

Request for Prader-Willi Syndrome Research 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.

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

Regarding 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. Priority will be given to clinical studies, but we are open to other types of research as well as funding pilot projects and supporting clinical innovations to support individuals with PWS.

Types of Awards Available

PWSA | USA will consider two types of funding:

1. Applicants may request up to \$150,000 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 \$25,000 USD may be considered on an individual and rolling basis.

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.

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 PWSA | USA Clinical 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: August 1, 2025, 5pm EST.
2. All applicants will be notified of their status by September 8, 2025. A subset of the LOIs will be asked to submit full grant proposals, no later than October 17, 2025, 5pm EST.
3. Announcement of the award will be made on November 14, 2025.
4. Funding will begin on January 1, 2026 (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 2 pages] including:
 - a. Title of the proposal
 - b. Specific Aims
 - c. Research Plan: brief introduction/background, preliminary data (as applicable), and general description of experimental methodology and techniques to complete the study aims.
 - 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)
 - h. Provide a 1-3 sentence summary describing the study in layman's terms.

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.

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