

*Take flight  
with hope*



**RSD** Reflex Sympathetic  
**SA** Dystrophy Syndrome  
Association

© Elizabeth McBride Nielson 2006

STORIES OF HOPE AND TRANSFORMATION

# Introduction



**F**requently I'm asked by individuals struggling with CRPS, "What's going to happen to me? Am I going to get better?" I often struggle with my answer. "Better" is a strong possibility. Will people be like they were before getting CRPS? Absolutely not.

The reality is, some individuals with CRPS do not get better or resume former activities, and those that do often make concessions to their former lives. Ask a person who has CRPS about their syndrome and 99% of the time they will tell you the exact date when their life changed. I encourage people to cope with this change in the most positive ways possible. I always encourage people to stay informed and connected: with RSDSA, another association, or a support group. It's important to communicate that they are not alone. There is hope. Research happens each day that will bring us closer to solving the puzzle of intractable chronic pain. We are constantly lifted by the inspiring stories of others who are

winning the fight against chronic illnesses, or who are doing wonderful things despite their disabling pain and other maladies. That is the basis of this little book. People make changes, they move forward, they live lives they never imagined they could or would. CRPS brings huge losses, but, as you will read, there are significant gains as well.

Elizabeth McBride Nielsen discovered art, which grew from her own form of imagery therapy. "While therapists were encouraging me to make therapeutic use of my mind's capacity for imagination, I taught myself to use that cerebral part of art as a distractive tool against pain," she says. Elizabeth's art ability was a "piece of me that I didn't know existed. If I had been in a position to be graded or I felt I had to perform, it wouldn't work. Art for me was a safe way to express myself. I had to give myself permission to let the art be what it was, without expectations." Her book of art, *Distraction to Abstraction*, was printed in 2005, and she created the artwork for the cover of this book.

As Elizabeth says, "**Take flight with hope.**" You never know where it will take you.

Jim Broatch, MSW  
Executive Director  
RSDSA

# I Have CRPS

I have Complex Regional Pain Syndrome (CRPS), also known as Reflex Sympathetic Dystrophy Syndrome (RSD).

Physicians do not know why it develops or what causes it, but CRPS is a nerve disorder that usually occurs after a traumatic injury, surgery, sprain, fracture, or a period of immobilization. The principal symptom is pain dramatically disproportionate to the injury.

More than 140 years ago, Dr. Silas Weir Mitchell, a Union Army surgeon, first described the excruciating pain that we know as CRPS.

CRPS can lead to disability.

I may look "healthy," but I often suffer unbearable, unrelenting, and burning nerve pain. The pain associated with CRPS has been rated worse than that of people who suffer from cancer.

My skin may swell, sweat, change colors, change temperature, or hurt to the slightest touch.

CRPS can spread.

Often it is difficult for me to sleep so I may have trouble with attention and concentration.

I am frequently following a prescribed medication regimen that usually involves powerful drugs with many side effects that may affect my alertness or attentiveness.

It is often hard to move easily, or keep my body steady.

Chronic pain, like that caused by CRPS, often leads to depression because we undergo significant, and often negative, life changes.

I have good and bad days, even hours. Stress increases my pain.

Presently, there is no cure for CRPS, but there are several successful treatments. I always have hope because of the support of my family and friends.

## Here's How You Can Help Me

Please believe that the pain is real even though it is invisible and may not be readily apparent in my demeanor or activities.

I am learning various coping mechanisms to get through the day, but the chronic pain is always there. I cannot predict how I will feel each day.

Sometimes it hurts to be touched anywhere, so please ask before you touch me.

It is OK to ask me about CRPS. Better yet, visit [www.rsds.org](http://www.rsds.org) and learn all you can.

# CRPS in Adults



## KATHRYN

When I was 15, I fell off a horse I was training and hurt my knee. After three months, my doctor said she thought I may have RSD and referred me to a pain specialist.

