STXBP1disorders
Science + Love = Cure

Welcome to the October 2023 issue of the STXBP1 Foundation Newsletter

STXBP1 Meeting with FDA

Just a Few Days Away with the FDA

Join in this Friday, October 20 any time from 10am-3pm ET as we help to inform the FDA and other stakeholders about the patient perspective of living with STXBP1-related disorders. Not many rare disease organizations get an opportunity to present to the FDA so this is your chance to see it firsthand and participate. Easy ways to do this is by participating in the interactive polls throughout the meeting, and calling in to share your experience. The bigger our audience, the more we demonstrate the incredible love and engagement that comes from our community. Information from this meeting 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 this Friday. Learn more and sign up HERE.

Nearly 1,000 STXers in our Q3 2023 Census

We just published our count of STXBP1-related disorder patients around the world and we have seen quite a bit of growth as more and more families uncover their diagnosis. You'll find the data interesting as we anonymously group our afflicted patients by age, gender, and geography. Take a look HERE … and see how you can be counted if you haven't already joined in.

STARR
The STXBP1 Natural History Study

Enroll in the STARR Natural History Study

The STARR Natural History Study launched in July. There are already 40 STX'ers who have enrolled and had their first clinical site visit. But we're far from done! Our goal is to enroll 50-100 STX'ers so we can develop a strong understanding of STXBP1.

Because our patients span many ages and different presentations, it's essential to see a lot of patients to develop this understanding.

You can be seen at four sites: Children's Hospital of Philadelphia, Colorado Children's, Baylor / Texas Childrens and Weill-Cornell. Also there is travel support for families from both STXBP1 Foundation AND Clara Inspired. Learn more and get enrollment information here.

There's Still Time to Donate to Move to Cure STXBP1

26 teams have brought in over 400 donations for Move to Cure STXBP1 2023, raising just over $42,000 to date. Donations are still trickling in, and the Move to Cure STXBP1 campaign site is open through the end of October. A couple teams rescheduled and will Move to Cure STXBP1 Disorders soon! **There is still time to donate...let's get to $50,000 and beyond!!**

We also want to give a big shout out to Celanese Corporation for their sponsorship of the Move to Cure STXBP1 event...Thank you Team Celanese for your support!!

Donate Here

Global Genes®
Allies in Rare Disease

STXBP1 Foundation at the Global Genes Conference

Speaking of the big picture, we had a solid presence at the leading industry event for the rare disease community. Our own Charlene Son Rigby is the CEO of Global Genes and she represented us well along with two other STXBP1 board members, Russ Novy and Melissa Hioco, at their annual conference which was tied to the Week in Rare this past September in San Diego. The event was a huge success with hundreds of attendees from our peer groups, research centers, pharmaceutical companies, and more.

STXBP1 Summit+ 2024

We're excited to be headed back to the Philly area for the 2024 STXBP1 Summit+ Researcher & Family Meetings!

Mark Your Calendars
Researcher Meeting - July 18-19
Family & Researcher Dinner - July 19
Family Meeting & Support Sessions - July 20-21

Read our past issues here. We'll see you next month.

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