RSDSA is committed to assisting those who suffer from CRPS as well as the people who support them.

RSDSA offers hope and emotional, financial, educational, and medical support to people suffering with CRPS. Please contact our organization.

Join us and receive our informative monthly digital newsletter free.

WE ARE HERE TO SUPPORT YOU
- YOU ARE NOT ALONE -

Reflex Sympathetic Dystrophy Syndrome Association
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Milford, CT 06460
Tel: 203.877.3790
Toll Free: 877.662.7737
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Raising awareness of CRPS since 1984

OTHER HELPFUL PUBLICATIONS AND VIDEOS YOU CAN ACCESS ON OUR WEBSITE OR BY CONTACTING RSDSA

• Dental Guidelines for the CRPS Patient: Handle with Care!
  Planning a dental procedure? Please read and share with your dental professional.

• Emergency Guidelines for the CRPS Patient: Handle with Care!
  This sheet contains patient tips and hospital procedures for an emergency room protocol for the CRPS patient. Included are hospital procedures, how to take blood pressure and pulse rate, transport, and identify CRPS patient. Don’t leave home without it!

• Hospital Guidelines for the CRPS Patient: Handle with Care!
  The document lists over two dozen specific suggestions for a care plan in areas including: setting up the patient room, performing medical procedures, taking blood pressure and pulse rate, transporting, feeding, and identifying CRPS patients.

• Guidelines for Health Care Aides, Personal Care Assistants, and Certified Nurse Assistants

• I Have CRPS Cards
  This card describes CRPS from the point of view of a person with the syndrome and some suggestions on how others might help. Cards are free. We only ask for a small good-will donation to defray costs and to support our mission.

• An excellent Guide on Functional Rehabilitation for CRPS

• A video on desensitization with CRPS

• The experience of having CRPS and the need for early diagnosis and treatment: a video for friends & family.

• A video on brain retraining and mirror therapy.

• A video on Aqua Therapy: a key ingredient in treating CRPS.
Since the Federal Drug Administration classified CRPS as a rare disease, RSDSA has been even more committed to supporting those in the CRPS community.

In 2014, RSDSA established the International Research Consortium, uniting forty participating research sites and specialists worldwide. By pooling their considerable resources, the IRC will facilitate RSDSA’s mission to develop better treatments for the disease and ultimately a cure.

COMMON SYMPTOMS

• Pain described as deep, aching, burning, or stinging
• A prior trauma (fracture, sprain, surgery, etc.)
• Abnormal swelling
• Excessive sweating in the affected area
• Changes in skin color
• Noticeably altered skin temperature (increased or decreased) in the affected limb
• Weakness of affected limb
• Limited range of motion
• Paralysis or dystonia (muscle contractions resulting in abnormal positions)
• Allodynia (pain from stimuli that are not normally painful, e.g., the touch of fabric or the wind blowing)
• Hyperalgesia (excessive sensitivity to pain)

CRPS is a multifaceted medical condition best managed by an interdisciplinary team coordinated by a physician or pain specialist with a special interest and experience in treating CRPS. You must become the “captain” or CEO of your team. Although no one treatment works for everyone, remain hopeful. Your first step is to educate yourself. RSDSA’s website has a very informative section, Diagnosed: Now What? Learn about current research especially about neuroplasticity by visiting https://noigroup.com, The Retrain Pain Foundation - MOVE Pain Care, and www.curablehealth.com

An interdisciplinary team typically includes physical and/or occupational therapists (ideally, trained in Graded Motor Imagery), pain psychologists especially trained in cognitive behavioral therapy and current neuroscience of pain, anesthesiologists, or interventional pain specialist (when warranted), and your support people. Your treatment goal is to reduce your pain while focusing on improving function.

Treatments may include medications especially corticosteroids during the acute phase (first six months), topical medications, oral medications, warm-water therapy, physical and occupational therapies, pain-focused psychological interventions, virtual reality, acupuncture, biofeedback, an anti-inflammatory diet, participation in a virtual or face-to-face support group, and more invasive treatments such as, nerve blocks, intrathecal drug infusion, neurostimulation, IV ketamine or IVIG infusions. If you are unsure of the evidence for a particular therapy, visit https://pubmed.ncbi.nlm.nih.gov/ or, https://rsds.org/wp-content/uploads/2022/06/CRPS-practical-diagnostic-treatment-guidelines-5-edition.pdf. Investigate whether there is a CRPS clinical trial by visiting https://clinicaltrials.gov.

THE DIAGNOSIS

There is no definitive diagnostic test for CRPS. Only a careful exam and review of medical history can produce the proper diagnosis.