



rsdsa
SUPPORTING THE
CRPS COMMUNITY

RSDSA ANNUAL REPORT FOR THE YEAR 2016



Reflex Sympathetic Dystrophy Syndrome Association

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From Our Presidents



2016 was a year of both challenges and successes for RSDSA. Many of the targeted goals established by the Board in late 2015 were achieved, and in some cases, even exceeded expectations.

Conferences for individuals with CRPS and their caregivers were held in three different sites across the country. RSDA also sponsored a groundbreaking scientific meeting dedicated to the use of ketamine as a treatment for Complex Regional Pain Syndrome. As a result, we have begun to develop a reference protocol for its use in CRPS. Its safety and efficacy

will be tested in a prospective, multi-center observational cohort study.

The International Research Consortium continues to make strides towards becoming its own entity, independent of RSDSA. We are proud to have been instrumental in its formation; prior to its inception, there was no single reporting agency which collected data on CRPS cases and their treatment, both successful and unsuccessful. It currently includes 64 sites from across the globe as its members.

RSDSA is committed to supporting young people with CRPS. Last year, we co-sponsored our second kids' camp at the Center for Courageous Kids. Plans are underway for a weekend get-away for young adults. New publications were developed to help educational institutions accommodate students with CRPS; others aid young adults in their transition from school or home to independent living.

Fundraising continues to be a challenge. This year we initiated several new concepts; a "Longest Day of Golf" which we hope to be able to replicate across the country, and a West Coast "Bounty of Hope." Unfortunately, we participated in what will be our last Achilles Walk in Central Park, NY. Although we had more than 400 people registered in 2015, last year our group was limited by the NY Road Runners' Club to only 150. One of the highlights of the year, it was a day filled with joy and laughter, inspiration and hope.

Each tag sale, concert, mini golf tournament. "Beef 'N Beer," or Bounty of Hope enables RSDSA to fulfill its mission: to fund research, and to help those who turn to us for support. This past year, our Brand Jenkins Fund and our Maria Lane Fund provided emergency assistance to 25 members of our community.

2016 was a good year. International expansion, enhanced social media presence and our lay and professional conferences all advanced RSDSA as the 'go to' organization for those affected by CRPS/RSD. We look forward to continuing these initiatives and embarking on several new ones in 2017.

Hank and Mary Beth Ludington

Our Mission

The mission of the RSDSA is to provide support, education and hope to everyone affected by the pain and disability of CRPS/RSD while we drive research to develop treatment and a cure.

Our Values

Our values guide everything we do at RSDSA:

- **COMMUNITY RSDSA** is committed to developing and maintaining meaningful relationships with our patients, volunteers, supporters, and funders for the entire CRPS community. Our community embraces diversity and tolerance. We promote leadership and responsibility within the community as demonstrated through partnerships, opportunities and active involvement within the community at large.
- **RESPECT RSDSA** respects every individual and their unique qualities and abilities. We will continue to honor the legacy of our founders by upholding their vision of a world without CRPS.
- **EXCELLENCE RSDSA** provides the best possible education, support and information to our community. We strive to empower people with CRPS to take control of their lives and give researchers and physicians the resources necessary to develop innovative and effective treatments in the search for a cure.
- **REPUTATION RSDSA** values our long legacy of providing services that change the lives of all those with CRPS. We continue to operate the organization with a commitment to integrity, honesty and accountability.

VISION

By the end of this decade, RSDSA will:

- Expand our organization to maximize our abilities to best serve our community, providing support for all people with CRPS.
- Continue to seek and actively pursue collaboration with the community, organizations and individuals to provide greater opportunities for people with CRPS.
- To be recognized as the leader in providing the best and most up to date information and support for people with CRPS.
- To be recognized as the leading CRPS support organization whose sound fiscal management and use of best practices promotes maximum growth for the future.

Officers

Mary Beth Kenny Ludington
Co-President

Francis (Hank) Ludington, III
Co-President

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Chairman of the Board

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Vice President

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Vice President, Living with RSDS, Inc.

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TCAPP

Ilona Thomassen
Patientenverenigin CRPS

Billy Alexander, MD

Rachel Charlesworth
RideScout

Stephen Bruehl, Ph.D
Vanderbilt University School of Medicine



RSDSA Scientific Advisory Committee

Stephen Bruehl, PhD (Chair)

Vanderbilt University School Medicine, TN
Diagnosis, pathophysiology, treatment and psychological aspect of CRPS

Norman Harden, MD (Research Co-Chair)

Athens, GA
Diagnosis and Treatment of CRPS

Charles Berde MD, PhD

Children's Hospital Dept. of Anesthesiology
Pediatric CRPS

Frank Birklein, MD

University of Mainz, Germany
CRPS mechanisms and treatment, neurological aspects of CRPS

