We invite you to create your account in the Global PWS Registry and add your story. The purpose of the Global PWS Registry is to collect and analyze PWS patient data to enhance the understanding of PWS. The Registry will also help connect registry participants with clinical trials and other research studies for which they may be eligible. If at any time you have questions or need assistance, contact us at info@pwsregistry.org.

The Global PWS Registry is the next step in PWS research and will help advance PWS research and care. 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
- Accelerate solutions for PWS
STEP 1: Create an account

a) Go to the Registry homepage: [https://pwsregistry.org/](https://pwsregistry.org/) and click the “Register” link in green on the right side of the page.

b) You must be a legal adult age 18 or older to create an account in the Registry.

Register

You must be a legal adult (at least 18 years of age, or the age of majority in your state, province, or country) to register.

Please fill out the form until all ☐ symbols turn into a ☑ symbol.

Before we begin, are you a legal adult (at least 18 years of age, or the age of majority in your state, province, or country)? *

- [ ] No
- [ ] Yes
c) This is the name of the person physically filling out the Registry, *most likely a parent/caregiver for the person with PWS.*
For contact preferences, it is important to click all 4 boxes so that you receive all information and reminders coming out of the Registry. We will only contact you with information directly relevant to the Registry. Contact preferences can be changed at any time.

Contact Preferences

Yes, I would like to be contacted about...

☐ Reminders to update my survey responses

☐ Clinical trials I may be eligible for ↑

☐ Potentially donating biospecimen and/or DNA for future research studies ↑↑

☐ Educational information including but not limited to, PWS care, PWS research breakthroughs, and the clinical trial process. This is usually a maximum of 1-2 emails per month.
STEP 2: Add the “Participant”, this is the person with PWS

a) Activate the account by either clicking the link in the confirmation e-mail, or by entering and submitting the confirmation code

Verify Registration

Thank you
A new user account has been created.
A confirmation message has been sent to [Your email].
You must verify receipt of this email before participation in the Global Prader-Willi Syndrome Registry registry.
Activate your account by entering the confirmation code from the welcome e-mail you received. Alternatively, you may click on the link within the e-mail. Please note that using the link will require that you re-enter your username and password.

b) Click “Participant Enrollment”
c) Add a “PARTICIPANT”, this is the name of the **person with PWS**. If you are a parent/caregiver for someone with PWS, you are adding “someone else” as the participant.
**STEP 2 (con’t): Add the “Participant”, this is the person with PWS**

| Your relationship to the participant | —— |
| Participant First Name | —— |
| Participant Middle Name | —— |
| Participant Last Name | —— |
| Participant Birthdate (MM/DD/YYYY) | —— |
| Participant Date of Death (MM/DD/YYYY) (if applicable) | —— |
| Country of Residence | —— |

**Can we contact the participant directly?**

| Preferred Contact Method | —— |
| Preferred Contact Language | —— |

**Email**

| Home Phone | —— |
| Work Phone | —— |
| Mobile Phone | —— |
| Address Line 1 | —— |
| Address Line 2 | —— |
| City | —— |
| State, Province, or Prefecture | —— |
| Postal Code | —— |

Select “No” if you only want Registry information to be sent to the Respondent. Select “Yes” if you want the person with PWS to receive information as well.

The “participant” is the name of the person with PWS.
STEP 2: Grant Consent (You will need to read the consent document and grant consent before filling out surveys)

a) Click “Grant Consent”

b) The informed consent contains important information about the registry to help decide if you would like to take part. If you have any questions about the consent, contact us at info@pwsregistry.org

c) At the bottom, there are (3) places to confirm having read the informed consent and to grant permission
STEP 3: Start Taking Surveys

a) Click “Return to Participant Enrollment”

Consent Email Was Sent Successfully

An email with the Informed Consent document was sent to Your email for participant.
If you do not receive the email, check your spam folder.

Return to Participant Enrollment

b) Click “Take Surveys” – surveys may take a few moments to load

Participant Enrollment

Welcome! You are in good company. There are currently 57 Participants in this registry.

Home / Participant Enrollment

Active Participants

Consent Granted

Participant  Take Surveys  Edit  Manage Consent

Add Self  Add Participant  Start Transfer
c) There are (2) surveys that must be completed first. Click “Take” next to the survey for “Consent for Future use of de-identified data”

![Image of survey page]

There are (2) surveys that must be completed first. Click “Take” next to the survey for “Consent for Future use of de-identified data”

![Image of survey page]

d) This additional consent question asks if your de-identified data within the Registry can be used for future projects that may come up and are not currently detailed in the informed consent. All identifying information such as DOB, name, address, etc… would be removed before the data was used. You can choose yes or no.

![Image of survey page]

This additional consent question asks if your de-identified data within the Registry can be used for future projects that may come up and are not currently detailed in the informed consent. All identifying information such as DOB, name, address, etc… would be removed before the data was used. You can choose yes or no.
e) Complete and submit the survey by clicking “I’m Finished” in the **bottom right hand corner**.

f) Confirm survey submission by clicking “Yes, I’m Finished”.

Confirm Survey Submission

Are you sure you are finished and want to submit your survey?

- [ ] No, Return to Survey
- [ ] Yes, I’m Finished
g) Click “Take More Surveys”

h) Click “Take” next to the survey for “Getting Started”

i) Complete and submit the Getting started survey by clicking “I’m Finished” in the bottom right hand corner. Surveys can also be saved as drafts and completed at a later time.
j)  **Confirm survey submission by clicking “Yes, I’m Finished”**

Confirm Survey Submission

Are you sure you are finished and want to submit your survey?

- No, Return to Survey
- Yes, I’m Finished

k)  **Click “Take More Surveys”**
STEP 4: Complete all surveys (to log back into the account at a later time, see pg 18-19)

a) In the account, the tab for “Initial Surveys” is the list of all surveys not yet taken. Click “take” next to the name of a survey to access that survey

b) Click “take” to access each survey
c) Complete the survey and submit by clicking “I’m Finished” in the *bottom right hand corner*. Surveys can be saved as drafts and completed at a later time.

d) Click “Yes, I’m Finished” to confirm survey submission.
*BONUS* STEP 5: Visualize results to see how your answers compare to the rest of the community

a) In the Participant’s account, click the tab for “Graph Results”. Note that this is only available for surveys that have been completed.

b) Click “Graph Results”

Graph Results
You have completed these surveys and may now view your answers by clicking on the View button next to the survey title. Visually compare your answers against those of other participants by clicking on the Graphed Results button.
Sample Figure of Visualized Data

What subtype of PWS does the participant have? (Responses: 340)

- Deletion: 177
- UPD (uniparental disomy): 125
- ID (Imprinting defect): 23
- Translocation
- Other
- Don't know
LOGGING BACK INTO YOUR ACCOUNT IN THE FUTURE

a) Go to the Registry homepage: https://pwsregistry.org/

b) Click the “Log In” link in the top right corner of the page

c) Your “Username” is an e-mail address

If you don’t remember the e-mail address used, contact us at info@pwsregistry.org. If you don’t remember your password, click the reset link.
STEP 2: Access surveys

a) The name of the person with PWS should be listed as an Active Participant. If this is NOT correct, click ‘Edit’ to correct the information, or contact us at info@pwsregistry.org

b) Click “Take Surveys”
Thank you!

Your participation in the Global PWS Registry is vital to accelerating PWS research!

Please contact us at info@pwsregistry.org with any questions