their Action Stations, which introduced new cultural tastes for the Denver fans. He gained much confidence and grooming, working with Regional Executive Chef Matt Antonvich, and, Executive Chef Carmen Callo.

Currently, Chuck works with the Golden State Warriors, Oakland Athletics, and the Oakland Raiders organizations preparing food for both patrons and athletes. He was blessed to be selected as an alternate for the reality show of Top Chef in 2012. ■

Chuck Hood and Hostess Top Chief Padma Lakshmi

CUCUMBER MINT AND MELON SALAD

Ingredients:

- 2 medium cucumbers, peeled, seeded and cut into 1 inch pieces on a bias (1 1/2 cups)
- 1 1/2 c ripe cantaloupe or watermelon, seeded and diced into 1 inch chunks
- 1/4 c tightly packed mint leaves, torn in half
- 1 garlic clove, cut in halve, peel
- 1 Tbsp, scallions or chives, green only for garnish
- 1 Tbsp white wine
- fresh ground black pepper/salt for taste
- 1/4 tsp sugar(optional)
- 1/4 c crumbled ricotta salata or pecorino cheese

Directions:

1. SPRINKLE the cucumbers with salt let them rest 30 mins in refrigerator.
2. RUB the mix bowl with halved garlic
3. ADD cucumbers, melon and mint to bowl along with chives, wine and oil.
4. ADD salt and pepper, sugar for taste
5. TOSS and serve.
6. GARNISH with 1/4 c of cheese.
7. EAT immediately

This is a perfect dish to accompany any grilled meat at a BBQ.

MEDICAL & SCIENTIFIC NEWS

The Autoimmune Hypothesis for CRPS

BY **DR. ANDREAS GOEBEL**

Dr. Goebel is a research professor focused on chronic pain with appointments at the University of Liverpool's Department of Translational Medicine and The Walton Centre. He is currently conducting a clinical trial in the United Kingdom based on his findings as discussed in this article.

Why some people contract CRPS following limb trauma remains poorly understood. As is why 15% of CRPS cases do not resolve.

Some researchers are exploring whether a malfunctioning immune system contributes to how CRPS develops and persists.

Our immune systems are complex operations carried out by many "employees" with specialized skills. Some patrol our blood and body for things that do not belong, like bacteria or viruses. These patrolmen drag their finds to merciless bodyguards, who obediently rip apart the accosted outsider. This arrangement usually functions very well, protecting us from thousands of attackers every day.

Patrolmen, however, can confuse our own cells for outsiders. These situations, while rare, lead to serious autoimmune diseases, such as rheumatoid arthritis or AIDS. (Autoimmune disease simply means a disease in which a body's immune system is directed against itself.)

Researchers studying the immune system's potential role in CRPS are interested in one particular type of patrolman, proteins called immunoglobulin G, or IgG for short. Some of our body's best immune system employees are IgG. (In fact, about three-fourths of our "patrolmen" in our blood are IgG.) Thus, when some IgG confuse friend and foe, our body endures a terrible assault.

Investigating IgG

We found, in previous studies, that patients with CRPS have "abnormal" IgG in their blood. The IgG are found in the CRPS-affected limb, including in the local nerve cells.

We recently followed up on these findings in a recent study, **published in 2014 in the journal *Pain*.** Our new data suggest abnormal IgG are not only present at the scene of the crime, but also can in fact cause features of CRPS.

We found that when mice had a small injury to one hind paw and also received a CRPS patient's IgG, the mice frequently developed a syndrome similar to CRPS in the injured hind limb. The syndrome included limb sensitivity to light pressure and light swelling, but occurred only in the injured limb. Additionally, IgG taken from healthy human volunteers did not elicit CRPS-like responses to the same extent.

Furthermore, we observed an increase in 'substance P', a molecule secreted by nerves and associated with pain. Substance P is found in CRPS patients at abnormal levels and has long been suspected to cause some of the symptoms of CRPS.

We suspect that the abnormal human IgG bound to some cells in the injured paws, leading to misdirected assaults from the animals' own immune systems. The uninjured paws did not display a CRPS-like syndrome, indicating that abnormal IgG by itself is not problematic unless an injury occurs.

