

WAGR SYNDROME PATIENT REGISTRY

A POWERFUL TOOL FOR RESEARCH

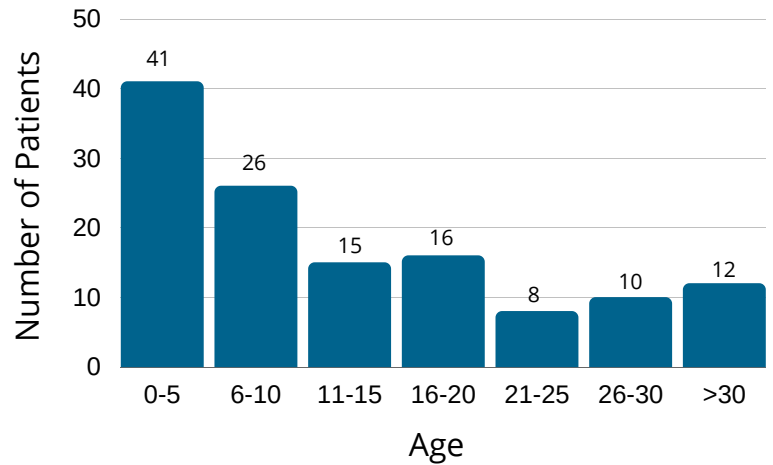
Registry Data

W Wilms tumor **A** Aniridia **G** Genitourinary abnormalities **R** Range of developmental delays

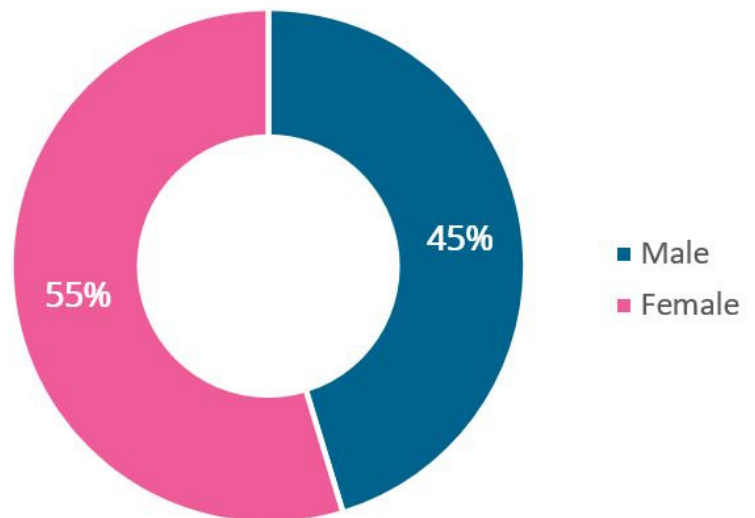
Patient Country

Country	Number	Percentage
Argentina	2	2%
Australia	3	2%
Belgium	1	1%
Brazil	1	1%
Canada	4	3%
Ethiopia	1	1%
Germany	4	3%
Ireland	2	2%
Italy	4	3%
Japan	3	2%
Mexico	3	2%
Netherlands	4	3%
New Zealand	1	1%
Norway	1	1%
Peru	1	1%
Slovenia	1	1%
Spain	1	1%
Switzerland	1	1%
Turkey	1	1%
UAE	1	1%
UK	18	14%
USA	70	55%
Total	128	100%

Patient Age



Patient Sex



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Compiled September 2020

"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)

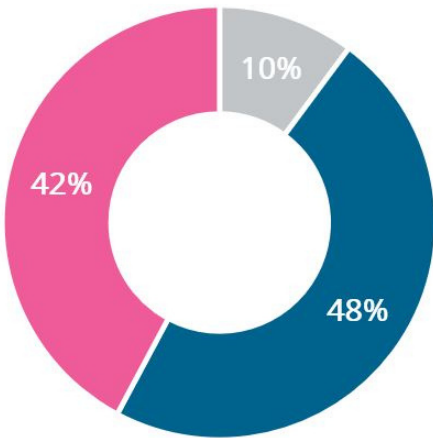
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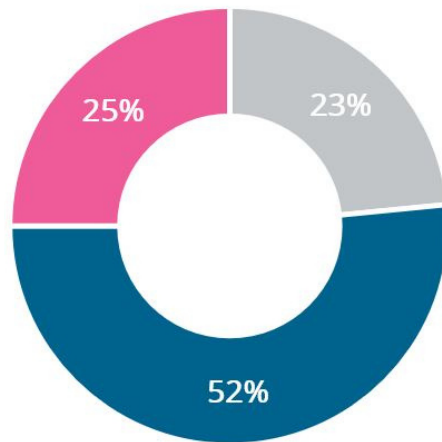
Registry Data

