

IN RARE FORM



The Challenge of a Sudden Disability

by Felice Ivy

The disabilities a person may face can range from loss of a limb, loss of hearing, and loss of vision or speech, among others. It can be a physical, emotional, or psychological challenge. Some people are born with a disability and are taught to adapt to that disability early on. Others, like me, acquire a disability later in life due to an accident or illness. In my case, I became disabled in the blink of an eye at age 47. I was nearing the end of my workday and had just one more stop to make. I was working as a marketer for a skilled nursing facility, and it was my responsibility to visit various health related locations to obtain referrals and meet with staff, patients, and families. That particular day I was grateful to be at my last appointment and was looking forward to returning home. I got on an elevator to the seventh floor to meet with the unit staff. The elevator doors opened, and I stepped out. Unfortunately, the elevator stopped short of the floor and created a ledge which I did not see. My foot caught and I went flying. I immediately felt pain in my left leg and all I could think of was, “please, don’t let me need surgery”.

Well, be careful what you wish for. I did not need surgery, but instead developed a debilitating chronic condition called CRPS. As a result, I have permanent damage to the leg which has resulted in requiring a cane. It has been quite the adjustment. Going from able-bodied, where you don’t worry about things like parking spaces, stairs, shopping, or activities of daily

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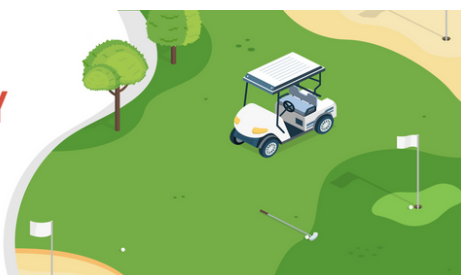
RSDSA's Longest Day of Golf is Monday, September 19, 2022

For the past 38 years, RSDSA has faithfully served the CRPS community. We provide up-to-date information, compassionate support, and funding for research while continuing to look for a cure. One of our major annual fundraising events, the [Longest Day of Golf](#), will take place on **Monday, September 19, 2022**. Our golfer, Tony Consiglio, will complete as many holes as possible from 7AM to 7PM. **Donors will have the opportunity to contribute per hole completed, give a one-time gift, or a recurring monthly gift.**

Please consider giving a gift for our 5th Annual Longest Day of Golf to support individuals and their families who live with the pain of CRPS every day and every night. We at RSDSA try to help those with CRPS find the best treatment and learn to live fulfilling, functioning lives despite their unrelenting pain through initiatives and programs like:

Virtual Educational Opportunities Because of Covid, we have not held in-person conferences. Instead, RSDSA provides current information and support by offering webinars via Facebook Live. To date, we have hosted more than 50 presentations on the science, treatments, and pain management of CRPS. Our YouTube Channel has over 1 million views as our webinars are viewed across the globe. The RSDSA website is visited more than 10,000 times each month by both newly diagnosed and longstanding CRPS Warriors for information and guidance.

**RSDSA'S
LONGEST DAY
OF GOLF
FUNDRAISER**
SEPTEMBER 19, 2022



Zoe's Zoomalong Camp RSDSA has previously sponsored Pediatric Pain Week, which includes sponsoring the Camp for Courageous Kids (CCK) where kids with CRPS and a family member could spend a week at camp having fun, meeting others with CRPS and experiencing new adventures. In 2022, RSDSA launched a virtual alternative to CCK, Zoe's Zoomalong Camp due to the pandemic. Virtual campers actively participated in interactive sessions and together, watched each other laugh, smile, and develop friendships with those who "get it." Living in chronic pain is difficult for anyone but seeing children in chronic pain is heartbreaking. Pediatric Pain Week and Zoe's Zoomalong Camp give families hope and the opportunity to make life-long connections.

Later this month, RSDSA is sponsoring a translational research meeting in Toronto. **The critical research question is "Which treatments work for which sub-types of CRPS?"** We propose that the efficacy of CRPS interventions could be improved by using a precision

medicine approach, in which treatments are targeted based on a patient's CRPS subtype and the presumed mechanisms contributing to CRPS in that patient. That could be the key to funding the studies required to produce meaningful, relevant, and statistically robust results.

