rsdsa community update

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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 the RSDSA Community Update include? We would love to hear from you. Please email your thoughts to info@rsds.org.

SPECIAL THANKS

Thank you to everyone who contributed to this newsletter, including four captivating volunteer writers and advocates for the CRPS community. We would like to acknowledge our Corporate Members whose generosity has helped to underwrite this issue of the RSDSA Community Update. Our Corporate members include Axsome Therapeutics, Grunenthal, Medtronic, Innovative Health Solutions Neurologic Relief Center, Florida Spine Institute, and the law firm Pond Lehocky Stern Giordano. For more information about becoming an RSDSA Corporate Member, please contact Jim Broatch at info@rsds.org. Thank you also HDMZ, a life science marketing agency, for helping to edit and produce the newsletter.

THE DIRECTOR'S LETTER

A Summer Update

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

Ketamine: The State of the Science Conference

Intravenous ketamine infusion is increasingly used to treat intractable complex regional pain syndrome (CRPS). Comparing the safety and efficacy outcomes among the many different infusion protocols for CRPS patients is difficult. Meaningful clinical research requires a reference protocol for the use of ketamine in the treatment of CRPS.

The RSDSA is conducting a survey to describe how ketamine is used to treat CRPS now. Knowing the range and prevalence of ketamine protocols will help to develop consensus on guidelines for ketamine administration and a reference ketamine infusion protocol. We will report the results at an international meeting this fall with the ultimate goal of improving the quality of CRPS research and quality of care to CRPS sufferers. The survey results will be discussed at the RSDSA-sponsored conference, Ketamine: The State of the Science, which will be held on October 22-23, 2016 in Chicago. On Sunday October 23, we host a half-day seminar for people with CRPS, Treating the Whole Person: Optimizing Wellness. For registration information, please email us at info@rsds.org.

The survey is supported by a research grant from the RSDSA. Please help the RSDSA by sharing this survey with any **medical professional** who is using intravenous ketamine to treat CRPS or take this survey if you are a medical professional who uses intravenous ketamine to treat CRPS: https://www.surveymonkey.com/r/ZPP9BXY

New Brochure on Pediatric CRPS

Two volunteers, Leigh Smith and Kristen Blake, authored a new brochure on pediatric CRPS. Download the brochure here: http://rsds.org/wp-content/uploads/2016/06/RSDSA_brochure_children_v2.pdf

Upcoming Conferences

The RSDSA is organizing three Treating the Whole Person: Optimizing Wellness conferences in Chicago on October 23, in La Jolla on November 6, and in Nashville in spring 2017. The conference aims to: increase information and understanding about CRPS, increase awareness of coping strategies, increase awareness of therapeutic strategies for pain relief and restoration of function, and stress the importance of not just treating CRPS' symptoms but to focus on the entire person.

RSDSA has approached the Osher Center for Integrative Health at Vanderbilt Health and the National University of Health Sciences in Lombard, IL to partner with us as we are strongly emphasizing the philosophy of focusing on treating the individual, not simply the disease or diagnosis. Treating holistically means looking at all the factors that comprise health, with the ultimate goal of restoring balance and supporting the natural healing process. Sessions will also focus on interventional pain medicine, rehabilitation therapies and medications. The conference sessions will be videotaped and the lecture slides will be archived on our website and our YouTube channel.

The RSDSA's YouTube channel is full of informational videos from our conferences. It also features videos from some of our board members and various members of the RSDSA community. They make for a great watch. Check it out and subscribe today! https://www.youtube.com/user/RSDSAofAmerica

It's Macy's Coupon Time Again

Date: Friday, August 26 through Sunday, August 28, 2016

Where: Any Macy's Store

Cost: $5.00

What you'll get: Save 25% all day, Save 10% on electrics/electronics, watches, furniture, mattresses, rugs/floor coverings

Contact: If you want to make a huge difference, contact Sue Pinkham at suepinkham@comcast.net or by phone call 781.771.2095. Sue will mail you 25 coupons.

James W. Broatch

COMMUNITY & CULTURE

A Voice for CRPS Awareness: Learning and Instruction in Online Support Groups

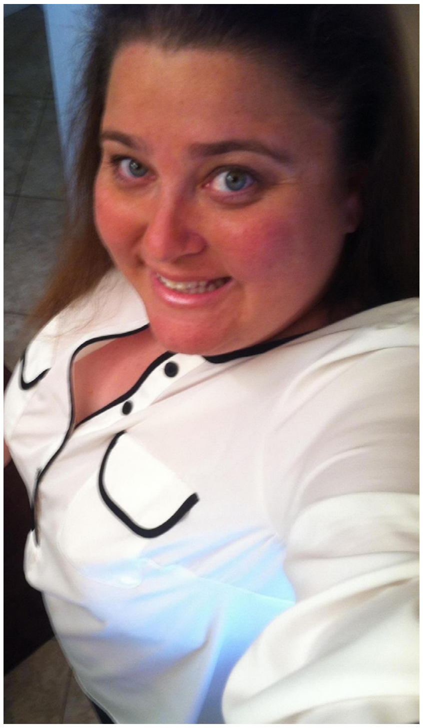
BY JENNY PICCIOTTO

Anyone who knows Heather Gilmore will agree that she is vivacious, tenacious, and courageous. She is an advocate for CRPS awareness, with a presence on several social media platforms. She also participates in state and national groups, such as the RSDSA and the Orange County CRPS Survivors and Caregivers.

