



**'SUICIDE DISEASE' UNITES NEW YORKERS FOR
3RD ANNUAL AWARENESS WALK EVENT**

**Complex Regional Pain Association Hosts Long Island
Fundraiser for Rare Neurologic Disorder**

EAST MEADOW, NY – April 25, 2018 – Metro New Yorkers struggling with the worst-ranked chronic pain will gather Saturday, September 15, 2018 at Eisenhower Park in East Meadow for the third annual Long Island fundraising walk event to create awareness for Complex Regional Pain Syndrome (CRPS). The Reflex Sympathetic Dystrophy Syndrome Association (RSDSA), which supports people and caregivers diagnosed with Complex Regional Pain Syndrome (aka RSD), is once again sponsoring the event to raise awareness, fund better treatments, and find a cure for the disabling and debilitating neuro-inflammatory disorder named for this organization.

A rare neurologic disorder that plagues some 1,000 Long Islanders, CRPS is ranked among the most painful of all medical problems and has been nicknamed the 'suicide disease' because there is no cure and limited effective treatments. The pain from CRPS is so severe that it has been known to drive people to the brink of death. On the McGill Pain Index, CRPS ranks 42 out of 50, making it one of the most severe pain conditions of all, even rated more painful than childbirth, amputation and the pain associated with cancer.

Despite studies that show an estimated 50,000 people join the CRPS population annually, CRPS is under-reported and under-diagnosed disease and classified as a "rare disease" by the FDA.* Moreover, the vast majority of US medical schools, four percent* according to one report, fail to offer dedicated courses on pain. This further contributes to improper treatment for those diagnosed with CRPS and overall failure in care.

This year's walk will take place from 8 a.m. until 2 p.m. at Eisenhower Park's 1K and 2.5K paths, which will be reserved for this event. Last year's event attracted nearly 450 walkers and 50 volunteers, and raised more almost \$56,000 for RSDSA. Funds raised in 2017 more than doubled those from 2016.

"At a time when people with CRPS are under increased scrutiny and regulation to manage their pain due to the so called 'opioid crisis,' it is imperative that we enhance awareness of this disorder and educate our communities about all of the resources available to improve pain and control the disease," says Jim Broatch, RSDSA's executive vice president and director. "The Long Island walk event is one of the most significant fundraisers for RSDSA and brings together people diagnosed with CRPS and their caregivers throughout the metro NY, NJ and CT regions and beyond. "Last year's event surpassed all of our goals thanks to the enthusiasm, generosity, time, and dedication of our volunteers, many of whom have CRPS themselves. Anyone, regardless of their ability, is encouraged to participate in the walk individually or form a team."

CRPS occurs when the nervous and immune systems malfunction in response to tissue damage from a trauma (such as nerve or musculoskeletal injury, surgery, or immobilization). CRPS causes nerves to misfire and generate constant pain, skin discoloration, temperature changes, and other disabling symptoms. Many of those with CRPS also suffer from extreme sensory and motor dysfunction, painful burning, numbness, allodynia, atrophy, tremors and other medical complications that grossly affect their quality of life.



2018 RSDSA Walk / 2

There is presently no cure for CRPS/RSD and very limited treatments available to manage the disease which often migrates from one extremity to other parts of the body including internal organs.

Finding a diagnosis for CRPS pain and its other symptoms often takes individuals several months and often years, and an average of five doctor visits. CRPS does not discriminate - it affects both adults and children of all ages. Treatment requires coordinated and Inter-disciplinary patient-centered care to achieve pain reduction/cessation and better function.

Registered participants may choose to walk, run, roll or simply just attend. Walk admission for 2018 will cost \$25 for adults (ages 12+); \$10 for children ages 6-11, and free for children under 5. A free t-shirt will be distributed to pre-registered participants. Educational resources, sponsors, and health professionals will be on hand during the walk, along with entertainment, and craft activities for children. Admission includes a complimentary bagel breakfast. The walk will be followed by a barbeque lunch to encourage socializing with other CRPS patients, care givers, sponsors and medical professionals. Raffles prizes will help generate additional funds for RSDSA.

For more information about the September 15, 2018, RSDSA Long Island Awareness Walk Event, visit: <https://www.firstgiving.com/event/rsds/3rd-Annual-Long-Island-CRPS-RSD-Awareness-Walk-Event>

Formed in 1984, Reflex Sympathetic Dystrophy Syndrome Association (RSDSA) is an international 501 (c) (3) not-for-profit organization based in Milford, CT. Its mission is to provide support, education and hope to all affected by the pain and disability of CRPS, while driving research to better develop treatments and a cure. RSDSA, which has sponsored similar walks in seven cities across the US this year, aims to improve the lives of those affected by Complex Regional Pain Syndrome/Reflex Sympathetic Dystrophy.

For more information about RSDSA, visit <http://rsds.org> or call 877-662-7737.

Facebook: https://www.facebook.com/pg/RSDSA/events/?ref=page_internal

Twitter: <https://twitter.com/RSDSA>; #RSDSA2018LIWalk

Instagram: https://www.instagram.com/rsdsa_official/; #RSDSA2018LIWalk

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*Based on the less than 200,000 people across the United States with the diagnosis.

NOTE: MEDIA INTERVIEWS AND QUALITY IMAGES FROM LAST YEAR'S RSDSA WALK ON LONG ISLAND ARE AVAILABLE UPON REQUEST

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