W Wilms tumor A G R

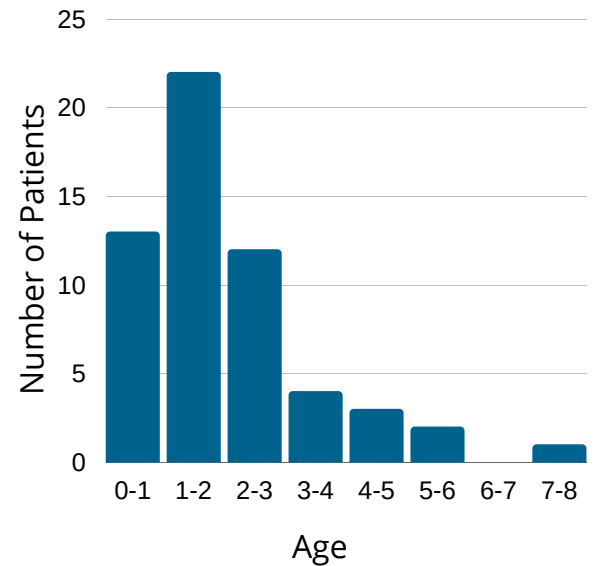
Wilms Tumor



Nephrogenic Rests



Age at First Treatment



Yes/Has Been a Problem
 No/Never a Problem
 Blank/Unsure

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"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

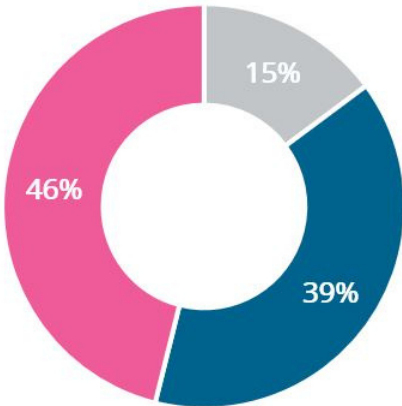
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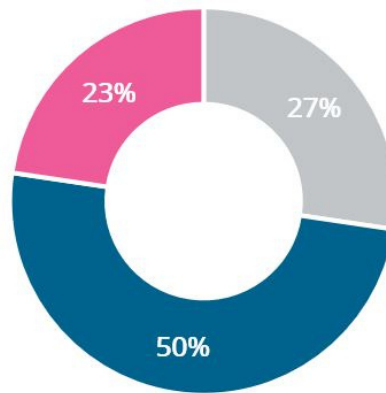
Registry Data

W A Aniridia G R

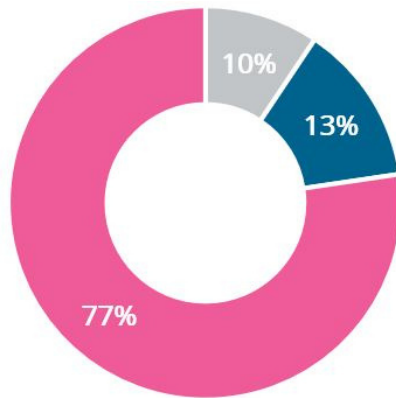
Glaucoma



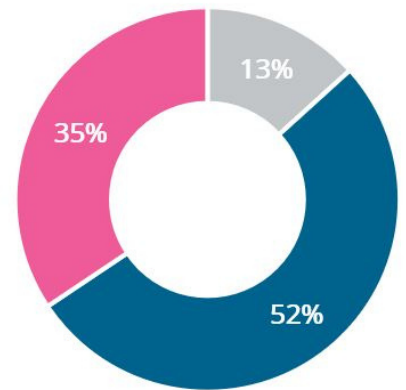
Aniridic Keratopathy



Cataracts



Cataract Removal Surgery



Yes/Has Been a Problem
 No/Never a Problem
 Blank/Unsure

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"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)

