Simons Searchlight Registry Update SETBP1
June 2021

Ages in Years

Developmental & Behavioral Diagnoses

Notes:
- Graphs show counts of individuals in each category. Individual participants may appear in more than one category if they report multiple conditions.
- Additional information is included on the 2021 quarter 1 registry report available on simonssearchlight.org/research/what-we-study/setbp1.
- Medical information presented does not include participants with Schinzel-Gideon Syndrome.

Participation & Registration
This ever-growing database is made possible by the active participation of the SETBP1 community! Progress for individuals in your community with a SETBP1 variant is shown below -- log in to your simonssearchlight.org dashboard today to check for new surveys and other priority tasks. Your unique data could hold the clues scientists need to make progress and 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
Information Spotlight: Child Behavior Checklist

The Child Behavior Checklist (CBCL) is a survey used to understand behavioral and emotional concerns in children.

The bars in the graphs show the overall level of concern reported by Simons Searchlight caregivers who completed the CBCL survey about their children with SETPB1. Individual caregivers may have indicated a lower or higher level of concern than indicated by the overall group.

Behavioral Concerns for ages 6-18 yrs

Oppositional behavior
Attention/hyperactivity
Aggression
Anxiety
Sadness

Not a concern | Mild concern | Significant concern

Top Behavioral Concerns
Ages 6-18 yrs

Speech problems
Acts young for his/her age
Inattentive or easily distracted
Can’t pay attention for long