

Batten Disease Overview

Juvenile Batten disease (CLN3) is a rare, fatal, inherited disorder of the nervous system that typically begins in childhood. The first noticeable sign of juvenile Batten disease is often loss of vision, which begins between the ages of 5 and 10 years in previously healthy children and tends to worsen rapidly.

Other early signs are more subtle and include personality changes, behavioral problems, and slowed learning. Recurrent seizures typically begin around age 9 and motor problems appear in the early to late teenage years. At first, children may stumble or shuffle, followed by Parkinson-like symptoms and eventually, a complete loss of mobility.

Disrupted sleep and psychiatric conditions may appear at any time during the course of the disease. Some affected teenagers and young adults have cardiac problems that require pacemakers. Eventually, young adults become blind, bedridden, and physically and mentally incapacitated, requiring 24-hour care until premature death sometime between their teens and thirties.

What is ForeBatten Foundation?

After receiving their twin daughters juvenile Batten disease diagnosis in early 2017, the Kahn family created ForeBatten Foundation. "Fore" means "ahead" or "forward," and those familiar with golf know it's a term you hear when something unavoidable is heading your way-much like Batten disease. ForeBatten is driving progress for children with Batten disease through research funding, advocacy, and partnerships with world-class scientists. The foundation has raised millions to advance innovative treatments that give families more time, more joy, and more hope than ever before.

ForeBatten's Impact can best be explained by the researchers and families that we have helped:

From Batten Families:

"Our Batten girls take up so much time, energy, and patience that our other children often don't ever get alone time with mom and dad or any normal time. We could sleep in, snuggle, talk about silly things or serious things without interruption. We played and had fun. We may have spoiled them a little, but it was worth it. Thank you Fore the Journey Fund, for giving us an opportunity to reconnect with our children who endure this disease in only a way a Batten sibling can" Batten Mom, Beth

Fore the journey • Fore the cure • ForeBatten

From Researchers:

"ForeBatten has paved the way for new research studies by providing lab resources including new animal models and screening platforms for drug development. We are incredibly excited to push these initiatives forward and have a positive impact on patients and their families." Jon Brudvig, PhD Weimer Lab, Sanford Research, Assistant Professor, Pediatrics; University of South Dakota Sanford School of Medicine

"ForeBatten supported research enables the discovery and development of new therapeutic strategies for CLN3 Batten. New research tools benefit the entire Batten disease community and will impact other neurodegenerative diseases, such as Alzheimer's disease. Innovative research and approaches to understanding and treating CLN3 Batten are critically important to finally finding an effective treatment for the disease. ForeBatten Foundation, through its commitment to and support of research, is helping us move towards that goal." Michelle L. Hastings, PhD, Director, Pfizer Upjohn Research Professor of Pharmacology, University of Michigan Medical School, Professor of Medicinal Chemistry, College of Pharmacy, UofM, Director of the M-RNA Therapeutics, UofM.

Sweet 16 golden birthday 'rare opportunity'

"For sixteen years, we have been incredibly grateful for every moment with our girls," said Karen Kahn, co-founder of ForeBatten Foundation and the twins' mother. "Because of the generosity of this community, Amelia and Makenzie have access to an experimental treatment that simply didn't exist a few years ago. Their Sweet 16 is a celebration of hope, but also a reminder that time matters. We feel a deep urgency and determination to keep pushing research forward so more families can have the same chance."

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