



**Terms, Privacy Notice, and please confirm that you have read the Terms, Privacy Notice and Disclaimers.**

## PWSA | USA ECHO® Program - Participant Registration Information

### PWSA | USA's Privacy and Media Consent Notices

By accepting PWSA | USA's terms and privacy notice, you authorize and grant full permission to Prader-Willi Syndrome Association | USA (PWSA | USA) to collect, use and store personal information, including, without limitation, likeness, image, voice, and/or statements ("the personal information") for posting on the PWSA | USA website or social media pages, to use for printed publications or for other purposes that may convey identity (names may be used unless otherwise specified), diagnosis and other information.

I acknowledge that:

1. I have the authority to grant this authorization and I hereby waive any rights of privacy and other cognizable claims which I may have in connection with the use of the personal information on the PWSA | USA website or social media pages, in printed or other publications, or for other purposes. I understand that this consent is intended to release from liability all personnel of PWSA | USA and is valid unless and until revoked as described below.
2. I understand that the personal information provided to PWSA | USA may reveal sensitive health information about me, including health conditions, diagnosis, and treatment.
3. I understand that any personal information I share with PWSA | USA may be included in various media, including, without limitation, print and digital media, audio and video recordings, photographs, and written statements.
4. I agree that PWSA | USA shall own worldwide copyright and other intellectual property rights in any work product incorporating the personal information. Under this authorization, I assign and transfer to PWSA | USA full worldwide right, title, interest in and ownership of all copyright and other intellectual property rights in such work product without payment of any fees, royalties, or other compensation.
5. I understand that I may revoke this authorization at any time by sending an email to PWSA | USA at [info@pwsausa.org](mailto:info@pwsausa.org), which identifies the information covered by the revocation. Upon receipt of this notice, PWSA | USA will endeavour to stop using this information within a reasonable time after receipt of such notice.
6. I acknowledge that I am signing this authorization voluntarily and that I am not required to sign this authorization as a condition of eligibility to receive any benefits or services from PWSA | USA. I understand that I may refuse to sign this form.
7. If I have any questions about my privacy rights under this authorization, I understand I may contact PWSA | USA by sending an email to: [info@pwsausa.org](mailto:info@pwsausa.org). The terms of this authorization are not linked to any other agreement, nor to the term of any other agreement, and the terms of this authorization will survive until a request for revocation is submitted as described above.

## Project ECHO®

Project ECHO® has been developed and is owned by the Regents of the University of New Mexico ("UNM"), the rights to which have been assigned or licensed to the University of New Mexico Health Sciences Center ("UNMHSC"). More about Project ECHO can be found on the following website: <https://echo.unm.edu/>

## How will my data be used?

Project ECHO® collects registration, participation, questions/answers, chat comments, and poll responses for some ECHO programs. Your individual data will be kept confidential. These data may be used for reports, maps, communications, surveys, quality assurance, evaluation, research, and to inform new initiatives.

## Recordings:

PWSA | USA will record the ECHO® sessions and each participant understands and agrees that his/her image and voice may be recorded as part of the record of the ECHO® session. While the recording will be primarily for internal PWSA | USA use, some parts of the ECHO® sessions may be edited and form part of an ECHO® resource library. The recordings will not be used for commercial purposes. Any participant who for religious or ethical reasons does not wish his/her image to be recorded may switch off the video camera and participate on a voice only basis. Please advise [info@pwsausa.org](mailto:info@pwsausa.org) in advance if you wish to adopt this approach.

## Who, other than PWSA | USA staff has access to my data?

In order for the ECHO Project to report on the ECHO movement, access is granted to a restricted number of UNMHSC staff - the Director of IT, lead iECHO application developer, information security lead, quality assurance lead, data visualization lead, partner liaisons, Director of ECHO Replication, and other members of the ECHO Institute on an as-needed basis.

## Where will my data be stored?

Your anonymised data will be securely stored within the UNMHSC's data center. The data centre is regularly tested for its security, and the UNMHSC is working towards gaining HITRUST certification. Access to your data is strictly limited and password protected. Your data is encrypted whilst transferred to the UNMHSC's data center.

With regard to PWSA | USA, data will be stored as per our Privacy Policy (outlined above).