

rsdsa community update

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Spring 2017

Join us as we gather across the country to promote awareness of CRPS, and raise funds for better treatments and patient assistance.

Visit page 20 to locate an event near you!



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Editor

Lauren Bentley

laurenbentley93@gmail.com

CALL FOR AUTHORS & IDEAS

Do you have a personal story, art, or knowledge to share with the CRPS community? Did one of these articles resonate with you? Is there a special topic you would like to see included in the RSDSA Community Update? We would love to hear from you. Please email your thoughts to info@rsds.org.

SPECIAL THANKS

Ketamine Treatment Centers Partnership.

We would like to acknowledge our Corporate Partners whose generosity has helped to underwrite this issue of the RSDSA Community Update. Our Corporate Partners include Abbott, Aetna, Axsome Therapeutics, Grunenthal, McLarty/Pope, Medtronic, Neurologic Relief Center, NoPainHanna.com, and Purdue. For more information about becoming an RSDSA Partner, please contact Jim Broatch at info@rsds.org.

THE DIRECTOR'S LETTER

A Spring Update

BY JIM BROATCH, RSDSA'S EXECUTIVE VICE PRESIDENT, DIRECTOR

Please support your RSDSA Community Update

After a long hiatus, RSDSA has resumed publication of the *RSDSA Community Update* under the direction of Lauren Bentley, our new editor. Because we do not collect membership dues, RSDSA depends upon voluntary contributions in order to support our publications. Please consider making a tax-deductible donation in the enclosed envelope to support this newsletter and our other awareness-related causes.



Free Accredited Courses on CRPS for Physicians, Nurses, and Psychologists

We need your help. RSDSA has partnered with the American Academy of Integrative Pain Management to offer two free accredited courses, <http://rsds.org/accredited-course-on-crps-for-mds-ph-d-s-and-rns/>. The accredited courses are for MD's, Ph.D.'s, and RN's and consist of "Comprehensive Overview of Complex Regional Pain Syndrome" as well "An In-Depth Look at CRPS: From Diagnosis to Treatment as Illustrated by Case Histories." Philip Getson, DO, is the presenter for both of these programs.

The number of medical professionals who have participated is still very low. Please help promote these courses by alerting physicians,

nurses, and psychologists about this opportunity. We can also provide you with materials to distribute in your community. If interested, please call us at 877-662-7737 or email me at info@rsds.org

Major Upcoming Walks

Please review our calendar of upcoming events in this newsletter. Although we will not be participating in the Achilles Walk for Hope and Possibilities, we will hold a major walk at Eisenhower Park in East Meadow, NY on September 9 and walk in Cherry Hill on September 16.

New Items in our Store

RSDSA has added dog bandanas and RSDSA awareness car magnets to our online store. Please visit <http://rsds.org/store/> to shop.

RSDSA's Longest Day of Golf (LDOG)

On September 26, RSDSA was lucky enough to take part in a golf marathon at Innis Arden Golf Club in Greenwich, Connecticut. Zach Baron, from Arccos Golf, golfing on our behalf. While Zach doesn't have CRPS, he felt compelled to participate on our behalf when he heard more about RSDSA. Other golfers took to the golf course trying to complete as many holes of golf as possible to raise money for the charities they were representing.

Prior to the event, which we deemed our very first Longest Day of Golf event, we collected donations. Some people submitted pledges on a per-hole basis. For every hole Zach completed, these donors gave a certain amount. Other donors

gave one-time donations towards the event.

Zach played 72 holes and RSDSA raised more than \$11,000 in one day. Due to the success of this event, RSDSA hopes to have more Longest Day of Golf events all over the country. As more events pop up, we will continue to share them on our social media pages and are a golfer and would like to organize a Longest Day of Golf event, please email SBarrett@rds.org

RSDSA would like to thank Zach Baron, Innis Arden Golf Club, and all of our donors! Your support made this event a success! Click here to view a segment of this event, which aired on the local news, <http://connecticut.news12.com/news/group-of-golfers-play-in-greenwich-to-raise-money-for-charities-1.12366622>

CRPS Clinical Trials/Studies

There are a number of ongoing trials and studies that may be of interest to the CRPS community, <http://rds.org/current-research/> I recommend that you frequently check www.clinicaltrials.gov for CRPS trials.

RSDSA's 20-year Study

If you are not participating in RSDSA's ongoing study, please do. RSDSA is recruiting individuals with CRPS to track CRPS' impact on an individual's health over 20 years. To enroll, please visit, <http://crps20yearstudy.com/>

James W. Broatch



4th Annual Color the World Orange is NOV 6.

Help us Color The World Orange™ on November 6 by turning the night orange! A number of buildings and landmarks have the ability to be cast different colors and we want to request that they turn orange for CRPS/RSD Awareness. In 2016, almost 50 buildings and landmarks in four countries turned orange- let's try to top that this year!