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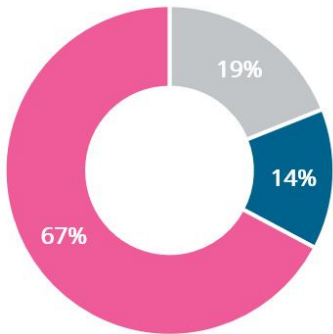
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W A G R

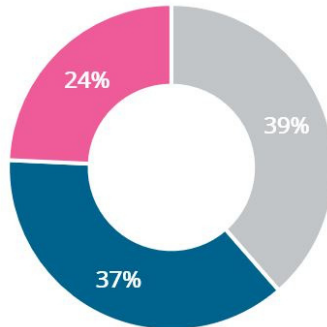
Genitourinary abnormalities

Male Genital Abnormalities



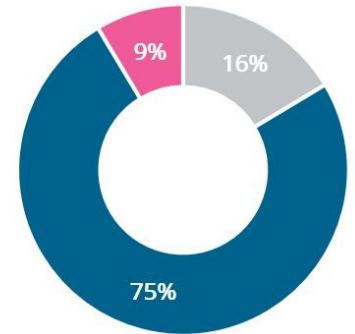
Includes hypospadias, micropenis, and cryptorchidism (undescended testicle)

Female Genital Abnormalities



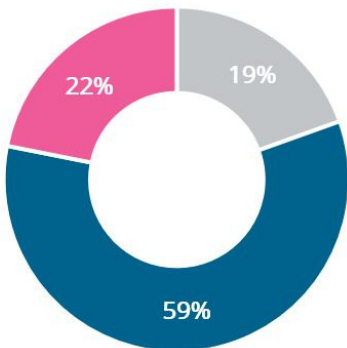
Includes bicornuate/septate/small uterus, double vagina, and streak ovaries

Ambiguous Genitalia



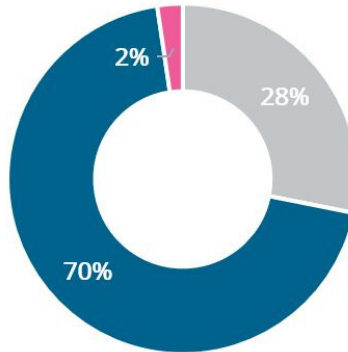
External genitals at birth not clearly male or female

Kidney Conditions



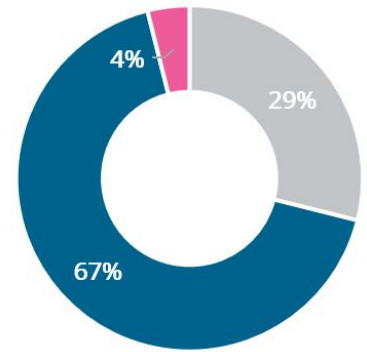
Includes cystic/duplicate/horseshoe/malformed/missing kidney, dilated renal pelvis, and kidney reflux

Urethral Conditions



Includes posterior urethral valves and urethral duplication

Bladder Conditions



Includes bladder diverticulum, bladder extrophy, and small/large bladder

Yes/Has Been a Problem
 No/Never a Problem
 Blank/Unsure

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"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)

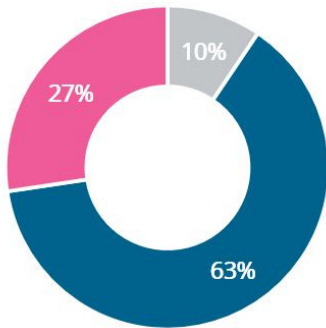
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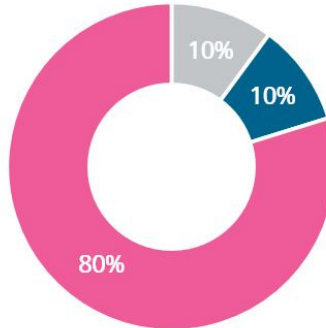
W A G R **Range of developmental delays**

Sensory Integration Disorders



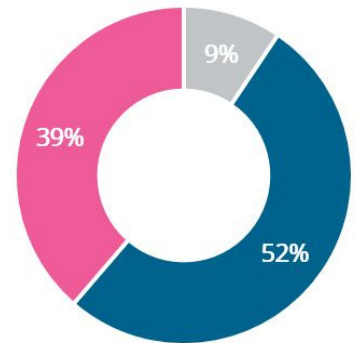
Includes sensory processing and sensory modulation deficit

