

IN RARE FORM



I Strapped Up My Boots and Dug In My Roots

In our first 2023 edition of In Rare Form, we sat down with Country Music Artist Annie Vander to discuss her journey with CRPS and how music has changed her life.

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How and when did you develop CRPS/RSD?

I developed CRPS after a fall on the ice in January of 2019. I shattered my wrist on a 60 below zero degree day, as my husband and I were trying to leave for a Southern Caribbean cruise. Needless to say, that cruise did not happen for us. I had to have surgery to repair my injury, and the doctor rebuilt my wrist with titanium hardware. I thought all seemed to be healing well for me, until a few weeks later. I remember waking from a nap on a Friday evening, literally screaming because of extreme pain, and I was convinced my arm was broken again, though it wasn't. My arm began to swell back up, (not that it was back to normal at that point in time), but it became much, much worse. The pain was unbearable, and something that is hard to describe for anyone who doesn't have this condition. I will never forget going to my next appointment with the occupational therapist I was working with, who was already concerned at the fact that we had lost some progress, and the now increase in pain and swelling. She told me to go back to my orthopedic doctor, but I had already gone there that very morning because of the severity of the pain. When I told her the doctor was concerned I had CRPS, she just said, "Don't Google it right now, because it can be scary, but I have a referral for you." She said she could lose her job if she told me to go somewhere else for therapy, but she did not feel comfortable

treating me with this condition, and knew it was important for me to see someone who had experience working with patients who have CRPS. I am so thankful for her and the referral she had for me. She took a chance at losing her job, but knew it was the right thing to do.

What has daily life been like since your diagnosis?

Daily life right after my diagnosis was difficult at best. I felt my world was turned upside down. At the time of my accident, I had been working in the pet care world, I was a triathlete, so I was very active. After my fall, I had a hard time moving around and completing daily tasks for myself, so taking care of animals and running, or participating in triathlons wasn't in the cards for me for the foreseeable future. Though my wrist was broken, pain had spread up past my shoulder. I had to figure out how to do everything one handed, and cope with the daily extreme pain. If I even overdid it a little bit, I would set myself back 100 steps. I had to stop working, was relying on others to drive me places, pain and stress kept me sleepless, and I was scared. My mother had passed away in 2010 from an "unknown neurologic disorder" after spiraling out of control in pain after a fall where she broke her arm and shoulder as well. I was so worried I would end up like her. I and some of my family still wonder if she had CRPS, and was undiagnosed. So, I was terrified for many, many reasons.

All of that said, after seeing the specialist I was referred to, we worked through so much together. He reminded me, at almost every appointment, that I was NOT my mother. He ALWAYS kept trying to lift my spirits. He would remind me every day I saw him of something I should be happy about and/or grateful for. He was very good at explaining what I was going through, and I believe, helped to rewire my thinking, so to speak, as he worked with me on the PT exercises. He had encouraged me to try different activities, slowly, of course, when he thought I was physically ready to try. Some attempts went better than others. So, when I couldn't do something physically, I would find something that made me happy to take my mind off of the pain. I remember days at home by myself just using an old karaoke machine and singing my heart out, as singing was something I was passionate about when I was younger and it brought me joy. I focused on the positive of being able to sing through the music and forgetting the pain for a few moments.

Fast forward, I finished treatment with him in late spring and then transferred out to another PT, closer to home, as I started to improve. It took me until October of the same year to finally finish PT and feel ready to get back to life again. I reached a point where I had some pain free days, or it was only very minimal. I reached remission.

I am so grateful to now be able to accomplish most of my everyday tasks without pain. I have learned to play piano since, began writing my own music, can care for my own large dogs at home, and even go for an occasional run here and there. As long as I slowly work up to certain things and respect my body's limits, so far so good.

What is one thing you wish those without CRPS/RSD could understand?

I feel like it is hard to put into words just how bad the pain is and how frustrating it can be to explain to doctors, nurses etc... at new appointments, exactly what CRPS is. I don't think anyone can truly understand it until you go through it for yourself, and I don't wish that on anyone!

So, that said, if someone could understand that they need extra patience for someone going through a tough time with CRPS. This is a disorder where everyone experiences things differently and reacts to certain treatments and therapies differently. Help be a voice for them and just offer an extra hand or smile when they need it. Encourage them when they need it, or be a shoulder to cry on, or an ear to listen to them, when necessary. I wish people knew how challenging it can be to find your way with a disorder that is not well understood in the medical community.



