

December 3, 2024

Subject: Letter of Support for TRAN1-16907

Dear Members of the Application Review Subcommittee,

My name is Kelly Chan and I live in Sunnyvale, CA. I am a former elementary school teacher and a mother to 3 children. I am friends of the Lau family, a family affected by MPSIIIB. I am writing to encourage the funding for TRAN1-16907 led by principal investigator Katelyn Masiuk, MD, PhD.

I had never heard about San Filippo disease until our dear friends' son was diagnosed with it this past year. I felt devastated when we found out the results of several tests over many months. I wish there was something that I could say or do to offer them support. The family experienced highs and lows as they researched online, but the heartbreaking reality was that there was no cure and no active testing to find a cure. As a parent and educator, I can only imagine the sense of loss and helplessness that many feel when their loved ones face the reality of this diagnosis. I would love to see San Filippo being studied and a cure to be sought for it. There would be hope for all those affected.

I hope and pray that children such as Matthew would get to experience the fullness of childhood before time runs out. With a disease such as this, it is paramount that this is done soon. Thank you so much for your consideration of TRAN1-16907. May this be the long awaited hope that many families are waiting for... thank you for considering.

Sincerely,

A handwritten signature in cursive script that reads "Kelly Chan". The ink is black and the signature is fluid and legible.

Kelly Chan