Welcome to the September issue of the STXBP1 Newsletter.

September is **STXBP1 Awareness Month**! This is our fourth year of dedicating the entire month of September to STXBP1 with ongoing communications and activities.

Why September? September is the 9th month and the STXBP1 gene is on the 9th chromosome.

Join in all month long and we'll work together to create more awareness for this rare genetic disorder. Don't miss community spotlights, social media updates, Did You Know cards, and of course our **6th annual Move to Cure event**!

That's a Wrap! STXBP1 Summit+ 2022

The STXBP1 Summit+ was a success... because of you! Thanks to our community of families, researchers and clinicians. We had an amazing turnout of 300 attendees in Philadelphia and 240 virtual attendees!

The STXBP1 Summit+ brought together researchers, clinicians, and families together to review the latest work on STXBP1 disorders, participate in research opportunities, provide networking opportunities, connect researchers with families, and provide social opportunities for families.

The livestream recording of the Family Meeting is already available.

Our Scientific Director, Jim Goss, wrote a summary of the Research Roundtable.

Recordings of the Research Roundtable and individual Family Meeting sessions will be posted by 9 September on our website.

$174K in STXBP1 Grants: LOI Due Sept 16!

Thank you Lulu's Crew!

The Million Dollar Bike Ride took place on Saturday, June 11. Lulu's Crew Team STXBP1 raised over $174,000! 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 $87K 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.

6th Annual Move to Cure STXBP1 Disorders

The 6th Annual Move To Cure STXBP1 Disorders event will take place September 24 - 25. We are so excited for this year's Move to Cure Challenge!

Be part of the movement around the world as we gather together to support and raise awareness for STXBP1 Disorders. Last year we had **250+ participants all across the world raising more than $80K**!

trail or you jump on a scooter and go as far as you can!

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! **#move2cureSTXBP1**

Sign up here: Move to Cure Virtual Challenge sign up

Buy custom shirts from Bonfire here: Team shirt

Questions? Contact Allison Michels.

FLOURISH: Art Auction for STXBP1

On September 29th, accompanied by the support of artists and friends, The Finn Beaubien Family, will host *FLOURISH: Art for STXBP1* at Christie’s, New York, an auction of contemporary art benefitting the STXBP1 Foundation.

All works included have been generously donated to this cause by the artists who made them. We are so grateful to them for their generous support.

Read more about Florence and the event on the Flourish blog.

Are You All In?

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Building STXBP1 Natural History

Natural history studies are very important to rare disease communities like STXBP1. They collect information on a disease over time, and can be helpful in improving care for the

generated from the study. This is where we need your help.

STXBP1 affects our children in different ways, so it's important that we have broad representation of our patients.

From now until end of September -- STXBP1 Awareness Month -- the STXBP1 Foundation will be giving out $25 Amazon gift cards for those who enroll into the Contact List and at least one of these Natural History Studies: Simons Searchlight, Ciitizen, or RARE-X.

Send us a snapshot of verified enrollment to naturalhistory@stxbp1disorders.org. Gift cards will be sent at the beginning of October, and limited to the first 100 people.

New STXBP1 Foundation Grant Program

The STXBP1 Foundation has launched a revamped grant program. The foundation funds multiple types of projects aimed at addressing diverse research needs in the STXBP1 field. The objective of the STXBP1 Foundation grant program is to identify promising research projects that address specific areas of interest to the Foundation. These areas include but are not limited to the following:

1. Biomarkers and clinical endpoints development
2. Neurodegeneration
3. Pathomechanisms of STXBP1 mutations and genotype-phenotype relationships
4. Non-CNS functions of STXBP1
5. Drug repurposing

Check out the newly revamped Science and Research section of our website, and learn more and apply here!

Science Saturdays Videos with Jim Goss

Jim Goss, our Scientific Director, recorded Science Saturdays videos leading up to Summit. These short videos are posted on our website, and include these topics: what are natural history studies and why they are important, an introduction to the field of gene therapy, what do scientists and drug developers mean when they talk about preclinical studies, and the types of clinical studies and how they are run.

We are excited that Jim will continue to post science updates, as they occur, on this page through blog posts and videos.

STXBP1 World Map

STXBP1 disorders is a rare genetic disease that affects patients worldwide. We've built a map as a visual representation of where our community is located across the globe. **Patient families, please sign up for our Contact List** (at this link) **to be added to the map.** We have over 350 families in 36 countries so far!

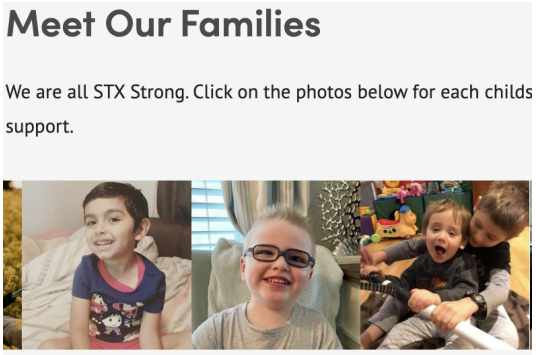
In addition to showing the variety of locations where STXBP1 patients live, this information helps us to connect you to research studies in your geographical area and Foundation activities. Listings on the map can be anonymous; you can choose to show age and/or first name, or only a location pin. **View the** STXBP1 World Map here**.**

Neurogenetics Clinic at Children's Hospital Colorado

Andrea Miele, PhD, presented on our Neurogenetics Multidisciplinary Clinic at the Children's Hospital Colorado. We are partnered with 3 other rare disease organizations to

The clinic is being held once a month. Learn about the Colorado clinic here. You can schedule an appointment by calling 1.720.777.7453 or emailing BNDP@childrenscolorado.org.

STX Strong Sundays



The STXBP1 Foundation is excited to announce a new, weekly series spotlighting an STX'er and their family every Sunday, called STX Strong. A total of 28 STXer's have been featured to date. Please follow along on Facebook and Instagram here: #stxstrong

We recognize how meaningful the individual introductions are for both our families and their personal support communities. Donors have also expressed appreciation for the opportunity to learn a little bit about the individuals whose lives their generosity impacts. Make sure to follow us on social media, so you don't miss the chance to meet any of these special STX'ers and their families.

You can "Meet our Familes", and learn how you can participate here.

Together we are STX Strong!

Your Feedback Please!

STXBP1 Community, the STXBP1 Foundation wants your input on needs, priorities, feedback and how we can better serve the community.

Please answer this short survey.

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

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.

- **Volunteer Lead** - Recruit and manage volunteer network and to assist the Foundation with areas of need. Hours will vary, anticipating commitment of 10 hours per month
- **Community Communication Volunteer** - Prepare monthly newsletter. Approximately 1-2 hours per week
- **Social Media Volunteer** - Promote content on Social media platforms. Approximately 10 hours per month
- **Fundraising Committee Volunteers** - Involved with developing fundraising ideas, implementing fundraising initiatives including grants, and collaborating to promote

To volunteer or to get more information on any of the above volunteer opportunities, please contact Melissa Hioco.

Calling all Grandparents to the Grands Society!

Grandparents, join the Grands Society!

STXBP1 Grandmother, Helen Rigby, has started a grandparents group within our STXBP1 community, so grandparents can connect, stay informed, and support STXBP1.

Read her blog post, and reach out to grands@stxbp1disorders.org to join.

STXBP1 Now Accepts Donations of Stocks and Cryptocurrency

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 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 within the U.S.A.

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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