

I would love to participate in a research program that allows some latitude for the actual experience of CRPS patients, including those for whom pain is neither the only nor even the dominant problem, those who have had CRPS for a very long time, and those who have had it more than once. Studies in such a program should compare and evaluate the diagnostic criteria, methodology, and symptoms used in diagnosing the different patients participating. They should study the medications, supplements, therapies, and other treatment regimens that they have used. They should explore the cardiovascular, gastrointestinal, and other major systemic malfunctions that *the patients* associate with their CRPS.

We may not know what CRPS is, what causes it, or how to cure it; but asking the questions, gathering the hard facts and looking at what *is* is always a good opening move.

I do appreciate the considerable efforts of everyone at the RSDSA and of everyone who is working on this knotty problem. I am, therefore, loath to find fault. I would refrain from any criticism were it not that the incidence of CRPS is increasing, that autonomic dysregulation is becoming more common, that it is afflicting children, and that we will be having many more war-related cases of CRPS in the very near future.

Sincerely,

Judith O'Halloran-Rosen

AS A MOTHER OF A 12-YEAR-OLD AFFLICTED with CRPS, I've found mirror therapy to be our saving grace. The pain docs and PTs I know and have worked with haven't been aware of this therapy. The PTs have been excited to hear about it.

We all know that CRPS is a problem with the central nervous system—after a surgery or injury, the brain began sending pain signals to an immobile limb, trying to get it to answer back. This is in the same category as phantom limb pain and post-stroke pain. The central nervous system needs a chance to be rewired. Anesthesiologists (pain doctors) are very frustrated by it. There was a big “what do we do with CRPS?” conference in LA a year ago.

My daughter's CRPS started after an ankle sprain in a soccer game last fall. Nothing would touch it, until I learned that mirror therapy can be effective for phantom limb pain. We tried it. It successfully “tricked” her brain into “seeing” her completely disabled foot as a working foot. After one session (and an evening of watching funny movies), she went from terrible pain and no blood circulation to “that's ticklish” when it was time for PT. We've used mirror therapy twice since then when she's had recurrences with the smallest of injuries (it hit hard and fast last week, but the mirror shut it down again).

Don't be fooled by her quick recovery—her brain is young and plastic, and she'd only had the syndrome for 4 to 6 weeks. Studies describe using this therapy for

weeks before getting results. But hey—it's free, easy to do, and low-risk!

For more information, search on “mirror therapy” on the net. For studies and case descriptions, search on PubMed (<http://www.pubmed.gov>).

Here's a quick “how-to” mirror therapy example:

For a foot, sit with a mirror between the “good” and “bad” feet. The mirror needs to be big enough that you can look down and see a full reflection of the “good” foot and lower leg. The “bad” foot is fully hidden behind the mirror. We picked one up at a thrift store that was tall enough that it could lean against her knee on her “bad” side.

Move the “good” foot. Keep it moving. Watch it intently as it moves. Do this for several minutes at a time. Meanwhile, the “bad” foot moves with it. (In pain-free people, keeping the hidden limb still while moving the reflected limb has been shown to confuse the brain and cause tingling and pain. So make every effort to move it.) In my daughter's case, she couldn't move the “bad” foot, so we had her picture it moving in her mind.

We also make a point of never using “bad” or “good” foot with her, since that kind of “factoring out” of the injured foot is what contributed to the CNS dysfunction in the first place. Instead, we've had her name each foot as though they are puppies she dearly loves! ■

—Kathe Gallagher, MSW