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Welcome to the August issue of the STXBP1 Newsletter.

September is **STXBP1 Awareness Month!** Get ready for all things STXBP1 including the STXBP1 Summit+ Virtual Family Meeting and the 5th Annual Move to Cure STXBP1 Disorders.

[Join in all month long](#) and we'll work together to create more awareness for this rare genetic disorder, keep up with the very latest research, and bring the community together ... virtually!

STXBP1 Summit+ Family Meeting



The STXBP1 Summit+ Family Meeting will be held virtually 17 - 19 September. All STXBP1 community members are welcome.

Get ready for research and clinical updates, informative and interactive workshops, social events, fun swag, prizes & more!

Register here: <https://stxbp1summit.org/register>

5th Annual Move to Cure

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The 5th Annual Move To Cure STXBP1 Disorders event will take place 25 - 26 September. We are challenging the community to move 9 miles - whether that's among 9 friends and everyone walks one mile, or one partner runs 3 miles 3 times or you hike a 9 mile trail! However you get to 9! 9 miles because STXBP1 is on the 9th chromosome!

The purpose of this challenge is to raise awareness of STXBP1 Disorders, fundraise for STXBP1 research, and bring the community "together" for an important cause and some fun! Keep it simple, and get Moving for a Cure!

Last year, we raised over \$65,000 for research, and 250+ people around the world participated. We can't wait to see how the community shows up this year!

Sign up here: [Move to Cure Virtual Challenge sign up](#)

Buy custom shirts from Bonfire here: [Team shirt](#)

Questions? Contact [Allison Michels](#).

\$160K Raised for STXBP1 at Million Dollar Bike Ride



The Million Dollar Bike Ride took place on Saturday, June 12. Lulu's Crew Team STXBP1 raised over \$160,000! Props to our organizing family Ben and Erin Prosser, parents of Lucy, and all of our riders! All funds will go toward STXBP1 research.

With these funds, two \$80K grants will be available for STXBP1 research through University of Pennsylvania's Orphan Drug Center! **Letters of intent are due September 16**; make sure your favorite researcher is aware of this opportunity! More information and the request for applications are posted on the [ODC site](#).

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Researchers, please Save the Date for the STXBP1 Research Roundtable Meeting 2021. The meeting will be held virtually on 18 & 19 November.

Questions? Please reach out to research@stxbp1disorders.org.

New iPSCs at Simons Foundation



Induced Pluripotent Stem Cells (iPSCs) are an important model in STXBP1 research, from basic science to drug development. iPSCs are cells derived from blood or skin cells that are engineered into being pluripotent or capable of being changed into other types of cells like neurons.

We are excited to announce that the Simons Foundation is generating 15 iPSC lines from STXBP1 participants in Simons Searchlight. The first six lines are complete and will be orderable shortly on [SFARI Base](#); nine more will be available in the fall. More information on the program and specific iPSC lines is [here](#).

We are very appreciative of our long-standing partnership with Simons Searchlight!

Call for Volunteers!



Looking for ways you might be able to help the STXBP1 Foundation? We are looking for additional help in the following [roles](#):

- * Community Outreach and Engagement
- * Community Support
- * Events
- * Fundraising
- * Grant Writing
- * Graphic Design

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epilepsy". This is an initiative of the ILAE Transition in Care from Childhood to Adult Task Force.

Transition is the planned process of moving patients with child-onset epilepsy to adult care. Transition usually starts several years before the patient becomes adult and ends when the patient stops seeing a child neurologist. For background on the study, [watch this video from Dr. Andrade](#).

Families of patients 12 and above, including patients who have already completed transition to adult care, can participate. We want STXBP1 experiences to be represented in this study.

To learn more or participate in the study, please contact Quratulain Zulfiqar Ali, MD at Quratulain.zulfiqar_ali@uhn.ca.

The study will be open until September 30, 2021.

Join an STXBP1 Regional Group!



Our regional groups have been growing despite the pandemic! Get involved to build a network of STXBP1 families for regional support. The groups are starting to take off. Although the pandemic prevented in person get togethers, it did not deter those groups from rising to the occasion when one of their members needed extra support and love.

Currently we have 8 regions around the US with 5 or more families that have formed regional groups. Additional regions are looking for a few more families, or parents to step up to lead the region. If you are interested in helping form a new regional group or joining a current regional group, contact community@stxbp1disorders.org.

- Northeast (NY, NJ, MA, CT)
- Mid Atlantic (MD, DE, VA, Eastern PA, Eastern NC)
- South East Region (TN, AL, GA)
- Florida
- Ohio River Region (OH, WV, Western PA)
- Michigan
- Texas
- California

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Donations of Stocks and Cryptocurrency



NEW for 2021! The STXBP1 Foundation is now able to accept gifts in the form of stocks, bonds, mutual funds and cryptocurrency! Please reach out to heather.jones@stxbp1disorders.org to find out more information and how this type of giving could benefit YOU!

Have other ways you would like to give in order to support our mission and our families? Please let us know!

We are a 501c(3) non profit, and all donations are tax deductible.

Also don't forget these other ways to donate and participate:

- Check out the [STXBP1 Foundation Bonfire store!](#) Proceeds go to STXBP1 research and clinical trial readiness.
- When shopping on Amazon, use smile.amazon.com and select the STXBP1 Foundation as your nonprofit. Every time you shop, a portion of the proceeds of the sale will come directly to us.



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