

REGISTRATION IS AT THE BOTTOM OF THIS PAGE

STEPS TO THE ENROLLMENT PROCESS

For the Global PWS Registry, the "participant" is the person with PWS, and the "reporter/respondent" is the person answering questions, often a parent or other legal guardian. There are a couple of steps to complete before entering information about the person with PWS (the "participant").

1. Create an account - After reviewing the Terms and Conditions, create an account with the name and information of the "reporter/respondent".
2. Once an account is created, there will be the opportunity to "add a participant". This is the name and information for the person with PWS. Review the "Informed Consent" which includes detailed information about the registry, and how data will be collected/used. Please note that if the person with PWS is over the age of 14, the registry will also ask for an "assent". This is a statement that indicates that the person with PWS is aware of and agrees to have his/her information added to the Registry. The "reporter/respondent" is responsible for asking the participant for assent and providing the electronic signature.
3. Complete the "Getting Started Survey" - this first survey will ask age and sex of the individual with PWS, and these answers will guide some of the questions throughout the other surveys.

Thank you for contributing to this important resource. If at any point you have any questions on this information or how to complete it, please contact us at info@pwsregistry.org

The Global Prader-Willi Syndrome Registry ("PWS Registry") is a project of the Foundation for Prader-Willi Research (FPWR) to collect patient information and medical information concerning Prader-Willi Syndrome (PWS) in order to better understand the full spectrum of PWS characteristics, to expedite the completion of clinical trials, and to determine areas of needed research and treatments to improve the lives of those affected by PWS.

TERMS AND CONDITIONS

GLOBAL PRADER-WILLI SYNDROME REGISTRY REGISTRY ON THE NORD NATURAL HISTORY PLATFORM

PLEASE READ THE FOLLOWING INFORMATION CAREFULLY. IN UTILIZING THIS SERVICE, YOU REPRESENT THAT YOU ARE AT LEAST EIGHTEEN (18) YEARS OF AGE, OR HAVE THE EXPRESS LEGAL AUTHORITY TO ACT ON BEHALF OF A MINOR, AND YOU ACKNOWLEDGE THAT YOU UNDERSTAND AND ACCEPT THE FOLLOWING TERMS AND CONDITIONS. IN COMPLIANCE WITH THE CHILDREN'S ONLINE PRIVACY PROTECTION ACT, YOU MUST BE EIGHTEEN (18) YEARS OF AGE OR OLDER TO SUBMIT PERSONAL MEDICAL DATA AND INFORMATION. IF YOU DO NOT ACCEPT THESE TERMS AND CONDITIONS, YOU MAY NOT ACCESS THIS SITE OR UTILIZE ANY OF THE SERVICES PROVIDED ON OR THROUGH THIS SITE.

The Global Prader-Willi Syndrome Registry Registry ("Global PWS Registry Registry") is a project of the Foundation for Prader-Willi Research (FPWR) organization to collect patient information and medical information concerning rare diseases in order to accelerate research and find better treatments and ultimately a cure for these conditions.

1. General, Purpose, and Acceptance of Terms and Conditions

a. General. Use of the Global PWS Registry Registry website (the "Website") and the services associated with the Global PWS Registry Registry website (the "Services") is governed by the following terms and conditions herein (the "Terms and Conditions") and the NORD Natural History Study Platform Service and Use Agreement ("Agreement") to which FPWR is a signatory. All pages within the Website are owned by the National Organization for Rare Disorders, Inc. ("NORD") and FPWR owns and retains ownership of all data submitted to the Global PWS Registry Registry.

b. Purpose. The purpose of the Website is to allow individuals, families, and medical and research providers to enter certain information to the Global PWS Registry Registry. The voluntary information provided by the registrant, during registration, is maintained in a secured database and identifiable data will not be shared outside FPWR without the registrant's express consent. However, FPWR may allow researchers and other approved third parties to search and access *de-identified* information.

c. Acceptance of Terms and Conditions. By using the Website, you represent that you accept and agree that you have read all of the Terms and Conditions, and been informed of the Agreement, and that you agree to accept these terms. If you do not agree to be bound by the Terms and Conditions and the Agreement, you may not submit data to the Website.

2. Intellectual Property Rights and Ownership

FPWR owns and retains ownership of all personal data submitted to this Website, including: all personal, identifiable data and metadata collected through the Registry, and all Intellectual Property Rights thereto, except for NORD's rights to de-identified data. NORD owns and retains ownership of all Intellectual Property Rights in the NHS Platform, including the core data set, and any and all material that would enable the NORD NHS Platform to be reproduced, recreated or recompiled, including the standard program templates. Unless noted otherwise in the Agreement, FPWR and NORD retain right, title and interest to all of each of their own Intellectual Property.

