"We hold the keys to help people like doctors, pharmacists, and geneticists unlock and discover the best treatments and guidelines for our children."

- Cathryne Cansler, Mom to Wesley (WAGR)
"The information you provide could help scientists and physicians discover new ways of improving the health and quality of life of children and adults with WAGR syndrome."

- Joan Han, MD

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Compiled September 2020
"If by filling out the registry, we can help another parent not have to have that 'What do I do?', 'Where do I go?', 'What is this?' moment, it's so worth it."

- Taylor Rogers, Mom to Rubye (WAGR)
"Please fill out the registry, to give the medical personnel the information they need to be able to research this disease more."

- Alex Sena (WAGR)

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Compiled September 2020
No/Never a Problem

Registry Data

Sensory Integration Disorders
- Includes sensory processing and sensory modulation deficit
- 27% Yes/Has Been a Problem
- 10% No/Never a Problem
- 63% Blank/Unsure

Cognitive Impairments
- Includes global developmental delay and cognitive impairment
- 10% Yes/Has Been a Problem
- 10% No/Never a Problem
- 80% Blank/Unsure

Learning Disabilities
- Includes learning disability in math/reading, nonverbal learning disability/Asperger's syndrome
- 9% Yes/Has Been a Problem
- 52% No/Never a Problem
- 39% Blank/Unsure

Visual Processing Disorders
- Includes visual-perceptual disorder, and visual motor deficit
- 12% Yes/Has Been a Problem
- 10% No/Never a Problem
- 78% Blank/Unsure

Auditory Processing Disorder
- 25% Yes/Has Been a Problem
- 9% No/Never a Problem
- 66% Blank/Unsure

Language Delays
- Includes language delay, speech delay, and mutism
- 9% Yes/Has Been a Problem
- 25% No/Never a Problem
- 66% Blank/Unsure

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Compiled September 2020

"It’s so exciting to know there are researchers that are interested in WAGR Syndrome that want to use the information that we put in the registry. It could make a huge amount of difference."

- Nicola Davies, Mom to Emilia (WAGR)
Registry Data

**Range of developmental delays**

**ADD or ADHD**
- Yes/Has Been a Problem: 22%
- No/Never a Problem: 65%
- Blank/Unsure: 13%

**Autism or PDD**
- Yes/Has Been a Problem: 32%
- No/Never a Problem: 55%
- Blank/Unsure: 13%

**OCD**
- Yes/Has Been a Problem: 25%
- No/Never a Problem: 47%
- Blank/Unsure: 28%

**Aggressive Behavior**
- Yes/Has Been a Problem: 57%
- No/Never a Problem: 30%
- Blank/Unsure: 13%

**Anxiety Disorder**
- Yes/Has Been a Problem: 37%
- No/Never a Problem: 38%
- Blank/Unsure: 25%

**Hyperactivity or Impulsivity**
- Yes/Has Been a Problem: 61%
- No/Never a Problem: 24%
- Blank/Unsure: 15%

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Compiled September 2020

"The more patients in the registry, the more valid our conclusions can be and the more apt we are to make observations and discoveries that could lead to new treatments."

- Andrew Murphy, MD