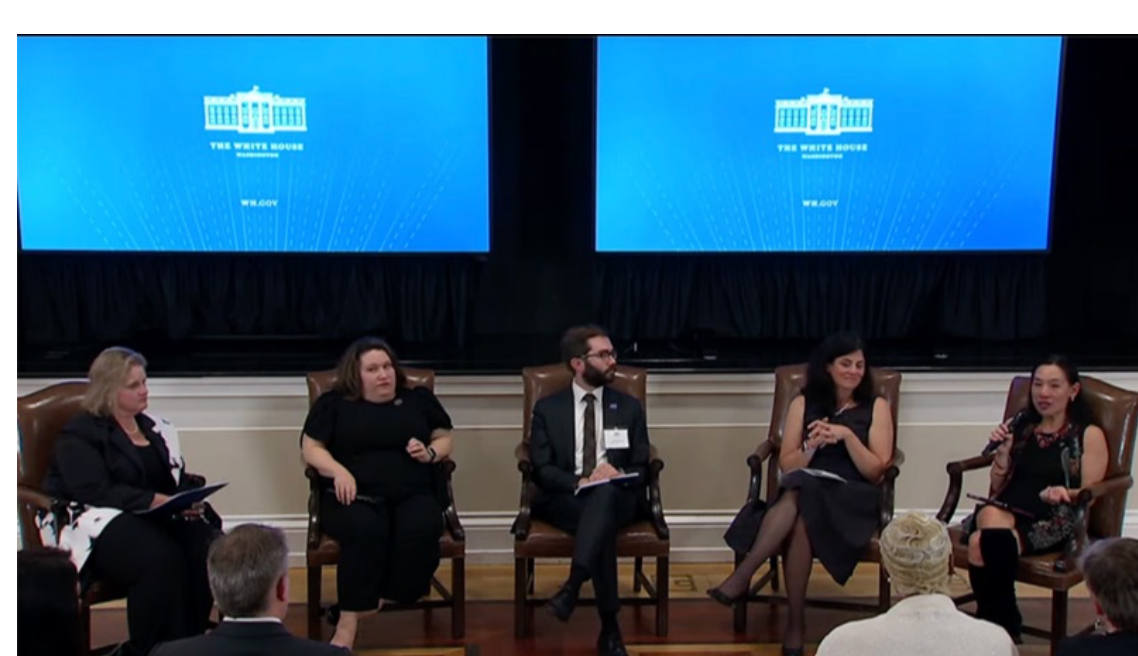


[View this email in your browser](#)



Welcome to the March 2024 issue of the STXBP1 Foundation Newsletter



We Were in the House ... The White House

Our own Charlene Son Rigby was a panelist at the Rare Disease Forum on Wednesday, February 28, 2024. Charlene shared her thoughts on Next Gen Advocacy and how the role of Patient Advocates has changed and evolved in advancing therapy development in rare diseases. Read more in this [blog post](#) which includes a link to the panel recording on The White House YouTube channel.



Rare But Not Alone

February 29th was Rare Disease Day and the STXBP1-related Disorders community participated in various ways around the world. See all that went on in this [blog post](#).

And, we want to say a huge THANK YOU to everyone who made Rare Disease Day a success, raising more than \$12,000 for STXBP1 Disorders research. Whether you proudly sported our new "rare" shirts, made a personal donation, or bravely shared your family's STXBP1 story with the world, you helped amplify our collective voice for awareness. Let's stay loud for STXBP1!

MILLION DOLLAR BIKE RIDE REGISTRATION IS OPEN!

We are riding as "Lulu's Crew - Team STXBP1" on June 8
[CLICK HERE TO REGISTER FOR THE RIDE NOW](#)

Join Erin Prosser on Monday, March 18 for a live webinar and Q&A to learn all about the ride and how you can participate from anywhere. Register for the informational webinar [HERE](#).

Professional cyclist? Prefer your wheels stationary? Whether you can join us in Philly on June 8—or virtually from anywhere in the world—we need you to roll with us!



The STXBP1 community raises funds in so many meaningful ways throughout each year, and this is our annual signature opportunity to saddle up with "Lulu's Crew - Team STXBP1" and DOUBLE THE IMPACT of the dollars we raise for STXBP1 research. Let's Roll and make this our biggest year yet. Registration is open NOW to ride, volunteer, or volun-cheer, with Lulu's Crew - Team STXBP1 at the Million Dollar Bike Ride in Philadelphia on June 8. Learn more [here](#).



What is a Natural History Study

Learn all about Natural History Studies and why they are so important for rare diseases in the next in the "From Our Scientific Director's Desk" series by James Goss. Read the blog post and watch the accompanying video [here](#).

STXBP1 SUMMIT+
 Presented by the STXBP1 Foundation

★ 2024 ★

☆☆ FEATURING ☆☆
 RESEARCHER & FAMILY MEETINGS

18-21 JULY	RESEARCHER MEETING JULY 18-19	RESEARCHER & FAMILY DINNER JULY 19	FAMILY MEETING JULY 20-21
---------------	----------------------------------	---------------------------------------	------------------------------

MORE INFORMATION :
STXBP1DISORDERS.ORG/2024-SUMMIT

LOCATION
 The Drexelbrook Event Center
 6700 Drexelbrook Drive
 Drexel Hill, PA 19026

2024 Summit+ Registration is Open

Get ready to join us this summer for our annual STXBP1 Summit+ Researcher and Family Meetings. Registration is open for attendees who will attend onsite in Drexel Hill, PA. Go [here](#) for more detail.

Sponsor the 2024 Summit+ Family Meeting

Corporate sponsorship opportunities are available for the STXBP1 Summit+ Family Meeting in Philadelphia. For more information, or to pledge your sponsorship today, contact us [here](#). Please note the deadline to be included in on-site printed recognition materials is June 28.

STARR
 STXBP1 CLINICAL TRIAL READY

Want to participate in the first ever natural history study focused solely on the STXBP1 patient? The purpose of the STARR Natural History Study is to better understand STXBP1-related disorders, and ultimately lead to improved care and treatment. The study is now enrolling at four sites (Children's Hospital of Philadelphia, Children's Hospital Colorado, Weill Cornell Medicine, and Texas Children's Hospital) with a goal to see 100 patients in the first year. To learn more about the study, how to register, and for information on travel reimbursement, go [here](#). If you have any questions, send us an [email](#).

CALL FOR VOLUNTEERS

Share your talents and time while helping to further the mission of the STXBP1 Foundation. We are looking to fill the following volunteer positions:

- **STXBP1 STARR Site Ambassador** - Do you want to become more involved with the STXBP1 Community? We are looking for 1-2 passionate volunteers to serve as STARR Site Ambassadors who can assist families with the logistics of the in person visits, and follow up with families on the next steps.
- **Gratitude Specialist** - Passionate about expressing gratitude? Join as a volunteer and share your ideas! Partner with us to develop creative and fun ways to express our community's appreciation to our donors and partners for their generous support. Ideally, this volunteer has a background in fundraising or customer service.

To volunteer or to get more information on any of the above volunteer opportunities, please contact [Melissa Hocco](#).

Read our past issues [here](#). We'll see you next month.



Copyright © 2024
 All rights reserved.

Our mailing address is:
 STXBP1 Foundation
 P.O. Box 1148
 Holly Springs, NC 27540
 USA

Want to change how you receive these emails?
 You can [update your preferences](#) or [unsubscribe from this list](#).

Email us at info@stxbp1disorders.org