The Global PWS Registry is managed by the Foundation for Prader-Willi Research (FPWR) with the mission to support and accelerate PWS research.

Why is the Registry important?

The Global PWS Registry is the next step in PWS research and will advance PWS research faster than ever before.

The Registry will:

- Document the full range of PWS characteristics
- Enable data trend analysis to generate new insights into PWS and identify areas for additional study
- Facilitate partnerships with university researchers and pharmaceutical companies
- Guide the development of standards of care
- Expedite the completion of PWS clinical trials
- Allow participants to store their PWS medical data in one place
- Accelerate solutions for PWS

www.pwsregistry.com

Version 1.0
7Apr2017

We are the Key

Generate new insights into PWS

Drive unmet research and treatments

Expedite the completion of clinical trials

Guide standards of care

Improve the lives of those affected by PWS

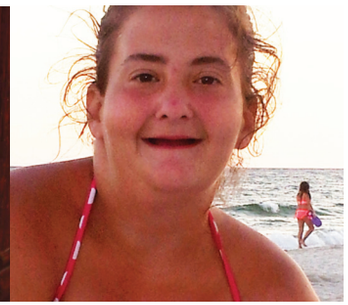
Hummingbird IRB
Approved
04/12/2017

What is the Global PWS Registry?

The purpose of the Global PWS Registry is to enhance the understanding of PWS by describing the full spectrum of PWS characteristics. The Registry will also facilitate the completion of clinical trials and other research studies in the field of PWS.

The Global PWS Registry is a comprehensive and secure database, compliant with health information privacy laws.

The Registry is hosted by the National Organization for Rare Disorders, a nonprofit organization that has served the rare disease community for more than thirty years.



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Your Registry Involvement is Critical!

The power of a patient registry is dependent on community participation. The key to better treatments for PWS lies within YOU!

How do I Participate?

If you have PWS, or if you are the parent or legal guardian of a person with PWS, we invite you to participate in the Global PWS Registry. The Registry is open to all individuals with PWS and can be completed by a parent or guardian, or by the person with PWS, if s/he is able.

The Registry consists of a series of electronic surveys to collect information on developmental history, medical complications, and quality of life. You will be asked to provide details on topics such as as developmental milestones, scoliosis, medications, appetite, behavior and other clinical symptoms.

Go to
www.pwsregistry.org
to get started!

How will my information be used?

Registry participants will be asked to update their data annually. The information you provide will be made anonymous and will be summarized along with data from other registry participants so that those researching PWS can understand common characteristics and what treatments are being used.

Your de-identified data may be shared with individuals or institutions conducting clinical trials or research studies, companies developing potential drugs or other treatments for PWS or to other parties involved with PWS research. Any information that identifies you will be removed. The Global PWS Registry is governed by a board that includes scientists, doctors and parent advocates, which will review and approve research studies.

This Registry will help match participants with potential clinical trials. If your profile matches the needs of an upcoming clinical trial, you will be notified of the opportunity to participate.

Who should I contact if I have questions about participating in the Registry?

Please send inquiries to:
info@pwsregistry.org

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