I Get Knocked Down, but I Get Up Again

BY JENNY PICCIOTTO

Gracie Bagosy-Young packs a punch; with her take no hostages attitude, she is a formidable chronic pain warrior. She is the mega-force behind Gracie Gean Chronic Pain Advocacy and Consulting. Her mission is to provide support, resources, and tools for people who are living with chronic pain and challenged by conditions such as CRPS, Fibromyalgia, Lyme disease, Cancer, and AIDS.

Gracie suffers from both CRPS and Lyme disease. Her journey with chronic pain began when she was a divorced single mom with two small children. She developed CRPS after undergoing a series of surgeries to address wrist injuries sustained while kickboxing and soon found herself unable to work. The classic CRPS symptoms of pain, swelling, burning and allodynia affected her right hand, wrist, and forearm. Like so many of us, she wasn't given much information about her diagnosis. Without a support system at home, she had nobody to talk to about the frightening changes in her body. She began trying various treatments, most of which did nothing to alleviate the pain. Gracie felt as though she was stuck in a "completely dark and lonely place" - a place she never wants others to have to experience.

"Taking stock of the parts of herself that living with chronic pain could not take away, she discovered that she could also be an empowered advocate with 'additional value in this world by helping others'"

An electronic engineer, Gracie wasn't about to stay down for long. She began doing what she was trained to do - find answers to the problems she confronted. She went online and began to research CRPS and look for online support groups. She calls the people she met there her "support system saviors."

The computer became her lifeline. In the privacy of closed support groups, she found a community of people who shared their experiences and learned from each other. There were nights when she didn't think she would survive until morning, but she found sustenance in a virtual community in which strangers reached out to one another to offer support. "When I was raw and vulnerable, they helped me pick myself up" she says.

Before CRPS, Gracie was a confident and active full-time mom with a full-time job, and a full volunteer schedule. In an article she wrote for the *National Pain Report* called "CRPS Took My Identity - I Took It Back," she discussed the process of redefining herself. Taking stock of the parts of herself that living with chronic pain could not take away, she discovered that she could also be an empowered advocate with "additional value in this world by helping others."

While looking for support, she began creating support for others. She kept detailed and meticulous notes, photos, and videos from her treatments. She has since shared her experiences publicly writing and talking about the various therapies she has tried from mainstream treatments such as nerve blocks, to experimental therapies such as Calmare, Ketamine Infusion and Transcranial Magnetic Stimulation. She believes that by sharing her successes and failures, other people can learn about treatment options their doctors may not have discussed with them. Her success challenging an insurance denial of coverage has provided ammunition for others seeking access to new therapies.

Putting her considerable skills to use in the service of other pain patients, Gracie is once again working in multiple directions. She believes that knowledge is empowering and that every patient should have access to it. She advocates for others, while helping them develop skills to advocate for themselves. Patients are never charged for her services.

The heart and soul of her mission happens “where the rubber meets the road,” working one-on-one with pain patients. Gracie helps individuals find information and resources, providing consultation and other services such as medical records management, insurance guidance and patient/provider mediation. Her typical day includes organizing and mailing research information, driving patients to appointments, home visits, writing for her blog, and working with individuals by phone, Skype and support groups she hosts online.

She collaborates as a volunteer for numerous nonprofit pain advocacy organizations including US Pain Foundation, iPain, RSDSA, Fibromyalgia Care Society of America, and the Lyme Advocacy Network of the North Shore. She is also a contributing writer for the National Pain Report, maintains a blog, and is active on Facebook.

She is the organizer of the Midwest Pain Treatment Education Expo, which is free and open to the public. This was the third year that this event brought together a diverse group of patients and health professionals,

including six speakers and 21 exhibitors. This one-day event attracted 227 attendees and was streamed to 2,123 virtual attendees. Gracie is already organizing sponsors, donors, and speakers for next year’s Expo. The 4th Annual Midwest Pain Treatment Expo will take place on August 12th, 2017 at the Hilton Hotel in Northbrook, IL.

To fund her volunteer work, Gracie puts her professional skills to work for hospitals and clinics, with web consulting and literature editing. She is also a frequent speaker at chronic pain events. She invests earnings back into her organization to fund her volunteer activities, ensuring that patient advocacy work is always free of charge.

Gracie was the keynote speaker at the RSDSA’s “Treating the Whole Person: Optimizing Wellness” conference, which was held last October in Rosemont, Illinois. Her keynote topic was “Straight Talk About Every Day Maintenance for CRPS Warriors.” When asked if she could share three tips from her presentation, Gracie said that everyone can benefit by managing their diet, their surroundings and utilizing their pain management tools.

