STXBP1 Foundation Organizes 5th Annual Family Conference for STXBP1-Related Disorders

For the first time, the STXBP1 Foundation will hold the yearly event in the Western US, and provides an inclusive agenda encompassing scientific updates and community building.

San Francisco — July 10, 2023 — The STXBP1 Foundation has announced that it will be holding its annual STXBP1 Summit+ Family Meeting on July 22-23 at the Westin Westminster in Westminster, CO. The STXBP1 Summit+ conference will bring researchers, clinicians, and families together to review and understand the latest work on STXBP1-related disorders. Families will also have networking and social opportunities.

“We are thrilled to hold this year’s STXBP1 Summit in Colorado. There is such tremendous progress being made in research on STXBP1-related disorders that it is important to share these advances amongst our researchers and our families frequently,” says Charlene Son Rigby, President and Co-Founder of the STXBP1 Foundation. “Our tagline Science + Love = Cure brings together two vital ingredients: robust research plus our families’ strong love of our children. It’s this special combination that we bring together at our annual Summit+ and we feel it’s these two ingredients that will accelerate the development of therapies and eventually get us to a cure”.

At the Summit+ meeting, STXBP1 families will hear from researchers and clinicians who are working to improve the lives of STXBP1 patients and families. Families can also attend a new set of tracks entitled, “Be Ready. Be Real.” These breakout sessions empower parents and caregivers to share their related experiences and discover the benefits of advocacy. Combining updates on cutting-edge scientific advancements with loving involvement from caregivers.
provides hope of better treatments and ultimately a cure to families across the globe afflicted with STXBP1 disorders. Find the STXBP1 Summit+ 2023 agenda here.

This STXBP1 Summit is being held in conjunction with Children’s Hospital Colorado. A neurogenetics clinic serving STXBP1 patients with a comprehensive multi-disciplinary approach was funded in part by the STXBP1 Foundation, and launched in January 2022. According to Scott Demarest, MD “Colorado Children's Hospital welcomes the STXBP1 Community to Colorado. The Neurogenetics Clinic, launched in January 2022, currently serves four rare neurodevelopmental disorders including STXBP1 and provides a multi-disciplinary clinical center as well as research expertise. We are pleased to be a site for the new STXBP1 natural history study.”

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Founded in 2017 as a 501c3 non-profit organization, the STXBP1 Foundation is a parent-led advocacy organization comprised of a diverse team of afflicted families and their supporters, scientists and medical professionals, and industry partners all dedicated to ending STXBP1 disorders. Individuals with this rare genetic disease may display some of these symptoms in varying severities: Epilepsy, Global Delay, Cognitive impairment (mild to profound), Movement Disorders, and Autism. STXBP1 changes impair the vesicular release of neurotransmitter along the synapses and these changes are typically new in families and a single copy of a damaged gene is enough to cause the disorder. The estimated incidence rate for STXBP1 disorder is ~1:30,000, and STXBP1 was recently identified as one of the five most common genes for epileptic encephalopathies and related neurodevelopmental disorders.

For more information on STXBP1 disorders, visit https://www.stxbp1disorders.org/