## Symposium on Hereditary Sensory Neuropathy Type I April 23 and 24, 2008

**Post-Symposium Update:** The conference was very exciting. The collaboration--both at the dinner, afterwards and at the conference--was obvious and had the presenters very excited about working together. They all came away with new ideas to work on and a committed willingness to continue the collaboration through at least email. The group shows all of the participants. Submitted by: Rory Robb-Deater



Over the past few years several groups of scientists have been exploring the molecular biology of Hereditary Sensory Neuropathy Type I (HSN-I). The Deater Foundation has supported the research being done at the Day Neurological Research Laboratory at Massachusetts General Hospital. This group has generated a HSN-I mouse model that appears to mimic the human clinical symptoms of the disease over time. This has given researchers new insight into the disease process and an opportunity to consider options for potential treatment.

Prior to moving into the next phase of research, Dr. Robert Brown, the Director of the Day Lab, and Dr. Florian Eichler, who is doing extensive research with the mouse model, have invited a group of experts in the field to discuss the implications of the molecular changes caused by the gene mutation and how that pathology is observed in the mice.

Researchers from around the world will gather at the Day Lab in Charlestown, Massachusetts, just across the river from Boston for the conference. Along with Dr. Robert Brown and Dr. Florian Eichler, some of the expected participants are:

Teresa Dunn, PhD

Department of Biochemistry and Molecular Biology

Uniformed Services University of the Health Sciences

Bethesda, Maryland

Dr. Dunn has been working with Dr. Brown and Dr. Eichler on the mouse model project, funded by a grant from the National Institutes of Health.

Dominic Campopiano, PhD School of Chemistry, University of Edinburgh Edinburgh, Scotland

Christopher Haynes

Biology Graduate Student, Doctoral Program

Georgia Institute of Technology

Atlantic Georgia

Mr. Haynes works with Dr. Alfred Merrill Jr. in the Department of Chemistry and Biochemistry.

Thorsten Hornemann, PhD Institute for Clinical Chemistry

University Hospital Zurich

Zurich, Switzerland

Dr. Hornemann presented at the Glycolipid and Sphingolipid Biology Gordon Conference in Italy in February. Dr. Eichler presented at the same conference.

Garth Nicholson, PhD

Concord Clinical School

The University of Sydney

Sydney, Australia

Dr. Nicholson's research team first identified the chromosomal defect that causes HSN-I. The paper from this team was co-published with the confirmation study by Dr. Khemissa Bejoui, then with the Day Lab.

Alex McCampbell, PhD

Neuroscience Drug Discovery

Merck Research Laboratories

West Point, Pennsylvania

Dr. McCampbell developed the initial mouse model for HSN-I when he was at the Day Lab.

Ann Moser, BA

Research Associate in Neurology

Kennedy Krieger Institute

**Baltimore Maryland** 

Kurt Fischbeck, PhD Neurogenetics Branch National Institute of Neurological Disorders and Stroke Bethesda, Maryland

Dr. Fischbeck will lead the group discussion. Eric Newcomer, Larry and Rory Robb Deater, and Ellen Deater Burns will represent the Deater Foundation at the meeting. Eric Newcomer will share the cumulative results of the lifestyle and health survey completed by (and for) affected members of the Deater family.

Your contributions to the Deater Foundation support this opportunity to share research ideas and possibilities. This Symposium is expected to be "informative, stimulating, and productive." It is the great hope of the family that with such talented and dedicated researchers gathered together, new ideas will be generated for the treatment and eventual cure of this disease.