Diagnosed with CRPS in 2008, she was determined to pursue her education despite disabling pain. With the support of her family, the university, and a team of medical providers, she took each challenge as an opportunity to develop strength.

"People ask me how I did it," she says. "I believe that nothing is impossible – it's all about accommodation. I don't always feel optimistic, but I will not go down without a fight. I'll figure it out." And she did. She completed her coursework online, creating functional work space that included a modified bed, and voice controlled software that allowed her to work hands free. She recently graduated from Walden University, with a Ph.D. in education.

> *"Connecting with people who are similar to you allows you to better understand yourself in the context of your illness and how it affects your life."*


Heather Gilmore

Having participated in both traditional face-to-face and virtual support groups, she knows how valuable they are for the chronic pain patient. They can provide not only much needed information, but also offer understanding, a sense of belonging, and friendship. Heather discovered that while there is a lot of research about traditional support groups, "little has been studied about the learning and instruction that occurs in online social support groups, especially in groups about chronic pain." She decided to make that the topic of her dissertation. She designed a case study to explore "participants' perceptions of their learning and instruction in virtual support groups."

I spoke with Heather recently about her research, and her experience as a member of support groups. Here is a sampling of her insights:

- The unique environment of an online support group accelerates learning through information sharing. Because the internet allows a much wider variety of people living in different locations to connect, the pool of information that is shared is much deeper than in a traditional support group. Information is also shared at an accelerated rate; new information is constantly emerging, and is rapidly passed along.

- Most of the participants interviewed agreed that they learned more about their condition through their online support group than they did from their own doctors. Group members shared first-hand experience and emotional support, discussing a wide range of topics including: signs and symptoms, treatment protocols, medications, doctors, worker's compensation, social security disability, research articles and other resources. Many were empowered to discuss new treatment options with their doctors.

- "Participants in this study indicated that convenience, quick response time, and being able to get information at all hours directed solid connections, hope, and an enhanced understanding of their illness."

- Technology and connectivity afford new ways of learning through information sharing. Because social media is available anytime, anywhere, participants can readily find support, reducing the sense of isolation. Some participants may be more comfortable in the online environment than they would be in a face-to-face group.

- There is a strong sense of acceptance within the virtual support group. If negativity is expressed, most participants don't take it personally. Instead, they chalk it up to someone having a bad day, knowing that living with pain affects how we interact with the world.

- Relationships that develop within the virtual community can blossom into friendships. After interacting in the group, members may get to know each other well enough that they connect outside the group. This can be someone who lives just around the corner, or in another part of the world. Sometimes traditional face-to-face support groups emerge out of online groups.

Heather offers a few tips for people new to virtual support groups:

- Be aware that the information shared may not be accurate. While most people understand that treatment results vary from person to person, some members may promote or urge others toward specific treatments.

- As in any situation, sharing private information with others entails some risk. If you are concerned about your privacy, or involved in a lawsuit, be aware that some groups can be accessed by the public, while others are restricted to members only. Certain groups allow members to register with an alias.

Heather says that joining a support community "is a definite must," especially with a condition like CRPS, where so little is known. Support groups are beneficial for patients, families, and caregivers. "Connecting with people who are similar to you allows you to better understand yourself in the context of your illness and how it affects your life."

"I have always been told I have a voice," she says. Her positive outlook, along with her belief that "with time, acceptance, and accommodation, nothing is impossible," has helped Heather overcome many of the challenges of living with CRPS. Having completed her Ph.D., she continues to look forward. She plans to devote herself to CRPS education full time, advocating and motivating others to follow their dreams. Not a bad way to use your voice.

Read Heather's Dissertation

You can read Heather's dissertation, "Case Study of Learning and Instruction for Members of an Online Reflex Sympathetic Dystrophy Support Group", at: http://scholarworks.waldenu.edu/cgi/viewcontent.cgi?article=2994&context=dissertations)

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.

RESEARCH & MEDICAL

Recovery from CRPS:

How do patients define recovery? What would be their treatment priorities to achieve recovery?

BY YVETTE HIBBERD

Deciding when someone has recovered from Complex Regional Pain Syndrome (CRPS) can be difficult due to a number of different factors. Firstly, the common signs and symptoms of CRPS change over time. This can mean that although someone met the Budapest Diagnostic criteria for CRPS at one time point, they may not meet it at a later date. However, the patient may still experience some of the symptoms of CRPS or have some long-term disability as a result of having CRPS, even though they no longer meet all the diagnostic criteria. Are these people recovered from CRPS or not?

