

WAGR SYNDROME PATIENT REGISTRY

A POWERFUL TOOL FOR RESEARCH

Registry FAQ

1 How do I enroll in the WAGR Syndrome Patient Registry?

- cordsconnect.sanfordresearch.org
- OR
- To receive a paper version, email reachingout@wagr.org

2 If I have already enrolled, how do I update my information?

- cordsconnect.sanfordresearch.org
- Enter your username and password to access your questionnaire

3 What if I forgot my password or am having technical issues?

- Contact cords@sanfordhealth.org
- OR
- Call CoRDS at 877-658-9192

4 What device can I use to enroll online?

- Computer
- Laptop
- Tablet
- Smartphone

5 What if I am not sure how to answer a question?

- You may answer "unsure" to any question
- For assistance, contact reachingout@wagr.org

6 What does it mean if I give permission to share my information with the IWSA?

- Your permission will allow the IWSA to create educational materials for the patient community
- The IWSA will NOT share personal information

7 Are translation options available?

- If you need translation assistance, reach out to a friend, family member, or coworker for help
- If you need further assistance, contact reachingout@wagr.org

8 Is my data secure?

- The information will be "de-identified" with a unique code, not your/your child's name
- All information is stored on secure servers

9 Where can I find more information about the registry?

- WAGR.org
- OR
- research.sanfordhealth.org/rare-disease-registry