Simons Searchlight Registry Update HIVEP2

June 2021

Ages in Years

- 0-4: 3
- 5-9: 7
- 10-14: 4
- 15+: 1

Developmental & Behavioral Diagnoses

- Intellectual Disability/Development Delay: 13
- Language Impairment: 5
- Autism: 10
- ADHD: 2
- Anxiety: 1

Neurological Problems

- Low Muscle Tone: 7
- Clumsy: 1
- Large Head Size: 5
- Small Head Size: 4
- Movement Disorder: 1
- Tic Disorder: 3
- Cerebral Palsy: 1
- Seizures: 1

Gastrointestinal Problems

- GERD: 5
- Diarrhea: 1
- Constipation: 2
- Other: 6

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/HIVEP2.

Participation & Registration

This ever-growing database is made possible by the active participation of the HIVEP2 community! Progress for individuals in your community with a HIVEP2 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.

Behavioral Concerns for ages 1.5-5yrs

- Oppositional behavior
- Attention/hyperactivity
- Aggression
- Anxiety
- Sadness

Behavioral Concerns for ages 6-18 yrs

- Oppositional behavior
- Attention/hyperactivity
- Aggression
- Anxiety
- Sadness

Top Behavioral Concerns
Ages 1.5-5 yrs

- Quickly moves from one activity to the next
- Discipline doesn’t influence their behavior
- Doesn’t display fear of getting hurt
- Disobedient

Top Behavioral Concerns
Ages 6-18 yrs

- Frequently distracted
- Hyperactive
- Demands frequent attention
- Obsessions

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 HIVEP2. Individual caregivers may have indicated a lower or higher level of concern than indicated by the overall group.