



D.C. FLY-IN

MAY 13-15, 2024
Washington, D.C.

Application Package

Grant funding provided by



Return via email to: Advocacy@pwsausa.org

Attendees will be chosen on a first-come-first-served basis. Applicants who have not attended PWSA | USA's in-person events will receive priority. Applicants who are active members of PWSA | USA's Advocacy Committee will receive priority. Because this is a grant funded event, it is ESSENTIAL that ALL attendees are actively engaged and participate in ALL areas of the D.C. Fly-In. By completing and signing this application, you agree to participate in ALL event activities. By not participating in all activities, attendees may be disqualified from participating in future PWSA | USA volunteer and/or advocacy events where costs are covered by PWSA | USA.

By signing and submitting the application, you acknowledge that you will be responsible for the cost of your own airfare and also be required to make your own travel arrangements. Furthermore, you acknowledge that PWSA | USA has secured a block of rooms for Fly-In participants at YOTEL Washington DC (415 New Jersey Avenue, NW, Washington D.C., 20001) and PWSA | USA will cover the cost at our selected hotel for up to three nights. Each attendee will be assigned a roommate (you can specify a preferred roommate in your application). If you prefer to have a room to yourself or plan to bring additional family members to stay in your room, there will be a \$150 per night surcharge. Once approved, participants will receive an email with additional registration details.

Preliminary Agenda

Monday, May 13, 2024	Travel Day	
Tuesday, May 14, 2024	11:00AM - 12:30PM	Advocacy Workgroup & Subcommittee meetings
	12:45PM - 1:45PM	Lunch
	2:00PM - 4:00PM	Panel discussion
	6:00PM - 6:30PM	Welcome cocktail reception
	6:30PM - 8:00PM	Welcome dinner
Wednesday, May 15, 2024	TBD	Hill Meetings
	5:00PM - 7:00PM	Cocktail reception Room 2044, Rayburn House Office Building

Please fill out your information below

First Name, Last:
Street Address: City: State: Zip Code:
Primary Phone Number: <input type="checkbox"/> Cell <input type="checkbox"/> Home Email Address:
How long have you been involved with PWSA USA? <input type="checkbox"/> 0-3 Years <input type="checkbox"/> 3-5 Years <input type="checkbox"/> 5-10 Years <input type="checkbox"/> 10-15 Years <input type="checkbox"/> 15+ Years
Please indicate at least one or more areas where you have helped PWSA USA: <input type="checkbox"/> Fundraising <input type="checkbox"/> Parent Mentor <input type="checkbox"/> Advocacy <input type="checkbox"/> Projects <input type="checkbox"/> Administration/Clerical <input type="checkbox"/> Education/Awareness <input type="checkbox"/> Public Relations/Communications/Marketing <input type="checkbox"/> Leadership <input type="checkbox"/> Accounting <input type="checkbox"/> Graphic Design <input type="checkbox"/> Special Events <input type="checkbox"/> Other:
If you are selected to participate in the D.C. Fly-In, what do you hope to achieve? <input type="checkbox"/> How to speak with my elected official <input type="checkbox"/> How to best advocate for my loved one with PWS <input type="checkbox"/> How to create, promote, and complete awareness/advocacy campaigns <input type="checkbox"/> Opportunity to share "my" story Other:

Personal Information

In order to develop tools to empower our diverse rare disease community, we are asking our participants to please select the response that best reflects their race and ethnicity.

What gender best reflects your identity?
Which race or ethnicity best describes you?
Have you or a member of your family ever served on active duty in the US Armed Forces, Military Reserves, or National Guard?
If yes, please indicate branch and level of service.

D.C. Fly-In Hotel Information

Hotel Room Request:

Unless otherwise specified, all rooms will be double occupancy. Single room are subject to a \$150 p/night surcharge, which will be collected at the time of booking. If you have a person with whom you would prefer to share a room with, please insert their name below. Otherwise, a roommate will be assigned to you. If you are bringing family members, you will be required to have a single room and are you are subject to a \$150 p/night surcharge; If applicable, we ask that you advise PWSA | USA in writing below:

Preferred Roommate: _____

I prefer Single Occupancy (*this will include a \$150 p/night surcharge*)

I will be bringing additional family members (please fill out their information below)
(*This will include a \$150 p/night surcharge*)

Child's Name
& Child's Age:

Will they be attending the D.C. Fly-In Dinner? YES NO

Child's Name
& Child's Age:

Will they be attending the D.C. Fly-In Dinner? YES NO

Additional Family Member's
Name & Relationship:

Will they be attending the D.C. Fly-In Dinner? YES NO

Additional Family Member's
Name & Relationship:

Will they be attending the D.C. Fly-In Dinner? YES NO

(*Please also include your family member's dietary restrictions in the next section*)

Dietary Restrictions

(PWSA | USA will make every effort to accommodate dietary restrictions, but cannot guarantee all requests will be granted)

Please indicate any dietary restrictions for yourself below:

- Gluten Free Dairy Free Vegan Vegetarian Keto
- Other:

Please indicate any dietary restrictions for your family members below (if applicable):

Child's Name:

