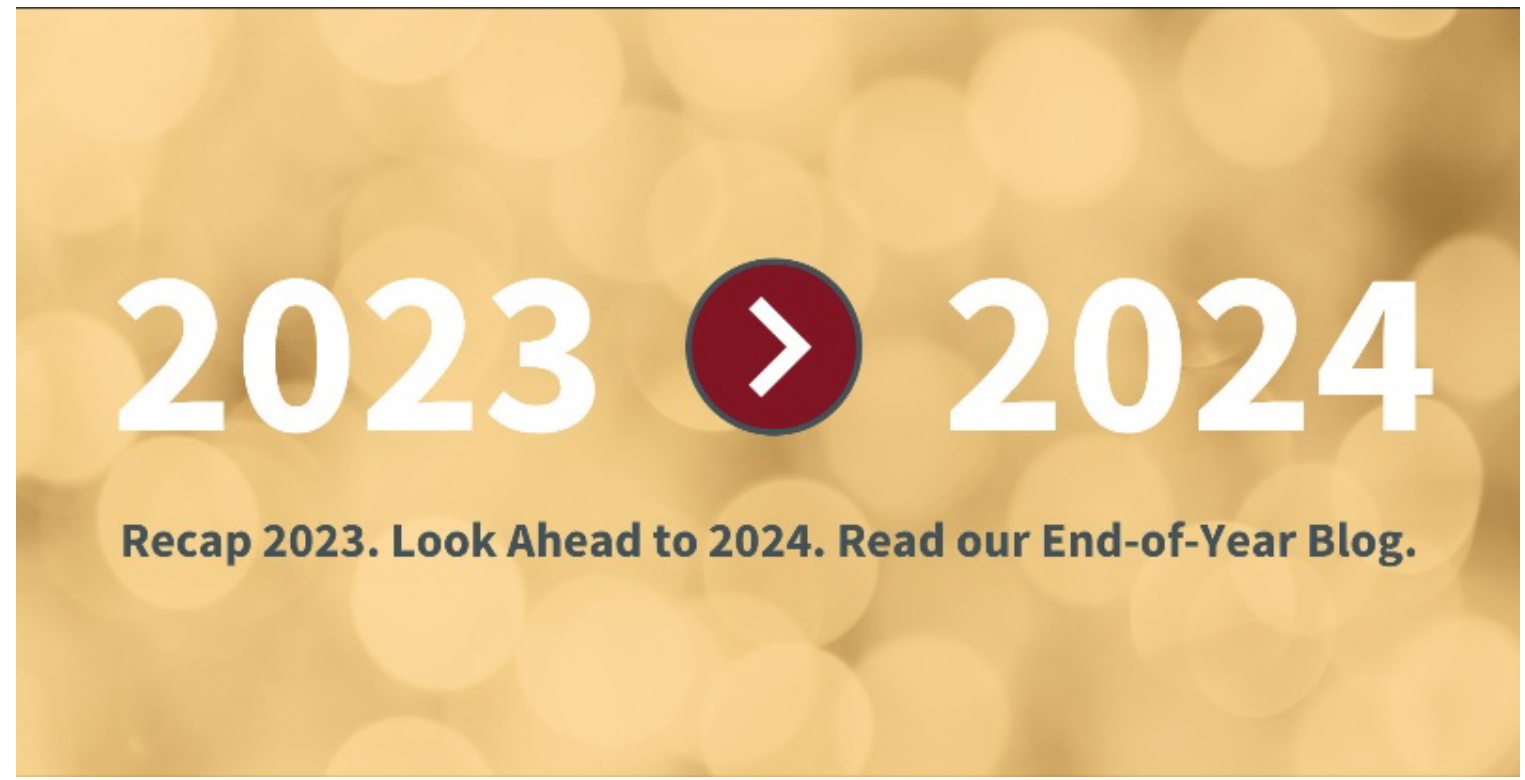


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Welcome to the January 2024 issue of the STXBP1 Foundation Newsletter

Celebrating 2023 and Looking Forward



2023 was a year of acceleration for STXBP1. We and our collaborators have collectively pushed the STXBP1 gas pedal. The progress we've made is both amazing and humbling. Check out our blog post on [Celebrating 2023 and Looking Forward](#), read our [Top 10 Foundation Achievements](#), see how our patient population grew in the Q4 [census](#), and kick-off 2024 with our latest [podcast](#).

2024 STXBP1 Summit+



We are saving a seat for you at the **2024 STXBP1 Summit+ Researcher & Family Meetings** this July, in Drexel Hill, PA (just outside of Philadelphia)!

Visit the [STXBP1 Summit+ site](#) for hotel info & reservation link, and more!

We know it might be difficult for some families to afford the travel expenses to attend the STXBP1 Summit+. The STXBP1 Foundation is offering family travel scholarships; applications available [HERE](#) through March 1, 2024.

Email [here](#) for sponsorship info



In partnership with [Uplifting Athletes](#), the STXBP1 Foundation has awarded Dr. Noah Guiberson, from Weill Cornell Medicine, a \$20,000 grant to characterize a novel STXBP1 missense mouse. This work will be important for using this animal model for research and clinical trial development. To read more, visit the our page [here](#).

Uplifting Athletes will be hosting an event to honor grant recipients and rare disease researchers on February 3, 2024. To learn more, click [here](#).



Two STXBP1 Research Projects Awarded Million Dollar Bike Ride Grants

[Lulu's Crew/STXBP1](#) rode for the fifth straight year to raise funds for STXBP1 research at University of Pennsylvania's [Million Dollar Bike Ride \(MDBR\)](#), hosted by the [Orphan Disease Center](#). We are excited to share that two STXBP1 projects have been selected for funding as part of the 2023 MDBR grants program. Read about it [here](#).

- Dr. Xuebing Wu from Columbia University was awarded \$75,460 to study a region of the STXBP1 gene involved in regulating the amount of STXBP1 protein made and testing antisense oligonucleotides (ASOs) that could increase the amount of protein made by interacting with this region.
- Dr. Wendy Gold from the University of Sydney was awarded \$75,460 to identify STXBP1 disease biomarkers using a novel 'multi-omics' approach. These biomarkers could be useful in predicting disease state and severity, help in the design and development of new drugs, and used as indicators to determine if a drug is potentially effective in treating STXBP1-RD.

Join Lulu's Crew (in person or virtually) at this year's MBDR on June 8th, 2024. More information to come soon!

New Rare Wear Design

Rare Disease Day 2024



"Leap" into our latest designed shirts just in time to celebrate Rare Disease Day on February 29--an especially *rare* day! Wear your awareness and make a statement that goes beyond style! A percentage of each shirt sale supports the STXBP1 Foundation, which is committed to expanding awareness of STXBP1 Disorders.

[Get Your Rare Wear HERE](#)

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



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