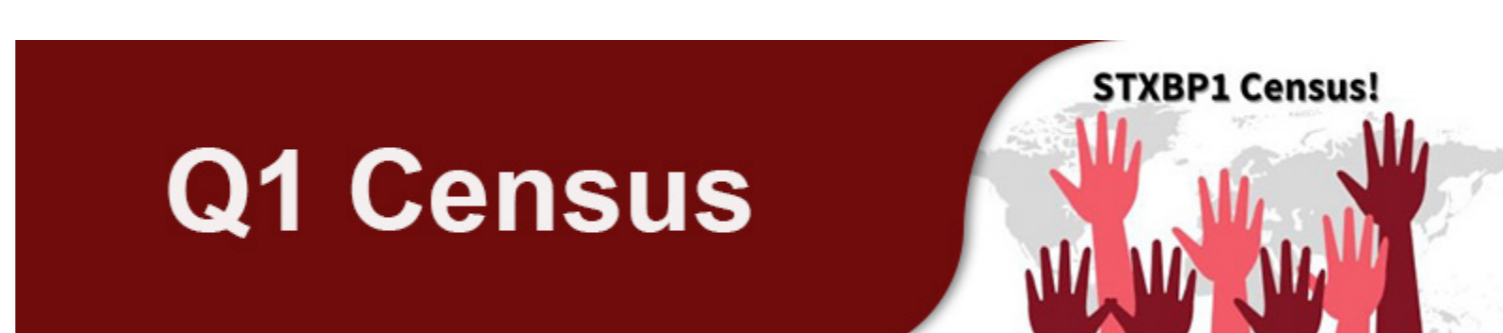


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Welcome to the April 2024 issue of the STXBP1 Foundation Newsletter



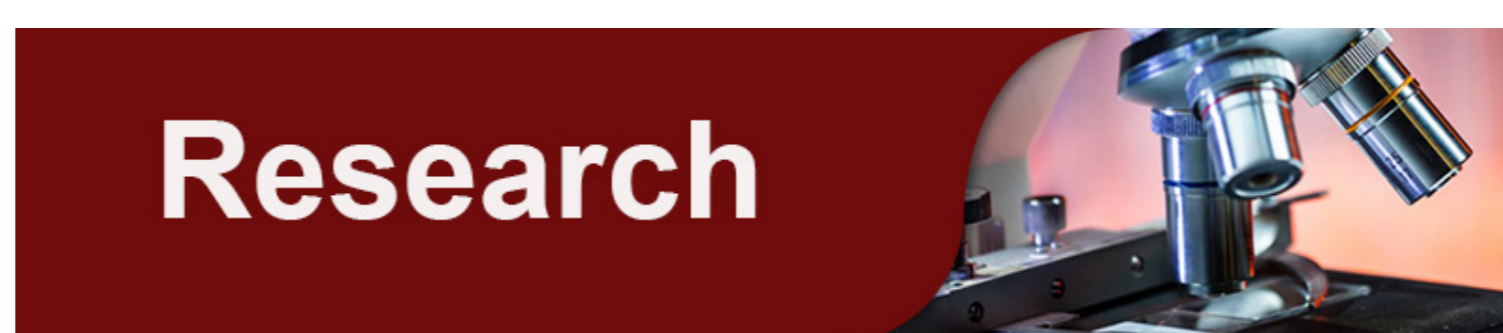
Over 1,000 Patients Counted in our Census! 112 new patients have been counted in our Q1 census through March 31, 2024. Our total is now 1,085 diagnosed patients with STXBP1-related disorders worldwide. Read more and see the demographic breakdowns in our blog post here.



Roll with "Lulu's Crew Team STXBP1" this June The Million Dollar Bike Ride (MDBR) is quickly approaching on June 8 and the STXBP1-related disorders presence promises to be big. Learn from Erin Prosser, mom to Lucy (Lulu), in a new webinar covering the MDR and how you can participate in STXBP1-related disorders fundraising from anywhere! Watch the recording here.

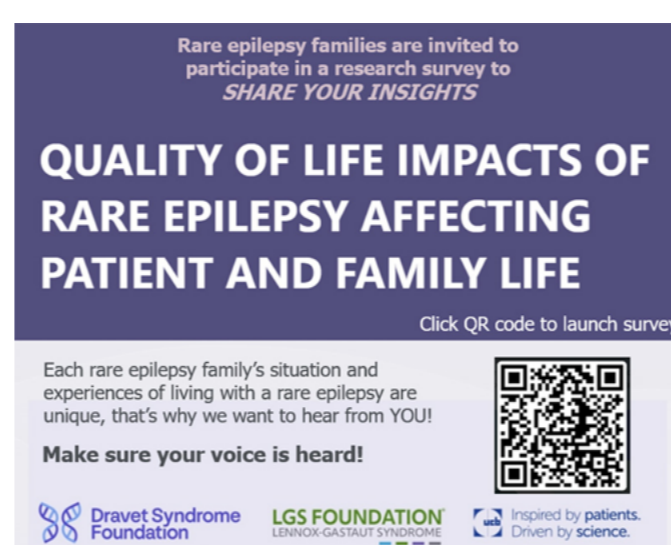


Registration is Open for the STXBP1 Summit+ Researcher & Family Meetings The STXBP1 Summit+ is back on the East Coast and will be held in Drexel Hill, PA from July 18-21. Session agendas and full event details are coming soon. Early Bird registration is open through May 25, so don't delay in registering today here.



Participate in these 2 Online Surveys Running in April

Quality of Life Impacts of Rare Epilepsy Affecting Patient and Family Life



- It is an online survey from UCB that takes roughly 10-15 minutes to complete here
All can complete (no restrictions for age or location) and survey available in English.
The aim is to "learn more about how each family defines what 'normal' and 'disruptive' means to your family's quality of life as it relates to your loved one's activities of daily living (ADLs), communication, behavior(s), sleep, and seizure(s)."

Sleep Intervention Questionnaire - A Needs-Based Assessment of Sleep Intervention for STXBP1

- It is an online survey from the Kennedy Krieger Institute that takes roughly 2-3 minutes to complete here
All can complete (no restrictions for age or location) and surveys available in English, Spanish, French, Italian, Portuguese and Chinese.
The results of the questionnaire will be used for developing a possible sleep intervention study involving multiple genetic disorders including STXBP1.



Stay Informed with "Strides in STXBP1" We've launched a new science series, "Strides in STXBP1", that you will find in our Scientific Director's Corner. Each month we round-up all the scientific news covering STXBP1 and present it in one easy to read report. Take a look here to be in the know.



Join our Natural History Study Want to participate in the first ever natural history study focused solely on the STXBP1 patient? The purpose of the STARR Natural History Study is to better understand STXBP1-related disorders, and ultimately lead to improved care and treatment. The study is now enrolling at four sites (Children's Hospital of Philadelphia, Children's Hospital Colorado, Weill Cornell Medicine, and Texas Children's Hospital) with a goal to see 100 patients in the first year. 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.



Got Siblings? Being the brother or sister of a child with a chronic illness like STXBP1-related disorders can be very challenging. Get your VIP Siblings! Caregiver & Sibling Kits today with these free resources to help. And, you can also help by providing input to the development of new tools for siblings at the Cincinnati Children's Hospital. Learn more in this flyer.

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



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