What advice would you give to newly diagnosed Warriors?

Seek out treatment with someone experienced working with this condition quickly!! Don't EVER lose hope, and find something positive to focus on daily, no matter how big or small, set achievable goals for yourself!! It is ok to be sad for a time and it is OK if you don't always make your goals. Just remember you are a WARRIOR and staying focused on small wins, daily, is so, so helpful. Don't do too much too fast, and find your team!!! Surround yourself with positive and uplifting people who will help advocate for you.... and have someone go with you to appointments when you can.

What activities or treatments have helped you find temporary or long term relief?

When I found myself singing again, on days I was at home, after or between my PT appointments, my mind was taken to a happier place and off the pain!!! Looking back, it unintentionally became distraction therapy. I was always involved in music, since grade school, and I am so happy I rediscovered it during my healing processes. Later on, finding out singing or humming stimulates the vagus nerve, it just encouraged me to sing more. I feel I found something I was passionate about, all over again, and I just didn't want to stop because it kept my mind off of the pain. With it I ended up finding myself a brand-new path in the country music scene, with a song I wrote, titled "Falling Into Nashville." I started writing my own music, and that song ended up landing me on a radio tour and charted on the Music Row Country Breakout Chart! It also charted in the Top 5 streaming and was also in the Top 18 Most Downloaded songs on PlayMPE, coming in right after Brett Eldredge.

"Falling Into Nashville" is actually based on the story of my accident, and how I rediscovered a happy place again. One of the lines being, "I strapped up my boots and dug in my roots, had to find a brand new way to get through the day" Basically, I picked up my pieces by falling back into music, or Falling Into Nashville, if you will. Singing and songwriting is an emotional outlet for me, and I feel it is so important to release that energy to help keep stress down, as well. With the singing and songwriting, I still have to keep active, be mindful to keep my schedule manageable to stretch and keep moving to keep the pain at bay.



Anything else you would like to add?

CRPS taught me a huge life lesson and that is to stay positive, grateful and patient. Maintaining a mindset like this can help with so much. I hope to spread that positivity through my music and be a voice for CRPS warriors and their loved ones.

With the grit and determination to move mountains and the endless talent she exudes, Annie Vander is the real deal. The Illinois native has always had a passion for making music, but life led her in a different direction to begin with. Her life-changing accident,

CRPS diagnosis, and unforeseen obstacles changed the trajectory of her career forever. Annie realized that she was always meant for making music, so she is making that dream come true and inspiring fans along the way. Her chart-topping single Falling Into Nashville received great traction at country radio and landed her first charting single on the Music Row Country Breakout Chart. This release also charted in the Top 5 streaming and was also in the Top 18 Most Downloaded songs on PlayMPE, coming in right after Brett Eldredge.

Connect with Annie via her website, AnnieVanderMusic.com, and her [Instagram](#). Check out her music on [YouTube](#) and [Spotify](#).

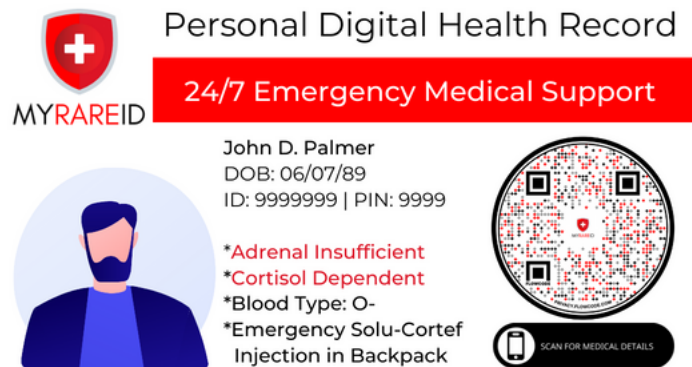


Learn More About My Rare ID

My Rare ID is a robust platform designed to provide support to rare disease patients and caregivers by making available instant rare disease education for emergency providers from trusted medical sources and secure 24/7 access to digital patient profiles.

My Rare ID is customized to each individual patient, featuring a patient's critical medical details from current diagnoses and medications to treatment protocols and historical records. The goal is to not only expedite the time to an accurate diagnosis and precision treatment, but to prevent medical errors and optimize outcomes.

To learn more, visit myrareid.co.



