

[View this email in your browser](#)




Welcome to the February issue of the STXBP1 Newsletter.



HOW TO PARTICIPATE

STEP 1
Sign up online and consent



Estimated time to complete this step: 10 minutes

QUESTIONS? Visit the Simons Searchlight ["Connect Us"](#) page.

Why is it important to join Simons Searchlight?

- Not enough is known about STXBP1. Join our search for answers by signing up for Simons Searchlight and help build a stronger sense of community.
- Your unique experience could hold the clues that scientists need to find answers for STXBP1.
- Sharing your information can improve our understanding of STXBP1, advance research and lead to possible future treatments.
- Participate in Dutch, English, French or Spanish.

The process

- Go to www.simonssearchlight.org to sign up for FREE!

"I'd do anything to help my son have the best possible chance for a long and happy life including contributing his medical history and completing surveys in Simons Searchlight"
- Vanessa, Parent

#ShineYourSearchlight! ✨ Not enough is known about STXBP1. Join our search for answers by signing up for #SimonsSearchlight and help us grow our community in 2023. Go to <https://www.simonssearchlight.org/about-connect/> to sign up for FREE!

Hold the Date! 2023 STXBP1 Summit+ Family Meeting in Colorado



Join us this July 22-23, for our 4th Annual STXBP1 Summit+ Family Meeting at the Westin Westminster in Westminster, CO (just outside of Denver). STXBP1 families make your hotel reservations [here](#).

This year's in-person event is in partnership with the Children's Hospital Colorado (CHCO) in Aurora, CO. Families will have the opportunity to connect with other STXBP1 families, learn the latest information on STXBP1 including research updates, participate in break out sessions for families, and have fun during social gatherings.

STXBP1 Clinic Day - a limited number of appointments are available on Friday, July 21, at the Neurogenetics Multidisciplinary Clinic at CHCO. Please contact Nurse Coordinator Tristen Dinkel at 1(707)777-7453 or BNDP@childrenscolorado.org, to schedule an appointment.

Summit registration information coming soon.

Registration coming soon!

We know it might be difficult for families to afford the expenses involved with travel to the STXBP1 Summit+ in Colorado. We want to help!

Complete the scholarship application form below if you are an STXBP1 family in need of financial assistance to attend the STXBP1 Summit+ Family Meeting:
<https://forms.gle/18VSED7iPgHpx7eP9>

Applications due April 1st, 2023



STXBP1 Foundation is participating in the Xcelerate RARE: A Rare Disease Open Science Data Challenge.

Xcelerate RARE is bringing together researchers and data scientists in a collaborative and competitive environment to make the best use of STXBP1 patient-provided data through the RARE-X - STXBP1 Disorders Data Collection Program.

RARE-X anticipates that some of the outcomes of Xcelerate RARE might be:

- Shortening the diagnostic odyssey with predicted diagnosis
- Identifying previously unrecognized symptoms associated with some of these rare diseases
- Generating useful insights for advancing therapeutic research

