We invite you to login to your account in the Global PWS Registry and update the answers to surveys. Some symptoms may have improved, new milestones may have been reached, and there may be new challenges. Many things can change including medications, therapies, and schooling. Capturing each individual's story of PWS contributes to the power of the data in the Registry.

Using the instruction below, you will be able to login, view your previous answers to surveys, and make any changes or updates!

Please contact us at info@pwsregistry.org with any questions or concerns.
STEP 1: Login to your account

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) After login, 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”
STEP 3: Update previously completed surveys

a) Surveys are divided into categories
   - “Initial surveys” = have not been completed
   - “Results” = where you can view the information entered in survey retakes
   - “Updatable” = have been completed and can be updated with new information
   - “Graph results” = shows aggregate data from the community for any surveys you have completed
   - “Surveys to Retake” = surveys that can be retaken every 6 months, starting from scratch

b) Click the “Updatable” tab to see a list of surveys available for update. Click “edit” next to the name of survey to be updated. The submitted date shows when the survey was last updated.
c) The survey will load with all of the prior answers. Make changes, add new information, and when complete, submit the updated survey, by clicking “I’m Finished” in the bottom right-hand corner even if no changes were made.

d) Confirm survey submission by clicking “Yes, I’m Finished”
STEP 4: Complete survey retakes

a) “Surveys to Retake” are surveys that are scheduled to be taken from scratch every 6 months. You can view the responses of previously completed surveys from this category in the “Results” tab.

b) Click the “Surveys to Retake” tab to see a list of surveys available for retake. Click “Retake” next to the name of the survey due for retake. The “Next Follow-Up” column shows the date when the survey will be available for retake.

<table>
<thead>
<tr>
<th>Survey Title</th>
<th>Last Taken Version Date</th>
<th>First Taken</th>
<th>Last Taken</th>
<th>Next Follow-Up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hyperphagia and Food Behavior</td>
<td>March 9, 2020</td>
<td>March 26, 2020</td>
<td>August 25, 2020</td>
<td>August 26, 2020</td>
</tr>
</tbody>
</table>
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 by clicking “Finish Later”.

d) Confirm survey submission by clicking “Yes, I’m Finished”
*BONUS* STEP 5: Complete any surveys not yet taken

a) From Step 3a, click the tab for “Initial Surveys” to see a list of surveys not yet taken.

![Initial Surveys (42)](image)

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

b) Click the blue “Take” button to access each survey

<table>
<thead>
<tr>
<th>Survey Title</th>
<th>Take</th>
</tr>
</thead>
<tbody>
<tr>
<td>Food Safe Zone</td>
<td></td>
</tr>
<tr>
<td>Pregnancy History</td>
<td></td>
</tr>
<tr>
<td>Biological Family History</td>
<td></td>
</tr>
</tbody>
</table>
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 by clicking “Finish Later”.

![Survey Submission Options]

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d) Confirm survey submission by clicking “Yes, I’m finished”.

![Confirm Survey Submission]

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1 August 2021
*BONUS* STEP 6: Visualize results to see how your answers compare to the rest of the community

a) From Step 3a, click the tab for “Graph Results”. Note that this is only available for surveys that have been completed

<table>
<thead>
<tr>
<th>Survey Title</th>
<th>Sub-Study</th>
<th>Survey Version Date</th>
<th>Submitted Date</th>
<th>Updated Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consent for Future Use of De-identified Data</td>
<td>View</td>
<td>June 6, 2017</td>
<td>May 4, 2021</td>
<td>May 4, 2021</td>
</tr>
<tr>
<td>Getting started</td>
<td>View</td>
<td>May 1, 2015</td>
<td>May 4, 2021</td>
<td>May 4, 2021</td>
</tr>
<tr>
<td>Contact information</td>
<td>View</td>
<td>May 1, 2015</td>
<td>May 4, 2021</td>
<td>May 4, 2021</td>
</tr>
</tbody>
</table>

b) Click “Graph Results”
Sample Figure of Visualized Data

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

Deletion □ UPD (uniparental disomy) □ ID (imprinting defect) □ Translocation □ Other □ Don't know
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