GLOBAL PRADER-WILLI SYNDROME REGISTRY

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/ and click the "Register" link in green on the right side of the page**
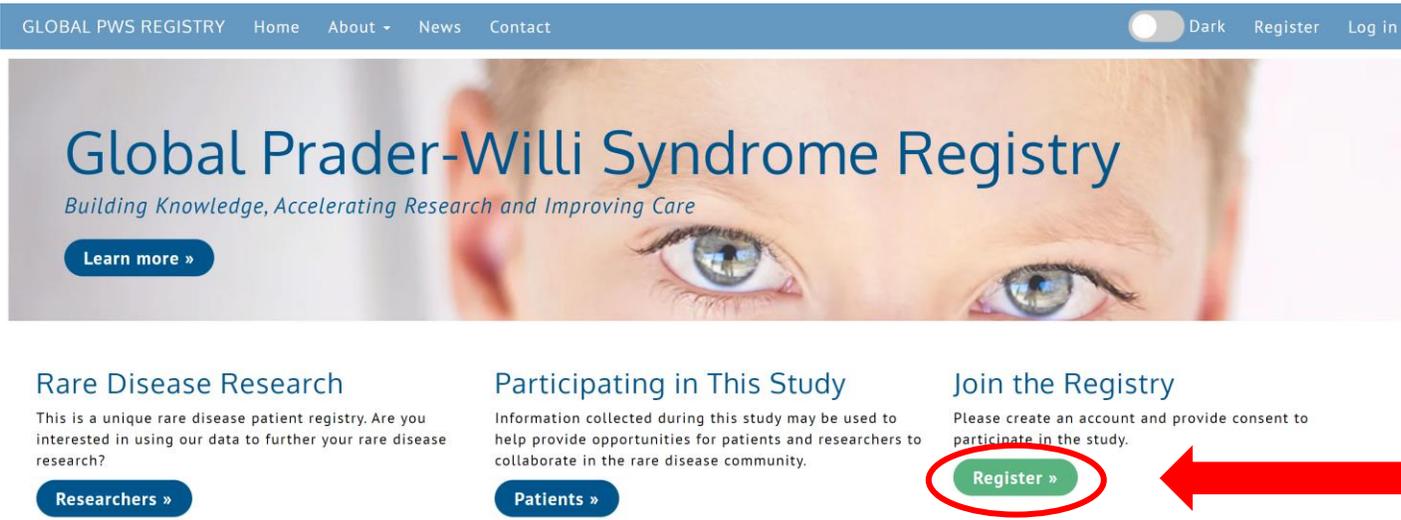
b) **You must be a legal adult age 18 or older to create an account in the Registry.**

c) This is the name of the person physically filling out the Registry, _most likely a parent/caregiver for the person with PWS_.

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.

🏠 Home / 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)? * Yes ✅

Enter your information here

First Name * [   ] ℹ

Middle Name [   ]

Last Name * [   ] ℹ

Country of Residence * [--- ▾] ℹ

Username (Email Address) * [   ] ℹ

Confirm Username * [   ] ℹ

A password must be at least 8 characters long: ℹ
- contain 1 uppercase letter ℹ
- contain 1 lowercase letter ℹ
- contain 1 digit ℹ
- contain 1 special character ℹ
- not contain text from top 1000 commonly used passwords ℹ

Password * [   ] ℹ

Confirm Password * [   ] ℹ

Additional Contact Information (Optional)

Home Phone [   ]

Work Phone [   ]

Mobile Phone [   ]

d) 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

🏠 Home / 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.

Confirmation Code [   ] [Submit]

b) **Click "Participant Enrollment"**

Account Validation Successful

🏠 Home / Account Validation Successful

Your account was successfully validated - Thank you.

[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**

Participant Enrollment

Welcome! You are in good company. There are currently **18** Participants in this registry.

🏠 Home / Participant Enrollment

I have a rare disease diagnosis and would like to answer surveys on my experience.

[Add Yourself as a Participant]

I am a parent or other legally authorized representative of a person with a rare condition and I would like to answer surveys on their behalf.

[Add Someone Else as a Participant] ⬅ Click here to add the name of your loved one with PWS.

STEP 2 (con't): Add the "Participant", this is the person with PWS

Add a New Survey Participant

If you are adding someone other than yourself as a participant in the registry, please ensure you are legally able to do so as the caregiver, guardian, or legally authorized representative.