Secondly, it is common for people who live with a long-term condition to adjust the way that they think about their health status over time. As the day-to-day signs and symptoms of their condition become 'normal' to them, they may start to consider that, although they are not back to their pre-CRPS self, they are actually much better than they were in the early stage of the condition, and therefore think of themselves as 'better'. Are these people recovered or not?

If we do not know what 'recovered' looks like in CRPS, then it is very difficult to decide if treatments are effective or not, and to also know what the natural course of CRPS is.

In 2013 RSDSA and the Dutch National CRPS Patient Organization provided funding for an international team of academics, clinicians and people with CRPS to conduct research to answer the questions:

- What defines recovery from CRPS from the patients' perspective?
- What are the priorities for recovery from the patients' perspective?

What did we do?

The research team invited people to participate in the study if they had been diagnosed with CRPS and were either already enrolled on a country specific CRPS database, or were attending a CRPS service in one of the 10 participating centres. These were located across 8 different countries: USA, Canada (2 sites), UK, Netherlands, Germany (2 sites), Denmark, Switzerland and Poland.

Once people had agreed to be involved in the study, they received two packs of questionnaires in the post over approximately a one year period. Both packs included questionnaires that asked them to tell the research team about different aspects of their health, including their pain, level of function, and psychological well-being. In addition, the first pack of questionnaires asked them to answer one of two questions:

1. **'**I would consider myself recovered from CRPS if…" or

2. 'I do consider myself recovered from CRPS because…'

The participants wrote their answers to one of the above questions in a free text box that allowed up to about 100 words. These responses were then analyzed by members of the research team, including some of the research patient partners to make sure that we had the patients' viewpoint. In the analysis, the responses were grouped under themes that described the data within them. For example, some of the themes were 'carrying out daily routine', 'self-care', and 'CRPS symptoms'.

The themes that were reported most commonly by the participants were then

> *[The study] helped us to know which particular areas people with CRPS want clinicians and researchers to focus on when developing new treatments and designing future research studies.*

formed into 62 different statements. These statements were sent out with the second questionnaire pack to all of the people who had responded to the first round questionnaire. Participants were asked to select the 10 items they felt were most relevant to their view of recovery and to rank these items in order of importance.

What did we find?

347 people participated in the first round of questionnaires, and 252 of these people also completed the second round of questionnaires. In the first round, 80.4% of participants were women, the average age of all participants was 53 years, and more than half of the participants had lived with CRPS for three years or more. Of the 310 people who told us their recovery status, 280 (90.3%) considered themselves to be "not recovered".

From the first questionnaire pack, the most frequently reported themes for patient-defined recovery were: activities of daily living, bodily functions (including CRPS symptoms and pain), external factors (including medication use), and participation (e.g., housework, shopping). Personal factors (anxiety, depression) were least represented.

From the second round of questionnaires, our participants told us that their top five priorities for recovery were to no longer have:

1. CRPS-related pain
2. Generalized pain and discomfort
3. Restricted range of movement
4. Need for medication
5. Stiffness in the affected limb.

The top three statements of most subgroups (including males, females, recovered, non-recovered, age groups 30–50 and 50+, paid employment, non-employed, all disease durations, upper and lower limb CRPS) were all within the overall top five priorities.

From the questionnaire that asked about different aspects of participants' health, the data showed that people with CRPS were more likely to report themselves as recovered if they had: fewer symptoms, knew their type of CRPS, and had caring responsibilities.

There was no relationship found between self-reported recovery and demographic factors (age, gender, etc.), disease duration, disease trigger, or which limb was affected.

People who did not consider themselves recovered from CRPS reported higher pain, lower quality of life, and had more difficulty with coping psychologically with their pain than those who were recovered.

Those people with lower-limb CRPS more frequently reported increased pain responses and pain to normally non-painful stimuli than those with upper-limb CRPS. They also more frequently reported hair changes, involuntary muscle movements, and greater overall pain, in addition to poorer quality of life, lower levels of physical functioning, and poorer energy/fatigue scores.

Function, psychological flexibility, and number of symptoms were found to be predictive of quality of life for non-recovered participants with upper-limb CRPS.

What can we conclude from this?

The data from this study suggests a very small number of themes are of highest importance to people with CRPS in their definition of recovery and these vary little across age groups, gender, nationality, employed or unemployed groups. People want their CRPS-related pain, generalized pain, movement difficulties, and medication reliance to be addressed, above all other factors, for them to consider themselves recovered.

Persistent CRPS has negative consequences for mental and physical well-being, and the poorest health outcomes were found for people with lower-limb CRPS.

How will this information help people with CRPS?

The conduct of this study and the new information gained from it has:

- Helped us to know which particular areas people with CRPS want clinicians and researchers to focus on when developing new treatments and designing future research studies.

- Given us new information about the impact of CRPS in different populations and insights into how people with CRPS define recovery when they have, or no longer have, symptoms.

- Helped us to select questionnaires that ask about these areas that are important to people with CRPS when we have been designing a new set of questionnaires to be used in all future CRPS clinical trials. Having the same set of questionnaires that can be used across all countries will mean we can conduct much larger, and therefore more effective, research studies and, hopefully, move ahead more quickly in helping people with CRPS.