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ID: 9999999 | PIN: 9999

- *Adrenal Insufficient
- *Cortisol Dependent
- *Blood Type: O-
- *Emergency Solu-Cortef Injection in Backpack

SCAN FOR MEDICAL DETAILS

You Can Plan a Special Event with RSDSA

You can make a difference in the lives of CRPS Warriors and those who love them by organizing a special event. When you host a special event you increase awareness, build community and raise funds. Invite your friends, family, coworkers, and everyone you know to get involved in our events.

You can organize in-person, virtual or hybrid events. Special events can be opportunities for fun, engagement, and education. Every dollar raised supports RSDSA's mission and makes our work possible. Your donations are gratefully received, impactfully used, and profoundly appreciated.

We are here to help you plan your own special event. When you are ready, please contact Jeri Krassner, RSDSA's Special Events Coordinator at jkrassner@rds.org or call or text 917-597-7256. Please provide your **email, contact number and your location** when reaching out!

Interested in Writing for the RSDSA Blog?

We're always looking for Warriors who want to tell the story of their CRPS journey story on the RSDSA blog!

If you're interested in sharing your story with us and fellow Warriors as a form of therapy and/or in order to help those who may be in the same part of their journey as you are, send us an email at alexisdavis@rds.org.



Contribute to a New CRPS Book

via Eric M. Phillips on [LinkedIn](#)

I would like to inform you that Dr. Alaa Abd-Elseyed and I are writing our seventh book regarding CRPS patient stories.

We would like to hear from anyone who would be interested in having their personal CRPS story published in our new book.

By having your CRPS story published, it would help other CRPS patients cope with their pain, help educate the medical community, help educate patients, family members, and friends. The following criteria is needed to submit your story:

- How did you develop your CRPS (trauma or surgery)?
- How long have you had CRPS (date of onset)?
- Type of surgeries you may have had. (Amputation, back surgery, carpal tunnel surgery, knee surgery, shoulder surgery, etc.).
- What type of trauma did you have (soft tissue injury, crush injury, Venipuncture injury (needle injury), etc.)?
- What treatments have helped or not helped? (Please write about your treatments, therapies, opioids, procedures (nerve blocks, SCS, infusion pump, sympathectomy, psychological treatment, dates, and duration of treatments).
- How has CRPS changed your life? (For example, divorce, addiction, losing your job, becoming homeless, suicidal, etc.).
- If you know of a CRPS patient who had committed suicide or died from complications due to CRPS, we would like to get in touch with their family.
- You can write as many pages of your story as you would like, and please add a title for your story. All stories require a title.
- Please feel free to add a few photos of your affected extremities (these photos will be used in our next volume of the CRPS Picture eBook series).
- For your story you have an option to use your first and last name, just your initials, or you can be anonymous. (Please choose and let me know which option you are most comfortable with using for your story).
- In regards to using a doctor's name in your story, you need to have their written permission (this needs to be sent to us) to use their name or you can just use their first and last initials in your story (example: Dr. B or Dr. E.B. or you can just say my Neurologist, Orthopaedic, or my Surgeon, etc...).
- In regards to using a doctor's website, it can only be used if you have written permission from the doctor to use his/her website address (this needs to be sent to us). If you do not have written permission, we will have to remove it from your story.
- If you have your own website address for an RSD-CRPS group, it can be used to help promote awareness for RSD-CRPS.

Please submit all stories in either a Microsoft Word document (.doc, .docx), a Google doc, or a .pdf file.

The deadline date to submit all stories is **Wednesday April 5, 2023**.

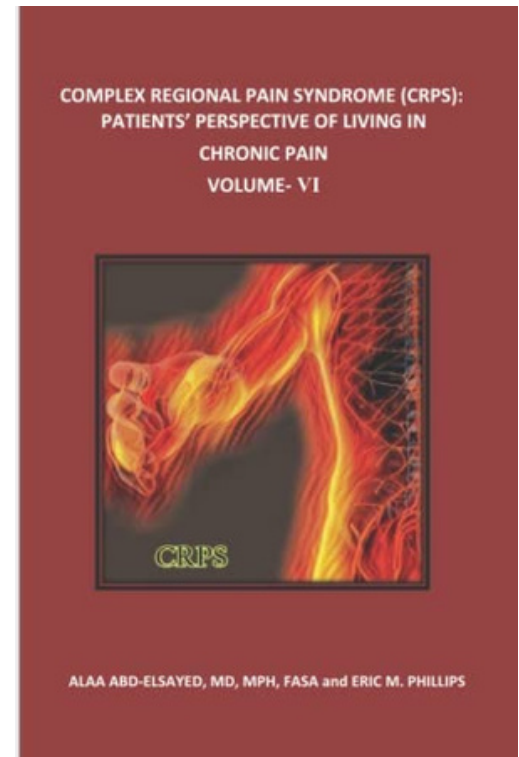
If you are interested in having your story published or have questions regarding this book project, please contact Eric Phillips by email at utopia33@prodigy.net (please put CRPS Book in the subject line) or by phone or text at 508-479-9888.

