

2009 Annual Report



Friends came together for the Achilles Walk in New York City and virtually around the globe on June 28: Courtney Pett, Holly Degner, Lauren Renda, Meri Craig Anderson, and Jamie Baum in Central Park.

I just wanted to thank everyone associated with RSDSA for all you have done in bringing awareness and help to all patients with RSD! Your tireless effort to make this serious disease known and accepted by the medical community and the world has not only helped people with the disease but also the people like myself, who was fortunate enough to have the proper care early enough so that my RSD was put into remission.

—Janet Richards

2009 marked a special anniversary for the RSDSA: 25 years of working to increase awareness of CRPS; resources for support; education of the public as well as those in the healthcare industry; and research into more effective treatments and a cure for CRPS. Notes like the one above from Janet Richards keep us focused on our mission and reinforce the importance of early diagnosis and treatment.

Over these 25 years, we have developed an informative, helpful website that attracts 27,000 unique visitors each month; established a quarterly newsletter, the *RSDSA Review*, which strives to encompass the varying aspects of living with CRPS; published evidence-based clinical guidelines for diagnosis, treatment, and management of CRPS; and much more.

Many people with CRPS become isolated and feel alone within their communities. The RSDSA provides support

I can't say how much your website and newsletter have meant to me over the years. The information has helped me to not only empower myself while defending myself against RSD but also to educate the referrals sent to me.

—Rhonda Guglielmi, nurse, patient advocate, and person with RSD

through a toll-free crisis intervention by a master's-level social worker for people in extreme pain and without hope; support listings throughout the US; and building online communication networks. Through our online resources, free electronic news alerts; Facebook page, which continues to thrive after a year at more than 4,000 fans, and the establishment of our Twitter page in 2009, we seek to help individuals feel connected and know that they are not alone in this struggle.

We have also held many conferences across the US to build community and educate healthcare professionals as well as people with CRPS and their support network, the most recent of which was held in Scottsdale, Arizona. *New Perspectives on CRPS: Research, Diagnosis, Treatment*, a two-day accredited conference in March 2009, was designed to ensure that frontline healthcare professionals have the information needed to make an early diagnosis and were informed of recent research; and to bring greater understanding of the syndrome to the people with CRPS attending.

Since service to people with CRPS and their support network has been an integral part of our mission, they have been giving back to their communities as well. We introduced our *Giving Back* project this year, which highlights people with CRPS from all over the country and the world who volunteer in their communities, even with the disabling pain of CRPS.

People with CRPS and their loved ones around the world also came out to show their support for Team RSDSA at

the Achilles Walk for Hope & Possibility, in New York and through our virtual team around the world. We had numerous satellite walks and fundraising events across the country as well—including yard sales, dinner benefits, “dough raisers,” bike rides, and concerts—that supported the RSDSA’s mission or research fund.

In continuing our commitment to research, the RSDSA launched an Internet-based study—*Long-Term Health Effects of CRPS: A 20-year Cross-sectional and Longitudinal, Observational Cohort Study*, funded by a grant from the Brodsky Family Foundation—to be used by clinicians and researchers over the next two decades to increase our understanding of how CRPS impacts overall health and its underlying disease mechanisms.

The 2009 Tobias Young Investigator Award was also granted to Jenny Lewis PhD, MSc, Dip COT, for a study to investigate the relationship between body perception disturbances and cortical representation of the affected limb in CRPS. The RSDSA funded \$155,029 in grants in 2008-2009. Since 1992, RSDSA has funded \$1,334,111 in fellowships and grants.

In September, the RSDSA was invited to exhibit at Veterans Administration/Department of Defense (VA/DOD) *Evolving Paradigms II*, a national conference for personnel and organizations involved in caring for returning veterans of the Iraq and Afghanistan wars. We were one of only two civilian chronic pain organizations in attendance. One result of this conference was the establishment of a resource and information hub on the RSDSA website for Veterans and Military Personnel with CRPS.

As the annual Bounty of Hope fundraising event was in honor of all people with CRPS, who remind us each day why the work we do is so important, the RSDSA continues to work towards increasing awareness, education initiatives, support, and research for CRPS into 2010 and beyond.

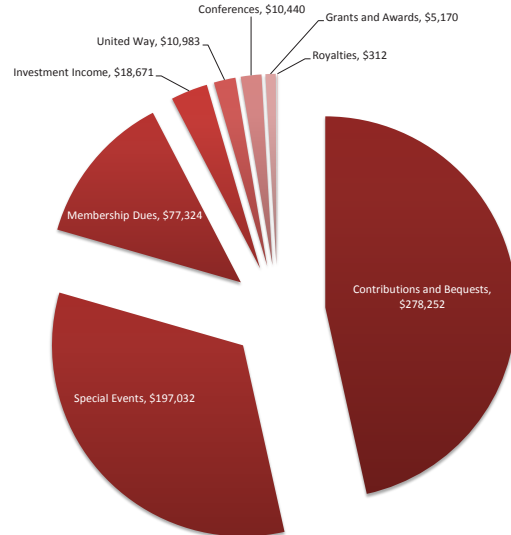
2009 Corporate Members

Boston Scientific
 Celgene
 Cephalon
 Endo Pharmaceuticals

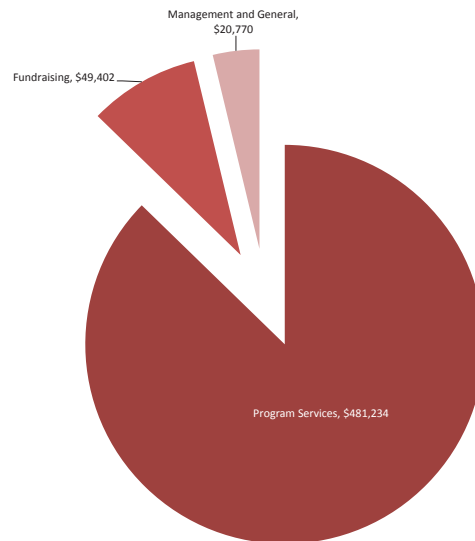
King Pharmaceuticals
 Medtronic
 Purdue Pharma L.P.

Financials

Total Revenue and Support, \$598,184



Total Expenses, \$551,406



RSDSA is audited by Solakian, Caiafa, & Company, CPAs LLC, Branford, Connecticut.

RSDSA
 99 Cherry Street
 Milford, CT 06460



Tel: 203.877.3790
 Toll Free: 877.662.7737
 E-mail: info@rds.org
 Website: www.rds.org

Raising awareness of complex regional pain syndrome (CRPS) since 1984.