



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

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.

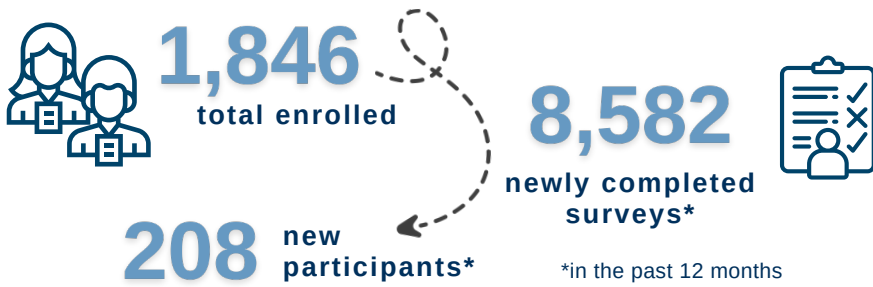
Visit the Registry Today!
www.pwsregistry.org

Need help getting started?
email info@pwsregistry.org

REGISTRY DEMOGRAPHICS (2021)



GLOBAL
PRADER-WILLI SYNDROME
REGISTRY



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

PARTICIPANTS BY COUNTRY



63
countries
represented



73%



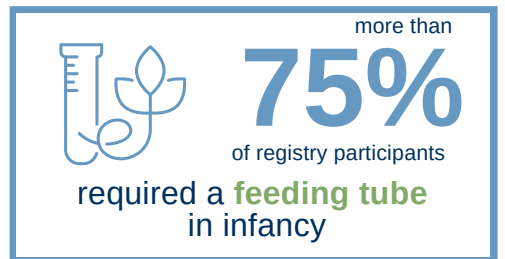
9%



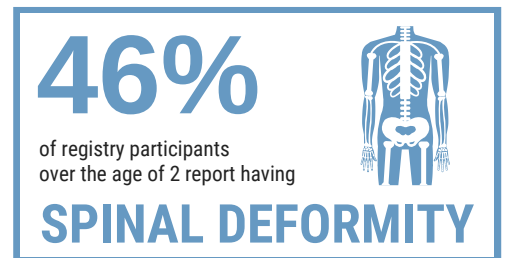
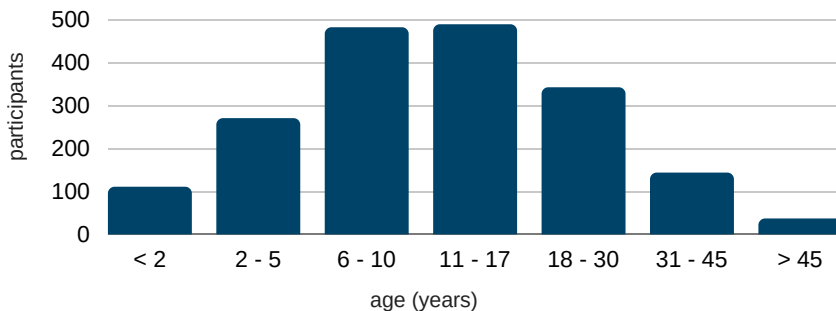
3%



3%



CURRENT AGE OF PARTICIPANT



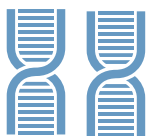
GENETIC SUBTYPE OF PARTICIPANTS

DELETION



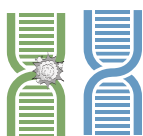
56%

UPD



39%

ID



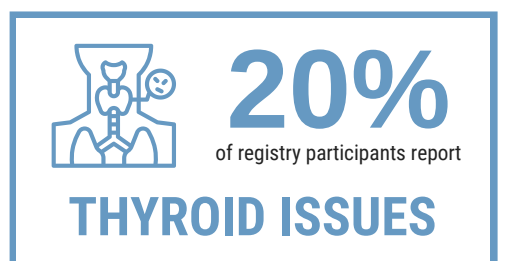
3%

OTHER



2%

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



WWW.PWSREGISTRY.ORG