

IN RARE FORM

THIS ISSUE WAS FUNDED BY A DONATION IN MEMORY OF RONNI JILL ZAGER BY HER PARENTS LAWRENCE AND JUDY ZAGER.



Patrick Boland

Ferocious Fighters - Where Attitude is Everything

by Jenny Picciotto

Patrick Boland is the standard bearer for Ferocious Fighters. He is the force behind their dedication to young people grappling with Complex Regional Pain Syndrome (CRPS). The non-profit grew out of his own experience living with its harrowing effects.

CRPS is a neurological pain disorder linked to damage to the nervous system. Presentation varies, with some people having a mild form that resolves on its own. At the other end of the spectrum are those who have severe prolonged pain, which can involve numerous body parts, or functional disability. Many people with CRPS experience improvement or stabilization of symptoms over time. The symptoms most commonly associated with CRPS include spontaneous pain described as fiery-burning or icy-cold, swelling, changes in skin color, and sensory hypersensitivity. Symptoms, which vary from case to case, can also include tingling, joint stiffness, and loss of strength, among others. The emotional toll of living with CRPS is a significant challenge. According to the National Institute of Health:¹

Most CRPS is caused by damage to, or dysfunction of, injured peripheral sensory neurons, which then has secondary effects on the spinal cord and brain. The central nervous system is composed of the brain and spinal cord; the peripheral nervous system involves nerve signaling from the brain and spinal cord to all other parts of the body.

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It is unclear why some people develop CRPS while others with similar trauma do not. In more than 90 percent of cases, CRPS is triggered by nerve trauma or injury to the affected limb that damages the thinnest sensory and autonomic nerve fibers. These “small fibers”—which lack insulating thick myelin sheaths (a protective coating, like insulation that surrounds a wire)—transmit pain, itch, and temperature sensations and control the small blood vessels and health of almost all surrounding cells.

Patrick was only eight years old when his journey with CRPS began. Jumping down the front steps of his home, he sprained his ankle. Instead of getting better, his foot swelled up, changed colors and soon even the touch of a breeze caused severe pain. He was diagnosed with CRPS. Although his family consulted specialists and he received many different treatments, in a few short years his condition deteriorated.

The burning, stabbing, icy pain, and sensitivity to touch became incapacitating. Once an active boy who loved to run and play baseball, Patrick found himself confined to a wheelchair. With CRPS symptoms spreading across his body, he could only watch from the sidelines while his friends played. Life would never be the same, but Patrick did not give up. Despite his personal difficulties, he found hope in his motivation to help others.

In an interview with The Denver Post, his mom explains:

“When Patrick was 10, he was alone, depressed and felt completely isolated...He started Ferocious Fighters so other kids wouldn’t feel that way.” [2](#)

Ferocious Fighters germinated as an elementary school project in fifth grade. Patrick wrote letters to young people with CRPS to inspire and encourage them. In 2014 Ferocious Fighters was registered as a non-profit organization in the State of Colorado.

Since its inception, they have delivered more than 1,120 letters and care packages to young people in 19 countries. Patrick continues to write the letters, which are personalized for each recipient. Volunteers fill boxes with an assortment of gifts such as: Ferocious Fighters T-Shirts, ‘Attitude is Everything’ bumper stickers, soft blankets, homemade rice-filled hot-packs, and more.

From the original idea, Ferocious Fighters has developed into a full-fledged community. They maintain a web page and social media site dedicated to offering online support, organizing events, and promoting CRPS awareness. It is a place where kids and their families make connections with people who understand.

According to their web site:

OUR MISSION is to create community and support for families of young people with CRPS all around the world.

Families of children with CRPS can find much more than just a care package when they join Ferocious Fighters. Our current programs include:

- Welcome Packages for all qualifying, nominated young people
- Online support available for CRPS kids, tweens, teens, and young adults
- Online support for parents and caretakers - both general and location specific
- Online support for siblings
- Encouragement mailings throughout the year
- Care Packages (our original program continues on!)
- Sponsored local meetups and events across the US and the world

After numerous interventions including hyperbaric oxygen and ketamine infusion therapy, Patrick, now 17, has regained his ability to walk. A junior in high school, he continues to experience ongoing severe pain, full body CRPS and multiple comorbidities. But he is determined not to give up. Even though his health challenges affect him every day, he is engaged in living life. He works part-time, takes on-line high school and college classes, and participates in sports.

Writing to members of Ferocious Fighters and staying active help Patrick take his mind off pain and keeps him focused on the future. He loves being on the baseball field with his team at Mountain Vista High School. "I don't even notice the pain when I'm pitching," he says.³

While an active lifestyle may be out of reach for many people with CRPS, we can all be mindful of the benefits of maintaining a positive outlook, setting goals, and engaging in activities we enjoy. Remember, for a Ferocious Fighter, "Attitude is Everything!"

For more information, visit Ferocious Fighters at ferociousfighters.org and facebook.com/ferociousfighters.

Visit RSDSA for youth and young adult specific information at rds.org/youth



Jenny Picciotto is a writer and Complex Regional Pain Syndrome patient who enjoys reading and playing the piano. She was a yoga instructor and massage therapist before CRPS changed her trajectory. She currently lives in Hawaii, where she facilitates the Oahu CRPS Support Group.

Join us for the CRPS Warrior Virtual Film Screening of "The In- Between"

RSDSA and Kristi Oen are hosting a virtual viewing of [The In-Between](#) from Saturday, January 9th through Sunday, January 17th.