Please let me know if you would like me to email you a sample story to use as a guide in writing your story.

We are looking forward to hearing from you.

Best regards,

Eric M. Phillips and Dr. Alaa Abd-Elseyed



Stem Cells Could Relieve CRPS Pain and Inflammation

The National Institutes of Health (NIH) recently awarded researchers at the Cleveland Clinic a \$5.5 million grant to develop a stem cell treatment for complex regional pain syndrome (CRPS). This is the first federally funded research to date on mesenchymal stem cells for pain, and the largest grant to support studies on CRPS.

Stem cell therapy is a type of regenerative medicine, a relatively new interdisciplinary field. “Stem cells can replace, restore, repair, and regenerate tissues,” explained Alan D. Kaye, MD, PhD, anesthesiologist and director of the Pain Program Fellowship at Louisiana State University School of Medicine. “They’re being studied for many different disease states, and CRPS is an exciting target related to stem cell therapy.”

In a press release announcing the funding, Jianguo Cheng, MD, PhD, medical director of Cleveland Clinic’s Consortium for Pain and the principal investigator on the study, noted, “This is an unprecedented opportunity to tackle this major problem using a novel mechanism guided by cellular interactions and addressing the condition on a cellular and molecular level.”

If this approach is effective, said Dr. Cheung, it could potentially open new treatment options for people living with other chronic pain conditions. Chronic pain affects more than 50 million American adults¹ and is one of the leading causes of disability and disease worldwide. ([Read more via Practical Pain Management](#))

Our Odyssey, Young Adults Journey of Living with a Rare and/or Chronic Illness

by Megwyn Sanders-Andrews, PhD; Executive Director, Our Odyssey and Jean Campbell, Board of Directors, Our Odyssey

Young adults, ages 18-35, have some things in common. Young adulthood is a time, for many, to begin planning for the future. That can mean preparing for college, making the first steps in your career, renting your first apartment, buying your first home, dating, navigating a committed romantic relationship, starting a family and more.

But what if plans for the future are impacted by a rare disease or chronic illness? Young adults with rare and/or chronic diseases have some specific things in common. They not only share the commonalities of their age group, but also may have the shared lived experiences of navigating young adulthood while dealing with illness, while struggling to cope with a diagnosis or while working to get a handle on a chronic health issue.

Our Odyssey was founded in 2019 by Seth Rotberg and Kristina Wolfe. They recognized and experienced the challenges facing young adults ages 18 to 35 whose lives were impacted by a diagnosis of a rare and/or chronic illness. Their goal was to create Our Odyssey as a way to connect this often-disenfranchised community with one another through social and emotional support.

What Seth and Kristina quickly realized was that the unmet needs of this young adult community were substantial. In 2021 there were 75.6 million people in the U.S between the ages of 18 and 34.¹ According to a 2019 CDC report, 53.8% of those young adults had at least one chronic condition.² 22.3% had more than one condition. Rare diseases impact between 3.5-5.9% of the population.³ This translates to between 2.6 and 4.4 million individuals in the U.S. alone.

Further, Our Odyssey's founders learned first-hand that young adults with rare or chronic conditions often endured depression and anxiety. This realization was validated by a cross-sectional study published by the NIH that found 42% of patients with rare chronic diseases have moderate to severe symptoms of depression and 23% have moderate to severe anxiety.⁴ Seth and Kristina saw that the young people in this group needed and wanted to build more connections with others who understood their unique situation.

As Toni Bernhardt writes in *Psychology Today*, young adults with chronic pain or illness face extra obstacles. People in this demographic may face disbelief about their condition, level of pain or disability status because they are young or their diagnosis is invisible. Young people may feel stigmatized by their condition and struggle when others in their age group participating in activities they can no longer enjoy. According to Bernhardt, young adults with rare and/or chronic conditions report they may also struggle to complete school and worry about finding a romantic partner.⁵

This is why the programs Our Odyssey provides are so vital. In the last three years, Our Odyssey has grown from an initial two-person partnership to holding multiple events each month and reaching over 600 individuals each year, representing 130+ different rare or chronic conditions, 36 U.S. states and 4 countries.

