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# STXBP1 disorders

— Science + L♥ve = Cure —

**Welcome to the December 2023 issue of the  
STXBP1 Foundation Newsletter**



## SEASONS GREETINGS

### **Thank you for a wonderful year!**

We are grateful for another year of exciting research, progress, and active engagement within the STXBP1 community. We wish everyone around the world a joyous season filled with warmth, togetherness, and an abundance of hope.

**Wrap Up the Year with our Latest Podcast**

Listen to the **Science + Love = Cure** podcast. This is a 10-minute quick update for the STXBP1 Community from the STXBP1 Foundation.



**In this episode**

“Give with Your Heart - Be the Love”

Fundraising campaign for Giving Tuesday, American Epilepsy Society (AES) Debrief, New to STXBP1 Research: The Nonsense Mouse Model, STXBP1 Contact List, and STXBP1 Global Connect.



All episodes are [now available](#) on Apple and YouTube.

**Give a year-end gift today!**

Be the Love in our equation: *Science+Love=Cure*



**Give hope for the future. Give with your heart.**

We asked families and caretakers to talk about their biggest worries for their loved ones with STXBP1 disorders. What keeps them up at night? They all shared one common answer—the future. Will you consider a year-end donation by December 31? Your gift today creates hope for a better tomorrow.

*To the families featured in this video, thank you for sharing your stories.*

DONATE

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### **STARR Clinic Updates**

The STARR Natural History Study has hit an impressive number of enrollees with 65 individuals registered since the study started this past July! Though this is a great start, we still need more participants to reach our goal of 100 participants for the first year of the study. The purpose of this study is to better understand STXBP1 disorders, and ultimately lead to improved care and treatment for the disorder. Four study sites (Children's Hospital of Philadelphia, Children's Hospital Colorado, Weill Cornell Medicine, and Texas Children's Hospital) are now enrolling and seeing patients. To learn more about the study, how to register, and for information on travel reimbursement, go [here](#). If you have any questions, send us an [email](#).

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### **A Strong Showing at the AES Meeting**



The American Epilepsy Society (AES) holds an annual meeting that brings together healthcare providers, scientists, advocates, industry, and other professionals dedicated to better outcomes for people with epilepsy. Read about our strong presence at this year's conference in this [blog](#) post.

## NEW: 14 Language Translations

### Read Our Website in Multiple Languages

auf Deutsch lesen

lire en français

leer en español

לקרוא בעברית

читати українською

leia em português

leggere in italiano

读中文

read in english

قراءة باللغة العربية

czytać po polsku

STXBP1-related disorders are diagnosed in patients around the world. To make the quest for information a little easier for families and caregivers everywhere, **we have added a language translation feature to our website.** Visitors can now select between 14 languages, other than English, to translate the entire site. Click on the "Select Language" bar on the bottom of our web [pages](#).

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## SAVE THE DATE

### STXBP1 Summit - July 2024



We are excited to host the **2024 STXBP1 Summit+ Researcher & Family Meetings** in the Philadelphia area in July!

#### Mark Your Calendars

Researcher Meeting - July 18-19

Family & Researcher Dinner - July 19

Family Meeting & Support Sessions - July 20-21

Email [here](#) for sponsorship info

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



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