Your relationship to the participant * `---`

Participant First Name *   ⬅ Name of person with PWS

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? ◉ Yes ○ No

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

Add Participant   Cancel

The "participant" is the name of the person _with_ PWS

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.

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**

Participant Enrollment

Welcome! You are in good company. There are currently **2105** Participants in this registry.

🏠 Home / Participant Enrollment

Active Participants

Name	Consents Granted Global PWS Registry	Actions
Participant	No	Grant Consent To Take Surveys Edit Delete

👤 Add Self   ➕ Add Participant   ⇄ Start Transfer

Click to complete Consent

c) **At the bottom, there are (3) places to confirm having read the informed consent and to grant permission**

Authorization

I have read this Consent and Authorization Form to donate data for future research purposes and have decided to donate the Study Participant's data to the Global Prader-Willi Syndrome Registry. The general purposes of registry participation, details of my and the Study Participant's involvement and possible hazards and inconveniences have been explained to my satisfaction. I understand that I will receive an electronic copy of this consent/authorization form.

Do you confirm that you have read the Informed Consent Agreement? ☐

I give permission on behalf of the Study Participant to provide research data to the Global Prader-Willi Syndrome Registry only for the purposes described above.   ○ Yes ○ No

💾 I Agree with the Terms of Consent   Cancel without Agreeing to the Terms of Consent

Version 2.0
1 August 2021

STEP 3: Start Taking Surveys

a) **Click "Return to Participant Enrollment"**

Consent Email Was Sent Successfully

🏠 Home / 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

Version 2.0
1 August 2021

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"**
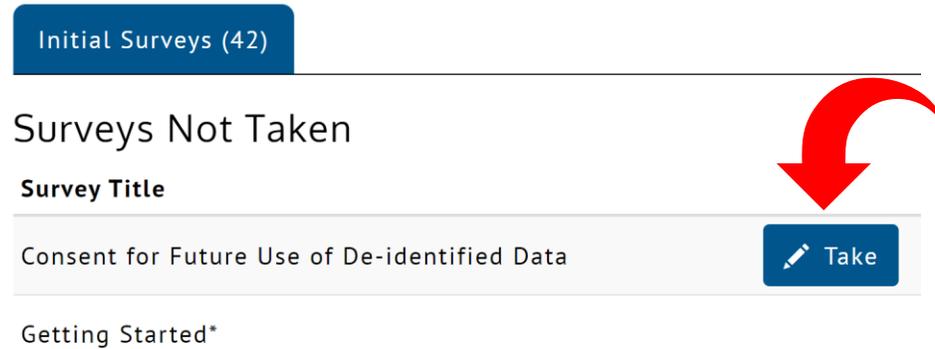
Initial Surveys (42)

Surveys Not Taken

Survey Title

Consent for Future Use of De-identified Data   ✏ Take

Getting Started*

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.**
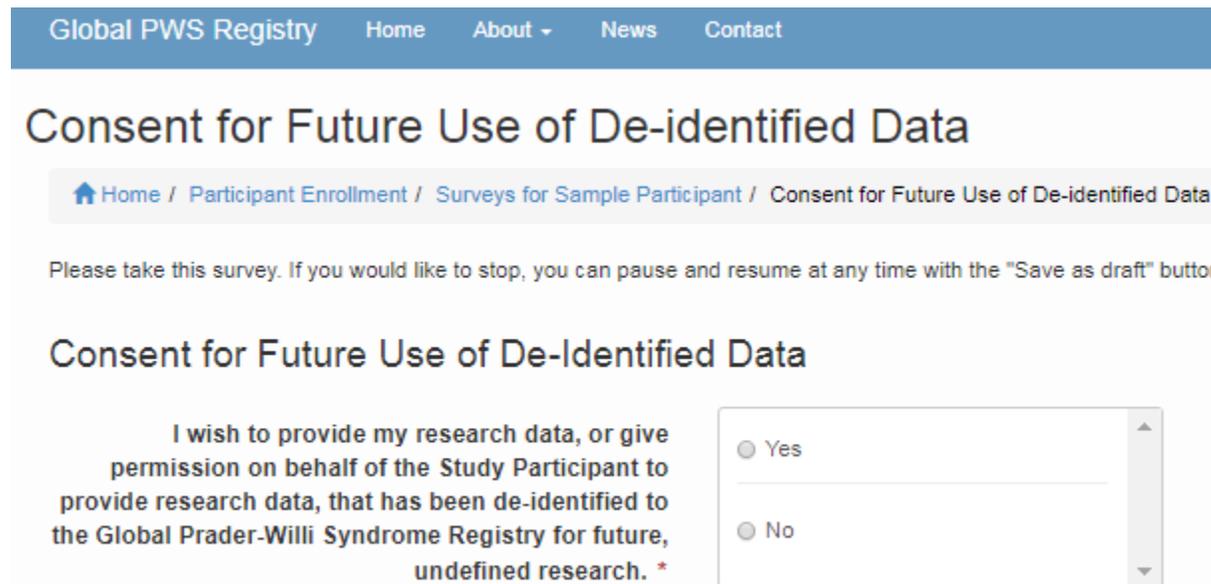
Global PWS Registry   Home   About ▾   News   Contact

