Simons Searchlight Registry Update ADNP

Ages in Years

Developmental & Behavioral Diagnoses

Neurological Problems

Gastrointestinal Problems

Participation & Registration

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

- **Intellectual Disability/Development Delay**: 16
- **Language Impairment**: 11
- **Autism**: 9
- **ADHD**: 3
- **OCD**: 1
- **Anxiety**: 3

**Low Muscle Tone**: 16
- **Clumsy**: 3
- **High Muscle Tone**: 5
- **Movement Disorder**: 2
- **Tic Disorder**: 6
- **Cerebral Palsy**: 4
- **Cortical Blindness**: 3
- **Seizures**: 4

**GERD**: 10
- **Diarrhea**: 7
- **Inflammatory Bowel Disease**: 2
- **Constipation**: 1
- **Gastric Ulcer**: 2
- **Other**: 1

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/ADNP.

**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 ADNP. 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

Top Behavioral Concerns
Ages 6-18 yrs

- Frequently distracted
- Demands frequent attention
- Repeats certain behaviors
- Obsessions