CRPS/RSD: After a partial knee replacement in 2011 at age 51, I was diagnosed with Reflex Sympathetic Dystrophy (RSD). RSD is now called CRPS/RSD as it has been combined with Chronic Regional Pain Syndrome (CRPS). As described below, there is no cure for CRPS/RSD, and medical treatment is limited to pain management only. CRPS can affect both adults and children. With less than 200,000 documented cases in the U.S., it is a rare disease.

CRPS is a rare, neuroinflammatory syndrome characterized by intense chronic pain, swelling, and functional impairment of the affected body parts, including bone deterioration. "It generally develops after trauma such as a fracture, sprain, surgery, crash injury, or immobilization of the limb." (rsds.org). CRPS pain generally starts in one limb, but often spreads both externally and internally. In my case, the CRPS has spread from my left knee to both legs, from my hips to my feet as well as my right hand. CRPS pain is chronic, constant, and disproportionate in degree to usual pain after a trauma. CRPS is sometimes called the "suicide disease" because the resulting hopelessness of many sufferers and many have taken their own life when they could no longer live with the daily intense pain.

PAIN MANAGEMENT: While pain management is the only available treatment, each patient's CRPS manifests differently and therefore, there is no clear standard protocol for pain treatment. Treatments may never be developed because of roadblocks in the development process, such as a lack of investment and a challenging regulatory environment. Additionally, while a few treatments have become available, patients struggle with insurance companies and government programs to afford these lifesaving treatments.

HOW TO HELP: I ask for your support by joining the Rare Disease Caucus. As you know, the Rare Disease Congressional Caucus helps bring public and Congressional awareness to the unique needs of the rare disease community (including patients, physicians, scientists, and industry), and creates opportunities to address roadblocks to the development of and access to crucial treatments. The Caucus can facilitate conversation between the medical and patient community and build support for legislation that will improve the lives of people with rare diseases. This gives a permanent voice on Capitol Hill to the rare disease community. Working together, we can find solutions that turn hope into treatments.

I have left my contact information with your office. Please contact me if I can provide any additional information, and I encourage exploration of the organization Reflex Sympathetic Dystrophy Syndrome Association (RSDSA) at www.rsds.org. with whom I have worked to bring educational and support conferences throughout the U.S.

Name
Address
Phone number and email

The parts underlined in Yellow is where you can add your story to personalize, make the letter your voice.