Cognitive Impairments



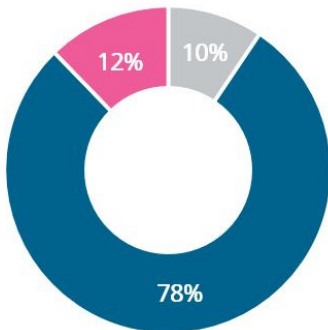
Includes global developmental delay and cognitive impairment

Learning Disabilities



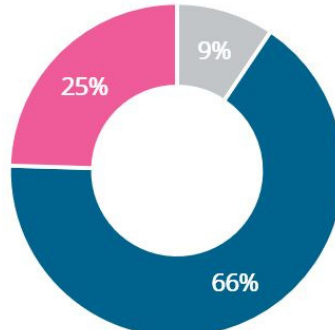
Includes learning disability in math/reading, nonverbal learning disability/Asperger's syndrome

Visual Processing Disorders



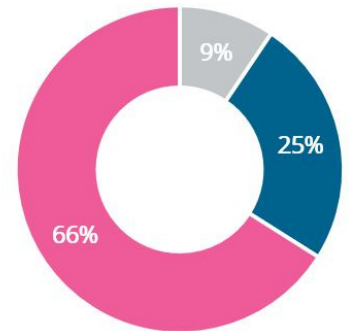
Includes visual-perceptual disorder, and visual motor deficit

Auditory Processing Disorder



Includes language delay, speech delay, and mutism

Language Delays



Yes/Has Been a Problem
 No/Never a Problem
 Blank/Unsure

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"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)

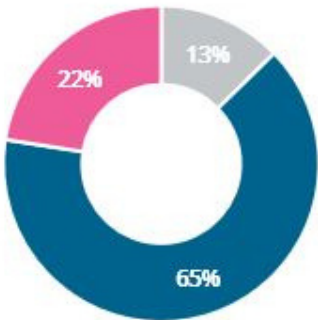
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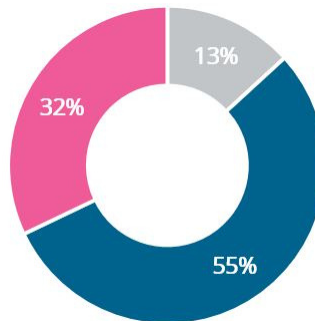
W A G R **Range of developmental delays**

ADD or ADHD



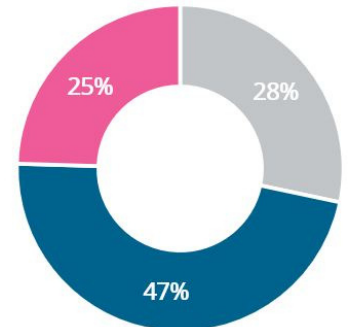
Attention Deficit Disorder (ADD)
Attention Deficit Hyperactivity Disorder (ADHD)

Autism or PDD



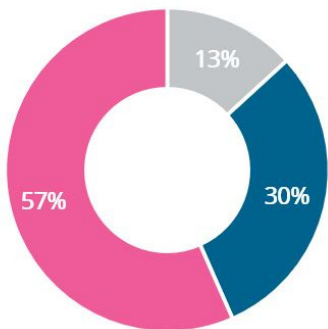
Autism Spectrum Disorder (ASD)
Pervasive Development Disorder (PDD)

OCD

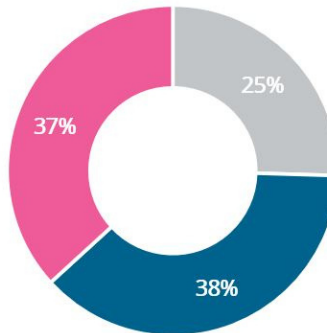


Obsessive Compulsive Disorder (OCD)

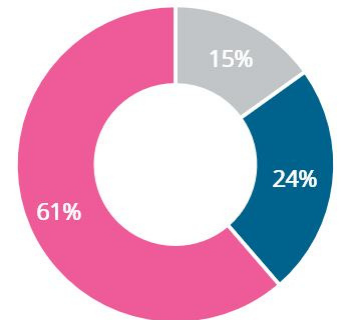
Aggressive Behavior



Anxiety Disorder



Hyperactivity or Impulsivity



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"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