

SETBP1 COMMUNITY RESEARCH STUDY (SCoReS)

**Do you have unmet needs being a parent of a child with SETBP1 disorder?
Do you want to learn more about the challenges faced by other parents
and children affected by SETBP1 disorder?**



Tarleton State University and SETBP1 Society are partnering together for a community-based project to develop and drive research to meet the needs of the SETBP1 Community. The aims of this project are:

- to identify and provide targeted resources to help parents of children with SETBP1 disorder
- for the parents' responses to guide the direction of the research

We are looking for parents/caregivers of individuals:

- suspected to have a SETBP1 loss of function variant or deletion by a genetic test
- aged 2 months – adulthood

What is involved?

- Complete online surveys at your leisure that help us to learn about SETBP1 parents' and children's unique needs and challenges.
- **Participants do not need to speak English.**



Email us to express an interest at:
SCoReS@setbp1.org or Visit
www.setbp1.org/SCoReS

About us: The research team includes Trina Geye, Stephanie Robertson and Haley Oyler. Trina and Stephanie are faculty members in the Psychology Department at Tarleton State University. Trina has training in experimental and cognitive psychology and a background in child advocacy, higher education disability services, and counseling. She serves on the SETBP1 Society Board of Directors. Stephanie is also a clinical psychologist, licensed specialist in school psychology, and director of the Tarleton Center for Child Well-Being. Haley Oyler is the president of SETBP1 Society, a parent of a child with SETBP1 disorder, and a committed advocate for the SETBP1 Community.