

AT THE AGE OF 11, MY DAUGHTER'S SIXTH grade classmates created the "Alli's a Faker Club," which was obviously not a school-sanctioned club. Struggling with undiagnosed CRPS pain in her ankle, she would attend school either limping, on two crutches, in a wheelchair, with the aid of one crutch, or walking just fine

Your child might also be eligible under the current special education law known as Individuals with Disabilities Education Act (IDEA 2004). According to the National Dissemination Center for Children with Disabilities (NICHCY) "IDEA is our nation's special education law. It guides how states and school districts

sickle cell anemia; and (b) adversely affects a child's educational performance."

Although CRPS is not specifically listed, it could qualify as a chronic health problem and may adversely affect educational performance. Educators will be keenly looking for the "adversely affects performance" component. Whether it is a 504 plan or an IEP under IDEA, there are laws that provide special help for your CRPS child.

You have the right to request an initial evaluation of your child (504 or Special Education), which must be conducted within established timelines. The evaluation determines if there is a disability present and to learn in detail about any specific needs of the student. The determination of whether a student has a substantially-limiting impairment is made on an individual basis. Such an evaluation can, and should, include input from your medical team.

School personnel will have valid input regarding the educational aspects, but

Does Your Child's School Have a "Faker's Club"? The CRPS Student's Rights

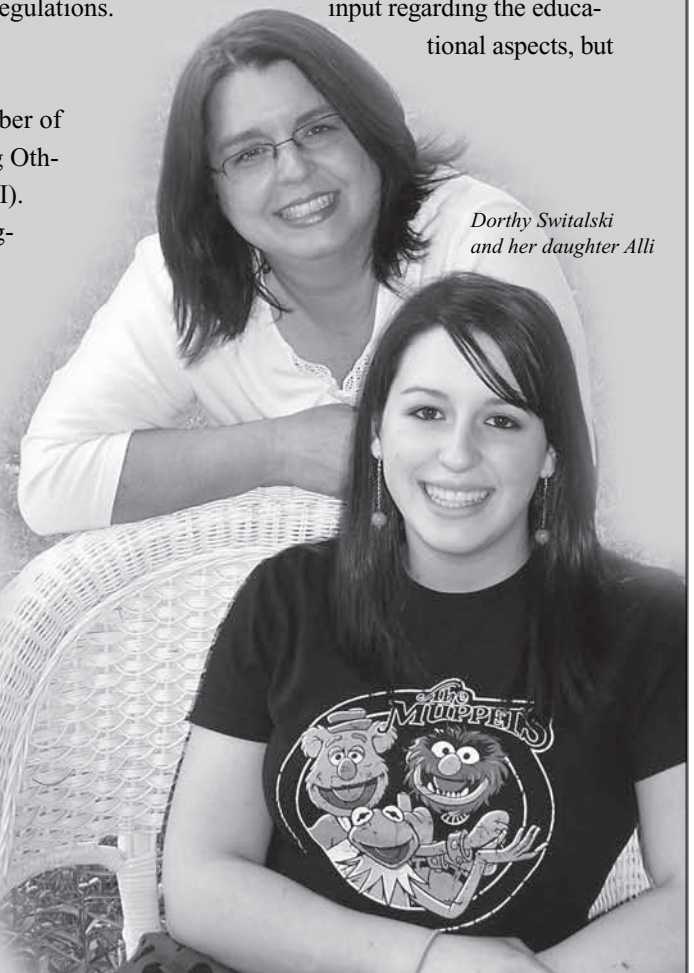
By Dorothy Switalski

This varied from day to day, depending on the amount of assistance she needed to walk. Her classmates came to the likely conclusion that she must be faking. After all, who uses crutches one day, walks the next, and comes to school in a wheelchair the next? It just didn't make sense...she must be faking. The cruel, taunting whispers in the middle school hall confirmed that they doubted her pain. Eight months later, the CRPS diagnosis came and things began to change, especially the atmosphere at school.

Students with CRPS have unique challenges when it comes to education, and may qualify for special services, including those under a 504 plan. Section 504 is part of the anti-discrimination law known as the Americans with Disabilities Act (ADA). According to the United States Department of Education (USDOE), students qualify for Section 504 protection "who have a physical or mental impairment that substantially limits one or more major life activities." The eligibility process should be in place for each local school district, and you should contact an administrator for assistance.

provide special education and related services." An Individualized Education Plan (IEP) is developed in accordance with IDEA law, and your state's special education rules and regulations.

Special education has a number of eligible categories, including Otherwise Health Impaired (OHI). The criteria for an OHI designation is "Limited strength, vitality, or alertness, including a heightened alertness to environmental stimuli, that results in limited alertness with respect to the educational environment, that (a) is due to chronic or acute health problems *such as* asthma, attention deficit disorder or attention deficit hyperactivity disorder, diabetes, epilepsy, a heart condition, hemophilia, lead poisoning, leukemia, nephritis, rheumatic fever, and



Dorothy Switalski and her daughter Alli

your child's medical team (e.g., physician, pain specialist, physical therapist, psychologist) should provide documentation regarding the diagnosis and your child's health history. As you know, CRPS is not easily diagnosed by those in the medical field and is often not a visible syndrome, making it even more difficult for educators to understand. Providing detailed information about CRPS to school personnel is crucial as part of the initial evaluation.

Once at the evaluation meeting, one of your questions should be "What are WE going to do to help my child?" It is very important that everyone involved is part of the team, which is sometimes easier said than done. Nevertheless, approach the meeting optimistically with an expectation that your child's needs *will* be met. If the evaluation team comes to a conclusion you disagree with, you have the right to proceed in accordance with both 504 regulations and special education rules. Requesting an evaluation is the first step to getting your child the help he or she needs and deserves.