- Gluten Free Dairy Free Vegan Vegetarian Keto
- Other:

Child's Name:

- Gluten Free Dairy Free Vegan Vegetarian Keto
- Other:

Additional Family Member's Name:

- Gluten Free Dairy Free Vegan Vegetarian Keto
- Other:

Additional Family Member's Name:

- Gluten Free Dairy Free Vegan Vegetarian Keto
- Other:

D.C. Fly-In Application Signature

Please be advised that photographs and/or video will be taken at the event for potential publication in print and/or electronic promotional materials. By signing this document, I agree to grant PWSA | USA its designee's, and transferee's the right to use such photographs and videos of you with or without your name for any lawful purposes, for example such purposes as publicity, illustration, advertising, and web content.*

Please read and accept the event Code of Conduct and the event Safety and Liability Waiver. You can find these documents by scrolling to the next page.

*I have read and accept the event Code of Conduct.**

*I have read and accept the event Safety and Liability Waiver.**

I do hereby hold PWSA | USA harmless from any liability, whether civil or criminal, that may arise as a result of attending the D.C. Fly-In. I further hold harmless any individual, agency, business, or corporation that provides information, accommodations, food, and activities to PWSA | USA during the D.C. Fly-In. I do hereby agree to participate in all D.C. Fly-In activities. Furthermore, I understand that not participating in the D.C. Fly-In may disqualify me from participating in future PWSA | USA volunteer events where costs are covered by PWSA | USA.

Signature: _____ **Date:** _____

Thank You! Now one more step...

To save this completed application, click the download button in the upper right corner of your browser screen (as shown below). Once the document is saved to your computer, please email your completed application to advocacy@pwsausa.org.



Code of Conduct for Prader-Willi Syndrome Association (PWSA | USA) Programs and Events

The Prader-Willi Syndrome Association | USA strives to create an environment of inclusion and belonging for all members of the rare disease community. Participants of all PWSA | USA-sponsored programs and events are expected to act respectfully.

Discrimination or harassment based upon race, ethnicity, religion, national origin, sex (including pregnancy, infertility, sex-related medical conditions, and intersex identity), sexual orientation, gender identity, gender expression, marital status, socioeconomic status, disability, age, political affiliation, status as a veteran, personal appearance, or other applicable legally protected characteristics at our events will not be tolerated.

By accepting this code of conduct, you agree to treat all attendees, members, and staff with respect and inclusion. Please inform a PWSA | USA staff member if you are exposed to inappropriate conduct at an in-person or virtual event. Attendees who violate the code of conduct may be asked to leave an event, to refund any travel reimbursement, and/or to avoid attending future PWSA | USA-sponsored events.

COVID-19 SAFETY ACKNOWLEDGEMENT, ASSUMPTION OF RISK, AND RELEASE AND CONSENT

By attending an event held, sponsored, or promoted by the Prader-Willi Syndrome Association (“PWSA | USA”) (an “Activity”), the individual acknowledges and agrees to the terms and conditions set forth in this agreement. This COVID-19 Safety Acknowledgement, Assumption of Risk, and Release and Consent is for both adult participants and parents/guardians of minor participants (under 18 years of age).

1. ASSUMPTION OF RISK: I am aware of the highly contagious nature of bacterial and viral diseases including COVID-19 (collectively, the "Disease") and the risk that I may be exposed to or contract a Disease by engaging in the Activity. I acknowledge that I derive personal satisfaction and benefit by virtue of my participation in the Activity, and I willingly engage in Activity. By signing below, I acknowledge and understand the following:

a. Participation in the Activity includes possible exposure to a Disease. I understand and acknowledge that such exposure or infection may result in illness, personal or psychological injury, pain, suffering, temporary or permanent disability, death, property damage, and/or financial loss.;

b. I acknowledge that this risk may result from or be compounded by the actions, omissions, or negligence of others, including PWSA | USA or PWSA | USA employees.;

c. I understand that PWSA | USA cannot guarantee that I will not become infected with a Disease while engaging in the Activity and that engaging in the Activity may increase my risk of contracting a Disease. I knowingly and freely assume all said risks related to a Disease, even if arising from the negligence or fault of PWSA | USA.; and

d. NOTWITHSTANDING THE RISKS ASSOCIATED WITH THE DISEASE, I ACKNOWLEDGE THAT I AM VOLUNTARILY ENGAGING IN THE ACTIVITY WITH KNOWLEDGE OF THE DANGER INVOLVED. I HEREBY AGREE TO ACCEPT AND ASSUME ALL RISKS OF ILLNESS, PERSONAL OR PSYCHOLOGICAL INJURY, PAIN, SUFFERING, TEMPORARY OR PERMANENT DISABILITY, DEATH, PROPERTY DAMAGE, AND/OR FINANCIAL LOSS RELATED TO THE DISEASE, ARISING THEREFROM, WHETHER CAUSED BY THE ORDINARY NEGLIGENCE OF PWSA | USA OR OTHERWISE.