Two and a half years later,

I'm a freshman in college, I live away from home and I'm a pre-med major. I want to be an orthopedic surgeon and not allow unnecessary surgeries to happen. I'm still on a fair amount of medication, but my pain is under control. The most important thing to me is that I started horseback riding again, and although it is taking a while to get my leg strength back, I'm doing it. I thought I was gonna have pain no matter what, so I might as well do something I like.

## SUZIE

**There is life after RSD!** My name is Suzi, and I am a police officer in a large metropolitan city. I was involved in an on-duty motor vehicle accident in 1998.

Four different physicians told me that I would never be able to hold even a part-time job. This devastated me, because my job was my life. Well, they didn't know me, and that I would return to work. After searching for the right doctor and going through a pain management program, I was able to go back to work (albeit a desk job!) five years ago. Yes, I still have some bad days, but I also have many more good days! Last fall, I went to Africa for a month, yes a safari in Africa (one of my life's dreams)! This year I am going to Costa Rica!

## MICK

I am a CRPS patient and have been dealing with the pain from this disorder since I was diagnosed in 1998. Through all of the years of tests, nerve blocks, and other diagnosis and

treatments methods, I have finally found a combination of medications that allow me to return to school for additional education.

Now I have been given a "Ticket to Work" through the SSA Disability division and have decided that I would like to take back the parts of my life I miss the most: work, adult interaction, a sense of self-worth, companionship, and a purpose. The organization I am working with is known as Vocational Rehab, and has agreed to pay for my Masters Degree and Practicum in Counseling. I would like to give back to those that have to deal with what I have been through and to let them know there is help and hope. I want so badly to live a semi-normal life again. I want to contribute as I realize I only have one chance in this world at making a difference. I want to be a **SURVIVOR!**

## PAT

I am 49-years-old and was diagnosed in June 2003. I had undergone hand surgery in March to fuse a joint. As the RSD spread up my arm, it was becoming increasingly difficult to perform my job, and I had concerns about being able to keep my position. My occupational therapists suggested I go to school for occupational therapy and come work with them. I was able to return to school full-time and also work part-time as a swimming coach for the Y team. I now work as an occupational therapist's assistant at a nursing home in the rehabilitation department, and in pediatric therapy.

## BARB

I developed RSD after getting up from my desk at work. I am a teacher and last year my position included teaching elementary-level special education and, at the district level, working with psychologists and the state department. When I went to work and scooted around in my desk chair, teaching my coworkers and students about RSD, I would still be able to work and not dwell on my situation. My usually naughty students were especially great at helping me retrieve things or warning others to stay away from my left foot. They learned to be considerate —something that was new to many of them.

## KIM

I got RSD in July of 1992 and was diagnosed a year later. I'm 42, and by the grace of God I am still working. I use arm crutches to get around when I am outside of my home or at work so I don't fall. I used to hate them, but now they are my buddies, my friends. I've come to look at getting RSD as a blessing in many ways. This may sound nuts to some of you, but there is a very good reason. I have made some of the best friends that I will ever have in my life since having RSD and I have met the most wonderful people since having RSD. People that I truly learned from and who changed my life.

---

*"I've come to look at getting RSD as a blessing in many ways."*

---

This is the path that I've been given and it isn't all bad. I have found many new things to do to occupy my time, things that I really enjoy and it has also made me appreciate the smaller everyday things in life – like a bird on my patio or a squirrel in the yard holding a nut. Where I used to love to play tennis and volleyball, I now play games on my computer. I read and escape into my books. I go to movies with my friends. I am so thankful that these are things that I can still enjoy.

---

## LOUISE

February 17, 1992 started out like any other day. I got up and got ready for work, got my daughter ready for school and then drove my 30-mile trip to work. The assembly area where I worked was totally automatic and had robots. This particular morning, I had some small parts that were sticking in the track and I had to go to the back of the machine to fix it. As I was coming up to a standing position, I struck my left knee on a metal bracket that was located on a support leg of the conveyor belt and I saw black for the first few seconds. As I got myself together, I took a step and the pain was so great that it felt like I was going to be sick of my stomach. So began my journey with RSD.

