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Contact: 1-866-287-7233

ANNUAL CONFERENCE FOR BATTEN DISEASE TO BE HELD IN CHICAGO

The Batten Disease Support & Research Association (BDSRA) will host their 22nd Annual Conference in Chicago July 29-August 1, 2010. Each year, BDSRA hosts a conference for families who have children with Batten disease including siblings, grandparents and the affected children.

Batten Disease is a rare genetic neurological disease that brings an early death to each child it affects. *"First it takes away their ability to function, then it takes away their ability to live",* stated Adina Ryan, Director of Development for BDSRA. *"The disease is extremely rare, affecting only about 400 children in the U.S. but its devastating affect on a family can be seen in numerous cities and towns around the country.",* she added.

BDSRA's annual conference allows families to connect with one another, provides educational sessions led by medical experts, offers classes on the many programs and services BDSRA provides, and provides an opportunity to hear directly from researchers who are actively searching for a therapeutic solution and ultimately a cure for Batten disease.

One of the most important parts of the conference is the opportunity to network with other families. *"We are always amazed at the people we meet, the passion they have for affected children and the kindness of words and actions from friends and family that attend. To be able to sit down in a room with others that know exactly what you are going through on a daily basis has no price tag. There is so much learning that goes on both in the meetings and the hallways. We also are amazed at the scientists and staff members that dedicate their hearts and souls to finding a cure for this horrible disease. They are true heroes!,"* said Chris Hawkins, board member and father of 2 sons, Brandon (11) & Jeremy (8) both with Batten disease.

Approximately one child is diagnosed with Batten Disease each week. While there is hope in research for a therapeutic treatment and eventually a cure, funding for such research is costly. For more information on how you can help support Batten disease and the families it affects, please visit our website at www.bdsra.org or contact Adina Ryan, Director of Development at aryan@bdsra.org.