Simons Searchlight Registry Update SETBP1 Loss of Function
September 2021

Ages in Years

Developmental & Behavioral Diagnoses

Data in these four graphs are from the medical history phone interviews collected in Simons Searchlight on 16 participants with SETBP1.

Notes:
- Graphs show counts of individuals in each category. Individual participants may appear in more than one category if they report multiple conditions.
- Information on reported seizure types is included on the 2021 quarter 1 registry report available on simonssearchlight.org/research/setbp1/.

Neurological Problems

Gastrointestinal Problems

Participation & Registration

The information in this report is made possible by the active participation of the SETBP1 community! Progress for individuals in your community with a SETBP1 loss of function variant is shown below – log in to your simonssearchlight.org dashboard today to check for new surveys and tasks. Your data could hold the clues geneticists need to find answers.

Step 1: Sign up online.
Step 2: Provide your clinical lab report.
Step 3: Schedule medical history phone call with a genetic counselor.
Step 4: Fill out surveys.
Step 5: Provide a blood sample if you are interested.
Step 6: We follow up with you over time.

Log in to see next steps