

TREATMENT OPTIONS

Ultimately your physician will prescribe the best program to meet your child's needs, but research has shown that physical therapy can be one of the most effective treatments for CRPS.

Other treatments, such as graded motor imagery, cognitive behavior therapy, or medication may be needed, so consult your physician as to the best course of action.

ADDITIONAL RESOURCES

CRPS is not life-threatening, but it can be highly disruptive and lead to excessive school absences if left untreated. Early diagnosis is key.

Once diagnosed, some students may require special school accommodations, such as ergonomic assessments, additional travel time between classes, revised schedules, and possibly a helper's aide.

Students who find their CRPS too painful to allow them to attend school may qualify for special services, such as a 504 plan or Individual Education Plan (IEP). For more information on available accommodations, contact your school's health services coordinator.



rsdsa
SUPPORTING THE
CRPS COMMUNITY

RSDSA is committed to assisting individuals with CRPS as well as the people who support them

RSDSA offers emotional, financial and medical support to people with CRPS. We can also provide referrals to pediatric rehabilitation programs.

Please visit our website, www.rsds.org, if you are in need or have questions.

If you think you or someone you know has CRPS, please visit your physician and provide him or her with educational information about the disease.

Much more can be accessed through our website. You may also contact us at **877-662-7737**.

Stay connected with us by subscribing to our free monthly e-newsletter, joining our community email news blasts, or visiting our Facebook page.

Visit <https://rsds.org/rsdsa-pediatric-crps-lecture/> to listen to a comprehensive pediatric CRPS lecture presented by Elliot Krane, MD FAAP from Stanford Univ., and the Lucile Salter Packard Children's Hospital.

RSDS.ORG
877-662-7737

WHEN YOUR CHILD'S PAIN WON'T GO AWAY

It could be **Complex Regional Pain Syndrome**



rsdsa
SUPPORTING THE
CRPS COMMUNITY



YOU ARE YOUR CHILD'S BEST ADVOCATE

Your child frequently experiences **severe pain following an accident, injury or other trauma**. It may be accompanied by **swelling, changes in skin color, temperature, or limited mobility**. He or she is suffering, and other treatments have been ineffective. Worst of all, he or she may not be able to tell you what's wrong. **Your child could have CRPS (Complex Regional Pain Syndrome) which is formerly known as RSD (Reflex Sympathetic Dystrophy).**

CRPS is a **neurologic syndrome** characterized by severe and often burning pain. While it **affects nearly 200,000 people in the U.S.**, it is **rarely mentioned in an initial diagnosis**.

There is no gold standard for diagnosing CRPS. Only a careful and thorough exam and review of medical history by your physician can produce the proper diagnosis and recommended treatment. **Pediatric CRPS is typically under-recognized and misdiagnosed by physicians, and you may have to advocate for proper testing.**

JUST BECAUSE YOU CAN'T SEE IT, DOESN'T MEAN IT DOESN'T EXIST. BUT TO RECEIVE HELP, YOUR CHILD MUST BE HEARD.

THE FACTS

What is CRPS?

CRPS/RSD is a **rare neurological disorder** that causes severe inflammation in the nervous system.

What Causes It?

It occurs after a **trauma**, such as a **musculoskeletal or nerve injury, surgery or broken bone**. Sometimes there isn't an initiating event.

The trauma causes the **nervous system and immune system to malfunction**. The nerves throughout the body misfire, **overwhelming the brain with pain signals**.

What Are the Affects?

CRPS is devastating. It causes **severe pain, swelling and sensitivity**. Many people are unable to walk, work, go to school, or wear clothes.

Who Can Develop CRPS?

Anyone can develop CRPS, regardless of race, age or gender. However, research shows that it is most common in girls and women.

SIGNS & COMMON SYMPTOMS

This is not an exhaustive list, but symptoms may include:

- A prior trauma (fracture, sprain, surgery, etc.)
- Constant pain described as deep, aching, burning or stinging
- If the pain is getting worse, not better, and if the pain is more severe than one would expect from the original injury it may be CRPS
- Abnormal swelling
- Excessive sweating in the affected area
- Changes in skin color
- Noticeably altered skin temperature in the affected limb
- Weakness in affected limb
- Limited range of motion
- Paralysis or dystonia
(muscle contractions resulting in abnormal positions)
- Allodynia *(pain from stimuli that is not normally painful, such as the touch of fabric or wind blowing across skin)*
- Hyperalgesia *(excessive sensitivity to pain)*
- Hair growth changes
(coarser, darker, rapid growth, loss of hair)



WHAT TO TELL YOUR PHYSICIAN

During your child's exam, ask your physician if he or she is familiar with CRPS. Also tell your doctor or clinician about any sprains, falls, surgery or other trauma your child has had recently. Provide them with information on timing, severity of pain and any other triggers you may notice.