

WAGR Spectrum Patient Registry

A free, secure, online database for people with WAGR spectrum and their families to share important health information

Data from the Registry Helps
Researchers learn more about WAGR
Doctors develop better treatments
Patients with WAGR live longer, healthier lives



Every Patient Counts

Current enrollment includes

- 125 WAGR patients
- 16 countries represented
- 38% male enrollees
- 62% female enrollees

Every Finding Matters

- 47% Wilms tumor **NEW** *lifetime screening is needed*
- 98% Aniridia **NEW** *vision is worse in WAGR*
- **NEW** 76% gastrointestinal problems
- **NEW** 83% report behavioral issues
- **NEW** 20% scoliosis
- **NEW** 38% chronic kidney disease

Your Child's Data Is Needed!

ENROLL in the Registry or UPDATE Now

<https://cords.sanfordresearch.org/activation-form>



wagr.org

WAGR Spectrum Patient Registry

An IRB-approved project of the International WAGR Syndrome Association, the Registry is a secure, online platform hosted by Sanford Research

The database contains patient-reported data on

- birth history
- development
- Wilms tumor diagnosis and treatment
- Aniridia
- vision and eye surgeries
- conditions related to WAGR spectrum and related disorders

Researchers may apply (at no cost) for access to de-identified data, and/or to recruit patients for IRB-approved clinical studies

**Researcher portal access at CoRDS,
<https://research.sanfordhealth.org/rare-disease-registry>**



Results From the WAGR Syndrome Patient Registry: Characterization of WAGR Spectrum and Recommendations for Care Management

<https://www.frontiersin.org/journals/pediatrics/articles/10.3389/fped.2021.733018/full>