I was fortunate that I didn't have to go to many doctors before I was diagnosed. It wasn't long after that my doctor suggested I attend the RSD Support Group. I was afraid to go at first, because I was a little afraid of what was happening to my own body. Going to the support group was one of the best decisions I've ever made. It was good to be around others who knew where I was coming from.

It seems like from the beginning, my RSD was a magnet for others who had RSD. I started meeting people who had RSD just about everywhere I went. I would invite them to the support group meetings. My time working was also coming to an end, and I started using the skills I formerly used at work in the support group.

In November 1993, I became the new director of the Greenville RSD Support Group. It was just what I needed to work on living with RSD. I had viewed RSD as ruining my life, because I couldn't do the things that I use to before. When I did things on a fairly good day, I would over do it and pay for it for weeks. It finally dawned on me that this was what my RSD liked. It also liked when I was down. This discovery was an important part of acceptance for me. It taught me that it's okay to make changes if it allows me to do what I want in life. I started setting priorities in my life. I realized that it wasn't how I accomplished my goal that mattered, but that I accomplished it.



*Louise with Jim Broatch*

RSD also brought out my fighting spirit. Everyone I met would say, "I have never heard of that." I wanted that to change, so we ended up forming the South Carolina RSD Association (SCRSDA). We made our mission to help educate everyone we could about RSD. Our first conference was held in September 1994, and

has been held annually since. Running the support group and SCRSDA have been like therapy for me. I have a strong support system of folks that help to keep me going. I will never give up working on myself or my RSD. So that is why I say, "I have RSD, but it Doesn't Have Me".

# JANE's Lessons Learned

1.

**Without a doubt, the fear of pain** is a principle driving force of pain. Pain can be so severe that we become afraid of it. We allow it to control our lives, anticipating its effect on everything we do. We become inactive, suffer atrophy, and the pain only grows. Once I was able to experience even a tiny bit of relief, I held onto that feeling and continually focused on mentally capturing it again, no matter what that required. I became more confident in pain control the more I experienced it. My pain no longer controlled me. When anxiety creeps up on me, I seek support immediately, recognizing that I won't allow myself to slide down the slippery slope of pain and fear again. My doctor is continually supporting and encouraging me.

2.

**Find an inspiration.** Mine was my family. I knew I couldn't let myself continue to be the mother in pain to my children, nor the wife in pain to my husband. I also dreaded the thought of being that "pain patient" I had cared for many times in my own medical practice. These inspirations kept me searching for answers, and continue to drive my determination to practice daily self care.

3.

**Don't isolate yourself.** Formerly a very social person who loved to entertain, I found I didn't want friends to see me hurting or unhappy. I knew I couldn't hold up through social gatherings very long due to the pain. Rather than isolate myself, I forced myself to frequently have friends over, hosting potluck happy hours often. I'd simply pull open my silverware drawer, let someone open the wine, and allow those I love to heal me with their friendships. I found that distraction is a powerful antidote to pain, often giving me several minutes at a time of pain relief, if I could relax enough to get caught up in intriguing conversation.

4.

**Seek professionals with experience** in trigger point release and biofeedback. Those suffering with CRPS develop trigger points frequently. Active release therapy (ART) and spray and stretch methods are very effective. Biofeedback must be done with a professional familiar with pain control. Search online. Write to textbook editors. Network with anyone you know who has experienced chronic pain. Be persistent!

5.

**Volunteer. Reach out to others.** It's so easy to feel despair and anger when CRPS is present. Force yourself to do something – anything – for others. Just making the elderly lady down the street a bouquet of flowers from your yard or listening to kids read at school gives our minds a good dose of fulfillment.

6.

**Stay the course.** Just recently, I became too confident of my recovery and slacked off on biofeedback. I suffered a setback with a large CRPS flare, and the accompanying anxiety it provokes. My doctor counseled me to get back on course, reminding me that I must work harder at my daily care regimen when I feel good. Everyday I remind myself that I am doing these things to manage CRPS for today. Tomorrow is another day.

7.

**Finally, believe in yourself** and others will too. Never, ever give up! Now, when I shop for running or swimming supplies and am asked what event I am training for, I say, "I am training for life."