Support our tireless golfer, Tony Consiglio, and RSDSA during our [5th Annual Longest Day of Golf](#) fundraiser to help individuals and families live with CRPS every day. Every day, we help CRPS Warriors find the best treatment and learn to live fulfilling, functioning lives despite their unrelenting pain.

This Might Hurt - 2 Week Screening Window + Live RSD/CRPS Focused Q&A



This Might Hurt is a movie focused on three chronic pain patients who have spent years trying to cure their illness without success and then enter an intensive program to retrain their brains.

The film will be available to watch [here](#) from **September 25th to October 9th**. Once you enter the code **RSDSA** you will receive the special discounted rate of \$7.99 instead of \$9.40. Please note that the code is case sensitive.

Join the Q&A on **October 5th at 7pm Eastern** with a panel including Dr. Howard Schubiner, CRPS Warrior Tamara Gurin, and the director, Marion Cunningham. [Register here](#).

Fight The Flame 5K is Sunday, September 25, 2022 in Charlotte, North Carolina

Fight the Flame's mission is to raise awareness and educate the medical field and the public about CRPS while providing resources to support the CRPS community.

Join Fight The Flame's 5K and 1K Family Roll & Stroll on Sunday, September 25, 2022 at McAlpine Creek Park in Charlotte, North Carolina. [Register here](#).



living, to being disabled where those, and many other things, have to be considered, is quite vexing. And not to mention the toll that a sudden disability takes on you psychologically. Life can change quickly.

Although I had spent my entire adult life working with disabled people for one reason or another, this was different- now the disabled person was me! I understood in an entirely new way what a disabled person goes through. At the beginning, before I got a handicapped parking permit, I had been unable to go to the supermarket or drug store many times because the nearest parking spot was too far away. I live on the third floor of a building without an elevator. Getting up and down the stairs, something which I never thought about, was now a twenty-minute ordeal on some days. I was also very self-conscious about the cane. I worried how people would view me. Would they think that I was a feeble old lady? Would they think I was less than I was before? Would they look at me with pity, or worse would I suddenly become invisible? Would they think I was helpless? I myself started to question, "am I helpless"? I wondered if I would now be viewed as a disability and not as a person. It is amazing what goes on in your mind when your life is upended by a sudden disability.

Working in health care gave me the advantage of knowing many wonderful doctors, nurses, social workers, physical therapists, and other professionals. After a brief period of feeling sorry for myself, I decided to talk to a wonderful orthopedist that I knew from the hospital, with the "killer elevator" as I had come to think of it. This kind man listened to my fear, my disappointment, and my pain, and with a smile looked at me and said, "you are still Felice". A very simple statement. My answer? I cried. They weren't tear of sadness though, but of relief. He was right, I wasn't the disability, I was Felice! Yes, Felice now has a disability but by golly that disability didn't have me! I was the same person, I had just as much to offer now as I did prior to the accident. I needed to adjust some things, but I was still me. Suddenly, I felt free! The doctor went on to tell me about several professionals I could talk to for help with the adjustments to make my new normal. He introduced me to a friend of his who was about my age and had been disabled as a result of a car accident. I went to good doctors who helped me manage pain and who taught me little tricks for handling the activities of daily living that had seemed so daunting. I spoke with a social worker who listened intently to my fears and then showed me how many of those fears didn't need to be fears because they were manageable. A physical therapist taught me exercises and desensitization techniques. I also spoke with other disabled people and asked them how they managed certain things that once were easy and now were challenging. The interesting thing is that I didn't look at them as their disability, I looked at them as Mary, and John, and Christopher, and realized they didn't look at me as the cane or the limp. They looked at me as Felice. I was still me; I was still Felice after all.

I learned some valuable lessons here.

