



Request for Prader-Willi Syndrome Research and Mini-Fellowship Grant Applications

The Prader-Willi Syndrome Association USA (PWSA | USA) is a nonprofit organization formed in 1975 to enhance the quality of life of those affected by Prader-Willi Syndrome (PWS) through research, family support, and advocacy. The purpose of this request is to solicit applications for research projects whose findings will directly impact individuals living with PWS and their families.

We are also proud to announce a new initiative to provide mini-fellowship grants to support providers to deepen their knowledge of Prader-Willi Syndrome through clinical proctorships with individuals with expertise in Prader-Willi Syndrome.

The PWSA | USA research priorities are to gather knowledge about PWS, support the application of therapies, and recruit new providers and investigators to the field.

With regards to research topics, a broad range of areas will be considered, from societal and behavioral to biological, particularly in understudied areas such as adult health, quality of life, positive health outcomes, and diverse populations. Support is limited to clinical studies on human subjects and includes retrospective/secondary data analysis and medical informatics.

Types of Awards Available

PWSA | USA will consider three types of funding:

1. Applicants may request up to \$100,000 USD to fund research on Prader-Willi Syndrome. The term of the award is 12 months, with the possibility of a second grant period of 12 months of funding upon competitive renewal.
2. Applicants may choose to request a smaller budget and/or shorter duration. Awards of up to \$10,000 USD may be considered on an individual and rolling basis until August 15, 2024.
3. PWSA | USA will also consider funding a mini-fellowship of up to \$25,000 USD to enable providers currently in practice to shadow providers with expertise in Prader-Willi Syndrome in combination with an academic project. The requirements directly below apply to any mini-fellowship to the extent that they are applicable. Please refer to the mini-fellowship application guidelines* at the end of this document for additional information.

Award Specifics

The total cost of the award includes indirect costs which should not exceed 8%.

Funding will be made directly to each institution according to the submitted budget, which should be proportional to the planned work at each research site. The award supports materials, supplies, professional and/or other services, and salary for key personnel in accordance with National Institutes of Health (NIH) guidelines. NIH guidelines for salary caps will be applied.

Call for Letters of Intent (LOI)



Awardees will be expected to provide a progress report 6 months after receipt of the award, provide a year-end review of activities, and present their findings to the PWSA | USA community via a virtual webinar or via an oral or poster presentation at the 2025 PWSA | USA Medical and Scientific Conference. Additional funding of up to \$2,000 will be provided to support related travel and expenses for the conference.

Special consideration will be given to **new or early-stage investigators to the study of PWS**, which includes, but is not limited to, established investigators in other areas of research who wish to enter the field of PWS research and investigators who have not yet successfully served as a principal investigator (PI) for a substantial PWS grant.

Special consideration will also be given to projects in **understudied research areas and understudied populations** (eg: adults, diverse, under-served, and/or rural populations)

Selection Process

The PWSA | USA Research Committee will review letters of intent (LOIs) to select submissions best aligned with their priorities as described in this request for research applications. Additional reviewers may be used, as needed, to consider technical elements, study design and scientific validity. Authors of a subset of the submitted LOIs will be asked to submit a full proposal. Guidelines for full proposals will be provided at that time.

Timeline

1. Letter of Intent deadline: September 1, 2024, 5pm EST.
2. All applicants will be notified of their status by October 1, 2024. A subset of the LOIs will be asked to submit full grant proposals, no later than November 15, 2024, 5pm EST.
3. Announcement of the award will be made on December 13, 2024. Written critiques will not be provided to unsuccessful applicants.
4. Funding will begin by the end of 2024 (release of funds to awardee is contingent upon IRB approval of the proposal).

Letter of Intent: Submission Content [submitted as a single PDF].

1. Cover page including contact information for each investigator and institution
 - a. The title of the proposal.
 - b. Investigator name, role, position/title
 - c. Institution, and type of institution [Educational Institution, Not-for-Profit Research Center, Other (please describe)]



- d. Contact information: address, email, and phone.
2. Proposal summary [limited to 800 words] including:
 - a. Title of the proposal
 - b. Specific Aims
 - c. Research Plan: brief introduction/background, preliminary data (as applicable), and general methodology.
 - d. Impact: briefly describe the importance of the research to the priority interests of PWSA | USA as described in this RFA.
 - e. Full grant proposals are limited to no more than a five-page research plan and include mention of IRB status (approval, under review, IRB application in preparation).
 - f. Proposed budget (budget rationale should be included within the full grant proposal)
 3. Short NIH Biosketch [limit 2-pages] for the PI and all Co-Investigators (Co-I).

Please indicate if the PI meets criteria for new or early- stage investigator to the study of PWS.

***Guidelines for Mini-Fellowship Grant Applications**

The mini-fellowship grant supports providers who are currently in practice in the United States and who care for patients with Prader-Willi Syndrome to deepen their knowledge of Prader-Willi Syndrome through directed clinical proctorship with clinicians who have expertise in Prader-Willi Syndrome. An academic project is required.

Providers who may apply for a mini-fellowship grant include but are not limited to physicians, nurse practitioners, physician assistants, nurses, physical therapists, occupational therapists, speech therapists, mental health counselors, teachers, behavior specialists, educators.

The length and specifics of the fellowship will be mutually agreed upon between the applicant and the proctor.

The applicant and proctor are expected to formulate an academic project or research study before the fellowship begins. The definition of an academic project is broad and includes but is not limited to case reports, literature reviews, educational presentations, podcasts, patient or caregiver infographics, educational materials for PWSA | USA.

The grant is intended to be used for the following, although other appropriate expenses will be considered as well:

Call for Letters of Intent (LOI)



- expenses related to travel and lodging for the applicant to shadow a provider with expertise in Prader-Willi Syndrome.
- expenses related to hosting a fellow/the applicant on-site
- expenses related to the costs of an academic project, if applicable

Letter of Intent for mini-fellowship grant: Submission Content [submitted as a single PDF].

1. Cover page including the following contact information for both applicant and proctor
 - a. Applicant and Proctor names, roles, positions/titles
 - b. Applicant and Proctor institution names, and types of institution [Educational Institution, Not-for-Profit Research Center, Private Practice, Other (please describe)]
 - c. Applicant and Proctor contact information: address, email, and phone number.
2. Essay (maximum 500 words)
 - a. The applicant will describe their current practice, their motivation to participate in a mini-fellowship about Prader-Willi Syndrome, objectives, and how they will apply knowledge gained from the fellowship to their future practice.
3. Educational Component Description is limited to 1 page and should include:
 - a. Site of proctorship
 - b. Dates of proctorship
 - c. Outline of activities during proctorship
 - d. Supporting letter from the sponsoring proctor
 - e. Supporting letter from sponsoring institution
4. Letter of reference for the applicant from a peer or supervisor
5. Academic Project Proposal

The proposal summary is limited to 800 words and should provide a detailed description of the project, to the extent applicable, including:

 - a. Title of the proposal
 - b. Specific Aims

Call for Letters of Intent (LOI)



- c. Research Plan: brief introduction/background, preliminary data (as applicable), and general methodology.
- d. Impact: briefly describe the importance of the research
- 6. Short C. V. or NIH Biosketch [limit 2-pages] for the applicant and proctor.
- 7. Budget
 - a. detailed budget for the on-site proctorship component
 - b. detailed budget for the academic project/research component

Please submit LOI's to: Stacy Ward at sward@pwsausa.org. If you have questions, please call (941) 312-0400.