Consent for Future Use of De-identified Data

🏠 Home / Participant Enrollment / Surveys for Sample Participant / Consent for Future Use of De-identified Data

Please take this survey. If you would like to stop, you can pause and resume at any time with the "Save as draft" button.

Consent for Future Use of De-Identified Data

I wish to provide my research data, or give permission on behalf of the Study Participant to provide research data, that has been de-identified to the Global Prader-Willi Syndrome Registry for future, undefined research. *

○ Yes

○ No

e) Complete and submit the survey by clicking "I'm Finished" in the _bottom right hand corner_
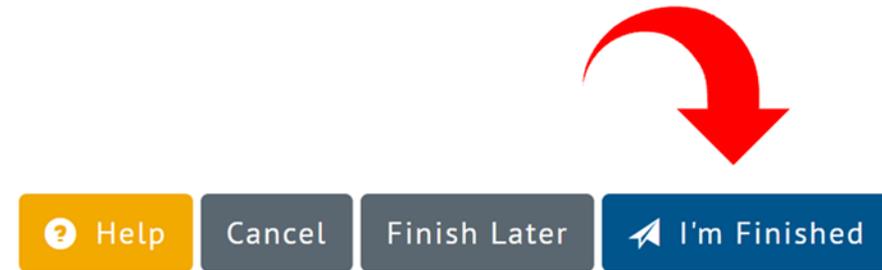
| ❷ Help | Cancel | Finish Later | ◀ I'm Finished |

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"**

GLOBAL PWS REGISTRY   Home   About ⌄   News   Contact

Getting Started

🏠 Home / Participants / Visualization of Getting Started

❓ Using this page

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**
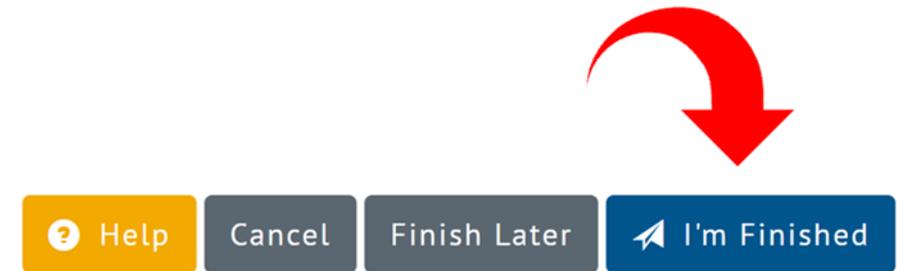
d) **Click "Yes, I'm Finished" to confirm survey submission**

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**

Initial Surveys (42)	Results (2)	Updatable (3)	Graph Results (2)	Surveys to Retake (1)

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.

Survey Title		Survey Version Date	Submitted Date	Updated Date	
Getting Started	👁 View	September 18, 2017	March 26, 2020	Never	📊 Graph Results
Consent for Future Use of De-identified Data	👁 View	April 26, 2017	November 6, 2018	Never	📊 Graph Results