- First, you are not your disability. You are simply you with a disability.
- Second, you are not alone. There are professionals and resources available for you to take advantage of.
- Third, life isn't over because you are disabled. Yes, adjustments need to be made but life is full of adjustments and challenges. It doesn't mean that you can't succeed or be happy.
- Fourth, a disability is not something to be ashamed of or to hide from.

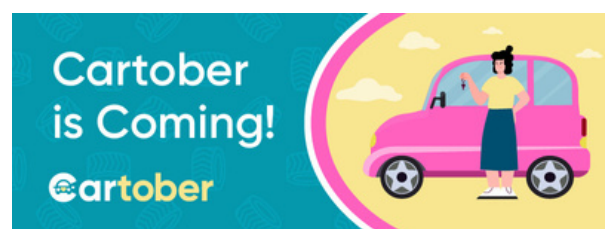
If I could go back to those sad and worrying days immediately after my accident, I would tell myself that it is okay to be sad for a short time. After all, a sudden disability does represent a loss. But I would tell myself to pick myself up and reach out for help after that short period. Talking to that wonderful doctor was the best thing that I did. He pointed me in the right direction and his words lit a fire in me that gave me the confidence that everything would be okay. I don't think anyone with a disability chooses to be disabled, but there are things beyond our control. However, today there are so many resources available which are designed to help the disabled. All you have to do is reach out and grab them. My life is different now than it was before, but it is still my life and it is still wonderful. I am still me.



Felice Ivy has worked in healthcare for the past 28 years. Today, she is the Director of Community Outreach for the Highfield Gardens Care Center in Great Neck, New York. Felice counsels families on services that the facility can offer them as well as engaging various community settings in health lectures, super bingo, health fairs, and other events.

Source: Lifeskills Magazine

Much like Giving Tuesday, Cartober is an online giving campaign held throughout the month of October to highlight the impact vehicle donations can make. Cartober also encourages people to drive change by donating their unwanted car, truck, RV, motorcycle, or boat to their favorite nonprofit or public media station.



CARS is a 501(c)3 nonprofit social enterprise owned by a nonprofit supporting only nonprofits through vehicle donations.

When you donate a vehicle to CARS, RSDSA receives 70% of the proceeds. Learn more about donating your car to benefit RSDSA [here](#).

Flame Out - A Walk to Extinguish RSD/CRPS is September 18, 2022!

The 4th Annual Flame Out - A Walk to Extinguish RSD/CRPS takes place on **Sunday, September 18, 2022** at Joe Palaia Park in Oakhurst, New Jersey. It's not too late to [register](#), [donate](#), and [participate](#)!

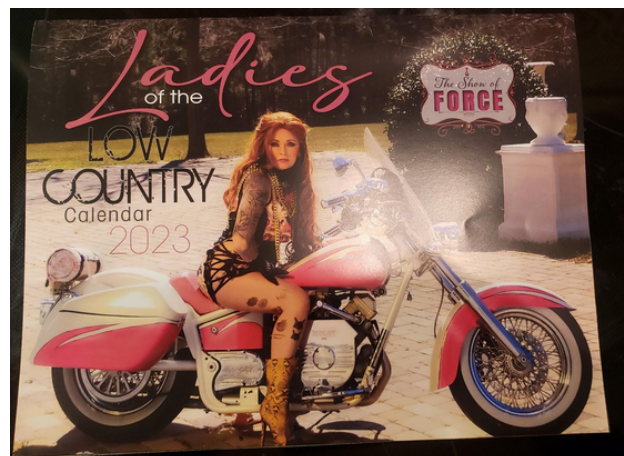
In loving memory of their daughter Stephanie, Peter and Diana Smith decided to provide additional support to RSDSA by matching all monies received for the 4th Annual Flame Out from **August 15 to September 14, 2022** up to a total amount of \$10,000. This is to thank RSDSA for all the support that they offer patients and their families as they struggle with this disease and for their efforts to find better treatments and a cure. We are thankful for their additional contribution.



