

13. Ask before touching the student—a simple pat on the back can cause increased pain.
14. Allow a student with RSD/CRPS to sit in a quieter area of the cafeteria if the noise is bothersome; however, do not isolate the student from others.
15. Students with RSD/CRPS are also sensitive to noise and vibrations. Please take this into consideration when fire drills, assemblies, and pep rallies are planned. Allow students to position themselves away from loudspeakers/intercoms — even the classroom bell for beginning and end of class may affect a student with RSD/CRPS.

## Limiting Stress

Because stress is a known cause of exacerbation of this syndrome, academic schedules and curricula may have to be modified, including:

1. Schedule all classes on one level or provide student with key to the elevator.
2. Implement flexible homework and make-up policies (homework and tests are a major cause of additional stress).
3. If a student is unable to write, modify normal test taking, and allow additional time for tests.
4. Reduce school time if necessary (students may be late due to pain flare-ups) and supplement with home-based instruction and tutoring.
5. If mobility is impaired, credit the student's physical/occupational therapy as the requirement for gym (if the school has a pool, allow the student to use the pool during gym).
6. Arrange special transportation if traveling on a crowded, bumpy school bus is too difficult.
7. For older students, provide a designated handicapped parking space.
8. Arrange for the student to meet with the school counselor on a regular basis.

## Acknowledgments

The above suggested classroom and academic accommodations have been submitted by students with RSD/CRPS, their parents, medical professionals and school educators.

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## Section 504

Section 504 of the Rehabilitation Act is a civil rights law. It prohibits discrimination against individuals with disabilities and ensures that a child with a disability, e.g., RSD/CRPS, has equal access to an education. The key portion of Section 504 of the Rehabilitation Act at 29 U. S. C. § 794 states:

### Section 794. Nondiscrimination Under Federal Grants and Programs

- (a) Promulgation of nondiscriminatory rules and regulations. No otherwise qualified individual with a disability in the United States, as defined in Sec. 705(20) of this title, shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance or under any program or activity conducted by any Executive agency or by the United States Postal Service . . .

### Section 504 protects all persons with a disability who

- Have a physical or mental impairment that substantially limits one or more major life activities
- Have a record of such an impairment
- Are regarded as having such impairment

Under Section 504, a child may receive accommodations and modifications if his/her impairment substantially limits the ability to learn. Children with RSD/CRPS may be entitled to special services under the Individuals with Disabilities Education Act (IDEA). IDEA requires the school to provide an individualized educational program (IEP) that is designed to meet the child's unique needs and provides the child with educational benefit. Fewer procedural safeguards are available for disabled children and their parents under Section 504 than under IDEA.



# Helping Children/Youth With RSD/CRPS Succeed in School

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*"I used to wish that I had a broken leg or something so people could see I was hurt. One of the problems with RSD is that it is an invisible disorder, so people don't believe you're in pain."*

—Aya Ravek, Ontario, Canada,  
diagnosed with RSD at 11 years of age

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**Children who suffer persistent pain**, such as that associated with Reflex Sympathetic Dystrophy (RSD), also known as Complex Regional Pain Syndrome (CRPS), need your understanding and support in order to have some semblance of a normal life. Because persistent pain is invisible, many health care professionals and school personnel assume the child is acting out for attention or even malingering.

We hope that after reading this brochure you will understand the impact of pediatric RSD/CRPS and will be able to visualize how children suffering from the syndrome, their families, and school personnel can work together to modify the school environment. Let's help our children succeed!

## What is RSD/CRPS?

If you haven't heard of RSD/CRPS you are not alone—many healthcare professionals are unaware of this neurologic syndrome characterized by severe and chronic pain. RSD/CRPS is generally the result of an initiating trauma but the resulting pain is disproportionate to the injury. In addition to pain, skin sensitivity, abnormal color changes, swelling, temperature changes, and sweating are also common (however, these symptoms may vary and are not present in all children and youth with CRPS).

