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Season's Greetings from the STXBP1 Foundation!

Welcome to our December newsletter. Read on to get an update on research funding, meet our new Scientific Director, sign up for the Parent & Caregiver Contact List, and learn about volunteer opportunities for 2022!

\$500K in Research Funding in 2021



Want to know what research your contributions are going toward? Check out the [new page on the STXBP1 Foundation's website](#) listing Research Funding Recipients.

Learn about a screen to identify FDA approved drugs that could work for STXBP1 disorders, a project to understand regulation of STXBP1 gene expression, and more. Over \$500K in funding has been awarded in 2021!

New Scientific Director, James Goss, PhD



We are delighted to welcome James Goss, PhD, as the new Scientific Director of the STXBP1 Foundation. With the accelerating pace of STXBP1 research and projects, we wanted a dedicated, experienced researcher to drive our work in collaboration with our

and was trained as a neuroscientist. Read [Dr. Goss' greeting and learn about his background](#) on our website.

New Neurogenetics Clinic at Children's Hospital Colorado



We are thrilled to be launching a Neurogenetics Multidisciplinary Clinic at the Children's Hospital Colorado. We have partnered with 3 other rare disease organizations to launch this new clinic to provide comprehensive patient care while better informing research on each disorder.

The clinic will be held once a month. An informational webinar will be held on 10 January with clinic co-Directors, Dr. Scott Demarest and Dr. Margarita Saenz.

Learn about the [Colorado clinic here](#).

Parent & Caregiver Contact List



Contact & Mail Lists

Stay Current

If you are the parent or primary caregiver for an STXBP1 patient, we encourage you to register in our [Contact List](#). The Contact List is used to communicate research and clinical trial opportunities, to share educational and advocacy resources, as well as to help families connect with each other.

Since launching in September, we've had >150 parents & caregivers register! We've also recruited for 4 studies supported by the [Contact List](#).

For our broader community, anyone interested in learning more about STXBP1 disorders, supporting our community of families, and staying up to date on events and research can sign-up for [our Mailing List](#) and get this newsletter that you are reading right now!

STXBP1 Summit+



The STXBP1 Summit+ Family Meeting was held 17 - 19 September. With over 400 registrants, our virtual meeting brought researchers, clinicians, and industry partners together with our family community.

Check out the [session recordings](#)! Topics included research and therapy development updates, transition to adulthood, and advocacy.

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](#).

Interested in Joining the Board?



The parent-led STXBP1 Foundation is seeking a committed parent volunteer who is passionate about finding a cure for STXBP1 Disorders to serve as Secretary on the Board. Board members are actively engaged throughout their term, including attendance at events, fundraising, and participation during board calls. Board positions are voluntary, and have a three-year term. Applications accepted through January 31 for this position.

If you would like more specifics about this role or to request an application please email [Melissa Hioco](#).

Roundtable

Recordings Available!

The STXBP1 Researcher Roundtable was held 18 - 19 November. We heard exciting scientific talks on current knowledge, discussed key gaps in knowledge and ways to address these gaps to accelerate therapies for STXBP1.

[Session recordings](#) are posted!

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 at the start of 2022.

- **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.
- **Warrior Wednesday Initiative Volunteers** - Develop and implement the new Warrior Wednesday initiative by recruiting families and promoting their stories. Approximately 2-3 hours per week
- **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.

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

Survey on Transitions to Adult Care: Share Your Perspective!



The International League Against Epilepsy and the Epilepsy Genetics Research Program at Toronto Western Hospital are sponsoring a study on the "Perception of transition from pediatric to adult healthcare system in patients with epilepsy".

this study! The survey is available in English, Spanish, Portuguese, Romanian and Chinese.

You can learn more about participating in our blog post [here](#).

This Giving Season Give the Most Meaningful Gift of All



The perfect last minute gift idea is just a click away! Donate “in honor” of your gift recipient, and send them a personalized message. This is truly a gift which gives back! A donation to the STXBP1 Foundation funds science to give children and families MORE... MORE research, MORE clinical trials, and MORE hope for a successful treatment and a cure.

Donate [here](#) in honor of your gift recipient.

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



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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