I also asked how she manages all of her commitments and her busy schedule. “How do I do it?” she replied, “I just do! I don’t want anyone to ever be in a completely dark and lonely place- to feel like I did. I reach out to find people who don’t have anywhere to go for information, or who don’t have the skills to navigate the challenges of living with chronic

pain.” With big goals, Gracie still faces her own limitations. Working only as much as her conditions allow, she practices self-care every day.

Gracie’s story is inspiring. While searching for her own support, she became an “unintentional advocate” for others. What was once a search for her own strength is now a calling to bring hope to others. She makes it her business to advocate for those who have been knocked down by chronic pain. Gracie knows that with the right tools, you can get up again.

You can learn more about Gracie’s work by clicking here: <http://www.ggpainadvocacy.com/about-us.html>

You can learn more about the RSDSA Conference by clicking here: <http://events.r20.constantcontact.com/register/event?oeidk=a07ed10ajny3cb58e68&llr=dhaazxbab>



ABOUT THE AUTHOR

Jenny Picciotto is a CRPS patient, yoga instructor, massage therapist, and writer. She currently lives in Hawaii, where she leads the Oahu CRPS Support Group, and is active in the online support community.

EVENTS

RSDSA to Host First Young Adult Weekend

BY SAMANTHA BARRETT

For the very first time, RSDSA is hosting an event for young adults. From June 16 through June 18, 2017, we will be hosting CRPS Young Adult Weekend: Taking Care of Ourselves for our community members that fall between the ages of 18 and 29. This retreat will be at the Shawnee Inn in Shawnee on Delaware, PA.

For the past few years, RSDSA has co-sponsored a pediatric pain camp. Although designed for young patients, this camp was not open to young adults and we soon realized that something this group of patients needed a program of their own. Young adults with CRPS can face more obstacles than their peers living without chronic illness and can face more difficulties transitioning from pediatric to adult life. We want to help address some of the obstacles these young adults could face and help provide them with the tools to navigate their health during adulthood. More importantly, we want everyone to be able to meet and network with a community. Knowing someone who can understand what you are going through can make a huge difference. Having a support network is important and conducive to hope, which is why support and hope are a huge part of our mission statement.

“Young adults with CRPS can face more obstacles than their peers living without chronic illness and can face more difficulties transitioning from pediatric to adult life.”

Our weekend at the Shawnee Inn will include educational opportunities, discussions, water sports, canoeing and kayaking, bonfires, and walks along the Appalachian trail, among other activities. The registration fee will cover the cost associated with these activities, room and board, and meals. We have a great program planned that was created by a committee of young adults with CRPS designed to meet the needs of their peers. A non-refundable deposit of \$50 is required to hold your spot. A final sum of \$200 is due on May 1, 2017. If you have any questions, please email the RSDSA Young Adult Weekend Committee at RSDSAyaWKND@gmail.com. We look forward to seeing some of you there! Stay tuned for an update on the outcome of this pilot event.



ABOUT THE AUTHOR

Sammie Barrett, RSDSA's Special Events Coordinator, is a 10-year CRPS warrior. When she's not planning events, you can find her playing with her dog, Phantom, spending time with her family, visiting her local Starbucks, or doing something Disney related.

To learn more, or to register, click here, <http://events.r20.constantcontact.com/register/event?oeidk=a07edqlyko56479674c&llr=dhaazxbab>

EVENTS

Summary of Conversation, January 23, 2017

BY PETER MOSKOVITZ, MD

Linda Watkins is a basic neuroscientist at the University of Colorado in Boulder and takes special interest in pain and the treatment of pain. She has been a good friend to the RSDSA and to the CRPS community as a whole.

Dr. Watkins has identified and supervises the production and study of two compounds of vital interest to both the CRPS community and all people who suffer chronic pain. One of which is a gene therapy compound, known as a plasmid, which induces local cells to produce a strong anti-inflammatory compound, the cytokine, IL-10 (Xalud Therapeutics' XT-150; xaludthera.com). The second compound is a variation of the opioid antagonist naltrexone. The molecule, called + (plus) naltrexone, has the same composition as naltrexone but is a mirror image in its three-dimensional structure. As such, it fails to bind to classical opioid receptors on neurons that are the target for morphine and other opioids. Rather, it plugs up the activation receptor on glial cells that are triggered by opioids to create a neuroinflammatory

response that opposes the ability of opioids to control pain.

Naltrexone holds great potential for pain sufferers. In one survey conducted by the RSDSA, 62% of CRPS sufferers rely on chronic opioid therapy to preserve their daily function. Additionally naltrexone does not compromise the pain-relieving qualities of morphine but, given in combination with opioids, provides greater opioid safety and efficacy. (+)-Naltrexone is also a stand-alone treatment for neuropathic pain, as the activation receptor on glia is likewise triggered by substances released by stressed, damaged and dying cells, as occurs in the spinal cord under neuropathic conditions. It does all this by blocking pain without inducing glial activation, a cause of neuro inflammation and exacerbated pain, nor does it cause gastrointestinal adverse effects. It does not have addictive potential or the adverse effects of morphine. Laboratory studies are very promising, but human trials are a ways off. It's hard to get funding for the study of a

pharmaceutical for which the patent has expired. However, Dr. Watkins may have solved this problem. Our fingers are crossed.