- Given us an opportunity to translate a large number of questionnaires into different languages, which will make our future international studies much quicker to establish.

- Built a new CRPS international research community that includes patient researchers, and has demonstrated we can conduct research that is important to people with CRPS in an efficient and effective manner.

Acknowledgements and thanks

This study would not have been possible without the generous financial support from the Reflex Sympathetic Dystrophy Syndrome Association, and the Dutch National CRPS Patient Organization. We would like to thank our funders and the patients who kindly participated in this study.

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Who was in the research team?

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Yvette Hibberd is a researcher focused on chronic regional pain syndrome at the Royal United Hospitals in Bath, UK.

RESEARCH & MEDICAL

Hope on the Horizon

BY **KAREN E BINKLEY, MD, FRCPC**

If you have CRPS, you may already realize that existing treatments do not work as well as we would like. The best hope for improved treatments will come from a better understanding of what is going wrong in CRPS, so that we are better able to fix it. In this column, we review new developments in our understanding about CRPS and implications for treatment.

CRPS treatment: one size does not fit all!

There is even more evidence that CRPS is not the same in all patients, and that treatments that are effective for one type of patient may not work for another.

In my last column, I described research from a group in Philadelphia that showed that while some patients responded to ketamine, others did not. They were developing a blood test to predict which patients might respond to ketamine in advance. Now there is evidence from researchers in Europe that another subgroup of patients might respond to corticosteroids.

Remember that after an injury or trauma, the body responds with inflammation. This helps to bring blood and nutrients to allow tissue repair. When no longer required, this process is normally shut down. In CRPS, it is thought that there is damage to nerve cells called neurons. Supporting cells, called microglia, release substances to cause inflammation and start the healing process. But in CRPS, for reasons not completely understood, the process of inflammation is not turned off as it normally should be.

Corticosteroids are medications that reduce inflammation. However, when used long term, corticosteroids have many unwanted side effects. Steroids have long been known to be effective early in the course of CRPS, but their usefulness later in the condition was uncertain.

Researchers in Liverpool and Amsterdam recently studied 31 patients with CRPS of at least 3 months duration, and investigated whether or not they responded to corticosteroids. Overall, patients experienced no reduction in average pain intensity. However, a small subgroup of 3 patients did well on the treatment and found their average pain intensity improved significantly. The side effects of long-term use of corticosteroids are many, and patients would need to weigh these against the potential benefits. Many patients will not respond to corticosteroids, but will be exposed to their side effects, as there is no means to predict who will respond.

Are the patients who don't respond to ketamine, but do respond to corticosteroids the same? Only further investigations will tell, but if so, and a blood test for ketamine responsiveness is validated, then it could theoretically be used to predict steroid responsiveness. This is a long way off, but it may be the start of tailoring treatment to individual patients.

More importantly, these observations are highlighting the different mechanisms that may lead to CRPS in different patients. Hopefully, this improved understanding will lead to even better treatments.

Plasma exchange for small fiber neuropathy/CRPS?

More news from Philadelphia: researchers there have studied plasma exchange in a specific type of CRPS and have found it to be helpful. They studied CRPS patients who presented with a clinical picture of small fiber neuropathy or damage to small nerve cells in the body.

Plasma exchange involves removing the patient's plasma and replacing it with those of donors. In theory, this should remove any harmful antibodies that might be attacking the nerve cells in the CRPS patient.

The researchers found that, except for 3 of the 33 patients in the study, plasma exchange achieved a median pain reduction of 64%. The researchers felt it was patients with the greatest small fiber loss and greatest temperature sensory deficits that benefitted the most.

While this is exciting news, it may not be for everyone. The number of patients studied was fairly small, and additional studies will likely be required to verify the results. Also, the study focused on a very specific type of CRPS patient; as noted above, there are clearly different types of CRPS that may require different types of treatments.

Plasma exchange is not without side effects and risks. The patient must have large accessible veins, otherwise they will need a permanent port inserted into the upper chest/neck area, which does carry some risk and limits activities. Plasma exchange means receiving a blood product, with the remote risk of infection. There are other side effects of plasma exchange as well. That said, for a certain group of CRPS patients, if the benefits outweigh those risks, plasma exchange may be an option.

Opening the blood brain barrier

This may not seem like it has much to do with CRPS, but it really might! Researchers in Toronto have found a way to temporarily open the blood brain barrier. Normally, the blood vessels supplying the brain are very tightly closed, unlike blood vessels in the rest of the body. This protects the brain from harmful substances, as they cannot get in, but it can prevent the entry of useful treatments as well.

> *There is even more evidence that CRPS is not the same in all patients, and that treatments that are effective for one type of patient may not work for another.*

The researchers studied patients with brain tumors. Chemotherapy does not penetrate well because of the blood brain barrier. The researchers injected a chemotherapeutic agent along with some microbubbles intravenously into the patient. Then they put the patient in an MRI scanner and used it to target the area of the tumor with high-intensity focused ultrasound. The high-intensity ultrasound caused the bubbles to vibrate, and temporarily opened the blood vessels in the area of the tumor. This allowed the chemotherapy to cross into the brain tumor.

