

September 25, 2024

RE: Personalized medicine for Amelia and Makenzie

We would like to share our perspective as both parents and representatives of the ForeBatten Foundation regarding the announcement of Zebronkysen, a personalized antisense oligonucleotide (ASO) for Amelia and Makenzie's unique CLN3 mutation.

When the girls were diagnosed, we were **filled with hope**. We believed we could treat them within a year and save them! We immersed ourselves in research, driven by a determination to persevere and succeed. However, as time passed, we were forced to accept that each day our girls' bodies were growing weaker than our **resolve to fight**. Although they are stubborn and brave, 'Bad Batten' has taken a heartbreaking toll on their little bodies. Our naive hopes for a miracle evolved into an understanding that **science takes time**.

As parents, we have done everything possible to ensure our girls have the **best quality of life** and happiness. Our family made an **informed and rational decision** to pursue this treatment; we have confidence in the researchers and scientific advisors who have been with us since diagnosis. While it is too soon to determine how Zebronkysen will affect the girls' disease trajectory, we find great excitement and comfort in **accomplishing what we set out to do seven years ago**.

We aspire to contribute to the greater narrative of personalized medicine and **pave the way for other diagnosed children** to access treatment earlier. We feel energized to continue this momentum and help facilitate similar paths for others.

This would not be possible without the **incredible emotional and financial support of the ForeBatten community and the passionate development team**.

Sincerely,



Karen & David Kahn
Co-Founders, Mom & Dad
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Zebronkysen is named in honor of Zebra and Monkey who have comforted Makenzie and Amelia at every doctor's appointment and snuggled them for every goodnight kiss.

Fore the journey • Fore the cure • ForeBatten