

#### **WAGR SYNDROME PATIENT REGISTRY**

A POWERFUL TOOL FOR RESEARCH

#### **Registry FAQ**



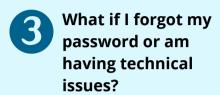
# How do I enroll in the WAGR Syndrome Patient Registry?

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



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

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



• Contact cords@sanfordhealth.org

OR

• Call CoRDS at 877-658-9192



### What device can I use to enroll online?

- Computer
- Laptop
- Tablet
- Smartphone

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

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



# 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



### 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 <u>reachingout@wagr.org</u>



#### Is my data secure?

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



# Where can I find more information about the registry?

WAGR.org

OR

<u>research.sanfordhealth.org/rare-disease-registr</u>y