



A note from Karen and David

It has been an eventful summer for Amelia and Makenzie. It started with a 15-day stint in the hospital for Amelia, hoping to alleviate some of her anxiety, agitation, and other behaviors. Midway through Amelia's hospital stay, Makenzie's G-tube button fell out! Luckily, the complex care team replaced the button without sedation. Amelia is better, but we are still tweaking her medications. Unfortunately, RSV and the pneumonia infection earlier this year combined with Batten have left some long-term effects. She is now on night oxygen, which she tolerates once asleep but rips off her thing in the morning. And that is okay! We have always said Amelia will lead the way.

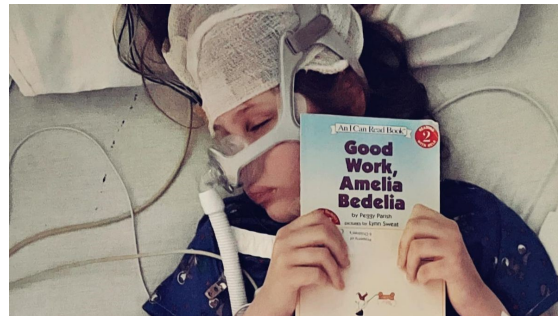
We have been able to sneak in some fun this summer too. Makenzie had a special behind-the-scenes day at the Greensboro Science Center, petting various animals, including a python! We also spent a week at the beach soaking up the sun. Now, we have our sights set on the first day of 8th grade at the end of August.

Preparations for our unique golf tournament at [Tobacco Road](#) and the 6th annual [Take A Swing ForeBatten](#) auction are in full swing. [Only 8 tickets](#) remain for this year's tournament. The online auction will be held from September 20th to October 4th. **If you have an item or experience you would like to donate** or have questions regarding the tournament, **please contact Stan Kahn** at stan@forebatten.org or 440.725.3395. Get a jump start on your bidding by visiting ForeBatten2023.givesmart.com to check out the growing list of auction items.

With Hope,

A handwritten signature in black ink, appearing to be 'K', followed by the word 'MOM' in a simple, sans-serif font.

A handwritten signature in black ink, appearing to be 'DK', followed by the word 'DAD' in a simple, sans-serif font.



About ForeBatten Foundation

ForeBatten Foundation is a 501(c)3 with a mission to fund pioneering research and support the Batten community. We work with researchers to develop therapies to detect, treat, and potentially cure CLN3 Batten disease.

About Batten Disease

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 vision loss, which begins in previously