Interestingly, we drew IgG from six different CRPS patients. All were active, indicating that IgG may be involved in CRPS' development as a rule rather than as an exception.

This phenomenon of IgG from an unhealthy human affecting a mouse has occurred before. For example, transfer of IgG from patients suffering with a condition termed 'myasthenia', which is associated with muscle weakness, will cause weak muscles in mice.

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Why would our body allow IgG, one of its most important “employees”, to cause such abnormal effects? We don’t fully understand why this happens, but environmental stressors, such as certain infections, and potentially a genetic vulnerability may lead to the malfunction of B-cells, which produce IgG.

What do our new findings mean?

Our study hints at the possibility that longstanding CRPS develops from an active, ongoing immune-disease process — which may well be treatable — rather than being due to some peculiar irreversible neurodegenerative development. Since four of the six patients in the study had CRPS for more than five years, it is possible that abnormal serum IgG is important in Budapest-CRPS no matter how long the condition has been ongoing.

Our next focus is, as is true for any careful science, repeating our observations to be more confident in IgG’s specific effects. We will also explore how IgG may malfunction as CRPS develops. There will be other contributing factors unrelated to the immune system, but the tantalizing question is: what will happen if treatments can lessen the autoimmune contribution?

At present, a number of treatments exist for autoimmune conditions, including myasthenia, pemphigus, rheumatoid arthritis, and multiple sclerosis. These therapies suppress the body’s immune response, reducing how much abnormal IgG is produced by abnormal B-cells.

We should examine whether any of these existing therapies can also help CRPS, but also weigh the potentially serious side effects of therapies that suppress the immune system. What side effects are or are not acceptable? From speaking with my patients, I suspect that many would opt for trying immune-suppressive therapies and accept the known serious side effects. That said, we need more robust data.

We need deeper studies of how exactly, on a molecular level, IgG binds cells to contribute to CRPS. If we can understand this, we may ultimately be able to devise specific therapies that can precisely target the offending abnormal IgG molecules. This is work for the future; such precision approaches have not yet been achieved for many other autoimmune diseases. ■

Word Up!

DYSTONIA SPOTLIGHT

People with dystonia experience involuntary muscle contractions that force abnormal postures and repetitive movements similar to tremors. The movement disorder’s symptoms can be mild or severe and may interfere with daily life. Dystonia may affect one area of the body (focal dystonia), two or more adjacent areas (segmental dystonia), or most all of the body (generalized dystonia).[1]

The disorder can be caused by inherited genetic mutations, damage to the brain from trauma or poisoning, and some medications. Quick cessation of a problematic medication can often eliminate symptoms.

What does this mean to CRPSers?

Dystonia is the most common movement disorder affecting people with CRPS. The involuntary muscle contractions and twisting it causes can be painful themselves, but they may also compound CRPS pain. Doctors may use medications, such as baclofen, and orthopedic procedures, such as tendon release or serial casting, for treatment.[2]

1. National Institutes of Health, National Institute of Neurological Disorders and Stroke. (Updated 2015 February 23.) Dystonias Fact Sheet. Available: **http://www.ninds.nih.gov/disorders/dystonias/detail_dystonias.htm**. Accessed 2015 April 30.

2. Harden, R. N., et al. (2013), Complex Regional Pain Syndrome: Practical Diagnostic and Treatment Guidelines, 4th Edition. Pain Medicine, 14: 180–229. doi: 10.1111/pme.12033

TREATMENT

Can breathing mindfully help your CRPS?

BY **MATTHEW HALEY**

When you are frustrated, stressed, tense, or in pain, your mind and body cannot relax. Without relaxation, life spirals. It becomes harder to focus on anything but your pain or flare up.

Deep, focused breathing can help to short-circuit this vicious cycle. The wilful choice to control your breathing can relax your mind, which in turn signals your body to relax and stabilize. Your blood pressure will drop, heartbeat will slow, and breathing will calm.
Although breathing exercises will not by themselves cure your **CRPS** or **chronic pain**, they could help get you through the day.

