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BDSRA Foundation Announces Boys Town National Research Hospital as New Site in Clinical Centers of Excellence Program; Two Sites Earn CoE Promotions

GAHANNA, OH (January 29, 2026) – The [Batten Disease Support, Research, and Advocacy \(BDSRA\) Foundation](#) has officially announced [Boys Town National Research Hospital](#) as the newest site in the [Batten Disease Clinical Center of Excellence Program](#) and the promotion of [NYU Langone Health](#) and [UNC Hospitals](#) from “Affiliate Centers” to “Centers of Excellence.”

Boys Town National Research Hospital, in Boys Town, Nebraska, has been awarded a Batten Disease Center of Excellence “Affiliate Center” designation, becoming the 11th site to join the BDSRA Foundation’s Batten Disease Clinical Center of Excellence (CoE) Program.

Led by Clinic Director and pediatric neurologist Isabella Herman, MD, PhD, Batten disease specialty care is provided through the Neurogenetics and Rare Disease Clinic, delivering comprehensive, patient-centered care for individuals affected by Batten disease and their families.

In addition, UNC Hospitals and NYU Langone Health have been promoted from “Affiliate” to “Center of Excellence” status, bringing the total number of “Excellence” designations to seven across the United States.

“This is a significant time for the BDSRA Foundation and the Batten disease community. We are proud to see the continued expansion of the CoE Program, which is a testament to the exceptional expertise, quality, and dedication of our Batten disease clinicians and centers nationwide,” said Dr. Ineka Whiteman, BDSRA’s Head of Research and Medical Affairs. “We are deeply grateful for their sustained commitment to delivering high-quality, specialized care, advancing clinical research, and supporting individuals and families affected by Batten disease.



This momentum reflects meaningful progress and a strong foundation for continued advancement.”

The Clinical Centers of Excellence Program, chaired by Dr. Jennifer Vermilion, pediatric neurologist at the University of Rochester Batten Clinic in Rochester, New York, is a national network of Centers that provide the highest level of comprehensive Batten-specific care for patients and their families. With seven “Centers of Excellence” and four “Affiliate Centers,” the Program aims to optimize patient outcomes, accelerate clinical research, and improve the quality of life for individuals affected by Batten disease and their families.

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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