



For Immediate Release

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Batten Disease Awareness Weekend

Bringing Hope for Children with a Fatal Disease—and No Cure in Sight

June 3-5, 2011

June 1, 2011 (Reynoldsburg, OH) – Batten Disease Support and Research Association (BDSRA) is holding its 3rd annual Batten Disease Awareness Weekend, June 3-5, 2011 to bring recognition to a rare but devastating disease. Batten disease is a genetic neurological disease that brings an early death to each child it affects. The disease may not be well known, but its effects on a family can be seen in numerous cities and towns around the country.

“Approximately 30 children will be diagnosed with Batten disease this year, and about the same number will also pass away before the end of 2011”, said Adina Ryan, development director for the BDSRA. *“That is simply too many children and families who will not get to celebrate their 3rd birthday, play little league, or simply fulfill all the plans and dreams that every mom and dad wished for.”* she continued. *“Our only hope is that scientists and researchers will find a cure that will save future generations of our children,”* she added.

While there is hope in research for a treatment or cure, the funds are hard to come by. Families around the world will be doing their part this weekend to raise both awareness and funds for children suffering with this fatal disease. **You can help spread awareness about the cruelty of this disease. On June 3-5, 2011, please take a moment to tell someone about Batten disease and how it can steal a precious child’s hopes and dreams.** You can also donate to the Batten Disease Support and Research Association by visiting our website at www.bdsra.org. Every story and every dollar makes a difference. **The cure depends on us...we depend on you.**

A Deadly Disease with No Cure

Batten disease is a genetic neurological disorder that affects children and adolescents. Over time, affected children suffer mental impairment, worsening seizures, and progressive loss of sight and motor skills. Eventually, children with Batten disease become blind, bedridden, and unable to communicate. Presently, there is no effective treatment for the disease and the disease is always fatal.

About the Batten Disease Support and Research Association

The Batten Disease Support and Research Association (BDSRA) is the largest support and research organization in North America for families that have children with the disease. *“Over 50% of our annual budget goes toward research, and more than 96% of our funding is provided through families of children with Batten disease and private contributions,”* said Lance W. Johnston, Executive Director. ***“In order to find, and fund the cure, we simply have to broaden our horizons and get more interest in helping these children,”*** said Adina Ryan, Director of Development.

BDSRA has been supporting families with programs, services and research funds since 1987, and we encourage you to **visit our website at www.bdsra.org or call 800-448-4570 to learn more about Batten disease and what you can do to help.**

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