A Note from Karen and David,

From wheelchairs to virtual meetings, last year brought a lot of changes for the foundation and our family. We are sharing a recap of the year with a sigh of relief that we made it through 2020! For 2021, we will continue our aggressive fight for a cure and treatment for our girls and all children affected by this horrific disease.

Also, don't forget our upcoming online silent auction "Take a Swing Fore Batten IV" taking place March 15-29. You can register, check out the growing list of auction items, become a sponsor, or donate an auction item here.

With Hope,

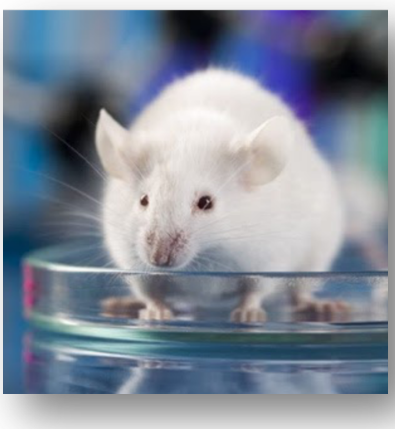
MOM DAD

2020 Year in Review

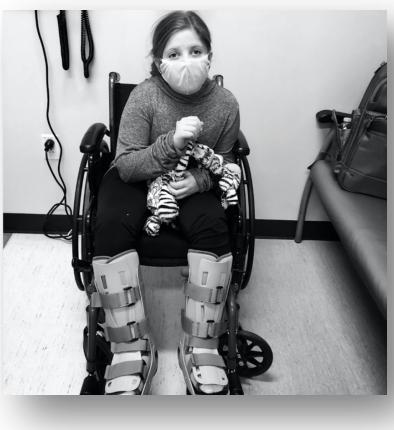
Makenzie was admitted to Phoenix Children's Hospital for two nights after her seizures returned.

Fore the Journey Fund was launched which brought smiles to several Batten families. The fund is a joint collaboration with BDSRA.

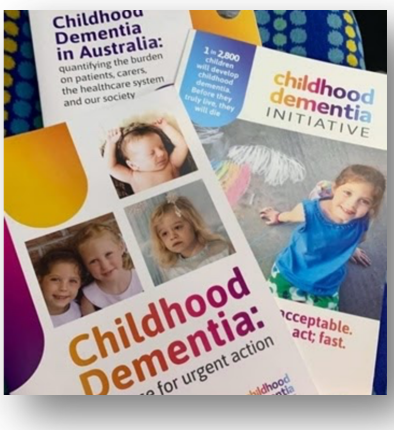
Amelia's purple wheelchair arrived in late 2020 making school and outings much easier.



Nature Medicine published Therapeutic efficacy of antisense oligonucleotides in mouse models, based on research funded by ForeBatten.



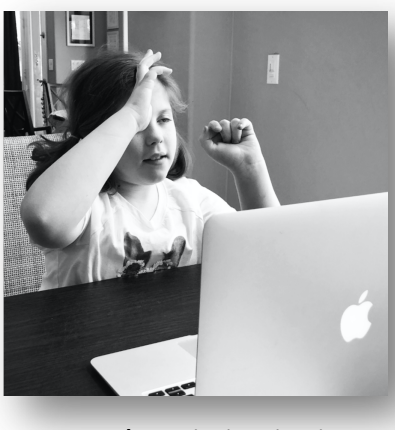
Makenzie broke bones in both feet! She fought through pain, figuring out how to blindly walk with double boots.



Karen raised awareness of childhood dementia by sharing our family story with the Childhood Dementia Initiative.

We attended 50 doctor appointments including virtual appointments, a favorite of the whole family. Palliative care is now taking a major role in the girls' treatment.

Karen and David shared the Foundation's journey at the International Young Investigators Symposium to advance science in rare disease research.



Here Makenzie is signing "I love you, Daddy": sign language is one way the girls are adapting to the loss of language.

Karen and David participated as panelists with Amicus Therapeutics on the inspiring Two Disabled Dudes Podcast 'Coping in Times of Uncertainty'.

Double quarenTEN! Makenzie and Amelia celebrated their 10th birthday quarantine style at home.

Our Scientific Board Meeting brought researchers together to collaborate as we fight for a cure.

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 gene therapies to detect, treat and potentially cure Batten disease. Rare diseases like Batten do not receive the same government assistance as other, more prevalent diseases, so we must join together as parents and caring individuals who are not willing to accept the fate of our children.

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 often loss of vision, which begins between the ages of 5 and 10 years in previously healthy children and tends to worsen rapidly. Eventually, young adults become blind, bedridden, and physically and mentally incapacitated, requiring 24-hour care until premature death.