



Courtesy Stacey Udell

THE REFLEX SYMPATHETIC Dystrophy Syndrome Association will hold its third annual walk to spread awareness for Reflex Sympathetic Dystrophy or Complex Regional Pain Syndrome on Sept. 15.

RSDSA gearing up for third annual walk

By **BRIAN STIEGLITZ**

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Stacey Udell has a choice to make every day. “I can either stay in bed or get up and fight,” she said. “And it’s never easy. I’m in unbearable pain and people will look at me and say I look great.”

Udell suffers from Reflex Sympathetic Dystrophy Syndrome or Complex Regional Pain Syndrome, a disabling and debilitating neuro-inflammatory disorder. To spread awareness, she co-chairs an annual walk with the Reflex Sympathetic Dystrophy Syndrome Association at Eisenhower Park. This will be the event’s third year in East Meadow and it is set for Sept. 15, from 8 a.m. until 2 p.m.

“It’s become a major effort, it’s all hands on deck and we’re trying to get as much word out there as we can,” Udell said, explaining that RSDSA is an insidious disorder that does not always show on the exterior.

“There are so many people affected by it and it’s important for people to realize that there’s support out there,” she said. At the walk, participants will unify to raise awareness, fund better treatments, and find a cure for the rare syndrome. Based out of Milford, Connecticut, the organization has been holding its walk for several years in Central Park before expanding and moving to East Meadow.

RSDS occurs when the nervous and immune systems malfunction in response to tissue damage from trauma, such as nerve or musculoskeletal injury, surgery, or immobilization. There is currently no cure, effective form of treatment and diagnosis often takes months and sometimes even years, according to Jim

Broatch, the executive director of the RSDSA.

Because of the rarity of the syndrome, Broatch explained that many patients are not receiving effective treatment. Obstacles include accruing funding and proper medication, as there is no medication solely used to treat the syndrome.

Recently, however, strides were made in treating syndrome as it received national recognition as a “rare disease,” giving pharmaceutical companies the ability to extend experimental trials and test new medications known as bisphosphonates, including ketamine. Broatch said that this gives him hope for the future, but, as of now, there is much more to be done to support those living with the syndrome.

Educational resources, sponsors, and health professionals will be on hand during the walk, along with entertainment, raffles and craft activities for children. Walk admission is \$25 for adults, ages 12 and older; \$10 for children ages 6 to 11 and free for children under 5. Admission includes a complimentary bagel breakfast and a barbecue lunch, during which patients and caregivers could meet and socialize. Last year’s event drew nearly 450 walkers and 50 volunteers, and raised more than \$60,000 for the RSDSA, almost doubling their 2016 numbers.

This year, 240 people are registered to attend and Broatch said that they are hoping to beat last year’s numbers. The RSDSA is still looking for vendors and sponsors and donations in the form of food, gift certificates, raffle prizes and other financial sponsorships. To find out more or register for the walk, call 877 662-7737 visit <https://bit.ly/2Lgi7h2>.