



rdsda

community update

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Achilles 2014 Walk for Hope & Possibility

In conjunction with Achilles International, Reflex Sympathetic Dystrophy Association (RSDSA) will host its 9th Annual Walk in New York City on Sunday, June 29. More than 300 people from across the country and around the world will join Team RSDSA to participate in the 1.7 mile walk in Central Park to support education, research and awareness of the rare neurological disorder called Complex Regional Pain Syndrome (CRPS). More than one hundred virtual walkers will also take part in walks in their own cities across the United States to help RSDSA raise funds to assist people with CRPS.

Steve from Philadelphia attended last year, despite losing his job because of medical absences due to his CRPS. When asked why he came, he echoed the sentiments of so many who

joined Team RSDSA when he responded "Because I had to."

"The support of the CRPS/RSD community has been tremendous," said Executive Vice President Jim Broatch, "people from all over the country come out every year to support us and incur significant expenses to do so, it is humbling and greatly appreciated."

"This day means so much to me and others suffering from CRPS/RSD," said Casey Cashman, Chairwoman of RSDSA's Achilles Walk. "It brings us together to fight for the cause and proves to us we are not alone. It allows us and our support system to talk with other individuals with CRPS/RSD and get the word out about this horrible syndrome."



It's not too late to help Team RSDSA

Please call RSDSA at (877) 662-7737 or visit www.rdsa.org

Check out our First Giving website to learn more about the 2014 Achilles Walk for Hope and Possibility.

www.firstgiving.com/rds/2014-achilles-walk-for-hope-and-possibility.com

30 Years of Making a Difference

In 1984, a small group of concerned New Jersey families and physicians set out to support people with Complex Regional Pain Syndrome (CRPS). This year, thousands of people around the world will celebrate RSDSA's 30 years of service to the Complex Regional Pain Syndrome

(CRPS) community.

Over the past 30 years, you have helped to make many advances in our stated mission of providing support, education and hope to everyone affected by the pain and disability of CRPS/RSD while we drive research to develop treatment and ultimately a cure.

(continued on page 2)

- ◆ **Integrated Solutions to CRPS Conferences**
This series of educa-



**Honoring the Past, Forging the Future;
Envisioning a World Without CRPS**

For opportunities to donate, support, and volunteer, or to get up-to-date information, visit www.rds.org

"Honoring the Past, Forging the Future; Envisioning a World without CRPS."

RSDSA's 30th Anniversary Bounty of Hope Gala Princeton, NJ Oct. 25, 2014



Let's STOMP out CRPS!

"YOU can Help RSDSA change lives in Texas!"

09-07-2014

tional conferences each year provides hundreds of individuals with CRPS, their caregivers and medical professionals with knowledge and an



understanding of this syndrome. RSDSA supplies resources, alternative treatment options and emotional support to diminish their experience of pain and suffering and ultimately improve their quality of life.

◆ **The Patient Assistance Fund in Honor of Brad Jenkins**

Through this fund you provide financial aid to individuals with CRPS and their families.

◆ **The Maria Lane Fund**
Thanks to your generosity, this fund provides guidance and support to individuals with CRPS and their families in navigating the Workers' Compensation and Insurance system.

◆ **The RSDSA National Support Program**

This national network of community based support groups create community and connection for people living with CRPS and their caregivers. This program replaces the sense of isolation with a new sense of community filled with new resources, friendship, and experiences that enhance each group's capabilities to achieve their goals and needs.

◆ **CRPS: Pathophysiology, Research Synthesis, and Direction**

CRPS research has been limited by the

complexity of the disease and by the difficulty that any one research group has in recruiting a sample of patients large enough for conclusive results. This year, you helped bring together researchers from around the world to collaborate on the development of studies that hold the promise of finding the cause of and a cure for CRPS.

The theme for the 30th Anniversary is **Honoring the Past, Forging the Future; Envisioning a World without CRPS.**

Throughout 2014, there will be many opportunities to commemorate past accomplishments, as well as look forward to a bright future of research and support.



Donors Bring Integrated Solutions to CRPS to Dallas!
Help RSDSA Change Lives in Texas

On September 7, 2014, RSDSA, with your help, will bring the Integrated Solutions to CRPS Conference to Dallas.

People with CRPS and their loved ones require knowledge, tools to cope, reassurance from others, community support and hope!

The conference provides all this and more. We hope you will join us!

SPONSORSHIP OPPORTUNITIES

HELP US BRING INTEGRATED SOLUTIONS TO CRPS TO...DALLAS!

WHEN: FALL 2014

WHERE: DALLAS, TEXAS

SPONSORSHIP: \$500

FOR MORE INFO: CHRISTINE HOMA, DIRECTOR OF DEVELOPMENT

CONTACT: 860.987.8994 OR CHOMA@RSDS.ORG



Forging the Future of CRPS Research

International Researchers Gather in Chicago



On May 16th and 17th, RSDSA convened a two-day meeting of international researchers and clinicians at the Rehabilitation Institute in Chicago. The meeting was chaired by Drs. Gary Bennett and Norman Harden.

