



About Complex Regional Pain Syndrome (CRPS), also known as Regional Sympathetic Dystrophy

CRPS is a progressive, autoimmune neuro-inflammatory disorder. It is classified as a rare disease by the United States Food and Drug Administration. About 200,000 people, young and old, experience this condition in the United States alone.

CRPS most often occurs when the nervous system and the immune system malfunction as they respond to nerve and tissue damage from trauma. The nerves misfire, sending constant pain signals to the brain. Eventually, the brain and entire nervous system are involved as the disease progresses. The level of pain is measured as one of the most severe on the McGill University Pain Scale, more severe than cancer, amputation and even childbirth. Over time, victims are increasingly physically and financially disabled.

CRPS generally follows a musculoskeletal injury, a nerve injury, surgery or immobilization, but can occur spontaneously. It is incurable, gets worse over time and often spreads throughout the body. There is no cure, only therapies for pain management.

It has been shown that early diagnosis is generally the key to better outcomes. However, diagnosing CRPS is not a simple matter and lack of awareness in the medical community can leave many patients searching for months or years and seeing multiple doctors until properly diagnosed. Living with a chronic rare disease is an isolating experience and the disease can become incredibly debilitating.

Because CRPS is a rare disease, there is little funding for therapies or research. The treatments that do exist are considered “experimental” by insurers because funding for formal clinical studies is unavailable. As a result, CRPS individuals have no expectations of better treatments or a cure and the pain management treatments that are available are costly and mostly not covered by insurers.

What we ask:

- **Join the Rare Disease Congressional Caucus:**

The bipartisan and bicameral Rare Disease Congressional Caucus is led by Representatives G. K. Butterfield (D-NC) and Gus Bilirakis (R-FL), and Senators Roger Wicker (R-MS) and Amy Klobuchar (D-MN) to promote awareness of rare disease issues.

- **Support important rare disease FY 2022 appropriations priorities involving NIH, CDC and FDA**

Bill: Agriculture, Rural Development, Food and Drug Administration, and Related Agencies Section: Food and Drug Administration, Office of the Commissioner, Office of Orphan Products

Development Request: Fully fund the requested \$30 million for the Orphan Products Grant Program to support important research and clinical trials the market cannot provide.

- **Support mandatory Continuing Medical Education on rare disease to increase awareness.**