Although the incidence of pediatric RSD/CRPS has not been determined, physicians, including Charles Berde, MD, PhD, [Harvard Medical School and Director of the Pain Treatment Service at Boston Children's Hospital], report that RSD is being diagnosed more frequently in children and adolescents. **In a prospective study of wrist fractures (one of the most common fractures in children and elderly), there was a reported incidence of RSD of between 7 percent and 37 percent.** Dr. Berde notes that girls are affected roughly 5 times as often as boys; the incidence increases markedly just before puberty; and female dancers, gymnasts, and competitive athletes comprise a high percentage of the patients.

## Consider These Facts

- An estimated 2.2 million children ages 14 and under sustain school-related injuries each year.
- Children ages 10 to 14 account for 46 percent of school-related injuries [[www.safekids.org](http://www.safekids.org)]

Until medical researchers pinpoint criteria that allow RSD/CRPS to develop, any injured child is at risk of developing RSD/CRPS. Early diagnosis and treatment are key to avoiding disabling pain, but this syndrome is consistently under-diagnosed and under-treated.

In Dr. Berde's study of 70 children with RSD, the average time from the initial injury to the diagnosis was one year, which indicates that RSD remains under-recognized in patients in this age group.

Left untreated, the symptoms can become chronic, spread to other parts of the body and persist for years. The severity of the pain and the disruption of the child's life can lead to depression and anxiety, especially if it goes undiagnosed and untreated. Disability in pediatric patients with persistent pain (such as RSD) is defined in terms of school days missed. In evaluating 70 consecutive pediatric RSD patients at Children's Hospital in Boston, researchers reported "the average patient had missed more than 40 days of school in the year following the injury, nearly one-fourth of the academic year." The good news is that with treatment, school loss secondary to pain dropped to less than five days per year! Yet children with CRPS may still miss school occasionally due to ongoing treatment.

## How Can You Help?

Get involved. Because RSD is not well understood by the medical and educational community, a young person's pain often is ignored, questioned, or even mocked. **Only the child in pain knows how much it hurts and the limits that pain imposes.** Pain cannot be objectively measured.

Generally, because educators and classmates have never heard of RSD/CRPS, some parents have found it very helpful to arrange a meeting or a telephone conversation with the medical treatment team to educate the school staff about RSD/CRPS. RSDSA's website ([www.rsds.org](http://www.rsds.org)) contains a wealth of information about RSD/CRPS.

## Modifying the Classroom

Section 504 of the Rehabilitation Act prohibits discrimination against individuals with disabilities and ensures that a child with a disability, e.g., RSD/CRPS, has equal access to an education. It is very important to accommodate the unique needs of each student. Some accommodations that have helped students with RSD/CRPS are:

1. Because the slightest bump can cause lasting flare-ups of this very painful syndrome, every effort should be made to see that the child is not exposed to the bumping and jostling of school hallways. The student's desk in each classroom should be positioned away from traffic patterns to avoid inadvertent bumping.
2. Determine whether the student needs ergonomic seating/adjustable desk.
3. Designate another student as a helper who can carry the student's books/belongings during the day, help at lunch, and during the changing of classes.
4. Because students with RSD/CRPS in their upper extremity may have difficulty writing, allow the student to tape record lectures, use a keyboard with a portable word processor, or use another student's notes.
5. Given that RSD/CRPS symptoms can be exasperated by the cold, allow the student to bring a heating pad. Also, guidelines should be developed regarding whether the child should go outside for recess when it is excessively cold; care must be taken to see that the patient has adequate warm clothing, and is kept out of drafts.
6. Allow students to have an extra set of books at home in addition to school.
7. Permit the student to go to the nurse when needed (may be experiencing a pain flare-up).
8. Permit the student to leave 5 minutes prior to the end of class to avoid the congested hallways.
9. Let the student stretch or take breaks whenever needed.
10. Confer with parents as to whether they wish the child's classmates to be aware of the syndrome.
11. If there is a dress code, the child may need to adapt clothing due to sensitivity to clothing and increased sweating.
12. Special accommodations may be necessary for school field trips, including transportation, medication disbursement, and lodging (if an overnight trip).