3. Use of the Website

a. Legal Capacity. You may use the Website to register to be included in the Global PWS Registry Registry, if you are at least eighteen (18) years old or older or possess legal parental or guardian consent; that you are fully able and competent to enter into the terms and conditions set forth in these Terms and Conditions and are otherwise capable of forming legally binding agreements under applicable law; and that you agree to be bound by these Terms and Conditions. If you are not competent to form legally binding agreements, do not use this Website.

b. True, accurate and complete information. If you register to use the Website, you agree to provide true, accurate, and complete registration information.

c. Lawful Use. By accepting these terms and conditions, you agree to refrain from prohibited conduct, defined here as any conduct that is: i) abusive, harassing, or otherwise harmful to the Global PWS Registry Registry, FPWR, or any other party or property; (ii) that violates or tries to violate another party's right to privacy or; (iii) that seeks to disrupt the use or operation of this Platform. You also agree that: i) you will not submit data that you now or believe to be is false, fraudulent, inaccurate or misleading; ii) that you will not knowingly submit data from a computer that you know or believe may contain any viruses, Trojan horses, worms, time bombs, spiders, or other computer programming routines that may damage, detrimentally interfere with, surreptitiously intercept or expropriate any system, data or personal information. In addition, you will not use the Platform to make any defamatory, libelous or threatening statements or knowingly use it to generate any spam.

d. Website for Allowable Activities (defined herein) only. The Website is for the use of registered and authorized users only. The Agreement terms control the use of all data within the Website.

e. No Unauthorized Use. You may not attempt to gain unauthorized access to this Website or any services, other accounts, computer systems, or networks connected to any server or to any of the Services, through hacking, password mining, or any other means.

4. User Conduct and Responsibility

a. Security. You are solely responsible for the security of your password and your account, and are fully responsible for all activities that occur under your password or account with or without your knowledge. You may not knowingly provide your login and password information to another person. You agree to immediately change your password, and notify the Global PWS Registry Registry Coordinator via email at info@pwsregistry.org of potential unauthorized use of your password or account or any other breach of security. FPWR will not be liable for any loss or damage arising from your failure to comply. Certain portions of the Website and information contained on the Website may be accessible only to authorized registered users or to affiliates, service providers, or other business partners of FPWR, or may otherwise be password restricted. You agree not to (i) gain or attempt to gain unauthorized access to such portions of the Website or to information contained in such sections of the Website; (ii) obtain or attempt to obtain confidential, proprietary, and/or personal information stored on the Website; (iii) distribute passwords to unregistered or unauthorized users; or (iv) make any unauthorized use of the Website or information accessible on the Website. FPWR reserves the right to deny or revoke access to the Services, in whole or in part, if FPWR reasonably believes that you are in breach of these Terms and Conditions, or are otherwise using or accessing the Services in any manner inconsistent with the Terms and Conditions.

b. User Submitted Content. You are solely responsible for and will exercise caution, discretion, common sense and judgment in using and accessing both the Platform and the Website and all content contained therein. Content that is unacceptable, inappropriate or not in compliance with these Terms and Conditions may result in termination of User's access to the Platform and to the Website

You are responsible for any content you post, publish, display, or otherwise transmit to the Website. You agree not to transmit or otherwise make available on the Website any personal information of any other individual or any material protected by copyright, trademark, publicity, privacy, or other proprietary right without the express permission of such individual or the owner of such rights, respectively. The burden of determining that transmission of the information is permissible, or that the material is not protected by such rights, is on you, the user.

You further understand and acknowledge that you may be exposed to information that is inaccurate or otherwise objectionable, and you may report abuses of the Website to the FPWR Registry Coordinator with sufficient detail identifying the abusive conduct or content, so that FPWR may determine, in its sole discretion, whether to take action with respect to such alleged abuse.

c. Cooperation. You agree to cooperate fully with FPWR to investigate any suspected or actual activity that is in breach of these Terms and Conditions.

d. Research Studies The value and relevance of the information provided by the Global PWS Registry Registry is directly linked to the information provided by users. It is your responsibility to provide complete, accurate, and updated information to the Website.

e. Risk of Using the Website. You acknowledge and agree that any uploads or transmission you make to, from, or through these means may be intercepted and used by an unauthorized third party and that all of the risk associated with these activities is solely yours.

f. Links to Other Websites. The Global PWS Registry Registry and NORD NHS Platform may contain links to related websites. The inclusion of any link does not imply endorsement by the Global PWS Registry Registry or by NORD. It is up to you to take precautions to ensure that whatever you select for your use is free of viruses, worms, Trojan horses, and other items of a destructive nature.

6. Disclaimer of Medical Advice

All Website content is for informational only and is not intended to be a substitute for independent professional medical judgment, advice, diagnosis, or treatment. Any questions regarding your health should be directed to your physician or a qualified health provider, and you should neither disregard nor delay seeking medical advice relating to treatment or standard of care because of information featured on or transmitted through the Website.

