

Complex Regional Pain Syndrome an unrelenting affliction



RSD/CRPS Doesn't Own Me!

And it shouldn't own you. We face daily battles with our bodies and even some times our medical providers. And that is why we are here. We provide support when you need it the most and ask only in return that you try and respect each other because we all know that we have nearly daily bad days so the pain can make us hurtful because we hurt so badly.

But with each other we can find strength together because this battle is not easily done alone. Be it through faith, friendship, or just simply just having someone who knows this monster we call CRPS it can make the ordeals we face so much easier.

It is through awareness and great support that we create the best chance we have for a happy and full life.

RSD/CRPS Doesn't Own Me & it SHOULDN'T OWN YOU!

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RSD/CRPS Doesn't Own Me

We started off as a dream.

So many patients are disabled and we here wanted to remind not only ourselves but our fellow angels that life is still worth living.

Why we decided to call this organization "RSD/CRPS Doesn't Own ME" is because, yes, we have RSD/CRPS but that doesn't mean that we are less than amazing people. We have goals and we have dreams and no matter what people will try to tell us, we are worth more than gold or silver.

We deserve to wake up each day and smile. We are more than just patients, we are mothers, fathers, daughters, sons, aunts, uncles, nieces, nephews, grandchildren, grandparents, and more greatly we are unique. We are what we allow ourselves to be and if we allow a big bully like RSD/CRPS define who we are, then that is wrong!

We are strong! We walk through fire 24 hours a day 7 days a week, but we are still here. We are still smiling and living life. Albeit a little differently than before, but you can only make coal into a diamond through a lot of heat and pressure!

We find something each day to be thankful for. We try our hardest to get through and not let anyone dictate to us what we should be doing. We control our pain by what we do, not the other way around.

We are the RSD/CRPS Angels and we are fighting for a cure!

Partner to Share and Make Aware

Flora Langel DeKock
Media Relations Manager



Left: Prior to Treatment | Right: Day 1 post Treatment

Shared by our own George Robinson, husband, photographer & member of the group

Sharing our Lives

CRPS: Incurable but is still Survivable

When you're living with day to day pain that is unpredictable it can be very hard to plan your life and activates even a few hours out. But when we as a community come together, we can help each other by sharing our experiences and successes to give another a chance to survive through the hard times.

Treatments & Sharing Experiences

There are many doctors exploring ways to help us survive this disorder. Many of us find that we are guinea pigs for these treatments because the medical providers have no other way to learn about what we suffer. But with each of these treatments, we get closer to success. We can learn from each other and share these successes and failures so we know what may or may not work for us as an individual.

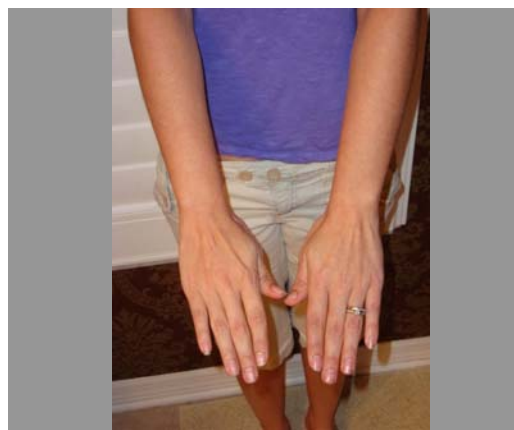
The best way to approach your experiences is to try and communicate them in a positive manner, because just as with medications, each treatment will affect one person differently than another. In turn these treatments maybe more or less successful for one person than yourself. Keep your mind and ears open & feel free to share with us anything you might find.

As support groups for alcoholics and the many other ranges of life's harder battles know all so well, the best person to help us through our darkest hour is someone who has walked that path before us and found their way out of the light. Because they can understand some of

the battles better than someone who sat and watched someone else succeed. And in helping a fellow sufferer escape any of these horrors, we can also help ourselves make a bad day so much easier.

Tips for Surviving CRPS at Home

- Avoid cotton material.
 - In later stages some have reported almost allergic type reactions and it could help avoid this if you minimize your exposures to this seemingly soft material.
 - Alternatives: polyester, silk, satin
 - Suggested items to replace:
 - Shirts
 - Pants
 - Bedding
- Use heat packs if at all possible
 - Avoid ice due to documented advancement of the condition when ice applied to the affected region
- Find a family physician you trust & can be honest with
 - A primary care provider allows for centralized treatment and review of new symptoms while allowing them to recognize what is not CRPS symptoms for proper treatment



Day 3: Congrats to George and his wife for her successful response to the treatments.

Please doctors, keep searching for a cure.

Early Signs of Complex Regional Pain Syndrome

These can be recognized by medical staff such as emergency room technicians, physicians and family members if they know what they are looking for.

Stages:

1. Severe, burning pain at the site of the injury. Muscle spasm, joint stiffness, restricted mobility, rapid hair and nail growth, and vasospasm (a constriction of the blood vessels) that affects color and temperature of the skin can also occur.
2. More intense pain. Swelling spreads, hair growth diminishes, nails become cracked, brittle, grooved, and spotty, osteoporosis becomes severe and diffuse, joints thicken, and muscles atrophy.
3. Irreversible changes in the skin and bones, while the pain becomes unyielding and may involve the entire limb. There is marked muscle atrophy, severely limited mobility of the affected area, and flexor tendon contractions (contractions of the muscles and tendons that flex the joints). Occasionally the limb is displaced from its normal position, and marked bone softening and thinning is more dispersed.

http://en.wikipedia.org/wiki/Complex_regional_pain_syndrome

There is even suspected/believed to be a possible fourth stage that more & new symptoms are starting to be found.