Once the need for special services is established, it is especially important for schools to understand that the needs of CRPS students change from day to day, sometimes from hour to hour. To that end one should be aware that CRPS may adversely affect a child's education when:

- Regular attendance is not possible (this is a biggie)
- Pain distracts a student from concentrating
- School personnel don't "believe" their pain
- They miss instruction and are expected to teach themselves
- They are expected to always be doing "make-up" work (a perpetual state of being behind is not good)
- Participation in gym class is not possible
- They are singled out from other students or by other students

- Social interaction is limited
- Cooperative learning is limited
- Vision is compromised

Flexibility in the 504 or IEP plan regarding accommodations and modifications is essential. Accommodations can be made to allow the student to complete the regular curriculum. Modifications differ from accommodations in that the regular curriculum is changed or modified to meet the needs of the student. Even secretaries, playground aides, and cafeteria workers should be informed of special circumstances, as they will also be dealing with your child. Accommodations can include:

- Access to a teacher consultant
- Absences are not counted against them
- Additional tutoring and/or instruction is provided
- Homebound instruction when needed
- Teacher-generated notes will be provided
- Laptop for use when writing is an issue
- Extended deadlines for assignments
- Additional time allowed for test taking
- Alternative assessment options (oral, project based, demonstration)
- Extra set of books for home use so carrying a heavy backpack is not needed
- Books on tape if vision is an issue
- Changing classes when other students are not in the halls to avoid bumping
- Use of the elevator
- Being allowed to call home when needed without question
- Being allowed to go to the nurse's office without question
- Being allowed to choose to go outside or stay in during recess
- Being allowed to make their own decision regarding gym participation
- Class lectures are video taped for student to view at home
- Class materials are available on Blackboard (online)
- Flexible schedule (no first hour, allowed to arrive late)
- If feeling better later in the day, allowed to participate in extracurricular activi-

ties, even on days when they have missed part or all of class.

Modifications can include:

- Exemption from Physical Education
- Not being required to make up "bell-work"
 - o Expected to complete coursework and master class objectives, standards and benchmarks just not the busy work, especially after an extended absence.
- Graded on completed work only
- Adjusted curriculum when appropriate

Please know that this is by no means a complete list. Also, the accommodations/modifications made for one CRPS student will be very different than for the next, depending on current symptoms and may change often.

Since my daughter's diagnosis in 2004, I have been very pleased with our school district's efforts to accommodate her ever changing needs. I know others have not been as fortunate, and have struggled to get their school to listen, understand, and provide needed assistance. In an attempt to help her teachers understand, I hold what I've coined "CRPS 101" at the beginning of each school year. The principal calls a meeting with all of her teachers, the special education teacher consultant and himself. I share with them her journey since CRPS; what she has been through, what could lie ahead, and what her current needs are. This has proven to be a wonderful tool and a way to get everyone on board and working as a team. Shortly after her diagnosis, I printed the RSDSA flyer *Helping Children/Youth with CRPS Succeed in School* and discussed it with the school counselor. We made the decision to share information about CRPS with her sixth grade classmates. On the same day each sixth grade teacher shared the following information with their class.

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Q: *The skin on my foot is thickening and my nails are brittle and cracking severely. I believe that I may lose some of my nails if I can't treat them or care for them properly.*

Are there any special tips for foot and nail care for those with CRPS?

taking this vitamin daily for a couple of months. If this fails, there are also some topical nail moisturizers and nail strengtheners that can be applied to the nails. One such product is Elon® Nail Conditioner, available online at <http://www.ilovemynails.com>.

CLINICAL Q&A: Foot and Nail Care for Those with CRPS?

By Elliot Udell, DPM

A: There are many conditions that can cause nails to become brittle and to crack. Two that come to mind immediately are fungal toe nails and vitamin deficiencies, but there are others. CRPS can cause nail problems, since it sometimes affects the circulation in the toes. I recommend that you see a podiatrist and have him or her evaluate the circulation in your toes. The podiatrist can then take a portion of the affected toe nail and send it to a laboratory. We have very sophisticated laboratory techniques today and fungi in nails can be seen through microscopic analyses.

If the test, however, comes back negative, you might want to try taking an over-the-counter vitamin called biotin. One company markets it as Appearex®. Many people suffering from brittle nails report gratifying results after

The bottom line, however, is that if you are having problems with your toe nails, a thorough podiatric examination is a worthwhile investment. Potential problems can often be averted by catching them early, before they become big problems. ■

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- It's called Complex Regional Pain Syndrome.
- CRPS is very painful (imagine putting your hand on a hot burner and not being able to remove it).
- CRPS symptoms can vary from day to day.
- CRPS can cause sensitivity to touch (be cautious about bumping).
- You cannot catch CRPS from another person.

Later that day, I received an e-mail from one of her teachers. After their discussion, she asked her students "Is there anything you can do now to help Alli?" One boy raised his hand and replied "Apologize." From that point on the "Alli's a Faker Club" ceased to exist.

The ultimate goal is to be sure your child's needs are addressed. When parents and school districts work cooperatively, it is the student who benefits. Oftentimes, providing knowledge and awareness about CRPS are the keys to success.

For further information, visit:

US Department of Education, Office of Civil Rights <http://www.ed.gov/about/offices/list/ocr/504faq.html>

National Dissemination Center for Children with Disabilities (NICHCY) <http://www.nichcy.org/idea.htm> ■

RSDSA has published a brochure called *Helping Children/Youth with RSD/CRPS Succeed in School*. You can find it on our website at http://www.rds.org/4/resources/pdf/helping_children.pdf.