Project Butterfly Update / Introducing Project Four Leaf Clover

May 24, 2025, marked **one year** since we received FDA clearance for FBF-001, now affectionately known as Zebronkysen, the personalized ASO medicine created for Amelia and Makenzie's unique variant of CLN3 juvenile Batten disease **made possible by the support of our loyal and generous donors.** This year has been filled with a new sense of peace, knowing that, as parents and the Foundation, we DID everything possible to fight this horrific disease. While we took a much-deserved break immediately following the first treatment to celebrate the entire Project Butterfly team's accomplishment, **the overwhelming desire and commitment to the Batten community**— which is the heart of the ForeBatten Foundation— quickly crept back to the forefront of our minds.

The primary goal of Zebronkysen was safety. As parents, we feel confident that this objective was met. **Amelia and Makenzie's legacy has grown bigger than their small bodies.** They represent our family, our Foundation, and the inspiration behind our fight for treatment and a cure for all affected children.

To that point, we **are happy to announce** that Vanguard Clinical Rare Disease Foundation **(VCRDF)** will be spearheading the development of an **individualized antisense oligonucleotide (ASO) therapy targeting** the 1-kilobase deletion, **the most common mutation in CLN3 Batten disease**. This venture will be known as Project Four Leaf Clover.

Zebronkysen received FDA clearance on an **accelerated timeline** due to Project Butterfly's passionate and dedicated Drug Development Team members from our Scientific Advisory Board Members, the Hastings Lab, Vanguard Clinical, Charles River Labs, BioDev Consulting, Keane Consulting, SciLucent, the Weimer Lab at Sanford Research, and University of North Carolina, School of Medicine – Neurology. We are thrilled that the **same group** of talented individuals and organizations **will participate in the VCRDF initiative**.

Since the formation of our Foundation, we have **invested in the ASO research** on the common mutation of Dr. Michelle Hastings, Pfizer Upjohn Research Professor at the University of Michigan Medical School. We are **honored to support the Hastings Lab** and are excited to see her work move to the drug development stage under VCRDF's leadership.

We will eagerly provide strategic guidance and community alignment to VCRDF, aiming to accelerate the development of therapeutics for all children with CLN3. Together, we're building **a new model** of collaboration that **puts patients and progress first**.

*We continue our fundraising efforts, in line with our mission, to compassionately support the Batten community through our Fore the Journey fund and to invest in leading edge research Fore the Cure. Our next major fundraiser will be a **golf tournament at Tobacco Road Golf Club on October 7, 2025**. Please contact carol@forebatten.org for more information about this announcement or our fundraising activities.*