Why might this be useful someday in CRPS? We know that in CRPS, there is inflammation in the central nervous system (brain and spinal cord). Some treatments that might be useful to reduce that inflammation may not be able to penetrate the blood brain barrier on their own. So this may be a way of delivering those treatments without having to inject them into the spine directly.

So there are lots of reasons for optimism for better CRPS treatments. But it is so hard to wait!

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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.

COMMUNITY & CULTURE

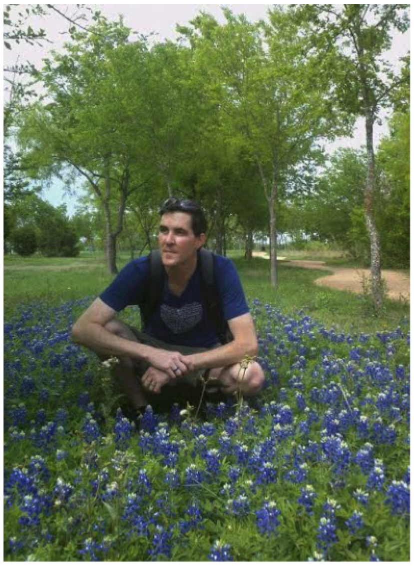
Driving for a Difference: Meet Michael Haymond

BY ANNA EVENOSKY

Sometimes while coping with Complex Regional Pain Syndrome (CRPS) the pain itself isn't the hardest part.

Rather, it is that you feel alone and helpless. You find yourself stuck in a dark place where there seems to be no answers, no awareness, and not even a glimpse of hope. This life not only affects the sufferer, but their loved ones as well. It puts us in a position where we want to help and make a difference.

Please meet Kyle Hoskins, the founder of RideCares. RideCares gives Lyft and Uber drivers the option to donate a portion of their tips to a cause that they are passionate about.



Michael donates a portion of the tips he receives to the RSDSA every month through RideCares.

Rewind to years ago when Kyle met a man named Michael Haymond, someone who would become a role model in the CRPS community. Michael Haymond is certified to drive for Uber, although he chooses to devote most of his time toward driving for Lyft as a full time job in Austin, Texas.

When Michael met Kyle at a drivers meet-up, he learned about RideCares. Instantly he decided that he wanted to have Kyle help him set up a webpage for CRPS: www.love.ridecares.com. (More information is at www.lyftdeal.com.)

Michael donates a portion of the tips he receives to the RSDSA every month through RideCares.

Why did he choose to support the RSDSA? After all, there are hundreds of causes he could have chosen to support.

CRPS has left a huge impact on Michael Haymond due to his wife's Shannon Haymond's diagnosis. His wife has suffered from CRPS for two years and the two of them have been exposed to the cruel and disheartening realities of having this illness.

Michael feels that the RSDSA is the most important of all causes to support due to the lack of awareness. He hopes to not only raise awareness for people like you and myself, but also for the doctors who have never heard and are uneducated on CRPS/RSD.

A long-term goal of Michael's is to open up a hotline for CRPS sufferers due to the high suicide rate. He and Shannon would like for it to serve as a place where CRPS sufferers can find support and understanding, 24 hours a day, whenever they need it.

Mike and his wife, Shannon Haymond

He hopes that down the road CRPS treatments will become more available to those who suffer. He would like to see treatments such as the ketamine-induced coma become more available in the United States. His hope behind this is that, with more treatment options, people like his wife will be given a break and can finally feel some relief.

Michael would like to send a message to everybody with CRPS: "We love you, hold on, and hope for a brighter future."

He would also like to encourage other people who drive for Uber or Lyft to donate a portion of their tips through RideCares just like he does.

He feels that it is a great way to raise awareness while raising money at the same time. Anybody who earns tips can do this too, even if you don't drive, stresses Michael.

If you are not interested in being a driver, you can still help out by voting for the RSDSA on RideCares.com. If the RSDSA receives the most votes in a week, we receive an extra $25 dollar donation.

Thank you Michael for all you do and for your acts of kindness.

You give CRPS sufferers hope and are an inspiration to those who want to make a difference.

ABOUT THE AUTHOR

Anna Evenosky was diagnosed with CRPS in 2012. Currently her neck down is affected. She also suffers from Postural Orthostatic Tachycardia Syndrome (POTS), anxiety, and depression.

She frequently contributes to the RSDSA blog as well as "The Mighty" and "Odyssey". She loves to express herself through writing and address common issues regarding chronic illnesses in hopes of helping others.

EMPLOYMENT & LEGAL ISSUES

Six FAQs about Social Security Disability Insurance

BY BRYNN LAPSZYNSKI

Over 200,000 individuals in the Unites States suffer with complex regional pain syndrome (CRPS) per year. Constant pain and inflammation cause many to consider applying for Social Security Disability (SSD) benefits, but uncertainty about the application process may unnecessarily delay or prevent CRPS patients from applying.