Clinical research on the IL-10 inducing plasmid (Xt-150) is farther along than research on the naltrexone variant. The IL-10 inducing plasmid has the same therapeutic potential as plus naltrexone by reducing the adverse effects of regular morphine and other opioids. Perhaps more importantly, perhaps, the IL-10 inducing plasmid has a direct anti-inflammatory effect when injected into a joint damaged by osteoarthritis or around the spinal cord of a patient suffering from neuropathic pain. Dr. Watkins and her veterinary colleague have produced strong evidence for this effect in dogs who suffer osteoarthritis. Controlled trials of plasmid injections in osteoarthritic dogs demonstrated its safety and effectiveness. The studies are prelude to an investigational drug application for animal use. Clinical trials for human use are

being developed but none have been approved for execution. The Investigational New Drug application for entry into human clinical trials for neuropathic pain are in advanced FDA review.

Behavioral Studies and gait analysis demonstrate that severely arthritic dogs injected with intra-articular IL-10 inducing plasmid experience improved comfort and function. The animals are more active and some who could barely walk can now climb steps. Testimonials from the dogs' owners are even more dramatic. Some are close to tears as they declare, "I have my puppy back!" RSD'ers know well the hopeful vision of the enjoyment like one imagines in a playful puppy. RSDSA wishes Dr. Watkins and her team all good fortune in their endeavors.



ABOUT THE AUTHOR

Dr. Moskowitz is president of the RSDSA Board of Directors and the International Research Consortium. Until retiring in 2106, Dr. Moskowitz was a practicing orthopedic surgeon. He is an avid fly fisherman, active grandparent, and truly a gentle man.

“Watch Dr. Watkins speak about glial dysregulation of pain, opioid actions and drugs of abuse <https://youtu.be/1zrXebDJWKE>”

Hope on the Horizon: Part 4

BY KAREN E. BINKLEY, MD, FRCPC

September 2016

Many people who have dealt with CRPS can attest to the fact that often times, existing treatments do not work well enough in eliminating the effects of this disorder. Having a better understanding of what happens in the body to trigger CRPS is the best hope for improving treatments. **In this column, new developments in understanding CRPS and implications for treatment are reviewed.**

International Research Consortium

You may have already heard about the most exciting development in CRPS research since the last RSDSA newsletter. The RSDSA has established an International Research Consortium to study CRPS. While it is still in the early stages of development, this is a tremendous accomplishment. This research consortium will allow researchers from around the world to share their ideas and collaborate to advance our knowledge about what triggers and fuels CRPS, and how to better treat this disorder. Because CRPS is relatively uncommon, it is often difficult for a single researcher to conduct large clinical trials; they simply do not have enough patients. The International Research Consortium will

facilitate the cooperation between various research sites to assist in the recruitment of a sufficient number of patients to make large clinical trials possible. These types of trials will give the most meaningful results and, in turn, identify the best treatments for CRPS. Another benefit of the International Research Consortium is that it will link basic science researchers with physicians to treat patients, allowing translation of new discoveries in the laboratory into the clinic setting, where they will directly benefit patients.

Is your treating physician also a clinical researcher? This may be the case, especially if you are getting treatment at a university affiliated institution. If your treating physician is engaged in CRPS research and interested in joining the International Research Consortium, your physician may contact Amy Kirsling at akirsling@crpsconsortium.org

A Critical Regulatory Node for Inflammation?

Once again, there is more news from the Philadelphia group. They are working diligently to identify how and why the inappropriate inflammatory response of the microglial cells contributes to CRPS. In order to do this, they have been studying interesting compounds called micro-RNAs that regulate the

expression of certain genes. You may recall from one of my previous columns that their research found a difference in micro-RNAs among patients who responded positively to ketamine treatment versus those who did not respond positively. More recently, it was found that a particular micro-RNA, miR-939, down regulates the production of several compounds responsible for inflammation, including IL-6, NF kappa B, NOS2A, and others. Their analysis predicts that miR-939 represents a critical regulatory node in a network of inflammatory mediators. They suggested that down-regulation of miR-939 in CRPS patients may increase the expression of genes coding for inflammatory mediators, resulting in amplification of pain and inflammation. This identifies miR-939 as a potential target that, if unregulated in some way, could reduce the pain and inflammation associated with CRPS. This has not yet been conducted with patients, but understanding what has gone wrong in CRPS will help to identify the best method of treatment.

