



Dear members of the SHANK2 community,

SHANK2 research is being conducted worldwide, SHANK2 disorders are being diagnosed at a faster pace than ever and pharmaceutical and biotech companies are developing treatments for even the rarest of diseases. Sounds great, right? The only problem is that the SHANK2 researchers in Boston and Heidelberg have never been introduced, some of our kids are being diagnosed with autism spectrum disorder while others are being diagnosed with intellectual disabilities, and even others, with schizophrenia. And most pharmaceutical and biotech companies have never even heard of the SHANK2 gene.

The SHANK2 Foundation wants to change all that, and we think we will...but we cannot do it without your help. We are parents of children with SHANK2 disorders and we are bringing together families, caregivers, researchers, clinicians, pharmaceutical companies and biotech engineers.

Every one of us holds valuable information that will lead to treatments for individuals affected by disease-causing SHANK2 variants. As parents and caregivers, we will share the unique traits and behaviors of our kids with the researchers and clinicians who will study these defining characteristics to better understand the underlying mechanisms of SHANK2 disorders. For example, collective information gathered by the foundation may reveal that a number of SHANK2 patients share atypical physical symptoms like a high pain tolerance, or clenched toes. Or we may learn that the vast majority of affected individuals experienced developmental challenges like delayed speech. Our scientists and doctors will investigate the biological factors that are causing these symptoms. They will then share their findings with pharmaceutical and biotech companies who will develop targeted therapeutics to achieve our mission to improve the quality of life for individuals affected by SHANK2 disorders.

So please reach out to us, join our registry, and sign up for our natural history study. Together we will make a difference.

Warmly,

Polly and Ben
Cofounders of the SHANK2 Foundation (<https://shank2.org>)