

We need your help to advance research and insights into PWS

YOU CAN PAVE THE WAY

“While we understand more than ever before, it is critical that we continue to build on the body of knowledge to improve care and explore new treatment options. Study participation contributes to the actionable information available to our community.”

- Theresa Strong, Ph.D., Director of Research Programs, FPWR, and lead PATH for PWS study investigator

Learn more about the PATH for PWS study and how to enroll at www.PATHforPWS.com or contact info@PATHforPWS.com



In collaboration with:



PATH for PWS

Paving the way for Advances in Treatments & Health for PWS

PATH for PWS is a non-interventional, observational study to advance the understanding of serious medical events in PWS.

You can pave the way for advances in treatment

PATH for PWS is a study to help us better understand serious medical events in PWS over a 4-year period, as well as evaluate how PWS related behaviors change over time. The data from this study is intended to inform the development and clinical trial design of potential new treatments.

There is no therapy provided as part of this study. Data will be collected through internet-based surveys.
NO CLINIC VISITS REQUIRED.

Why is the PATH for PWS study so important?

- Helps us understand the medical complications individuals with PWS experience, and what factors increase or decrease risk
- Paves the way for greater understanding of potential new treatments for PWS and informs drug development
- Track the changes of PWS behavior and hyperphagia over time

We hope you will participate!

Enrollment in the study is underway through the Global PWS Registry.



Who can participate?

To be eligible for the study, an individual with a confirmed PWS diagnosis must:

- Be a child, teenager or adult (ages 5 and up)
- Live in the U.S., Canada or Australia
- Be enrolled or willing to enroll in the Global PWS Registry
- Have a caregiver with internet access to enter study data

Is participation in other clinical trials allowed?

YES! Participation in other studies while enrolled in PATH for PWS is permitted.

What is involved in study participation?

Every 6 months, caregivers of those enrolled in PATH for PWS will be asked to update online surveys about medical problems and serious medical events, as well as provide information about conditions and behaviors often associated with PWS such as hyperphagia. Although the time it takes to complete the surveys may vary depending on the participant's medical history, we expect the initial surveys to take approximately 2 to 3 hours while the surveys given every 6 months will take approximately 1 to 2 hours to complete.

Participants will receive a \$100 e-gift card for completing the initial surveys and \$50 e-gift cards for completing the surveys every 6 months.

What are the benefits of participation?

- Participate from the comfort of your home - **no doctor visits required**
- See how your answers and experiences compare to other respondents in the PWS community
- Keep all of your medical information in one place for easy future reference

What types of serious medical events should be reported through the PATH for PWS study?

- Required hospitalization or ER visit
- Were considered life-threatening
- Were considered medically significant, such as blood clots, pneumonia, major infections, psychosis, significant self-injury, extreme aggression, suicidal thoughts, seizures, extreme food consumption in a short amount of time, severe edema

Want to help even more? Join our Blood Test Sub-Study.

Some researchers noticed that D-dimer levels, a potential marker of blood clots, are higher in individuals with PWS. In addition to the PATH for PWS study, PATH participants who live in the U.S. will be asked to consider joining an optional sub-study that involves providing a blood sample at a nearby local lab for analysis of D-dimer. Participants will receive an additional \$100 e-gift card after their blood draw is complete. Those who choose not to provide a blood sample for the sub-study remain eligible to participate in the main PATH for PWS study.