

Representative Mike Kelly
1707 Longworth House Office Building
Washington, DC 20515

November 13, 2023

RE: RSDSA Endorsement of the PROTECT Rare Act of 2023

Dear Representative Kelly:

At the Reflex Sympathetic Dystrophy Syndrome Association (RSDSA), our mission is to provide support, education, and hope to all affected by the pain and disability of Complex Regional Pain Syndrome, also known as Reflex Sympathetic Dystrophy Syndrome (CRPS/RSD), while we drive research to develop better treatments and a cure.

CRPS is a rare, neuro-inflammatory syndrome characterized by intense chronic pain, swelling, tropic changes, vascular changes, and functional impairment of a hand, limb, or entire body. It can become incredibly debilitating unless diagnosed early and treated appropriately. It is incurable and gets worse over time. There are less than 180,000 Americans affected by CRPS. Its most effective treatment is ketamine, a 60-year-old sub-anesthetic. It is opiate sparing (CRPS is the most painful condition known to medicine, opiates are often required to control the intense pain. Ketamine used in combination with opiates increases their effectiveness and duration meaning less are required for the same pain reducing effect).

More information is provided in our following release. Thank you for this initiative and please let us know how we can help.

Sincerely,

James W. Broatch, MSW
Executive Vice President & Director

A handwritten signature in black ink, appearing to read 'JD', with a stylized flourish at the end.

James Doulgeris
Chairman, RSDSA Advocacy Committee

RSDSA Endorses and Supports the PROTECT Rare Act of 2023

The PROTECT Rare Act, if passed into law, will help patients with rare and ultra-rare diseases in getting evidence-based, medically necessary non-FDA approved care like ketamine infusions and daily dosing therapy for CRPS (Complex Regional Pain Syndrome) covered by their health insurance.

James Doulgeris, Chairman, RSDSA Advocacy Committee

Ketamine has long become a standard of care because it is an opiate sparing drug that can reduce the daily dosages needed by increasing the effectiveness and duration of opiate therapy. Ketamine has also earned a strong reputation as an effective drug in treating chronic pain and CRPS' two primary co-morbidities – PTSD and treatment resistant depression. Treating depression is especially important because a well-respected South Korean study shows that suicidal ideation among CRPS patients is over 75 percent.

Ketamine infusions and daily therapies are presently off-label (not covered by insurance) because they are lacking definitive proof through a formal study of their safety in use over a longer period than 90 days. RSDSA has proposed teaming up with the US Veterans Administration, which is conducting such a study, to accelerate its completion and provide a statistically significant number of trial participants.

You can find the official [Press Release](#) from U.S. Reps. Mike Kelly (R-PA-16), Congresswoman Doris Matsui (D-CA-07), Reps. Neal Dunn (R-FL-02), and Mike Thompson (D-CA-04) by clicking on the blue portion above.

Full text of the bill is available [HERE](#).

For more information or questions or concerns, please contact James Doulgeris, Chairman RSDSA Advocacy Committee at advocacy@rdsd.org or directly at jim@jamesdoulgeris.com.

Please consider supporting RSDSA with a one-time or monthly gift

RSDSA receives no governmental support. We are totally reliant on donations from the CRPS community and from our fundraising events. I'm asking you to consider making a monthly donation. We receive monthly gifts as low as \$5 to over \$100. Dividing your gift over 12 months is very doable for most. Thank you for your kind consideration. <https://rdsd.org/donate>

Use [GoodSearch.com](#) Log in and enter RSDSA as your cause!

They will donate to RSDSA! Thank you for your support.

Other links that may be helpful:

<http://rdsd.org/youve-been-diagnosed-with-crpsrd-now-what>

<https://rdsd.org/wp-content/uploads/2022/06/CRPS-practical-diagnostic-treatment-guidelines-5-edition.pdf>

<http://rdsd.org/joinmembership> Please join us to stay informed and connected. We publish a free electronic monthly newsletter.

<https://rdsd.org/how-to-obtain-the-best-medical-care-for-crps>

<https://rdsd.org/understanding-crps-pain>

<https://rdsd.org/how-crps-is-diagnosed>