

RSDSA to Fund a New Opportunity in Clinical Research for CRPS Care

RSDSA's Board of Directors unanimously elected to fund a 2½ year clinical research project: **A multi-centre international study exploring the patients' definition of recovery from CRPS**. The principal investigator is Professor Candy McCabe, PhD, of the Royal National Hospital for Rheumatic Diseases in Bath, England. Her distinguished consortium of clinical scientists includes Andreas Goebel, PhD; Nicholas Shenker, PhD; and Richard Haigh, PhD; also of the United Kingdom; Johan Marinus, PhD and Roberto S.G.M. Perez, PhD of the Netherlands; Florian Brunner, PhD, of Switzerland; Professor Frank Birklein, MD, and Christian Maihöfner, MD, PhD, of Germany; and Professor Troels Jensen, MD, DMSc, of Denmark.

This research project holds the promise of setting the standard for outcomes measurement of clinical research trials of treatments for CRPS I into the future. It will also establish collaborative relationships among clinicians and scientists around the world. In some ways, RSDSA's support of this research may appear to be an extraordinary event, but perhaps not. Let me explain.

Since its founding in 1984, RSDSA's mission has included advocating for understanding CRPS and supporting people with the syndrome—individually, in their communities and across the country. RSDSA provides access to information and services to patients, their families and friends, their doctors, and to the medical and health care community at large. RSDSA also raises funds for these services and for innovative research that has the ultimate goal of finding a cure for CRPS, and short of that, treatments that relieve the suffering caused by the disease.

RSDSA's research mission has three parts. The first seeks new and improved diagnostic methods to identify CRPS faster and with greater accuracy (better sensitivity and better specificity). The second seeks to understand the mechanism of the disease that is CRPS: What is the cause? Why do some people get it and others do not? Why do some people recover and others do not? The third research mission of RSDSA seeks effective and safe treatments for CRPS. An overview of research projects that RSDSA has funded in these three areas is available at RSDSA's web site (www.rds.org/research.html).

Recently RSDSA worked with respected clinicians, notably among them Norman Harden, MD, and Steven Bruehl, PhD, to refine the diagnostic criteria for CRPS. RSDSA supported the basic science leadership of Anne Louise Oaklander, MD, PhD. On the tireless initiative of Mark Cooper, PhD, RSDSA sponsored a translational workshop on the basic science of neuroinflammation and glial activation www.rds.org/glial_workshop/glial_conference_summary.html.

Another workshop on the objective imaging of neuroinflammation will take place in October, 2011. Nonetheless, taking new knowledge from the laboratory to the clinic where it can be of service to real people in pain is difficult. RSDSA sought well-designed, innovative clinical research proposals, but few emerged that were worthy of support – until now.

As the sole funding agent for this project, RSDSA and its Scientific Advisory Committee has the opportunity to monitor and counsel the research process and build cooperative relationships for future research efforts. All parties benefit, not the least being people with CRPS and their loved ones. As Humphrey Bogart said in "Casablanca" (in the person of Rick Blain), "Maybe not today, maybe not tomorrow, but soon..." Prof. McCabe's research opens a new opportunity in clinical research for CRPS care. It is an extraordinary event, and perhaps not. It's just good scientists doing good science. That, in part, is what RSDSA is for.