

2023 Impact Report

Top 10 Achievements

1 Fast Forward

Launched new STXBP1 Fast Forward 3-Year Strategic Plan.



2 Disease Concept Model

Published the first peer-reviewed STXBP1 Disease Concept Model documenting our patients' **most significant symptoms** and their impact.



3 European Research Roundtable

Held first Research Roundtable in Europe bringing together **over 100 researchers** and clinicians in Milan.



4 STARR Natural History Study

Launched first longitudinal Natural History Study for STXBP1-related disorders **enrolling at least 100 patients at 4 sites** across the USA.



5 FDA Listening Session

Orchestrated first externally-led Patient-Focused Drug Development meeting with the FDA for STXBP1, as **288 attendees** joined in to discuss patient experiences and the **urgent need for treatments**.



6 Global Connect

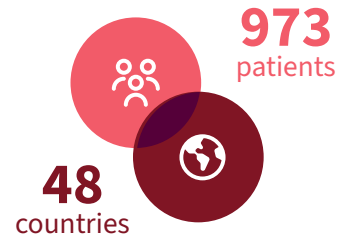
Exceeded **20 countries** in the STXBP1 Global Connect, our coalition of STXBP1 foundations and country liaisons.

STXBP1
Global Connect

20+
Countries

7 Patient Census

Initiated an STXBP1 patient census, which has counted **over 973 patients in 48 countries** around the world.



8 Grants & Research Funding

Awarded over **\$1.5M** to date for Patient Studies and Translational & Pre-Clinical Research projects around the world.



9 Patient Assistance Grants

Awarded over **\$20K** to date for support of STXBP1 patients and their families.



10 STXBP1 Summit + Annual Conference

Held our **first Family Meeting in Colorado** with over 300 attendees.

