Simons Searchlight Registry Update 17q21.31 deletion/KANSL1 (Koolen-de Vries Syndrome)

Data in these four graphs are from the medical history phone interviews collected in Simons Searchlight from 14 participants with a 17q21.31 deletion/KANSL1 (Koolen-de Vries Syndrome).

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**Ages in Years**

- 0-4: 2
- 5-9: 5
- 10-14: 2
- 15-19: 1
- 20-24: 1
- 25+: 3

**Developmental and Behavioral Conditions**

- ADHD: 4
- Anxiety: 4
- Autism: 1
- Intellectual Disability/Developmental Delay: 13
- Language Delay/Impairment: 14
- Obsessive Compulsive Disorder: 2

**Neurological Conditions**

- Seizures: 8
- Low Muscle Tone: 14
- Large Head Size: 3
- Coordination Problems: 2
- Cerebral Palsy: 1

**Gastrointestinal Conditions**

- Constipation: 6
- GERD: 4
- Other: 2

NOTES: Graphs show counts of individuals in each category. Individual participants may appear in more than one category if they report multiple conditions.

**How to participate?**

The information in this report is made possible by the active participation of the KdVS-17q21.31_KANSL1 community! Progress for individuals in your community with KdVS-17q21.31_KANSL1 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 genetic lab report

**STEP 3**
Share your important medical history

**STEP 4**
Fill out surveys

**STEP 5**
Provide a blood sample if you are interested

**STEP 6**
Update us every year

Log in to see next steps.