2. RELEASE AND WAIVER: I HEREBY RELEASE, WAIVE AND FOREVER DISCHARGE ANY AND ALL LIABILITY, CLAIMS, AND DEMANDS OF WHATEVER KIND OR NATURE AGAINST PWSA | USA AND ITS AFFILIATED PARTNERS AND SPONSORS, INCLUDING IN EACH CASE, WITHOUT LIMITATION, THEIR DIRECTORS, OFFICERS, EMPLOYEES, VOLUNTEERS, AND AGENTS (THE “RELEASED PARTIES”), EITHER IN LAW OR IN EQUITY, TO THE FULLEST EXTENT PERMISSIBLE BY LAW, INCLUDING BUT NOT LIMITED TO DAMAGES OR LOSSES CAUSED BY THE NEGLIGENCE, FAULT OR CONDUCT OF ANY KIND ON THE PART OF THE RELEASED PARTIES, INCLUDING BUT NOT LIMITED TO DEATH, BODILY INJURY, ILLNESS, ECONOMIC LOSS OR OUT OF POCKET EXPENSES,

OR LOSS OR DAMAGE TO PROPERTY, WHICH I, MY HEIRS, ASSIGNEES, NEXT OF KIN AND/OR LEGALLY APPOINTED OR DESIGNATED REPRESENTATIVES, MAY HAVE OR WHICH MAY HEREAFTER ACCRUE ON MY BEHALF, WHICH ARISE OR MAY HEREAFTER ARISE FROM MY PARTICIPATION WITH THE ACTIVITY.

3. COVENANT NOT TO SUE: I covenant not to make or bring any claim against the PWSA | USA or any Released Party, and forever release and discharge PWSA | USA and all other Released Parties from liability under such claims. This waiver and release does not extend to claims for gross negligence or any other liabilities that applicable state law does not permit to be released by agreement.

4. REPRESENTATIONS AND COVENANTS REGARDING COVID-19:

a. While participating in an Activity, consistent with CDC guidelines, participants are encouraged to practice hand hygiene, “social distancing” and wear face coverings to reduce the risks of exposure to COVID-19. PWSA | USA will follow the applicable COVID-19 health and safety measures put into effect for the time of the event by federal, state, and local public health and government officials. By engaging in an Activity, you voluntarily agree to follow federal/state/local public health and government guidelines on COVID-19 health and safety. Because COVID-19 is extremely contagious and is spread mainly from person-to-person contact, PWSA | USA has put in place preventative measures to reduce the spread of COVID-19. However, PWSA | USA cannot guarantee that its participants, speakers, volunteers, partners, or others in attendance will not become infected with COVID-19.

b. In light of the ongoing spread of COVID-19, individuals who fall within any of the categories below should not engage in PWSA | USA events and/or other face-to-face activities. By attending an PWSA | USA event, you certify that you do not fall into any of the following categories: i. Individuals who currently or within fourteen (14) days of participating in an PWSA | USA event have experienced any symptoms associated with COVID-19, which include fever, cough, and shortness of breath among others; ii. Individuals who believe that they have been exposed to a suspected or confirmed case of COVID-19 or have been diagnosed with COVID-19 and are not yet cleared as non-contagious by state or local health authorities or the health care team responsible for treatment.

c. Duty To PWSA | USA-Monitor: All participants agree to monitor for signs and/or symptoms of COVID-19 and to contact PWSA | USA at Advocacy@pwsausa.org if they experience symptoms of COVID-19 within fourteen (14) days of participating with PWSA | USA.

5. MEDICAL ACKNOWLEDGEMENT AND RELEASE: As a participant, I acknowledge the potential health risks associated with the Activity. I agree that if I experience any adverse symptoms during the Activity, I will discontinue my participation immediately and seek appropriate medical attention. I DO HEARBY RELEASE AND FOREVER DISCHARGE THE RELEASED PARTIES FROM ANY CLAIM WHATSOEVER WHICH ARISES OR MAY HEREAFTER ARISE ON ACCOUNT OF ANY FIRST AID, TREATMENT, OR SERVICE RENDERED IN CONNECTION WITH MY PARTICIPATION IN THE ACTIVITY.

6. IMAGES/STORIES/CONSENT: I hereby grant to PWSA | USA or its designees, the irrevocable right and permission to photograph, film, record, and otherwise capture my own name, image, voice, statement, photograph, or likeness (collectively, “Recordings”) and use or

sublicense them in any media throughout the world, in perpetuity, including for reproduction, display, or otherwise (e.g. on websites, on social media, in publications, or for informational, educational, promotional, or other purposes), without compensation to me. I agree that PWSA | USA owns its own respective Recordings and all copyrights to them. I waive any inspection or approval rights.

By checking the box in the D.C. Fly-In application, I accept for myself, the additional members of my party, and, if applicable, as the parent/guardian of a minor participant, the terms of this COVID-19 Safety Acknowledgment, Assumption of Risk, and Release and Consent and acknowledge that I am executing this Agreement knowingly, freely, voluntarily, without any inducements, duress, or coercion, intending to be legally bound. I UNDERSTAND THAT I AM VOLUNTARILY GIVING UP SUBSTANTIAL LEGAL RIGHTS, INCLUDING THE RIGHT TO SUE PWSA | USA.