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Welcome to the September 2023 issue of the STXBP1 Foundation Newsletter



STXBP1 Awareness Month is Always a Success

We've all been hard at work throughout September creating awareness for our rare genetic disorder. Our "Did You Know" social media cards were produced in 10 languages and shared all around the world. We posted new STXBP1 disorder videos and got moving for our 7th annual Move to Cure fundraising events. Please keep spreading the word however you can ... go here for resources and more [STXBP1 Awareness Month](#).



[Register or Donate](#)

Move to Cure STXBP1 Disorders

Be part of the global movement as the entire STXBP1 Community gathers near and far to **Move to Cure STXBP1 Disorders!**

Families and friends are encouraged to walk, run, hike or bike right in their own neighborhoods during the last week of September, as part of STXBP1 Awareness Month. Keep it simple, and get Moving for a Cure!

**Start a Team, Join a Team, or Donate!** We currently have 21 teams who have raised over \$30,000!

**Our goal is to raise \$100,000...**with your help we know we can get there!

Each individual registration includes Move to Cure STXBP1 swag including fun new STXBP1 socks.

Be sure to share your pictures with us on social media, and use the hashtag #move2curestxbp1

Send questions to [melissa.hioco@stxbp1disorders.org](mailto:melissa.hioco@stxbp1disorders.org)

STXBP1 Meeting with



FDA Externally-Led Patient-Focused Drug Development Meeting

On October 20, the STXBP1 Foundation is bringing the STXBP1 patient community together for a first ever Externally-Led Patient-Focused Drug Development Meeting (EL-PFDD), to inform the FDA and other stakeholders about the patient perspective of living with STXBP1-related disorders. This information can help the FDA to make informed decisions on approvals of potential medicines for STXBP1-related disorders, and pharmaceutical companies to design clinical trials that are meaningful for patients.

Please join us for this virtual meeting with the FDA on October 20! We need testimonials from our community; we need to hear your voice!

Learn more and sign up [HERE](#).



Missed the STXBP1 Summit this year? We have another opportunity to participate in the biorepository and in another biomarker study closer to you. Please consider donating at one of the Combined Brain Roadshow conferences even if you have donated in the past. To make the process at the donation site easier they aim to do consent prior to arrival.

Choose from one of these available dates below:

**IRF2BPL Foundation**, September 22nd, 9am-5pm (Home 2 Suites by Hilton, 7145 Liberty Centre Drive, Liberty Township, OH 45069)

**KCNQ2 Cure Alliance Conference**, September 29th, 9am-5pm September 30th, 9am-3:30pm (Hilton Hotel Chicago 300 E Ohio St, Chicago, IL 60611)

**Rory-Belle Foundation Conference**, October 1st, 9am-5pm (13550 Commerce Blvd Rogers, MN 55374)

**Prader-Willi Syndrome/USP7 Foundation**, October 5th-6th (1672 Lawrence St, Denver, CO 80202)

**TBR Community**, October 12th-13th 2023 (Morgan's Wonderland, 5223 David Edwards Dr, San Antonio, TX 78233)

**COMBINEDBrain Meeting**, October 16th 2023 (Washington DC)

**FAM177A1**, October 29th 2023, 9am-5pm (2737 77th Ave Se Suite 101 Mercer Island, WA 98040)

**COMBINEDBrain**, October 30th-November 1st 2023 (Los Angeles, CA)

**POTENTIAL** - Angelman Foundation, November 2023 (Miami, FL)

**SYNGAP1 Research Fund**, December 1st-3rd 2023 (8978 International Drive Orlando, FL, 32819)

**SLC6A1 Connect**, December 1st-3rd 2023 (9700 International Dr, Orlando, FL 32819)

If interested in donating at any of the above conferences, contact Jackie Steinberg at [jackie.steinberg@stxbp1disorders.org](mailto:jackie.steinberg@stxbp1disorders.org)



Our Community in Action. Summit+ Videos - Watch now!

We are very excited to share some short videos created at the Summit+ in Colorado. You can view them on the [STXBP1 Foundation website](#) or [YouTube](#) page. Enjoy them for yourselves or share them on social media to promote STXBP1 Awareness Month!

Exciting News: The STXBP1 Foundation is Growing!

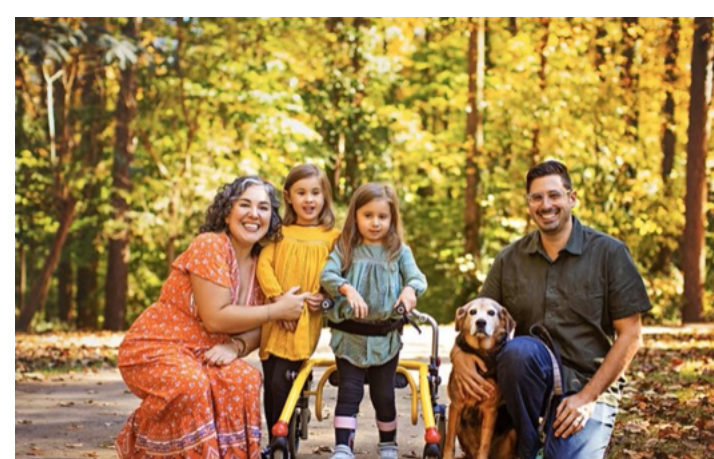
Hey, STXBP1 Community!

Exciting news! The STXBP1 Foundation is expanding its team to raise awareness and find a cure for STXBP1 disorders. The foundation is proud to introduce two new board members, Daniele Greiner, a seasoned nonprofit development expert, and Jason Stanaland, a healthcare marketing and technology leader. This expansion reflects the ongoing commitment to make a real difference in the lives of those affected by STXBP1 disorders. Read more about the STXBP1 Foundation's growth below.

Click on each of their pictures to read our blog post and see their full bio on our team page [here](#).



Daniele Greiner



Jason Stanaland

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



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