7. Disclaimer of Warranties

THERE IS NO WARRANTY THAT THE WEBSITE WILL BE UNINTERRUPTED OR ERROR-FREE OR THAT DEFECTS IN THE WEBSITE WILL BE CORRECTED, THAT ANY INFORMATION CONTAINED ON OR TRANSMITTED THROUGH THE WEBSITE IS COMPLETE, ACCURATE OR CURRENT, THAT USER OR OTHER INFORMATION WILL BE COMPLETELY SECURE FROM UNAUTHORIZED ACCESS OR DISCLOSURE, OR THAT ANY INFORMATION IS FREE OF VIRUSES OR OTHER ROGUE PROGRAMMING.

8. Limitation of Liability

NEITHER FPWR NOR NORD SHALL BE LIABLE TO ANY THIRD-PARTY ARISING FROM YOUR INAPPROPRIATE USE OF THE WEBSITE OR PLATFORM, AS SET FORTH IN SECTION 3 AND SECTION 4, ABOVE.

10. Copyright

You agree that content contained on, and the intellectual property by which the Website is produced may not be modified, copied, distributed, framed, republished, downloaded, displayed, or sold in any form or by any means, in whole or in part, without the prior written consent and approval of FPWR or NORD, as applicable, for a particular purpose.

11. Trademarks

The name Foundation for Prader-Willi Research, Global Prader-Willi Syndrome Registry Registry, the Global Prader-Willi Syndrome Registry Registry logo, and other FPWR logos, associated organizations, and names are trademarks of FPWR and associated organizations. You agree not to display or use these trademarks in any manner without FPWR's prior, written permission. The name NORD, NORD Natural History Studies Program ("NHS Program") and Natural History Studies Platform ("NHS Platform") and other related logos are the property of NORD. You agree not to use or display these trademarks in any manner without NORD's prior, written permission.

12. International Users

The Global PWS Registry Registry and NORD make no claims that information on the Website is appropriate or may be downloaded outside of the United States. Access to the Website may not be legal in certain countries or for certain persons. If you access the Website from outside of the United States, you do so voluntarily at your own risk and are responsible for compliance with the laws of your jurisdiction regarding online conduct and acceptable content. User personal information ("Information") that is submitted to this Website will be collected, processed, stored, disclosed, and disposed of in accordance with applicable U.S. law and our Privacy Policy.

13. General Practices Regarding Use and Storage.

You agree that neither the Global PWS Registry Registry nor NORD has any responsibility or liability for the deletion or failure to store any messages and other communications or other Content maintained or transmitted by the Website. You acknowledge that the Global PWS Registry Registry reserves the right to log off accounts that are inactive for an extended period of time. You further acknowledge that the Global PWS Registry Registry reserves the right to modify these general practices and limits from time to time.

14. Confidentiality and Use

You agree that the Agreement governs the collection, use and sharing of personal and non-personal information from you when using the Website. FPWR and/or NORD may disclose, or be required to disclose, certain information if they have a good faith belief that such disclosure is required by applicable law.

15. Termination

You agree that your account and access to the Website or Services may be immediately terminated, with or without cause and without prior notice. Without limiting the foregoing, the following will lead to a termination by the Global PWS Registry Registry of a user's use of the Website or the Services (a) breaches or violations of these Terms and Conditions or Agreement, (b) requests by law enforcement or other government agencies, (c) a request by you (self-initiated account deletions), (d) unexpected technical issues or problems, and (e) extended periods of inactivity. You agree that all terminations shall be made in the Global PWS Registry Registry's sole discretion and that neither the Global PWS Registry Registry nor NORD shall be liable to you or any third-party for any termination of your account or access to the Website or the Services.

16. Communications from Global PWS Registry Registry

From time to time, the Global PWS Registry Registry or other related entities will notify users of updates and other valuable information about the Global PWS Registry Registry, the Website and related clinical and research. By using the Website, or registering or subscribing for services provided on or through the Website, users consent to being contacted by the Global PWS Registry Registry and related entities, and to receiving such updates and information. Users acknowledge and agree that users must always accept email transmissions from the Global PWS Registry Registry, in order, to continue to use the Website or the Services.

17. No Cost to Participate

There is no cost to submit data to the Global PWS Registry Registry. Both registration and use of an account on the Global PWS Registry Registry are free.

18. Governing Law

Any disputes arising out of the use of the Website or the Services or these Terms and Conditions will be governed by the law of the Commonwealth of Massachusetts, regardless of conflict of law principles. Sole and exclusive jurisdiction and venue over any dispute arising out of or relating to these Terms and Conditions shall lie in the appropriate federal or state court in Massachusetts.

19. Statute of Limitations

Any cause of action you may have with respect to use of the Website must be commenced within one (1) year after the claim or cause of action arises.

20. Contacting the Global PWS Registry Registry Coordinator

If you have any medical, research, treatment or patient referral questions, contact the Global PWS Registry Registry Coordinator at: 843-302-6295

If you have questions about the Global PWS Registry Registry, or to report violations of these Terms and Conditions, please email the Registry Coordinator at: info@pwsregistry.org.

REGISTRATION

IAMRARE Registry Platform

