3 REASONS YOU SHOULD ENROLL IN THE REGISTRY

1. When you indicate in your contact preferences that you would like to learn more about clinical studies, you will be notified via email when you meet the eligibility criteria for a study.

2. As you complete each survey, you can immediately visualize the survey responses. This allows you to compare your responses with the greater PWS community.

3. Keep your medical records in one place! When you complete registry surveys, your responses will be available to you in the future so that your data is quickly at your fingertips.

THE GLOBAL PRADER-WILLI REGISTRY WILL:

- Generate new insights into PWS
- Drive unmet research and treatments
- Expedite the completion of clinical trials
- Guide improved standards of care
- Improve the lives of those affected by PWS

Visit the Registry Today!
www.pwsregistry.org

Need help getting started?
email info@pwsregistry.org
**REGISTRY DEMOGRAPHICS (2021)**

- **1,846** total enrolled
- **8,582** newly completed surveys*
  - **208** new participants* in the past 12 months

- **29%** of registry participants have also participated in a research study or clinical trial.

**PARTICIPANTS BY COUNTRY**

- **63** countries represented
  - **73%**
  - **9%**
  - **3%**
  - **3%**

**CURRENT AGE OF PARTICIPANT**

- Current age distribution of participants:
  - 0-2 years: 200
  - 3-5 years: 400
  - 6-10 years: 500
  - 11-17 years: 400
  - 18-30 years: 300
  - 31-45 years: 100
  - >45 years: 100

**GENETIC SUBTYPE OF PARTICIPANTS**

- **DELETION**: 56%
- **UPD**: 39%
- **ID**: 3%
- **OTHER**: 2%

11% of registry participants do not know their genetic subtype.

**FOR REFERENCE:**

WWW.ENTREPRISESCANADA.CA

**FOR REFERENCE:**

WWW.PWSREGISTRY.ORG

**91%** of registry participants have used GH

**WWW.PWSREGISTRY.ORG**

**91%** of registry participants have used GH

**WWW.PWSREGISTRY.ORG**

- More than **75%** of registry participants have required a feeding tube in infancy

- **48%** of registry participants ages 10 and up report anxiety

- **46%** of registry participants over the age of 2 report having spinal deformity

- **14%** of registry participants have been diagnosed with hip dysplasia

- **20%** of registry participants report thyroid issues

**WWW.PWSREGISTRY.ORG**