The In-Between is a film that portrays a CRPS Warrior as a main character. This is not a documentary about CRPS, but is a full feature film where one of the characters happens to have CRPS. In addition to directing the film, CRPS Warrior Mindy Bledsoe also plays a Warrior in the film. In the movie, she shares some of her deepest thoughts and trials as a Warrior.

Kristi is also hosting an interview with Bledsoe, the director and one of the main characters of the movie, on Wednesday, January 13th at 1p Eastern.

RSVP to watch the movie [here](#) for \$3 and click [here](#) to register for the Zoom interview.

Op-Ed: Don't Let COVID-19 Patients Die With Vitamin D Deficiency

The U.S. is breaking new records in the number of daily deaths from COVID-19. The breakneck speed with which several vaccines have been developed and deployed is nothing short of breathtaking. Yet we still have to confront the grim prediction that our national death toll will exceed 500,000 Americans before widespread vaccinations can dig us out of this crisis. The response to the pandemic, therefore, should include an effort to aggressively eliminate what is becoming apparent as a morbidity and mortality risk factor in COVID-19 -- vitamin D deficiency.

[Read the full article on MedPage Today](#)

Outcome in young adults who were diagnosed with complex regional pain syndrome in childhood and adolescence

Complex regional pain syndrome (CRPS) is a spontaneous or evoked disease state which results in longstanding, severe, spontaneous physical pain, hyperalgesia and allodynia, sensory distortion, and perfusion alteration of the affected body part, which is generally one or more limbs. Pediatric cases of CRPS typically begin in adolescence with a predominance in females, 17 which may be related to direct or epigenetic hormonal effects that are associated with puberty.

[\(Read the full article on PubMed\)](#)

Also take a look at [RSDSA's Pediatric CRPS Online Lecture](#)

Facebook Live with RSDSA's Advocacy Committee on Wednesday, January 27

Please join the Advocacy Committee for a Facebook Live session on Wednesday, January 27th to learn about public advocacy, how to lobby for upcoming issues in the CRPS community and how to effectively lobby when telling your story.



Advocacy Training offered by Rare Disease Legislative Advocates

The Advocacy Committee is working with Rare Disease Legislative Advocates (RDLA) a program of the EveryLife Foundation for Rare Diseases, an organization designed to support the advocacy of all rare disease patients and organizations. RDLA is committed to growing the patient advocacy community and working collaboratively, thereby amplifying the patient voice to be heard by local, state, and federal policy makers. They provide free grassroots advocacy resources such as webinars, newsletter, and legislative scorecard.

RDLA is hosting Rare Across America from February 22-March 5, 2021, a program of virtual meetings with your Senators and Representatives and advocacy events.

There will be a two Rare Across America training webinars available:

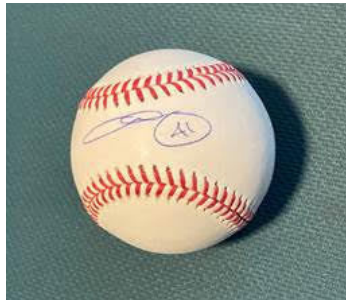
- Thursday, February 4th at 2:00pm Eastern
- First Time Advocates: Thursday, February 11th at 2:00pm Eastern



The deadline for registering is January 22nd. To get more information, the agenda or to register for Rare Across America, please [click here](#).

RSDSA Online Auction

It is with great excitement that we announce RSDSA's first online auction. It will run February 1st -14th, 2021. There will be a variety of items and services for every price range. Here is a sneak peak of a few offerings:



*Autographed by Red
Sox pitcher
Chris Sale #41*



*Snowy Owl –
photography by Chuck
Pink*



*BUNN Velocity Brew
10 Cup Coffee
Brewer*

Please send us an email at info@rsds.org if you are interested in donating items to the auction.

Should Individuals with CRPS take a COVID-19 Vaccine?

We asked this question to members of [RSDSA' Scientific Advisory Committee](#) and members of the International Research Consortium for CRPS.

Their consensus opinion was: “We unanimously agree that there is no reason that people with CRPS patients should avoid the vaccines, and they will not recommend that their patients avoid them. One did however note the recent British recommendation that patients with known severe allergies should avoid the Pfizer vaccine, due to possibly severe allergic reactions it may trigger. It is important that patients communicate with the healthcare provider giving the vaccines about any known specific immune issues they may have or immune-modulating medications they may be taking.”

Word Up

Glia [glee-uh]

Glia are nonneuronal cells that reside in the brain and spinal cord. New insights into how these cells, whose job is to nurture the activity of neurons, can themselves become unbalanced and disrupt neuronal function are sparking new ideas for treating chronic pain. After an injury, glia sensing that intensively firing neurons are in distress react to restore balance and promote healing. But these beneficial changes, if prolonged, can lead to chronic neural hypersensitivity that causes pain to continue after the original injury has healed. Often such neuropathic pain begins with nerve damage, which triggers glial responses that further excite neurons.

To learn more, please read Dr. Field's fascinating article in [Scientific American](#).

Ask the Doctor

RSDSA reached out to Dr. Pradeep Chopra to ask him what questions an individual contemplating IV ketamine infusions should ask prior to agreeing for that treatment. These include:

1. What is the dose?
2. Over how many hours is it administered?
3. How many days will I receive the treatment for?
4. Do you do boosters?
5. What kind of monitoring (EKG, pulse oximeter, BP) is done?
6. Are there any other drugs administered with the ketamine e.g., Versed, Zofran

Dr. Chopra also emphasized that the infusions must be administered in a dark and quiet room with a qualified person in that room which also has a nearby Crash cart.

Please send us feedback!

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