



A Note from Karen and David,

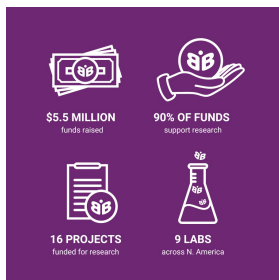
2022 will be remembered as the year we moved across the country primarily for more family support. We didn't anticipate that we would need that support so quickly and urgently as we did the last couple of months of the year! But after a combined 41 days in the hospital for both Amelia and Makenzie, we are thankful that we moved when we did. The warm welcome from our new neighbors and the girls' new school lls us with gratitude as well.

We also never imagined that in 5 years ForeBatten Foundation would become one of the largest sponsors of CLN3 research in the US. Equally important is our impact on the daily quality of life for Batten families through the Fore the Journey fund. None of this would be possible without YOU. Your support gives us and countless Batten families hope!

Happy New Year!



2022 Year in Review



Together with you, we have achieved so much 5 years. Imagine how much more we can accomplish!

Amelia and Makenzie said goodbye to the school they have attended since



Kindergarten with a 6th grade graduation party. Amelia spent 30 days in the hospital. She is now home gaining strength and brightening our days with her smiles. Makenzie's 11-day hospital stay brought a series of tough medical



decisions that have thankfully brought back her silly, happy self!

In March, Makenzie and Amelia celebrated their last birthday before becoming teenagers!



beyond grateful to

February 2022 marked



The Batten Disease Support and Research Association (BDSRA) held their annual family conference in Cleveland which was a great opportunity to connect with other Batten families.

Several families enjoyed grants from the Fore the Journey Fund. Two families received adaptive bicycles like the one Amelia and David especially enjoy!

The tally from TASFB V was a record breaking \$1,400,000! We are

everyone who donated, bid, spread the word, and followed along.

The 7th NCL Transitional Management Meeting was held in November where top Batten researchers met with researchers from other disciplines to explore gaps in NCL research. For the second year, we held Beat the Heat, Beat Batten events in neighborhoods around the country. Contact Carol at carol@forebatten.org to host an event in 2023!

ve years since Makenzie and Amelia were diagnosed with juvenile Batten disease.

Several of our sponsored researchers published articles in medical journals such as BioMarker Insights and Frontiers in Neuroscience to name a few.