Learning deep breathing exercises is simple, although it may take some time to adjust before it feels natural. Try to stay with it and remove your attention away from your pain. If you feel dizzy or light-headed during these breathing exercises, return your breathing to its normal rhythm.

Here are three beginner breathing exercises to help reduce your tension and relieve negative energy from your pain or flare-up. To start, close off a room to distractions, pull curtains and blinds, and switch off the lights. Settle on a chair or sofa. Close your eyes or focus on a space or item in the room. Sometimes, gentle music, softly scented candles, flowers, or aromatherapy oils can help relax you and improve focus on the exercises.

EXERCISE 1: RHYTHMIC BREATHING

- Notice how you are breathing as you start (no need to alter it).
- Start to slow your breathing by breathing moderately deep, but not too deep. Relax your mind, letting go of thoughts about your struggles today or what you need to do next.
- Continue this for 2 minutes or about 20 breaths.
- To help you focus on your breathing, try counting from 1 to 10 or back from 10 to 1. As you breathe in and out, count 1 – in, 2 – out, 3 – in, 4 – out, and so on.

EXERCISE 2: FEELING YOUR BREATHING

- Support your back so you can comfortably sit straight.
- Put one hand on your chest and the other on your stomach. Notice how you are breathing as you start (no need to alter it). Closing your eyes will help you concentrate on feeling your breaths.
- Try to slow down your breaths by taking a long, gradual breath in through your nose. At the same time, push out your stomach to draw that breath down to the lower part of your lungs.
- Hold that breath for three seconds. Slowly breathe out through your mouth, allowing your stomach to return to normal.
- Repeat this long breath, pushing your stomach out, pausing, and breathing out to relax your stomach again.
- Continue breathing this way until you feel your heart calm and spirit relax.

EXERCISE 3: MUSCLE TENSING BREATHING

- As you breathe deeply, close your eyes. Tense the muscles in your hands, feet, legs, or arms.
- Keep those muscles tense and hold your breath for two or three seconds.
- As you breathe out, let your muscles go loose.
- Repeat this cycle until you relax, although we do not recommend going longer than 10 minutes. ■

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SUPPORTING THE CRPS COMMUNITY

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THE RSDSA provides support, education and hope to everyone affected by the pain and disability of CRPS/RSD while we drive research to develop better treatment and a cure.

EVENTS CALENDAR

JUNE 13
CRPS/RSD Golf Tournament for Samantha Harber, Monticello, MN

JUNE 14
Walk 2 Miles in My Shoes Walk, Scranton, PA

JUNE 13 – 14
Integrated Solutions to CRPS Conference, Denver, Colorado

JUNE 20
2015 RSD/CRPS Motorcycle Run, Bear Creek Village, PA

JUNE 21
Father's Day

JUNE 28
Achilles Walk for Hope & Possibility, Central Park, NYC

SEPTEMBER 11
Integrated Solutions to CRPS Conference, Pennsauken, NJ

SEPTEMBER 12
CRPS/RSD Walk for Awareness, Pennsauken, NJ

NOVEMBER 1
Fight the Flame 5K, Charlotte, NC

NOVEMBER 7
Freeze the Burn 1K/5K Fun Run/Walk, Billings, MT

Don't see an event near you?
Contact Samantha Barrett (sbarrett@rsds.org) to discuss planning an event in your area!

PEER-TO-PEER CONVERSATIONS

The rsdsa Support Committee proudly presents a new peer support program.

VOLUNTEERS:

If you wish to volunteer, please do the following.

- **Please contact LindaLang@rsds.org**
- **Please tell Linda something about yourself and your experience with RSDS**
- **Please include your email and a phone number where you may be contacted.**
- **We especially need teens and parents of children with CRPS to volunteer.**

THOSE IN NEED OF SUPPORT:

If you wish to take advantage of this program, please do the following.

- **Please contact LindaLang@rsds.org**
- **Please provide your email, phone number and a little bit about yourself.**

Turn hurt into help. Donate today. Call 877.662.7737 or visit www.rsds.org