Interview with Jessica Dutkiewicz, Host of The Show of Force: Ladies of the Low Country Who Ride – October 1, 2022

The Show of Force is a unique fashion show experience, combined with gala art exhibits, auctions, catered dining and more, benefitting RSDSA. The event is hosted by CRPS Warrior Jessica Dutkiewicz.

Jessica wanted to use her platform to bring light to CRPS, so she used her background as an artist, storyteller, and philanthropist, along with her love of motorcycle riding, to create an exclusive art calendar that you can purchase for \$28.00 (shipping and handling included).



RSDSA Board Member Eric Moyal caught up with Jessica to learn more about her and this unique event.

Eric Moyal: How and when did you develop CRPS/RSD?

Jessica Dutkiewicz: I developed CRPS in November 2011 but would not be diagnosed until 2019. I had been suffering for eight years trying to get doctors to understand that after a chiropractic adjustment completely damaged my spinal cord and left me with a severely ruptured disk and drop foot and no choice but open back surgery. It is not known exactly whether it was the trauma to my spinal cord or the back surgery which permanently damaged my sciatic nerve, but I was never again the same. I was left in excruciating pain that started in the injury site of my drop foot leg for five years. I wanted to cut off my leg. I had numbness, excruciating throbbing pain and nobody could touch my toes or I wanted to hit them away. Yet they missed the diagnosis, kept increasing my meds and telling me it was just my nerves repairing themselves. Then the numbness and pain started spreading up my leg to my butt, waist, right side back and eventually hands after eight years. My hands and feet would also get really red, icy cold, and sweat would start pouring out of my extremities.

The icing on the cake was the wind or a sheet touching my legs would cause extreme pain. That is when I met a female doctor who actually listened to my story and said, “You have CRPS.” I was then left with the same question we all are: What the heck is CRPS/RSD, and how do we treat it?

I remember for the first time I no longer felt crazy when I read about it. I felt overwhelmed with happiness that I had an answer finally to my suffering, until I realized there was no cure and no real treatments. It was a bittersweet moment! That is when I did a search for support groups and found RSDSA, and then came across Eric Moyal’s story of looking for people to house him along his bike ride for RSDSA in 2019 to raise awareness. I was ready to do whatever he needed. We bought him dinner and he told me about his journey and how it was helping him meet others with CRPS.

EM: What advice would you give to newly diagnosed Warriors?

JD: Look into your options quickly. I was told ketamine infusions could have stopped my spread, but I did not have the money or resources to do it and mine spread within that year. Do not stop being your own advocate and fighting for what you need for your body because we all experience this journey differently.



The Show of Force

Ladies of the Low Country Who Ride

Benefitting the CRPS/RSD Foundation RSDS.org

Gala and Show

October 1st, 2022 6PM-10PM, Savannah, GA

Theshowofforce.com, Jessica@theshowofforce.com (912)446-2272

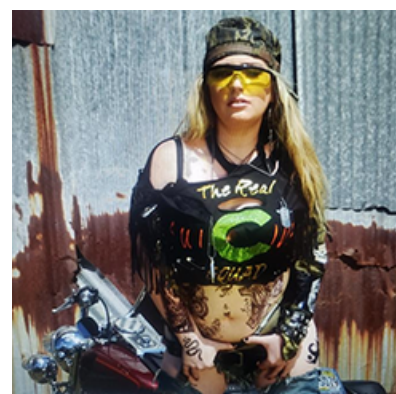
Find small goals to set each day to give you a purpose! YOU MUST FIND PURPOSE daily, no matter how big or small, so that you can focus on anything other than pain. Do NOT feel bad about taking strong medications, do not beat yourself up as you did not ask for this! DO TRY all types of methods to deal with your pain to find what works for you. Use the [RSDSA](#) website resources. Find buddies on the website to chat with to help get you through the bad days! DO NOT CARE what people think about your pain, YOU live with it, not them, but do respect that they do not have to be around forever to hear you complain.

And we all need people, doing this alone is near impossible, and you will likely be depressed from the chronic pain, have memory issues, and do a lot of crying. Use your therapist, the organization's resources or others who deal with pain to get you through those moments

EM: Tell us about *The Show of Force*. What inspired you to create it? What are your goals for *The Show of Force*?

