



First and foremost, we want to thank each of you from the bottom of our hearts for your support - emotionally, physically, and financially - over the past 20 months. When Amelia and Makenzie were diagnosed with Juvenile Batten disease in early 2017, we had never heard of the disease. Now it is all we think and talk about. Every day is both a challenge and a blessing as we watch our girls lose so much, yet we continue to celebrate their respective accomplishments. Our lives have forever been turned upside down, but we will not stop fighting.

Join us on our journey as we navigate the world of rare disease, scientific breakthrough, and fundraising for our girls and the Batten community as a whole.

[Signature] MOM *[Signature]* DAD

Fore the Journey



As we approach two years post diagnosis, so much has changed. Our once healthy girls have been met with the challenge of losing a significant amount of their vision and a struggle to keep up as normal kids. Last year at this time, Amelia and Makenzie were not on any regular medications. Today, they take various medications three times a day to manage everything from behavior to sleep to seizure prevention. The progression has been swift; Batten disease pulling us in full force. We watch as Amelia's health declines significantly faster than Makenzie's, fearful that Makenzie will be aware of what is to come.

We continue to keep the girls active. Makenzie enjoys horseback riding and recently began trotting which makes her (and us) incredibly proud! Amelia is now a Green Belt at Premier Martial Arts with her Sensei creatively adapting curriculum to accommodate for vision loss. While Amelia has learned to use a cane and compensates for lack of vision with a keen sense of hearing, Makenzie continues to enjoy reading at close distance and defying the odds by continuing to learn at school.

Fore the Cure



We are extremely lucky to have a brilliant group of doctors and researchers actively working with ForeBatten to identify the most progressive forms of treatment and research to help Amelia and Makenzie as well as so many other families dealing with this horrific disease. We recently held a scientific advisory board meeting to get updates on continuing research studies, clinical trials, and future opportunities to fund additional projects.

Currently, ForeBatten is proud to be sponsoring research focusing on pre-clinical studies on gene therapy treatments to add a healthy copy of the CLN3 gene into the cells of the nervous system. For these therapies, the healthy gene is transported into the body inside a vehicle called adeno-associated virus (AAV). AAVs do not cause any known disease in humans. Researchers changed them so they could use their ability to deliver healthy genes such as CLN3 to patients in need. Recent studies have shown that such therapies are very promising in many diseases, yet many questions remain to be answered. The research supported by ForeBatten helps to evaluate innovative AAV delivery methods to find the most effective and safe way to reach as many neuronal cells as possible. While our emphasis is CLN3-Batten Disease, this research will ultimately help many patients suffering from a wide range of neurodegenerative diseases. You can help now at www.forebatten.org

ForeBatten



TAKE A *Swing* FORE BATTEN

When we started ForeBatten, we knew we wanted to make a difference. That difference was also going to take a significant investment of funds. So we came out swinging and held our first event March 12th, 2018 at Topgolf Scottsdale. It was an incredible success thanks to our sponsors, friends, family and the kindness of philanthropic strangers. Through the collective efforts of many, we were not only able to raise invaluable exposure for Juvenile Batten disease, but also a staggering \$630,000 for gene therapy research. As a foundation and a family unit, we cannot begin to thank everyone enough for their continued strength and support as we strive to make a difference.

Throughout the year, so many of you found ways to contribute - from Birthday fundraisers on Facebook to bake sales to collaboration with the Fall Festival at the girl's school, Grayhawk Elementary. Every bit of awareness and fundraising helps to keep the researchers moving towards a miracle.

We are excited to announce that we will hold our 2nd 'Take a Swing Fore Batten' event on March 4th, 2019 at Topgolf of Scottsdale. You can visit the event website www.forebatten.givesmart.com to purchase a ticket, donate an item to the silent auction, or become a sponsor. We look forward to another night of swinging, giving and hope!

Thank you for going on this journey with us.
#ForeBatten



Photo credit Caitlin O'Hara