What is Social Security Disability?

SSD is an insurance program for individuals who are no longer able to work because of their physical or mental health conditions. Applicants must have been out of work for at least 12 months due to their condition or are expected to be unable to work for at least 12 months. Essentially, SSD is an insurance program for workers who have paid Social Security taxes, but are now prevented from working due to a serious health issue. Individuals are usually covered by this insurance program if they had worked five out of the last ten years prior to becoming disabled and have paid Social Security taxes.

What is Supplemental Security Income and how is that different from SSD?

Supplemental Security Income (SSI) is a separate program administered by the Social Security Administration (SSA). Unlike SSD, SSI is a needs-based program that provides financial assistance for disabled individuals who may not have worked in many years, only for a brief period of time or not at all. As with SSD benefits, the applicant must be out of work for 12 months or is expected to be unable to work for at least 12 months because of their medical condition. SSI applicants must have limited income and assets in order to qualify, whereas SSD applicants must have paid into the Social Security system.

> *SSD is an insurance program for workers who have paid Social Security taxes, but are now prevented from working due to a serious health issue.*

A good indicator of whether an individual will be eligible for SSI is whether or not they meet the financial criteria for public assistance benefits. As with public assistance benefits, SSI eligibility is based on household income.

What conditions are considered "disabling" by the SSA?

The SSA (who evaluates disability applications) considers a wide range of conditions disabling. Some examples include osteoarthritis, degenerative disc disease, congestive heart failure, epilepsy, as well as mental health conditions like depression and bipolar disorder. Painful conditions, such as CRPS, can certainly be a basis for an SSD application. The SSA evaluates whether a condition is severe enough to prevent applicants from performing work that they have done in the past or that their background prepared them to do. Consistent treatment with medical providers, including specialists such as rheumatologists and neurologists, is the best way to document the severity of a condition.

How does the application process work?

Once an individual applies for SSD or SSI, their application is first evaluated to ensure that they meet the technical requirements of either having sufficiently paid into the Social Security system or that they meet the financial requirements of SSI. Next, the individual may be asked to attend an independent medical evaluation at the request of the SSA. Reports from this examination, along with the applicant's own doctors' reports, will be evaluated to determine if their condition is severe enough to be determined disabled under the SSA's guidelines.

It is not uncommon for applicants to be denied at this initial stage. Individuals who are denied initially can appeal the decision. A hearing in front of a judge allows the individual to talk about their conditions, symptoms and how their everyday life is impacted. Since this is a more personalized approach, more applications are approved at the hearing level than at the initial stages.

What happens if my claim is approved?

Individuals who are approved for either SSD or SSI benefits are entitled to retroactive back pay from the date that the SSA determines the individual became disabled. It is important to note that SSI applicants can only receive retroactive pay dating back to the date of their application.

In addition to retroactive amounts, those approved are entitled to monthly benefits. For those awarded SSD benefits, the monthly amount is based on how much the individual contributed to the system while they were working. This amount differs based on a person's employment and earnings history. Those awarded SSI receive a rate that is set by the government and sometimes supplemented by the state. It can be reduced based on a person's household income, resources or living situation.

Along with monthly benefits, those awarded disability can also receive health insurance. Successful SSD applicants can receive Medicare 24 months after the date they became entitled to benefits. Individuals who are awarded SSI can receive Medicaid after their SSI application has been approved.

How can an attorney help with the disability process?

Having an attorney throughout the entire process ensures that all steps are completed correctly. Any missteps can lead to delays in receiving benefits. At the initial level, an attorney will act as a liaison between the individual and the SSA. An attorney will file the individual's application and follow-up regularly with the Administration to ensure the claim is being adjudicated. Although the SSA is responsible for gathering an individual's medical records at this stage, an attorney will communicate with the SSA to ensure that it has received important medical reports and that deadlines have been met.

Should an individual be denied at the initial level, an attorney will ensure that an appeal is filed right away. At this stage in the process, the attorney is now responsible for gathering updated medical records, tests and doctors' reports. The goal is to ensure that a judge has all of the most up-to-date medical information when making a decision.

In addition, prior to appearing in front of a judge, an attorney will prepare someone for the hearing by going over what to expect, common questions and their medical information. During the hearing the attorney will play a key role by outlining the details of the case for the judge and the reasons why the individual is unable to work.

ABOUT THE AUTHOR

Brynn Lapszynski is an associate attorney at Disability Justice. She focuses her practice exclusively on assisting Social Security applicants file and appeal for disability benefits.

Disability Justice has proudly represented thousands of Americans in all 50 states with their SSD cases. If you are interested in speaking with an attorney about applying or appealing for SSD, you can call Disability Justice for a free consultation at 800-773-1300 or by visiting www.disabilityjustice.com.

COMMUNITY & CULTURE

CRPS Recipes and Mainstays

BY KYLE VORCHHEIMER

CRPS is a terrible disease that affects our ability to stand and operate for a long period of time. However, let's face it: with the financial burden this disease brings, we cannot afford to eat out or take in nightly.