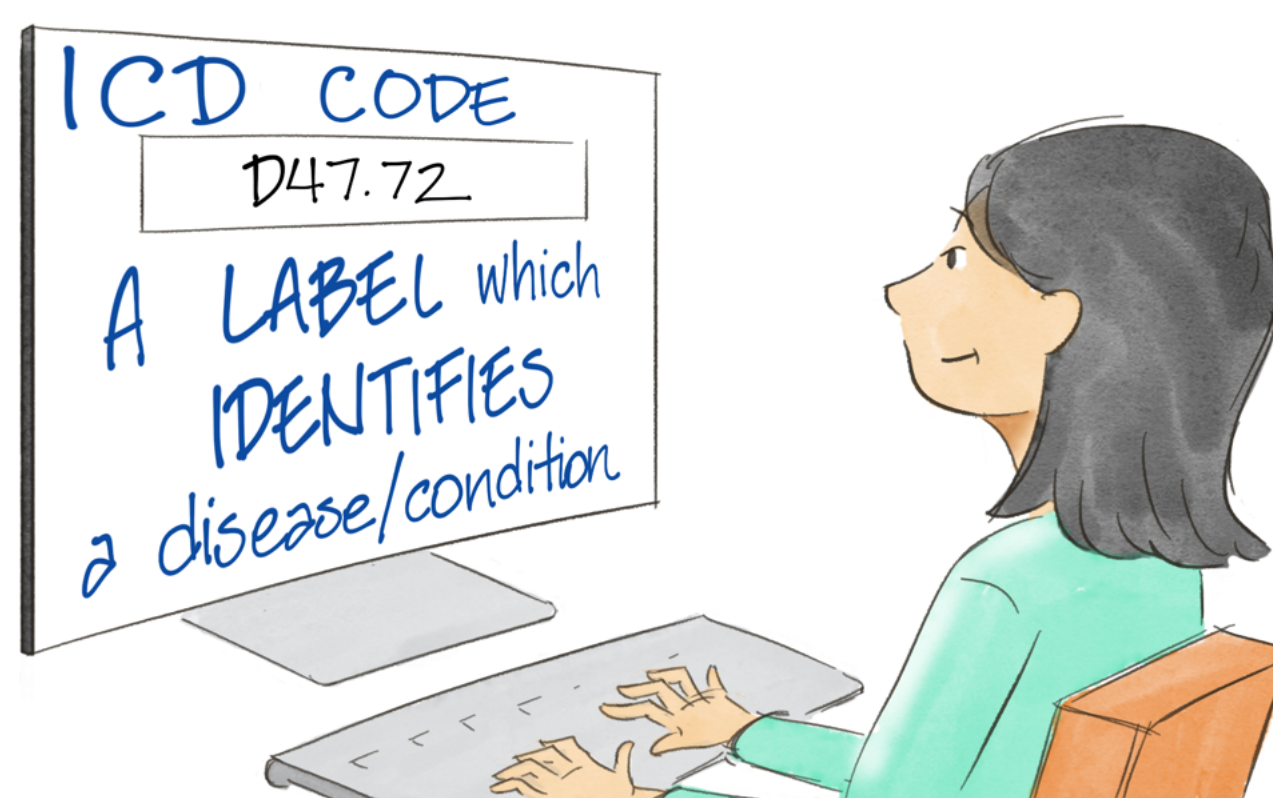
Enroll in the STXBP1 Disorders Data Collection Program today and not only **Be Counted**, but **Be Seen!**

Deadline Alert! Enroll in the STXBP1 Disorders Data Collection Program today and complete the surveys **before March 30** so the data you provide will be included in the Challenge.

To enroll, go to: stxbp1.rare-x.org/

To learn more about the Rare Disease Open Science Data Challenge, go to: rare-x.org/open-science-data-challenge/

Have questions on how to register? Contact naturalhistory@stxbp1disorders.org for help!



YOU CAN HELP!! Please sign up for our Contact List

The STXBP1 Foundation has requested an ICD-10 code for STXBP1, and after years of persistence we are excited to announce that we will present to the CDC on March 7 or 8!

- ➡ The CDC has indicated that a prevalence (known or diagnosed patients) of at least 1:1,000,000 may be necessary to get an ICD-10 code.
- ➡ If we could identify at least 330 patients in the U.S. now, we could show that prevalence is at least that high.
- ➡ Right now, we have 213 US families in our Contact List. **If you haven't signed up yet, now is the time!** 📍 **STXBP1 Families in the U.S....we need you to sign up here:** <https://www.stxbp1disorders.org/contact-list>

Learn more about ICD 10 codes here: <https://everylifefoundation.org/icd-code-roadmap/>



Copyright © 2021
All rights reserved.

Our mailing address is:
STXBP1 Foundation
P.O. Box 1148
Holly Springs, NC 27540
USA

Want to change how you receive these emails?
You can [update your preferences](#) or [unsubscribe from this list](#).

Email us at info@stxbp1disorders.org