

PO Box 30049
Gahanna, Ohio 43230
(800) 448-4570

BDSRA Foundation Announces Mount Sinai Health System as New Site in Clinical Centers of Excellence Program

GAHANNA, OH (September 22, 2025) – The [BDSRA Foundation](https://www.bdsrafoundation.org) has officially announced [Mount Sinai Health System](https://www.mountsinai.org) as the newest site in the [Batten Disease Clinical Center of Excellence Program](https://www.bdsrafoundation.org/clinical-centers-of-excellence).

“We are delighted to welcome Mount Sinai Health System as the newest Affiliate Center in our Centers of Excellence Program,” said Program Lead Ineka Whiteman, PhD. “This important designation not only expands our national network to 10 participating centers but also strengthens our shared commitment to ensuring families have access to comprehensive, expert care close to home.”

Mount Sinai Health System, located in New York City, becomes the fifth Batten Disease Center of Excellence Affiliate Center, joining C.S. Mott Children’s Hospital at University of Michigan Medicine, NYU Langone Health, Rush University Medical Center, and UNC Hospitals. An additional five sites across the United States have received the “Center of Excellence” designation.

The Clinical Centers of Excellence Program is a national network of Centers that aims to provide the highest level of comprehensive Batten-specific care for patients and their families. Together, the Centers aim to optimize patient outcomes, accelerate clinical research, and improve the quality of life for individuals affected by Batten disease and their families.

“Expanding the Centers of Excellence has been part of our long-term vision of offering crucial support for Batten families,” said BDSRA President & CEO Amy Fenton Parker. “So, we are glad to bring them into the fold.”



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 Batten disease.

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