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BDSRA Foundation Unveils Centers of Excellence & Affiliates; Announces Batten Disease Global Research Initiative

ST. LOUIS – The [BDSRA Foundation](#) announced its Center of Excellence & Affiliate members and the formation of the Batten Disease Global Research Initiative during Saturday night’s Dinner Dance at the Annual Family Conference in St. Louis.

This news marks a significant step forward for Batten disease family support and research.

Children’s Hospital Colorado, Children’s Hospital of Orange County (CHOC), Kennedy Krieger Institute, Nationwide Children’s Hospital, and the University of Rochester Batten Center earned Center of Excellence designations. C.S. Mott Children’s Hospital at the University of Michigan Medicine, NYU Langone Health, Rush University Medical Center, and UNC Hospitals were named Affiliate Centers.

BDSRA’s Center of Excellence Program aims to optimize patient outcomes, accelerate research, and improve the quality of life for individuals affected by Batten disease and their families by increasing access to the best possible clinical care and sub-specialty services through a national network of Centers.

With the help of these centers, Batten families can see multiple specialists and receive care all in one place.

“The collaboration with BDSRA and each other to form the Centers of Excellence has been phenomenal,” BDSRA Foundation President & CEO Amy Fenton Parker said. “They have developed great plans, and we look forward to bringing more into the fold so that our Batten patients and their families will have state-of-the-art care.”

The Batten Disease Global Research Initiative is a consortium of leading patient advocacy organizations worldwide, that share the common goal of advancing research for all forms of Batten disease.



The BDSRA Foundation, [BDSRA Australia](#), [BDSRA Canada](#), and [Batten Disease Family Association \(BDFA\)](#) are founding members of the Global Research Initiative. Under the guidance of the Batten Disease Global Research Initiative Grant Program, the group is working together to identify, foster, and collectively invest in the most promising research worldwide. The Batten Disease GRI aspires to accelerate therapeutic development, improve diagnosis and standards of care, and enhance the quality of life and outcomes for all individuals affected by Batten disease.

This grant program aims to invest in the most promising research worldwide that addresses key research questions and areas of unmet need in Batten disease. Grants of up to USD \$50,000 will be awarded for one year, with the potential of renewal based on outcomes in the first year. Expressions of Interest will open on July 29.

"We are thrilled to announce the launch of our new research grant program, aimed at fostering innovation and supporting groundbreaking research in Batten disease around the globe," BDSRA Foundation Head of Research & Medical Affairs Dr. Ineka Whiteman said. "This initiative underscores our collective commitment to advancing knowledge, empowering researchers, and really moving the needle towards more effective treatments and outcomes for our community."