# CRPS in Children and Teens



## YVONNE

I was diagnosed with RSD after a minor sprain to my left ankle. Walking had never been so difficult before. After working with the physical therapist for a few months, it happened: I was finally able to walk

again! It is so hard to describe the emotions that accompanied this event, because I was still in pain, but happy at the same time.

I am now faced with the challenge of accepting that this will always be a part of me. Throughout the past year I have discovered an inner strength I never knew I had. Although I have had to change my activities, I have found I can still be active. I swim a couple days a week to keep my ankle strong without inflicting pain. I also now horseback ride competitively. I can not end this paragraph of my life, because it is not yet over and perhaps never will be. All I know at this point is that my life is going to be full of adjusting and changing, but I will never let RSD stop me from living my life.



## JENNY

I was any normal eighth-grader playing basketball. I wanted to be in the WNBA. After one game in December of 1997, my dream shattered when I fell on my elbow and developed RSD, although the

diagnosis took a year. Without my mother, I wouldn't have been able to keep such good spirits. I started to work with the special education children and I realized that I am still very lucky and fortunate. Now I want to be a special education teacher. I still suffer from RSD, but I am in school and not letting it stand in the way of my dreams.

*"I still suffer from RSD, but I am... not letting it stand in the way of my dreams."*

## JESSIKA'S STORY: "LIVE LIFE UNINTERRUPTED!"

By Laura Bortolusso-Welch



WE LIVE ON THE TINY twin island republic of Trinidad & Tobago at the very bottom of the chain of Caribbean islands. It is not a first world country; there are not a whole lot of weekend choices for

entertainment. The pace of life here is slow and so, happily, here we live.

Our Jessika is a vivacious, bright, talented 11-year old. She has always excelled in everything and every sport she participated in. Telling her story is difficult, but it has a very happy ending. We have learned that one of the most important things in this incredibly challenging journey is to maintain a positive outlook, count your blessings, smile and create that happy ending.

Jessika began experiencing extreme pain on March 7, 2006, after an hour and a half of regular training at her swim club. By the following morning she was

unable to walk. On May 8, 2006, two months and several doctors later, we traveled to Florida and sought medical advice from a colleague of my sister who is herself a pediatrician in Jamaica. She was diagnosed with CRPS on May 10 by a pediatric rheumatologist. Jessika's CRPS was brought about by a pre-existing medical condition that we were never even aware of. She has pauciarticular Juvenile Rheumatoid Arthritis (JRA). The doctors believed that Jessika may have had JRA for some time, but due to her athleticism it had gone undiagnosed.

We returned to Trinidad the day after her diagnosis with a clear understanding of what we needed to do, but we had no idea where to begin. Of the four doctors that had seen Jessika in Trinidad, two pediatricians, an orthopedic surgeon, and a rheumatologist, not one of them had ever seen CRPS in a child. Jessika's orthopedic surgeon comforted me and reassured me that this was something we were very able to triumph over. He set up appointments with a pain specialist who had worked with CRPS in children before and a physiotherapist that had worked with CRPS patients. Today, she is 90% better – she put away her crutches

on June 24, 2006. On July 12, all of her pain medication (with the exception of the Cataflam®, which she continues for her JRA) were stopped, but let the picture below paint a thousand words. Jessika believes in herself and her motto is "Live life ...uninterrupted!"

We want as many people as possible to know about Jessika, because we believe it may be of great comfort for parents or relatives of children suffering from CRPS. You don't need live near big cities nor have the "top of the line" medical services available there to be successful in dealing with this medical condition. Let our Jessika's story give

you hope. Enjoy every moment of recovery and get on with the business of healing! Dealing with CRPS in tiny Trinidad has confirmed that very often, necessity is mother of invention! But it is doable. ■



Jessika on the rope swing in July 2006.



99 Cherry Street  
Milford, CT 06460  
Toll free #: (877) 662-7737  
E-mail: [info@rsds.org](mailto:info@rsds.org)  
[www.rsds.org](http://www.rsds.org)