I always make sure I have CRPS mainstays in my house at all times.

When I do work up the energy to cook a meal it has to be fast and easy. I have to be in and out of the kitchen quickly, or my pain will worsen quickly and my following days won't be easy. I don't have the energy to be proactive and go out and buy all the ingredients I will need for a night's meal.


Chef Vorchheimer frequently contributes his recipes to the RSDSA newsletter.

I also purchased a chair from Amazon that allows me to wheel around the kitchen without having my feet on the floor. It doesn't have arms, so I am able to grab onto anything to wheel myself from stove to fridge to sink and make meals for myself and the rest of my family. When finished, you will be amazed as what you did all in the comfort of your chair.

The chair is called (Boss B16245-BK Caressoft Medical/Drafting Stool with Back Cushion) and can easily be found on Amazon. It was delivered to my doorstep and is quick and easy to put together. I was able to do it all while sitting down.

My location of CRPS is in my feet so I have trouble standing. However, I know that many of us suffer from CRPS in the hands and arms. "Good Grips" is a company that provides utensils for those with hand issues. These items are weighted and have great gripping so that they are easy to hold and handle. I tried these items out for myself and I loved them. They are much easier to use than your average cooking utensil. They can be found at all your local stores or online for easy delivery.

Let me now share a few recipes that I use weekly to cook items in bulk! Why cook every night when you can cook a few items that are very versatile? These items are quick and easy to prepare and are tasty too!

Breaded Chicken

This is one of the most versatile things you can keep in your freezer or refrigerator. It can be cooked very easily and used for a variety of items, such as chicken parmesan, sandwiches, omelets and stir fries, in a salad, or just by itself with some ketchup or sauce. Once cooked, place in a large Tupperware, ensuring you use tin foil between layers to prevent sticking.

Chicken breasts work best for this recipe. You'll need three dishes to complete the breading process: a dish with flour, a dish with eggs that have been beaten, and a dish with your breading mixture. As for your mix, I use equal amounts of panko bread crumbs and Italian bread crumbs. Add a good amount of salt and then some pepper. Mix well.

To bread the chicken, start by coating it with flour, then dip it in the egg mixture, followed by the bread crumb mixture. The breading should be just thick enough so that you can no longer see the raw chicken.

Coat a skillet with oil, which should be halfway up the chicken when it's placed in the skillet. Cook the chicken in the skillet until both sides are nice and brown and the juices run clear when punctured with a fork. Or, use a thermometer to an internal temperature of 165 degrees.

Cool and enjoy.

Stir Fry

Stir-frying is a quick and easy way to make a great dinner that is tasty and good for you.

I usually pick up some rice from my local Chinese store to save me the time of cooking it myself; you can also use minute rice!

This recipe serves about four people. If you want to make it to last, feel free to double or triple. It will last in your refrigerator for about three to five days.

This recipe calls for 2 tablespoons vegetable oil, 1 pound chopped meat or beef sirloin cut into strips, 1 1/2 cups fresh broccoli florets, 1 red bell pepper cut into matchsticks, 1 carrot thinly sliced, 1 chopped green onion, 1 teaspoon minced garlic and 2 tablespoons soy sauce or bottled teriyaki sauce. Feel free to substitute out the beef for your protein of choice.

Start by heating vegetable oil in a large wok or skillet over medium-high heat. Cook and stir beef until browned, which should take about 3 to 4 minutes.

Move the beef to the side of the wok and add broccoli, bell pepper, carrots, green onion, and garlic to the center of the wok. Cook and stir vegetables for 2 minutes.

Stir beef into vegetables and season with soy sauce or teriyaki sauce. Continue to

Pantry Pointers

While the pantry should always be stocked with your favorite items, these items listed should be your mainstays for quick and easy cooking.

On the Shelf

My stocking list includes tomato sauce (bottled or fresh), ketchup, mustard, pasta, tuna, mayonnaise, canned beans, olive oil, preserves or jelly, peanut butter, a loaf of bread, canned and pitted olives, bread crumbs, taco shells, chips, crackers, and minute rice.

In the Fridge & Freezer

Refrigerator items include fresh salad greens, eggs for scrambles and sandwiches, chocolate chips, yogurts, milk, lemon juice, parmesan cheese, hummus, salsa, Dijon mustard, sour cream and butter or margarine.

Freezer items include frozen vegetables that can be steamed in the bag, frozen edamame, veggie burgers or meat burgers of choice, frozen berries for smoothies, pre-made pizzas, frozen mashed potatoes, french fries, breaded chicken (see recipe), meatloaf (see recipe), chicken cutlets, and chopped meat.

Spices

Seasonings are a great way to spruce up your meals with some added flavor. Ensure you have salt, black pepper, garlic salt, garlic powder, red pepper flakes, bottled crushed garlic, dried oregano, dried basil, and garlic.

The worst that can happen is you make a dish that doesn't taste great, but that's what seasonings are for.

cook and stir until vegetables are tender, about 2 more minutes. Serve over rice and enjoy.

