12/2/2024

Subject: Letter of Support for TRAN1-16907

Dear Members of the Application Review Subcommittee,

My name is Kevin Lin, and my wife, Rebecca, and I are long-time residents in the Bay Area. We are close family friends of a Californian family who has a son impacted by the Sanfilippo Syndrome Type B. We're writing this letter to encourage the California Institute for Regenerative Medicine to provide research funding for TRAN1-16907, Hematopoietic Stem Cell Gene Therapy for MPS-IIIB (Sanfilippo B) Syndrome, led by principal investigator Katelyn Masiuk, MD, PhD.

We have known our friends Daniel and Minnie Lau for almost a decade. They've raised their two boys in a warm and loving family, and their family has played an integral part of our community. We also walked alongside the Lau family when their son Matthew began exhibiting difficulties with hearing and speech development, later escalated to recurring seizures and trips to the ER, and eventually was diagnosed with Sanfilippo Syndrome Type B. When I first found out the diagnosis, I was devastated. It brought me back to my childhood memories of an elementary school friend in Cupertino, Brian. Brian was impacted by a regenerative disease. Over the years, I watched my friendship with Brian fade as he slowly lost his ability to speak, his ability to move, and eventually his life ended in middle school. There was no cure. And as a child seeing Brian's life first-handed and experiencing death for the first time, I felt it was unfair and wished there was a way for Brian to miraculously get better. As a parent now and walking alongside the Lau Family in their journey with MPS-IIIB, it pains me to know this may be the same reality that their family, community, and friends will face with Matthew's life.

I am motivated to write this letter because 20+ years later, there is now hope for a cure, and Matthew's life could be saved. As Matthew continues to grow older day-by-day, time is running out in the window for him to be cured. The Lau family, and many other families impacted by Sanfilippo Syndrome Type B, depend on CIRM to bridge the funding gap where the private industry falls short. I urge the committee to consider funding this research, which holds hope for developing a cure for Sanfilippo Syndrome Type B. This would positively impact the legacy of Matthew and many other children's lives forever. Thank you for your consideration of TRAN1-16907.

Sincerely, Kevin & Rebecca Lin

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