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BDSRA Foundation Announces Children’s National Hospital as 12th Site in Batten Disease Clinical Centers of Excellence Program

GAHANNA, OH (March 24, 2026) – The [BDSRA Foundation](#) continues to expand access to expert Batten disease care with [Children’s National Hospital](#) in Washington, D.C., officially joining its [Batten Disease Clinical Centers of Excellence Program](#) as an Affiliate Center.

Children’s National joins a growing network of leading institutions dedicated to delivering coordinated, expert care while advancing research and clinical collaboration. With this addition, the program now includes 12 sites nationwide, comprised of seven Centers of Excellence and five Affiliate Centers.

“The continued growth of the Clinical Centers of Excellence Program reflects what is possible when leading institutions commit to working together,” said Dr. Ineka Whiteman, BDSRA Foundation’s Head of Research & Medical Affairs. “The addition of Children’s National Hospital strengthens our ability to advance research, share expertise, and improve outcomes for individuals living with Batten disease.”

“On behalf of Children’s National Hospital, we are honored to receive an Affiliate Center designation from the Batten Disease Clinical Centers of Excellence Program,” Clinic Director [Dr. Laura Tochen](#) said. “We look forward to working with our fellow Centers of Excellence to ensure the highest quality of support and care for Batten disease patients and collaborating on key research developments.”

The Clinical Centers of Excellence Program, chaired by Dr. Jennifer Vermilion, pediatric neurologist at the University of Rochester Batten Clinic, brings together



expert centers committed to improving standards of care, fostering collaboration, and accelerating progress toward new therapies for Batten disease.

Visit bdsrafoundation.org/batten-disease-centers-of-excellence to learn more.

What is Batten disease?

Batten disease or Neuronal Ceroid Lipofuscinosis (NCL) is a family of inherited neurodegenerative disorders that primarily affect the central nervous system. It is characterized by the buildup of waste materials in cells, leading to a range of symptoms including vision loss, seizures, cognitive decline, and motor skill deterioration, ultimately resulting in early death. There are 13 known forms of Batten disease, named according to the affected NCL gene (CLN1 disease to CLN14 disease; there is no CLN9). It is estimated that 2-4 births per 100,000 in the U.S. are affected by Batten disease. Currently, there is no cure for any form of Batten disease.

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