

FOR IMMEDIATE RELEASE

Sweet 16 Celebration Becomes Lifeline for Twins Battling Rare Disease

ForeBatten Foundation launches national campaign to fund Batten disease research

CHAPEL HILL, N.C. — For most teens, turning 16 means independence, driving, and new possibilities. For twin sisters Amelia and Makenzie Kahn, it marks something far more urgent: another year fighting Batten disease, a rare and fatal childhood neurological disorder.

In honor of the twins' Sweet 16 birthday on March 16, the ForeBatten Foundation is launching the ForeBatten Sweet 16 Auction & Fundraiser, a nationwide campaign culminating in a three-day online auction running March 15–18, 2026, at www.forebatten.org.

Timed to follow Rare Disease Month in February, the campaign aims to turn awareness into action — accelerating research and treatment development for children diagnosed with Batten disease (CLN3).

Batten disease progressively robs children of vision, cognitive ability, and motor function, ultimately shortening their lives. There is currently no cure.

After years of donor-funded research supported by ForeBatten, Amelia and Makenzie began receiving an experimental, personalized genetic treatment in 2024; an early but groundbreaking step offering hope for families facing this devastating diagnosis. Continued funding is critical to build on this momentum and move toward accessible therapies for more children.

"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 this community, Amelia and Makenzie have access to an experimental treatment that didn't exist just a few years ago. Their Sweet 16 is a celebration of hope — and a reminder that time matters. We are determined to keep pushing research forward so more families have this chance."

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Founded by the Kahn family, ForeBatten Foundation invests directly in targeted, science-driven Batten disease research and therapy development. The organization has helped advance promising new approaches, including personalized genetic therapies now being studied for rare neurological diseases.

"This personalized genetic approach represents a new frontier in treating rare neurological diseases," said Michelle Hastings, Professor of Pharmacology, University of Michigan Medical School. "The progress we are seeing today is the direct result of sustained philanthropic support. Continued funding gives us a real opportunity to expand these advances to help more children."

To celebrate the twins' milestone birthday and raise critical research funding, the campaign will feature:

- A carefully curated national online auction featuring once-in-a-lifetime travel, golf, and luxury experiences, including:
 - 4-day, 3-night stay for three at Te Arai Links Resort in New Zealand, including three rounds of world-class golf
 - Exclusive access opportunity at Trout National golf club, Tiger Woods newest course, opening on April 16, 2026
 - Two days of golf (with carts) and one night of lodging for four at the renowned Sand Hills Golf Club in Mullen, Nebraska
- Multiple ways for supporters nationwide to participate, including bidding, direct giving, or purpose-driven shopping to advance Batten disease research
- Ongoing digital storytelling and video messages from the Kahn family, sharing impact and progress throughout the campaign

Rare diseases collectively affect an estimated 300 million people worldwide. Because each condition affects relatively small populations, fundraising and awareness efforts are critical to driving research forward.

"This campaign turns a birthday celebration into a chance to help children around the world," said Carol Schwimmer, Foundation Director of ForeBatten Foundation. "Every bid and every donation helps move research forward."

The ForeBatten Sweet 16 online auction runs **March 15–18, 2026**.

Learn more, sign up for updates, or participate at:
www.forebatten.org

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Press kit available at:

<https://www.forebatten.org/sweet16mediakit>

About Batten Disease (CLN3)

CLN3 disease is an inherited neurological disorder causing progressive vision loss, seizures, cognitive decline, and loss of motor function. There is currently no cure.

About ForeBatten Foundation

Founded in 2017, ForeBatten Foundation has raised and invested more than \$8 million in Batten disease research and therapy development.

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