More Ways to Overcome the Blood-Brain Barrier

In the previous column, I described how the use of high intensity MRI guided ultrasound could be used to get

medication across the blood-brain barrier. The blood-brain barrier otherwise prevents medication from entering the central nervous system, brain and spinal cord. This means that some medications prescribed to treat CRPS may not be able to reach their targets. Some researchers have also been able to deliver medications to the central nervous system with the use of nanoparticles. However, there are limitations to these techniques. A recent article in *Scientific American*, describes the work conducted at the California Institute of Technology showing that a harmless virus called AAV-PHP.B was very effective in crossing the blood-brain barrier. Theoretically, this virus could be engineered to deliver genetic information to the central nervous system to correct abnormalities in various neurological conditions, including CRPS. Although this has not yet been tried in patients, it is exciting to know that these technologies exist and, when the right information is available, will be available to researchers to employ in efforts to help those with CRPS.

Bisphosphonate Response in CRPS

There is evidence that bisphosphonates, drugs that are commonly used to protect bone density, can be helpful in CRPS treatment, although not all patients seem to respond. A group from Milan has reviewed their experience with 194

patients that were treated with three different schedules of bisphosphonate treatment over a five-year period. Overall, 71.6% of the patients responded, and the particular schedule of bisphosphonate treatment did not seem to matter. The patients who were most likely to respond were those who were treated early on, had CRPS as a result of a fracture and had “warm” CRPS. Once again, this is another study that demonstrates that there are different subtypes of CRPS, which respond differently to treatment. It offers hope to those who can be diagnosed and treated early.

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“Overall, 71.6% of the patients responded, and the particular schedule of bisphosphonate treatment did not seem to matter”

ABOUT THE AUTHOR

Dr. Binkley is an Associate Professor in the University of Toronto’s Department of Medicine, Division of Clinical Immunology and Allergy. She developed CRPS in 2007 after an otherwise trivial fracture.

Understanding Your Plan

BY KYLE VOREHHEIMER

Navigating through the health insurance marketplace is something we all wish we could live without. Unfortunately, with a CRPS diagnosis comes the need to use insurance plans more than the average person. When signing up for an insurance plan, there is no disclaimer stating “you will spend hours on the phone with our representatives in an attempt to understand why you are not getting paid for the claims you submitted.”

Healthcare companies set prices, pay facilities what they choose, and even make mistakes without any repercussions. This is why being a strong self-advocate comes is crucial.

Understanding Your Plan

First and foremost, identify what is offered and what is covered through your plan.

When choosing a plan, make sure you know whether you are limited to seeing doctors that are “in network” with your plan or if you have the ability to go outside of your plan and utilize “out-of-network” benefits.

Unfortunately, most plans do not cover out-of-network benefits, which limits which doctors you are eligible to see. It is important to note that most CRPS specialists are out-of-network. If your plan does not cover out-of-networks benefits, you will most likely be responsible for paying for visits and procedures.

Submitting a Claim

The most troublesome and time consuming thing about seeing a doctor doesn’t actually start until after you are finished with the appointment

Typically, a doctor will charge a co-pay and send you on your way. It’s not until a few months later that things start to get tricky. All of a sudden, bills from your doctors start to flow in - and the headache doesn’t stop once you have paid the co-pay. If your health insurance plan does not pay your doctor what they feel is reasonable or if you have not met your deductible, you could be balance-billed for the remaining amount.

Keeping yourself organized is key to avoiding trouble when it comes to doctor bills. The first step you

OUT OF NETWORK CLAIM SPREADHSEET					
DOS	Doctor	Date Mailed to Ins.	Total Billed	Total Received From Ins.	Status
16-Jun	Stevens	18-Jun	75	65	Complete
14-Jun	Shesky	27-Jun	159	159	Complete
18-Jun	Don	30-Jun	135	Did not meet deductible	Complete
7-Jul	James	20-Jul	135	No Payment Received	Wrong Codes-Resubmitted on 1/5
3-Aug	Parsons	10-Aug	135	No Payment Received	Receipt not Included/ Spoke to Doctors Office/ Receipt in Mail from Doctor
					Call again on 2/25 if you have not received
23-Sep	Von	2-Oct	135	22.56	Complete / Partial Deductible Met
3-Nov	Shin	8-Nov	135	108	Complete
4-Nov	Don	6-Nov	135	No Payment Received	Returned to Sender/ Wrong Address/ Resent 2/12
12-Dec	Gold	18-Dec	135	No Payment Received	Investigating: Ref # 1434/ Mary EXT 24 / Called on 1/13

can take in getting organized is to create a spreadsheet. In this document, include the date of service, name of doctor, and the amount charged at date of service. After you see your doctors, fill in the columns to ensure you have the exact amount you were charged in your co-pay the amount of the co-pay you were charged. This will make it easier in the future to confirm the bills you receive are correct.

