As a rare, inherited disorder of the nervous system, Batten disease has no known treatment or cure. Those affected with Batten disease suffer progressive neurological impairment, seizures, blindness, loss of motor skills, speech and sadly, life, taken too soon.

Batten disease or Neuronal Ceroid Lipofuscinosis (NCL) is a family of lysosomal storage disorders caused by autosomal recessive genetic mutations resulting in the build-up of fats and proteins, or lipofuscins in the body which cause cell death. There are more than 10 identified forms of the disease, which are most commonly diagnosed between infancy and school age. Kuf’s, Parry and ANCL disease are known adult forms of Batten. Though recent improvements in genetic testing have made diagnosing Batten disease much quicker and more reliable, families tell of very long diagnostic journeys, often years after the first signs of seizures or loss of sight. In a recent needs assessment completed by BDSRA, more than 30 different diagnoses were reported by families before the final Batten diagnostic determination. Autism, seizure disorder, epilepsy, PDD and others are common early diagnoses. According to the Centers for Disease Control, 2-4 births per 100,000 in the U.S. are affected by Batten disease, though some researchers in the field suggest these numbers are low.
Together we can do so much more for so many who need help. Our partnerships with families, researchers, community supporters and advocates for rare disease patients are vital to scientific discovery. Connect today with the Batten Disease Support and Research Association to give help and hope.

BDSRA: Leading the Way in Support and Research

The Batten Disease Support & Research Association (BDSRA) is the largest nonprofit organization in North America dedicated to funding research, advancing education, providing family support services, and raising awareness of the disease and its impact. Founded in 1987 as an international support and research organization, a focus of BDSRA is to help unravel the mysteries of Batten disease by bringing the worlds of science, research, and health care together toward a common goal: the discovery of treatments and cures.

Our Programs

The programs and services of BDSRA are designed to:

- Maximize opportunities for Batten families to manage the disease and its impact through medical, educational, and support resources
- Educate caregivers, medical professionals, teachers and the public about the special healthcare needs of those diagnosed with Batten disease
- Connect Batten families to appropriate resources to meet a wide variety of needs related to special education accommodations and specialized care within their own home communities

Research

BDSRA is dedicated to finding treatments and a cure for Batten disease. BDSRA research grants support scientists worldwide pursing basic and applied research, fostering partnerships, and facilitating innovative discoveries.

BDSRA’s Research Program:

- Funds cutting-edge technologies, including new developments in gene therapy, enzyme replacement, and drug discovery
- Provides for the continued development of an international Batten Disease Registry and natural history data project to ensure the rapid distribution of information to labs and scientists across the globe engaged in Batten disease research
- Supports both basic and applied laboratory studies to accelerate the pathway to clinical trials and treatments through collaborations with biotech and pharmaceutical partners

Advocacy

BDSRA builds alliances and networks across state and federal legislative channels to raise awareness about rare disease and the needs of Batten families. By educating policymakers and government leaders, BDSRA adds a unified voice to advocate for research funding and the need to expand the drug discovery process.

How Can You Help?

We are so glad you asked.

Programs, services, and research funding are made possible through charitable contributions. With donors and volunteers who want to make a difference, great things are possible to give families hope.

THANK YOU FOR YOUR SUPPORT.

Here are a few ideas:

- Make BDSRA your charity of choice through supporting our Annual Fund Campaign
- Follow us on social media and “like” our facebook page and share our posts and tweets
- Sign up for news updates and emails by sending us your contact information
- Organize a fundraising event, run a 5K, or walk a mile for the cause and donate the proceeds to BDSRA

Your support will advance research, provide family support services, and raise awareness of Batten disease. With your help, BDSRA can continue to search for the cure and discover more about neurological disease.

To give online today go to: www.bdsra.org and click the Donate button or call 800-448-4570 to give hope and help.

For more information visit our website at bdsra.org

Follow us on social media: www.facebook.com/bdsra  www.twitter.com/bdsra