Mac and Cheese

This is a quick and delicious meal that is hearty for the entire family. This recipe serves about 4 to 6 people. However, feel free to double, triple, or quadruple so you have it to last. It lasts about 5-7 days in the refrigerator.

This recipe calls for 8 ounces elbow macaroni, salt and pepper (about 1/2 teaspoon salt and 1/4 teaspoon ground black pepper), 8 ounces cheddar cheese blend or similar blend of cheeses, 1 1/4 cups light cream or half-and-half and 4 tablespoons butter cut in small pieces.

Heat the oven to 350°. Butter a 2-quart baking dish. Cook macaroni following the package's directions.

Drain in a colander and rinse with hot water.

Scoop about 2 cups of the drained macaroni into the prepared baking dish. Sprinkle with about 1/4 teaspoon of salt and 1/8 teaspoon of pepper, then top with about half of the cheese.

Layer the remaining macaroni on the cheese layer and sprinkle with another 1/4 teaspoon of salt and 1/8 teaspoon of pepper.

Top with the remaining cheese and dot with the butter. Pour the cream over everything and bake for about 25 minutes.

Meatloaf

Meatloaf is very versatile and also easy to freeze for later use. It also lasts about a week in the refrigerator or longer in the freezer.

This recipe will make enough for about four people. Feel free to double triple or quadruple this recipe so you can have it to last! I make enough for about 20 people at once and I individually freeze the pieces in the freezer and take it out to thaw when desired.

It makes for a great and hearty meal. You can eat it alone or as part of a sandwich topped with your favorite sauce. I sometimes break up the pieces and add it to a pasta dish for another quick and easy meal.

This recipe calls for 1 pound ground beef or turkey, 2 eggs, 2 cups milk, 2 cups dried bread crumbs, salt and pepper to taste, 4 tablespoons brown sugar, 4 tablespoons mustard and 1 cup ketchup. For some added flavor you can add 1 package chopped mushroom.

To prepare preheat oven to 350 degrees F (175 degrees C).

Finely chop mushrooms and sauté in a little oil or butter.

In a large bowl, combine the beef, mushrooms, egg, and milk, half of the ketchup and bread crumbs. (If you have trouble using hands, you can use a mixer as long as you use the lowest mixing setting!) Season with salt and pepper to taste and place in a lightly greased 5x9 inch loaf pan or form into a loaf and place in a lightly greased 9x13 inch baking dish.

In a separate small bowl combine the brown sugar, mustard and ketchup. Mix well and pour over the meatloaf. Bake at 350 degrees F (175 degrees C) for 1 hour or until the internal temperature reaches 145 F for beef and 165 F for turkey.

Being Your Own Chef

I hope these recipes and ideas help you as much as they help me.

I once attended culinary school, but I am no longer able to cook as exquisitely as I once did. We all need to adapt and live the life we can. Adapting is the best form of coping and getting into the kitchen has always been a great way for me to take my mind off things. Feel free to get creative; these are only ideas to help.

Cooking is what you make of it and we all have different palates.

The worst that can happen is you make a dish that doesn't taste great, but that's what seasonings are for. Remember to have fun and utilize the things around you to make things easier.

ABOUT THE AUTHOR

Kyle Vorchheimer trained as as chef before he developed CPRS.

Chef Vorchheimer's meatloaf is packed with flavor.

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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

JULY 25–29
PEDIATRIC PAIN WEEK AT THE CENTER FOR COURAGEOUS KIDS IN SCOTTSVILLE, KY

AUGUST 20
THIRD ANNUAL CRPS/RSD GOLF TOURNAMENT FOR SAMANTHA HARBER – MONTICELLO, MN

AUGUST 21
SECOND ANNUAL WALK OF HOPE – ERIE, PA

AUGUST 26–28
MACY'S SHOP FOR A CAUSE WEEKEND – NATIONWIDE

SEPTEMBER 10
LONG ISLAND CRPS/RSD AWARENESS WALK – EAST MEADOW, NY

SEPTEMBER 10
2016 CRPS/RSD WALK FRO AWARENESS – PENNSAUKEN, NJ

OCTOBER 22–23
KETAMINE CONFERENCE – CHICAGO, IL

NOVEMBER 5
THIRD ANNUAL CENTRAL NEW JERSEY WALK OF HOPE FOR A CURE – LINCROFT, NJ

NOVEMBER 6
FIGHT THE FLAME 5K – CHARLOTTE, NC

NOVEMBER 7
COLOR THE WORLD ORANGE – WORLDWIDE

NOVEMBER (DATE TBD)
CONQUER PAIN VIRTUAL WALK – WORLDWIDE

If you would like to plan an event, please contact Samantha Barrett at SBarrett@rsds.org. We are also planning The Longest Day of Golf at golf courses around the United States. If you are interested in assisting the coordinator of The Longest Day of Golf at a golf course near you, please email SBarrett@rsds.org

PEER-TO-PEER CONVERSATION

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