Out-Of-Network Doctor Bills

When seeing out-of-network doctors, it is not uncommon for the doctor to refrain from submitting claims to the insurance company. Some doctors will actually require you to pay for the visit up-front and provide you with the necessary paperwork to submit the claim to your insurance company. This process can prove to be troublesome, as often times the insurance company will deny your claim. Making sure you handle this process correctly is extremely important. First, call your insurance company to learn what is required in submitting a claim. Usually, they will tell you which documents you must obtain from your doctor's office and submit to the company, required codes and the correct form to complete. Be mindful that most companies have a special address just to send claims.

Also, make sure to confirm the correct address. Following these steps will make it more likely that the insurance company will pay out your claim on the first attempt.

Once you submit your claim, go back to your spreadsheet and add the amount the doctor billed you, the date of service, and when you submitted the claim. It is also extremely important to make photocopies of all the submitted documents, just in case you have to resubmit your claim. In addition, be sure to always send your items certified mail with tracking so you can confirm it was delivered. If you fax your claims, keep a copy of the fax confirmation.

The Resubmission Process

Unfortunately, claims are frequently denied, requiring you to appeal or begin the resubmission process. To resubmit your claim, call your insurance company to find out why the claim was denied. Sometimes it can be as simple as a clerical error on their part. In this case, they can resubmit the claim for you. In other cases, the denial of your claim can be due to a mistake made by you or the doctor's office, such as an incorrect diagnosis or procedure code. Another reason the claim was denied may be due to you forgetting to submit something the insurance company requested by the insurance company, wanted, such as a

receipt from the doctor's office. This is why it is vital to keep a list of all items the insurance company needs and keep copies for future reference.

When calling an insurance company, find out who you spoke to and write their name down along with the date you called. You can also find out if the person has a direct line or an extension to reach them easily in the future. Usually, the insurance company. They will also give you a reference number for the call. The company should also be able to provide you with a document number for the claim. My rule of thumb is to call every two weeks to receive an update on the status of your claim. Every time you call, you will need to state your reference number and who you spoke to previously. If you call and feel you are not being helped by the person on the line, hang up and call back or ask to speak to a supervisor. Never be ashamed to go after what you want, especially when it comes to your hard-earned money.

Bringing It All Together

Dealing with health insurance can be a daunting experience, but with good organization skills and a plan, you should be able to navigate through the process successfully. Be proactive, stay on top of your claims and keep a paper trail of documents until your claim is fully resolved.

Be Heard- CRPS Support Group

LUCRECIA R MARTINEZ, MES, CPT, CES & MATT TARZON, MS, NASM-CPT, CES, FNS

I will be honest, when I began working for the Bay Area Pain & Wellness Center (BAPWC) in 2005, I had no knowledge about CRPS. I heard the term mentioned around the clinic but didn't know what it meant.

In 2008, I began working in the functional restoration area of the clinic and met my first client with CRPS. I remember this day as if it was yesterday. The patient walked in using a single crutch, as he was unable to fully weight bear through his CRPS-affected lower extremity.

In getting to know the patient, I learned that he had a wonderful wife and two young children at home to care for and support. Despite the significant pain from his CRPS, he was such a pleasant and kind soul. Working with this patient truly brought me a sense of joy and reward. My goal was to help him not necessarily get rid of his pain because, as we know, CRPS does not yet have a cure. Instead, my goal was to help him enjoy and be there for what is most important in his life.



Before I knew it, one CRPS client turned into two, then three and four and so on. I realized that our clinic had several clients who suffered with CRPS; yet, many felt lost and alone with their diagnoses.

It was then that we decided to create what we call our Gratis CRPS Support class. You may ask yourself, "what does this class entail?"

This class consists of 30 minutes of exercise and a 30-minute guided relaxation class. While we may think to ourselves "wow-one-hour fitness and relaxation class is pretty generous," the truth is that it goes beyond that.

This class is also about the socialization and community clients experience with those

who share the same diagnosis. They come into the gym, meet each other and talk about their experiences with pain and CRPS.

What began as one CRPS client has become a solid group of support. This very special group of pain warriors now called

themselves the "Robles Group." Why? Robles is a type of tree (wood) in Honduras that is extremely durable and can withstand fire, floods, drought, along with the "normal" conditions experienced during its lifetime. It is strong and doesn't give way.

At first, these were clients consumed by pain and their conversations circled around the struggles faced living with CRPS. Now, as the group gathers weekly, they take turns bringing in treats to share. While they are doing gentle exercises in their social circle, they also talk, laugh, joke around and share happy moments.

Today, each client is around 2+ years into their diagnosis. They have been through rounds of

treatments that range from: PT, psychological therapy, chiropractic services, acupuncture, medications, etc. and still the pain persists.

