

## **Unified Batten's Disease Rating Scale (UBDRS) Project**

**...We are currently recruiting for the UBDRS study....**

The Batten Study Group (BSG), under the direction of Jonathan Mink, MD PhD (Principal Investigator, University of Rochester) and Frederick Marshall MD (Co-Principal Investigator, University of Rochester), is conducting a research study in individuals with Batten's Disease to continue refinement of the Unified Batten's Disease Rating Scale (UBDRS), a clinical rating assessment that was developed in 2002 to describe the features of Batten's Disease. Further work is planned to determine if the rating scale adequately captures clinical information in the following areas: speech, vision, movements, present of seizures, behavior and mood, and capabilities related to activities of daily living in order to learn more about the natural progression of Batten's disease.

Participants may be seen at the Batten's Center at the University of Rochester (Rochester, NY) and/or during the annual Batten's Disease Support and Research family conferences.

For more information, please contact the Batten's Center Project Coordinator Amy Vierhile at (585) 275-4762.