Andreas Goebel, MSc, PhD, FRCA, FFPMRCA

University of Liverpool, United Kingdom
CRPS mechanisms and treatment, neurological aspects of CRPS

Lorimer Moseley, PhD, FACP, HMAPA

University of South Australia, Australia
Brain mechanisms, physical therapy, interventions for CRPS

Candy McCabe, MSc, PhD, RGN

University of the West of England, United Kingdom
Body disturbance in CRPS, and treatment of CRPS

Frank Huygen, MD

Erasmus Medical Center, The Netherlands
Inflammatory and immune mechanisms of CRPS, Interventional treatment

Christoph Maier, MD

Ruhr University, Germany
Brain mechanisms of CRPS

Guillermo Alexander, MD, PhD

Drexel University, PA
CRPS mechanisms and treatments, including ketamine

Florian Brunner, MD, PhD

Balgrist Hospital, Switzerland
Rehabilitation, CRPS treatment

Peter Moskowitz

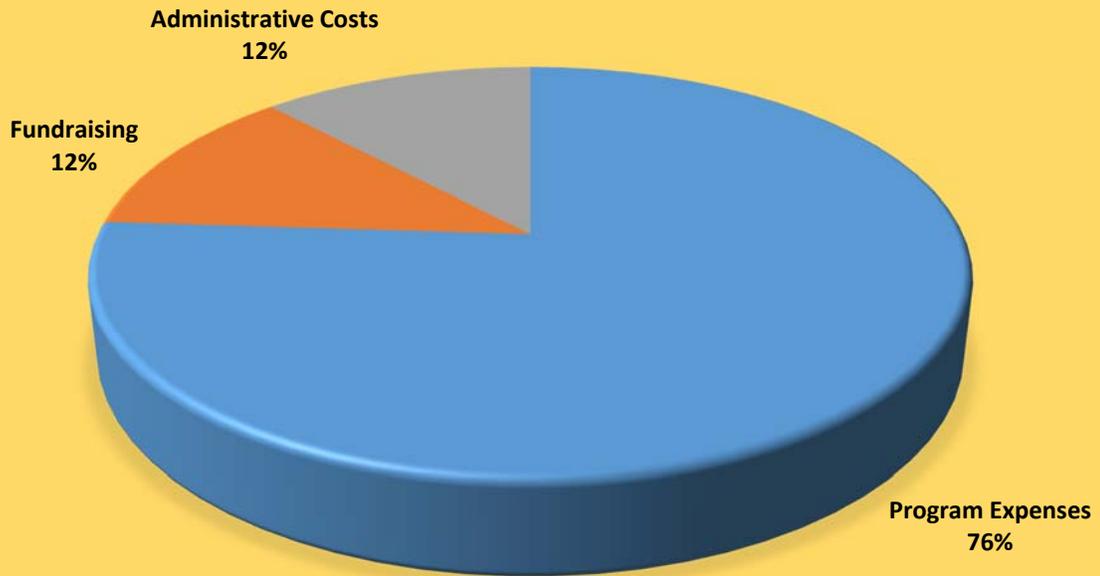
Washington, DC

2016 Highlights

- Co-sponsored the second summer camp experience for children in pain
- Sponsored Learning Live Well with Chronic Pain in Long beach, CA and Treating the Whole Person: Achieving Wellness in La Jolla, CA and Chicago, IL
- Convened a scientific conference for Ketamine Treatment for Complex regional pain Syndrome: art and Science in Chicago, IL. This will begin the development of conference protocol for CRPs which will be tested in a prospective, multi-center observational covert study of the safety and efficacy of the protocol
- Through the Patient assistance Program in honor of Brad Jenkins, RSDA provided funding in the amount of more than \$12,000 in emergency financial assistance to individuals with CRPS
- Funded an exploratory study of Genetic, epigenetic, Proteomic, Metabolomics, and Gene Expression on related factors in CRPS at Vanderbilt University.
- RSDSA funded, Pain Reduction by Inducing Sensory-Motor Adaptation: CRPS PRISMA TRIAL AT the University of Bath, UK
- Exhibited at the American Academy of Family Physicians to educate family physicians on how to diagnose, treat, and manage CRPS.



FISCAL YEAR ENDED DECEMBER 31, 2016



Revenue	\$765,777
Expenses	\$763107
Net	\$2,670

- Unaudited
- Audit will be completed in June 2017

A Special Thank-You to RSDSA's 2016 Corporate Partners

- **Title Partners**

- **Aetna Foundation Inc.**
- **Axsome Therapeutics, Inc.**
- **Baker Family Charitable Fund**
- **Grünenthal**
- **Purdue Pharma L.P.**

- **Gold Partners**

- **Medtronic**

- **Bronze Partners**

- **McLarty Pope LLP**

- **Orange Partners**

- **No Pain Hanna**
- **Neurologic Relief Center**