The goal of the meeting was to bring together prominent thought leaders involved in Complex Regional Pain Syndrome (CRPS) research to share their ideas and current

research, to identify research opportunities that hold the promise of finding the cause and cure of CRPS, and to create an International Research Consortium (IRC).

One of the fundamental problems hindering CRPS research is that few labs have access to large numbers of potential clinical trial participants and few labs have the money to conduct large trials. As a consequence, the resulting studies are too small, generally only involve one site, and subsequently are not replicated by other labs. The goal of the IRC is to improve and quicken

research that will benefit people with CRPS. Attendees were asked to confirm their institution's membership in the IRC by July.

RSDSA will supply the administrative support for the IRC and serve as the "lead" institution when applying for National Institute of Health grants. It is one of the IRC'S goals to favorably position itself to be a recipient of a \$6,000,000 NIH "Rare Diseases Clinical Research Consortia" grant from the NIH, as well as R01 grant awards for specific fields of CRPS research.



RSDSA greatly appreciates the generous donors to the Chicago International Research Conference.

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YOU are Taking the Lead

A Clinical Trial of Low-Dose Naltrexone (LDN)



Thanks to the ongoing support of individuals and corporations, a \$194,955 grant has been provided by RSDSA to Stanford University to fund a placebo-controlled, double-blind, cross-over trial of low-dose

naltrexone (4.5 mg) for the treatment of Complex Regional Pain Syndrome (CRPS). This study will be the first to test this novel treatment option for CRPS symptom relief. Evidence is mounting that LDN may block some of the neuro-inflammatory mediators that may underlie CRPS and other chronic pain syndromes.

Researchers at Stanford have published two papers

demonstrating its efficacy in treating fibromyalgia and it is being utilized in Crohn's disease as well as multiple sclerosis. The three aims of the study are to test the efficacy of LDN in reducing CRPS symptom severity, to analyze interrelations between changes in different symptoms, and to identify predictors of positive treatment response.

Bringing People Together Across the Country

Bounty of Hope Comes to Princeton and Sonoma Valley

The Annual Bounty of Hope Dinner brings together patients, caregivers, physicians and philanthropists for an evening of festivities that benefits RSDSA. Since 2000, we have come to-

gether to raise funds to support RSDSA's mission of providing support, education and hope to everyone affected by CRPS/RSD while we drive research to develop better treatment and a cure.

There's something for everyone at the RSDSA Bounty of Hope Dinner, including a raffle, balloon chance, silent auction, great food, and a fun-filled, entertaining live auction. This multi-faceted

Contact Us

RSDSA

P.O. Box 502
Milford, CT 06460

Tel: 203.877.3790
Toll Free: 877.662.7737
Fax: 203.882.8362
E-mail: info@rsds.org

www.rsds.org

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RSDSA 2014 Events

**RSDSA Walk for Hope
and Possibility**
New York, NY
June 29, 2014

**2014 Walk & Bake
Sale**
Bridgton, ME
July 26, 2014

**Integrated Solutions
to CRPS Conference**
Dallas, TX
September 7, 2014

**2014 CRPS/RSD Walk
for Awareness**
Cooper River Park
Pennsauken, NJ
September 13, 2014

**RSDSA's 30th
Anniversary Bounty
of Hope Gala**
Princeton, NJ
October 25, 2014

Taste of Hope Gala
Sonoma, CA
November 22, 2014

auction offers a wide variety of items for every taste, including goods and services, trips, dining, entertainment, home and garden décor, sports memorabilia, event tickets, gift items and more!

This year the 30th Anniversary Bounty of Hope Gala will take place October 25, 2014 in Princeton, New Jersey, while the Taste of Hope Dinner will be held on November 22, 2014 in Sonoma, California.



Start a Support Group with RSDSA!

The Safeway Foundation provided funding which has allowed RSDSA to produce a 14-minute video on how to start and maintain a thriving face-to-face or virtual CRPS support group.

It's a gem, click on the link to watch,

<http://youtu.be/5qYNUxJSfio>



Here is a link to two other videos of support group members discussing CRPS's impact on interpersonal relationships involving friends, family members, and spouses.

Here are the two links,

https://www.youtube.com/watch?v=ewDK4yKsk_0

<https://www.youtube.com/watch?v=dwwHX9Pxc30&feature=youtu.be>

RSDSA begins 5th Year of a 20-year study: How CRPS Impacts an Individual's Overall Health

RSDSA is encouraging everyone with Complex Regional Pain Syndrome to enroll in our ongoing Internet-based long-term study. There are absolutely no other long-term studies. To enroll, please visit, <http://www.crpssurvey.org/>

If keyboarding is difficult or painful, we can send you a paper survey and then we'll input your answers. This study was made possible by a **Brodsky Family Foundation** grant.

**Thank YOU for giving CRPS/RSD survivors
HOPE for a brighter tomorrow!**