Sample Figure of Visualized Data

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

125

23

177

Deletion ☐ UPD (uniparental disomy) ☐ ID (imprinting defect) ☐ Translocation ☐ Other ☐ Don't know
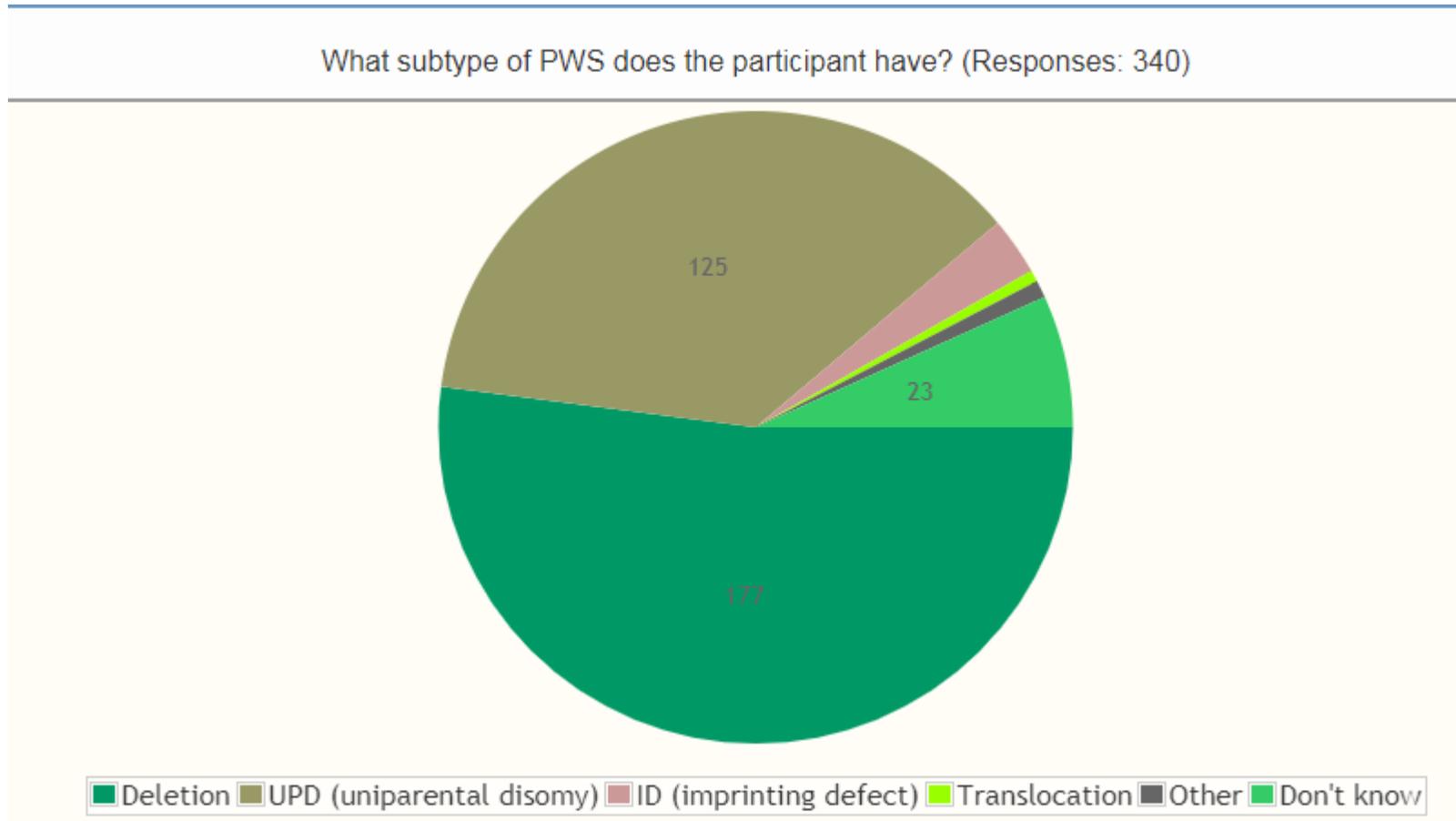
LOGGING BACK INTO YOUR ACCOUNT IN THE FUTURE

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

GLOBAL PWS REGISTRY   Home   About ▾   News   Contact   ⬤ Dark   Register   Log in

Global Prader-Willi Syndrome Registry

Building Knowledge, Accelerating Research and Improving Care

Learn more »

Rare Disease Research
This is a unique rare disease patient registry. Are you interested in using our data to further your rare disease research?

Researchers »

Participating in This Study
Information collected during this study may be used to help provide opportunities for patients and researchers to collaborate in the rare disease community.

Patients »

Join the Registry
Please create an account and provide consent to participate in the study.

Register »

b) **Click the "Log In" link in the top right corner of the page**

c) **Your "Username" is an e-mail address**

Log In

🏠 Home / Log In

Username * [   ]

Password * [   ]

☐ Remember me?

[Log in]

Register if you don't have an account.

Forgot your password? Click here to reset your password.

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