Through social meet-ups, speakers and educational workshops, Our Odyssey provides a place for young adults to connect, learn, and empower themselves and each other. And the connections Our Odyssey provides are effective. According to our post-event surveys, once leaving an Our Odyssey event, young adults feel happier (92%); feel hopeful (83%); feel excited (79%); and feel less sad (52%) and anxious (47%).

As we celebrate three years as a national leader in serving young adults with rare and/or chronic conditions, Our Odyssey is excited, too, about what the future holds. Our Odyssey launched a new Young Adult Programming Advisory Council (YAPAC) in 2022 to ensure that all Our Odyssey programs are designed **by** young adults with rare and chronic conditions **for** young adults with rare or chronic conditions.

Our Board of Directors, along with the YAPAC, are also gearing up to create future initiatives including: creating new dynamic, unique and accessible online spaces to build community, socialize, and gather; a local, grassroots ambassadorship program; and a leadership academy for emerging leaders in nonprofit management and patient advocacy. In addition, Our Odyssey is in the planning stages for a new, hybrid in-person/virtual conference specifically and solely for our community. This conference will bring together Our Odyssey ambassadors and participants throughout the U.S. and internationally.

Ultimately, by supporting young adults with rare and chronic conditions across the United States and beyond, Our Odyssey provides a reminder that no young adult should feel isolated. We are all on this journey, on this odyssey, together.

Join us at Our Odyssey today at ourodyssey.org or reach out to Executive Director, Megwyn Sanders-Andrews, Ph.D. at executivedirector@ourodyssey.org.

1 JC Lupis, "So How Many Millennials Are There in the US, Anyway? (Updated)," Marketing Charts, May 26, 2022, <https://www.marketingcharts.com/featured-30401>.

2 "Chronic Conditions among Adults Aged 18—34 Years - United States, 2019," Centers for Disease Control and Prevention (Centers for Disease Control and Prevention, July 28, 2022), <https://www.cdc.gov/mmwr/volumes/71/wr/mm7130a3.htm>.

3 "Chronic Conditions among Adults Aged 18—34 Years - United States, 2019," Centers for Disease Control and Prevention (Centers for Disease Control and Prevention, July 28, 2022), <https://www.cdc.gov/mmwr/volumes/71/wr/mm7130a3.htm>.

4 "Chronic Conditions among Adults Aged 18—34 Years - United States, 2019," Centers for Disease Control and Prevention (Centers for Disease Control and Prevention, July 28, 2022), <https://www.cdc.gov/mmwr/volumes/71/wr/mm7130a3.htm>.

5 "Chronic Conditions among Adults Aged 18—34 Years - United States, 2019," Centers for Disease Control and Prevention (Centers for Disease Control and Prevention, July 28, 2022), <https://www.cdc.gov/mmwr/volumes/71/wr/mm7130a3.htm>.

Create Content for RSDSA's TikTok Account

RSDSA has officially joined TikTok @RSDSAofficial in order to further educate others about CRPS in addition to our events and activities!

We want to ensure more people learn about CRPS, especially Gen Z (people born between 1997-2012) and Millennials (people born between 1981-1996) as they have a large footprint on the app in addition to being future + current medical leaders.

If you or your children, grandchildren, nieces/nephews, godchildren, etc. are interested in creating content for TikTok, please reach out to us at alexisdavis@rsds.org. And don't forget to tag us in any CRPS-related content you create!

Donate to RSDSA

Have you thought about your legacy? Are you looking for a long-term way to make a meaningful difference in the CRPS community?

Please consider making a planned gift to RSDSA today. Planned giving options include:

- Gifts of stocks and bonds
- Including RSDSA as a beneficiary in your life insurance policy
- Including RSDSA as a beneficiary in your will.
- Contributing via an IRA

Tax benefits apply to each of these options. Please contact your attorney, a financial attorney, or a financial advisor for more info.

We want your feedback!

Please send any suggestions or upcoming events of interest to our community to info@rsds.org and please consider donating at rsds.org/donate.

Thank you to our Title Sponsors

Our title sponsors make RSDSA events and awareness activities possible. Please join us in thanking and supporting them!

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