My goal with this very special group of individuals is to show them that, despite having this extremely difficult diagnosis, they can still live happy and healthy lives. My first CRPS patient continues to battle CRPS but he takes his kids to school, soccer practice, judo practice and gives them the love that no one else can give them. I congratulate him and all others in our group because, although they have the perfect excuse not to do things, they do not let that stand in their way. They simply do what they can when they feel able.

Allowing them to participate in this Gratis CRPS class gives these clients the opportunity to get out of their homes, avoid isolation, and socialize with others who fully understand and are dealing with the same battle. There is a sense of family and camaraderie that has formed within this tight-knit group.

Even with that, they always welcome new clients with open arms, ears and hearts.

Once they are ready and feel that they have established trust with the providers and within the group, they can begin their participation in our functional restoration program. This dedicates 6 weeks to the physical, functional, mental and spiritual aspects of their lives.

These clients worked hard on building relationships with peers and a variety of specialty providers while also learning to improve manage their pain, increase strength, practice relaxation and mindfulness, and manage emotions. Because of this, BAPWC decided that treatment must continue beyond the program. We continue to offer the same access to the Gratis CRPS class but expect them to become leaders in CRPS community and mentors to those who are newly diagnosed.

My colleague, Matt Tarzan, MS, NASM-CPT, CES, FNS, and I have created a blog that will provide excellent resources for those who suffer from chronic pain, want to maintain fitness, but do not have access to our clinic. Among other topics, we will post our advice, techniques and education when it comes to being fit while suffering from chronic medical conditions. We want to offer what we do in Los Gatos to anyone who has access to a computer. Check it out and send us your questions or topic suggestions.

www.needfitnessforhealth.com

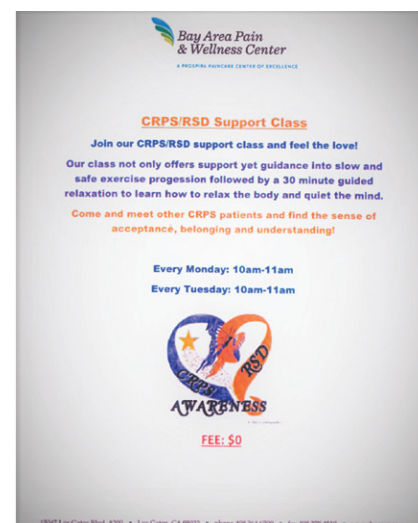
Here is what the patients have to say:

"This class gives us a reason to get out each week"

"You make us feel heard without being judged, you listen and you care"

"We come here and laugh and make jokes and make friends"

"You guys might not have all the answers to our questions but you have more than that, you have compassion and a heart to help us"



LUCRECIA R. MARTINEZ, MES, CPT, CES

I have worked for the Bay Area Pain and Wellness Center since 2005. I have been a personal trainer since 2003 and most recently became a Medical Exercise Specialist this year. My goal is to bring laughter and joy to those who are suffering and who have lost so much. In specific to our CRPS community, my goal is to help educate them on what CRPS is, help to educate their family on how they can help and be supportive and maintain my education on the latest research as far as treatment options and latest studies.

CRPS Recipes

BY KYLE VOREHHEIMER

Cooking while living with CRPS can be difficult. Regardless of which part of your body is affected, this daily task is not easy and will usually require a great deal of energy. In addition to the energy exerted, you will most likely need a full day of rest to recover from cooking the meal. In my previous article, I spoke about CRPS Mainstays: items you should always keep in your house for those evenings you decide to cook. Some of these items include salt, pepper, tomato sauce, pre-breaded chicken, pasta, frozen vegetables, etc. In this article, I will share some of my favorite recipes that I cook frequently. These recipes are relatively simple and can be made in a variety of ways. The dish can be prepared in a basic or more complex way, depending on how you feel that given day- but I will lean on the simpler side for all of my CRPS friends!



Sausage and Peppers

This is a great recipe that can be prepared using a variety of sausages such as pork, chicken, turkey, or even vegan. It's delicious and very easy to prepare. It can also be made in a larger quantity so that you have leftovers for the week. This dish can be eaten alone, over a quick pot of pasta, or even on your favorite type of bread. Overall, this is a versatile recipe and is something I always like having in my fridge.



Ingredients

4 Sausage links (Your favorite type)
2 tbsp olive oil
3 peppers, sliced into 2 to 3 inch long strips
4 garlic cloves, sliced into slivers
1 large sweet or yellow onion, sliced into 1/4-inch half-moons
1 half bottle of your favorite pasta sauce (You can substitute fresh sauce)
1 tbsp of dried oregano
Salt to taste
Red pepper flakes to taste

Steps:

1. Brown the sausages: Heat the olive oil over medium heat in a large pan that has a lid. When the oil is hot, add the sausages and brown them slowly. If they sizzle and crackle too much, turn the heat down. You want a gentle browning, not a sear.
2. Sauté the onions, peppers, garlic: Increase the heat to high and add the onions and peppers. Toss so they get coated with the oil in the pan and sear them as well as you can, stirring every so often.
3. Cut up sausages (You can also leave them whole). Slice to desired size.
4. Add the pasta sauce, oregano and red pepper flakes (if using) and stir well to combine. Add the sausages back in. Bring to a simmer then reduce the heat to low. Cover and simmer until the peppers are soft and the sausages are cooked through, which should take about 20 minutes.

