Each of these young people suffer from Complex Regional Pain Syndrome (CRPS), a neurologic syndrome characterized by severe and often burning pain. CRPS pain has been rated worse than cancer pain.

From left to right: Yvonne Larity, Clark Law, Aya Ravek, and Jessika Bortolusso-Welch

Just because you can't see their pain doesn't mean it isn't there.

RSDSA Reflex Sympathetic Dystrophy Syndrome Association

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Q: Which of these young people suffer chronic pain?

A: They all do.

Children and teens shouldn’t have to live with chronic pain, particularly the neuropathic (nerve) pain of Complex Regional Pain Syndrome (CRPS).

But thousands do.

CRPS (also known as reflex sympathetic dystrophy syndrome) is a debilitating neurologic syndrome characterized by

- Severe pain and hypersensitivity
- Skin changes (color, texture, swelling, temperature)
- Functional impairment

Most often, CRPS develops after a minor trauma, such as a sprain, fall, or even surgery. Nerves misfire, neurons and immune cells are activated—all of which result in unrelenting pain. One characteristic of CRPS is that the pain is more severe than expected for the type of injury that occurred.

Other symptoms of CRPS include

- Abnormal sweating at some point in the painful region
- Skin changes (color, texture, swelling, temperature)
- Difficulty (and fear) in moving the injured extremity

WHO CAN GET CRPS?

Anyone can, but it is far more common is girls than in boys. Active youths—dancers, gymnasts, and athletes—particularly those who play contact sports—appear the most vulnerable.

Treatment for CRPS includes team care that incorporates

- Physical therapy that leads to active normal use of the involved extremity is considered the most effective
- Behavioral and psychological treatments to help children manage the pain
- Nerve blocks
- Medication to control pain
- Educating parents and children that to hurt is not to harm

Family and friends of 7-year-old Savannah Sipsey participated in the Achilles Walk for Hope & Possibility/Team RSD in Atlanta to raise awareness and funds for research.

WHEN CHILDREN HURT, ENTIRE COMMUNITIES GET INVOLVED

Often when young people are diagnosed with CRPS, their communities get involved to raise awareness and funds for research. This can be small, like a party, or large, such as a walk-a-thon or sporting event. Often these people contact The Reflex Sympathetic Dystrophy Syndrome Association (RSDSA) for help. RSDSA is a not for profit organization dedicated to raising awareness of CRPS among the medical and consumer communities and funding research for improved treatment and, hopefully, a cure.

In conjunction with the Achilles Track Club, RSDSA hosts annual Achilles Walks for Hope & Possibility in New York, Atlanta, and other cities nationwide. Teams are made up of individuals who have CRPS, their friends, families, and co-workers. In the last three years, teams have raised more than $100,000 for research.

OTHER WAYS YOU CAN HELP

There are several ways for people like you to help. In addition to the Achilles Walks, RSDSA holds an annual fundraising dinner and silent auction, The Bounty of Hope. In 2007, it will be held on November 14 at the Union League Club in New York City.

You can have events in your community such as walks, parties, “hat days”—any event that raises awareness of this potentially disabling syndrome. We depend on financial help from people like you for our educational and research activities.

You can also work with your local media to help get the story told. RSDSA can provide any media person with information on CRPS.

You can donate to RSDSA through the “Donor Choice” option in many United Way workplace campaigns. Just write Reflex Sympathetic Dystrophy Syndrome Association in the Donor Choice Box. Also, RSDSA is participating in the Combined Federal Campaign as a member of Health & Medical Research Charities of America. You may also be eligible to double your gift if your employer participates in a matching gift program.

You can make a Coin Collection Canister to place in local stores, your desk at work, or other traffic areas to raise money and awareness of CRPS. You can download the labels from our website at http://www.rsds.org/6/ways_to_give.html.

Most of all, learn what you can, so that if someone you love develops this syndrome you will know what it is. Believe people who say they are in pain. With proper treatment, children and teens can get better.

Together we can make a difference.