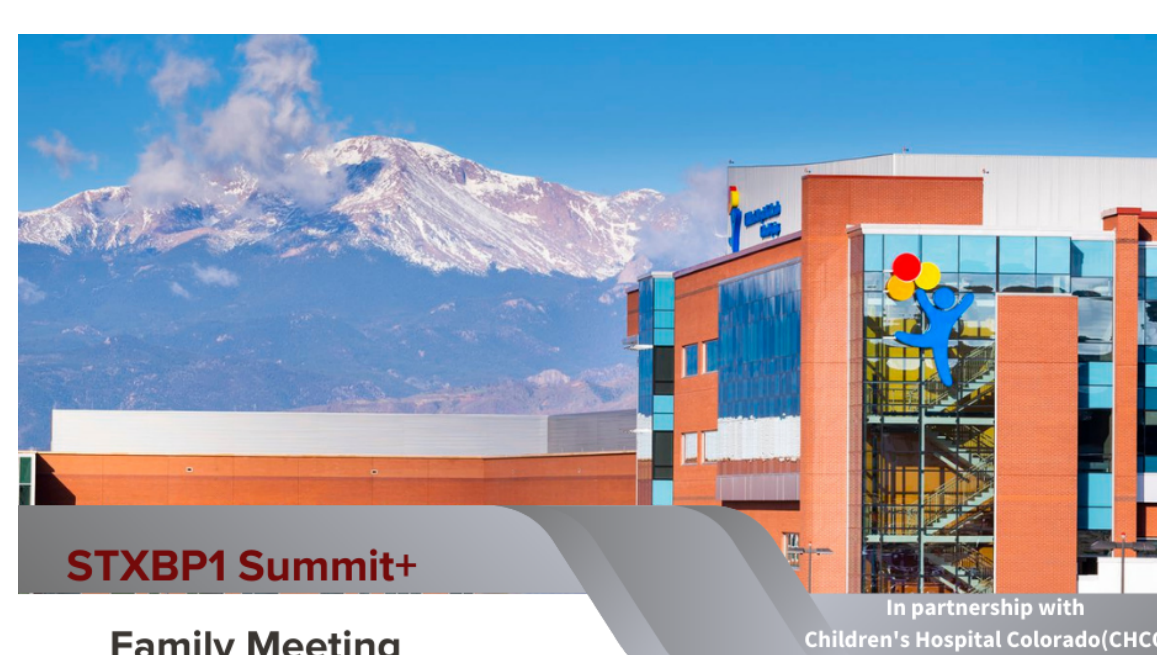


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### Welcome to the June issue of the STXBP1 Newsletter



**STXBP1 Summit+**  
**Family Meeting**  
 July 22-23, 2023  
 The Westin  
 Westminster,  
 Westminister, Colorado  
 (Just outside of Denver)

**Meeting at a Glance**  
 7/22 - Keynote Speaker, Research Updates  
 7/22 - Family Reception Dinner  
 7/23 - Family Break Out Sessions

In partnership with  
 Children's Hospital Colorado (CHCO)  
 STXBP1 Clinic Day at CHCO 7/21



### STXBP1 Families join us this July in Colorado!

The STXBP1 Summit+ Family Meeting is July 22-23 at the Westin Westminster in Westminster, CO (just outside of Denver). We can't wait to see you! Please review the newly posted [Agenda](#).

**Registration closes on June 22. REGISTER HERE!** Hotel Reservations can be made [HERE](#).

The STXBP1 Summit+ Family Meeting will bring researchers, clinicians, and families together to review and understand the latest work on STXBP1 disorders. Families will also have networking and social opportunities.

**Sign up! Research Study: COMBINEDBrain** The conference will offer opportunities to sign up for research studies and contribute samples to biorepositories - important for advancing research and clinical trial readiness. Non-profit **COMBINEDBrain** will collect biospecimen samples to be used in biomarker studies, and samples will be stored in our biorepository for future research. For more information and appointments, please reach out to Jackie at [jackie.steinberg@stxbp1disorders.org](mailto:jackie.steinberg@stxbp1disorders.org).

#### LIVE STREAM - Can't Make it to the STXBP1 Summit+ in Colorado?

Don't worry, we got you covered. You can join us virtually. We will Livestream all the Science and Research sessions from Saturday, July 22 on our YouTube channel. Plus, we'll post each individual session on our website 2 weeks after the conference ends. It's quick and easy to register for the virtual Livestream [here](#) right now. And you can also [subscribe](#) to our YouTube channel at any time for all our STXBP1 disorder videos and podcasts.

Thank you to our sponsors:



### Million Dollar Bike Ride 2023

Thank you to all who participated in the 5th Annual Million Dollar Bike Ride with [Lulu's Crew](#) on June 10! Donations are being collected through June 25 - [Donate here](#).

To see some of the research projects funded by this event in the past, click here <https://www.stxbp1disorders.org/researchfundingrecipients>

### See All the Updated Merchandise in our Store



Proceeds go directly to fund the mission of the STXBP1 Foundation

#### SHOP 'TIL YOU DROP!

<https://www.stxbp1disorders.org/store>

## SIMONS SEARCHLIGHT

#### Research Opportunity!

Simons Searchlight is an international research program with the goal of accelerating science and improving lives for people with rare genetic neurodevelopmental disorders. The information gathered from this STXBP1 Foundation partner continues to shed light on aspects of STXBP1 and we would like to share their newest campaign called "Shine Your Searchlight". Sign up today!!

<https://www.simonssearchlight.org/>



Thank you to all who participated in the RARE-X Xcelerate competition! As of the date of when the data was locked for the competition at the end of March, we had 141 people registered in the RARE-X platform. We recognize all the efforts it took for our community to participate and wanted to express our gratitude. The open science portion of the competition began 5/17 and will go on for the next several months. We hope to bring you news this Fall about projects and grants that come from this effort and will benefit our community.

Though the competition is now closed for any new data, the community can still participate by registering and completing surveys through the RARE-X platform. For more information, to go: <https://www.stxbp1disorders.org/naturalhistory> or email [naturalhistory@stxbp1disorders.org](mailto:naturalhistory@stxbp1disorders.org) for any questions or assistance.



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