Cook for several minutes, turning them occasionally so they brown on all sides. When the sausages are browned, remove from the pan and set aside.

"Sausage, peppers and onions will keep in the fridge for several days."

You want some blackening. After the onions and peppers soften, sprinkle salt on them. Once you get some searing on the onions and peppers, add the garlic and cook for 1 more minute. You want to add the garlic last to avoid burning.

ABOUT THE AUTHOR

Kyle Vorchheimer trained as a chef before he developed CPRS.

Easy Chicken Parmesan



This is a simple dish. It can be prepared fresh using chicken cutlets that you bread yourself, or you can buy pre-breaded cutlets that are already cooked and just have to be heated. Perdue makes a great product and offers different flavors. They can be found in the refrigerated aisle of your grocery store. You can also use a frozen product. For this recipe, I will be showcasing the pre-cooked Perdue product. Like the Sausage and Peppers, you can eat it alone, over pasta, or as part of a sandwich. It is also something that lasts in the fridge. You can also use breaded eggplant and prepare the dish the same way.

Ingredients:

Perdue Chicken Cutlets

Mozzarella cheese (fresh or store bought) sliced into cubes

Bottled sauce (fresh sauce is also an option)

Steps:

1. Preheat oven to 350 degrees
2. Line chicken cutlets in a sheet pan
3. Add a small amount of sauce and then mozzarella to the top of your cutlets
4. Place in the oven until cheese is melted and chicken is cooked through
5. Add to your favorite pasta, or top your favorite bread

Simple Baked Ziti



This is a great dish that everyone can enjoy. It can be consumed by itself, as it is a good source of calcium and protein. However, it can also be served with my other two dishes: chicken parmesan or sausage and peppers. I will showcase a simple recipe, but you can always add your favorite vegetable by mixing it in with the rest of the ingredients. It can also be cooked in a larger quantity so you have leftovers. You can add cooked chop meat or chicken to the mixture as well!

Ingredients:

- ½ lb ziti pasta
- 1 lb Ricotta cheese
- 3 cups Mozzarella cheese
- 3 cups bottled sauce (Fresh sauce is also an option)
- ½ cup parmesan cheese, grated

Steps:

1. Preheat oven to 350 degrees
2. Boil ziti, following package directions, drain and place in a large bowl
3. Mix all the ricotta cheese and half of the mozzarella with the ziti
4. Spray a 13x9 pan with cooking spray
5. Cover the bottom half of the pan with about half of the sauce
6. Put the ziti mixture on top of sauce
7. Pour remaining sauce on top of ziti
8. Sprinkle with the parmesan cheese
9. Top with the remaining mozzarella cheese
10. Bake for 20-30 minutes until cheese is melted and it is lightly golden

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FAX: 203.882.8362
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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

SPRING/SUMMER 2017 EVENT CALENDAR

- April 30:** Treating the Whole Person: Optimizing Wellness, Fayetteville, AR
- May 6:** TAILS of the CRPS 2nd Annual Dog Walk, Jacksonville, FL
- May 6:** 2017 RSD/CRPS Cruisin' For a Cure 1, 2, or 3 Mile Fun Walk, Ambler, PA
- May 20:** Stomping Out the Flames, Manassas, VA
- June 16-June 18:** CRPS Young Adult Weekend, Shawnee Inn Delaware, PA
- July 21:** CRPS Awareness and Fundraising Night with the Dodgers, Los Angeles, CA
- July 22-26:** Pediatric Pain Week at CCK, Scottsville, KY
- August 13:** 4th Annual Midwest Pain Treatment Education Expo, Northbrook, IL
- September 9:** Long Island CRPS/RSD Awareness Walk, East Meadow, NY
- September 16:** 2017 CRPS/RSD Walk for Awareness, Pennsauken, NJ
- September 17:** Knock Out Pain 5K Run & 1 Mile Family Roll and Stroll, Bethlehem, PA
- November 4:** 4th Annual CNJ Walk of Hope for a Cure, Lincroft, NJ
- November 5:** Fight the Flame 5K, Charlotte, NC and Mentor, OH
- November 6:** 4th Annual Color the World Orange, Worldwide

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.

Don't see an event near you?

Contact Samantha Barrett (sbarrett@rsds.org) to discuss planning an event in your area!

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