JD: The “Show of Force” is my brain child to showcase the career I lost to CRPS and to bring awareness to the Savannah, Georgia and southeast Georgia area. It is all my life experiences put into one big art installation and video fashion show using all of the skills I learned along the way.

I wanted to use my skills as a designer of creative clothes and the



fact I use motorcycle riding to get me through my day as a disabled female! I wanted to make a stand against all the misdiagnoses and mistreatments I had to deal with just to prove I was in pain and find a way to make it memorable for an audience so that they will forever remember the name CRPS/RSD. So they will see a “normal looking girl” and know you can look this way but still be fighting the fight of your life!

After meeting Eric Moyal, I wanted to turn my pain into something good and I knew I had to find a way, but my way! I knew I had to do it slowly because of my health issues, so I spread it out over a year and made smaller fundraisers along the way to keep the momentum going. I started with working on raising \$10,000 to pay for the dinner show, printing etc. and had the girls from the calendar help me find sponsors. Meanwhile I fronted the money to make the looks for the calendar as I wanted them to celebrate women, and each tell a story. I then started seven weeks of shooting the pictures while I rolled out a bike wash, motorcycle ride and calendar signings to keep raising money and awareness until I could get through the six months of painstaking photo editing to put the calendar together and the video fashion show for the October 1st dinner show.

The Dinner Show is the finale to *The Show of Force* where you get to be fed, entertained by all the clothes on display along with the video fashion show compilation of all the thousands of pics we shot. I am using this event to raise the final money and bring awareness by having Eric Moyal speak to the audience. My goal is not only to raise money and bring awareness to RSDSA, but to spread awareness in a heavily populated military area about what CRPS/RSD is!

I also plan to gift the calendar to RSDSA so they can use it the next year to keep raising funds along with the funds we have already raised. I'm ready to tell the world "I AM THE FACE OF CRPS TOO, look at what it took from me and LOOK how normal I look, yet I am dying inside from pain!"

EM: Do you have any advice for a Warrior organizing a fundraiser for RSDSA?

JW: My advice to anyone wanting to organize a fundraiser is to set your goal to your limitations then find the team around you to help you build the rest. Get advice from those who have done them and know it won't be easy, but it is doable with the right team!

I have GIFTED all of you a beautiful 2023 calendar to use at your events if you choose. They can be used as a tool to make money or give away with donations! You can stuff your information inside them so the RSDSA's message gets out there. These ladies modeled, raised money and we spent a year creating a tool to help bring awareness and money. Inside the calendar is a QR code that directs you to a webpage after October 1st so you can read why I designed each outfit and what I used, recycled etc. I used every angle I could to bring something unique to this event and calendar.

Picklin' for a Cure is October 14-16, 2022 in Tucson, Arizona



The 2nd Annual "Picklin' for a Cure" event supporting RSDSA, Lewy Body Dementia Association, and The ALS Association will take place **October 14-16, 2022** at Udall Park in Tucson, Arizona. Learn more [here](#).

Thanks For Attending our 2022 Treating the Whole Person: Optimizing Wellness Virtual Conference!

Thank you to everyone who joined this week's virtual conference! All sessions were recorded and will be posted on the [RSDSA YouTube Channel](#) once they are edited.

Behind the Mystery of Complex Regional Pain Syndrome (CRPS): A Neuropathic Disorder



The Balancing Act, a talk show hosted by Olga Villaverde and Montel Jordan recently featured a [segment](#) with CRPS Warrior Donna Artis. The segment also aired on Lifetime earlier this month!

Take a look and share with those who are interested in learning more about CRPS/RSD.

Looking for a therapist trained in Graded Motor Imagery?

Last year, the NOI group launched a NOI clinician [directory](#) of clinicians who have attended a recent Explain Pain course. You can search by location in the filters, then in the search tab type graded and it will filter down to clinicians who have also attended a Graded Motor Imagery course.

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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