

PWSA (USA) 2014 Grant Submission Information & Requirements

Prader-Willi Syndrome Association (USA) ["PWSA (USA)"] is pleased to offer grant assistance for scientific researchers with an interest in improving the lives of those with Prader-Willi syndrome (PWS). PWSA(USA) is seeking to fund projects for a maximum of \$75,000 total per project for a 1-2 year grant support aimed at discovering and developing treatments, cures and technologies benefiting those with Prader-Willi syndrome.

PWSA(USA) is especially interested in supporting research projects that have the potential for immediate and high impact to the PWS community. The research committee has decided that PWSA(USA) will support research-based translational grants or those showing high promise for translating basic biomedical knowledge to clinical application. The goal is to fast-track better treatment for the syndrome.

While PWSA(USA) is open to insightful grant applications in any subject area, the following areas are of particular interest to our constituency at this time. Research in these areas will receive the highest priority:

PWSA (USA) 2014 Research Priorities

- **Obesity** -- Obesity is the number one threat to the life expectancy and quality of life of someone with PWS. The combination of hyperphagia and slow metabolism can result in extraordinary weight gain which imposes extraordinary stress on both the person with the syndrome and their families. **Hyperphagia is the overwhelming problem preventing independent living by anyone with PWS.** Controlling the chronic insatiable feeling of hunger and/or extreme drive to eat and increasing the metabolic rate are issues that are the high priorities for PWSA(USA).
- **Behavioral/psychological issues** --Even if weight is controlled, the impact of complex behavioral and psychological issues is significant for the person with PWS and the entire family. Potential behavioral health interventions are a high priority for PWSA(USA).
- **Respiratory and Gastrointestinal (GI) complications** -- Due to lifelong hypotonia and complications of obesity, individuals with PWS are at-risk for pulmonary and severe gastrointestinal issues. These can be potentially life-threatening and PWSA(USA) believes of high priority.
- **Other complications** --There are other health related complications that are unique to PWS and are potentially life-threatening.

Grant Award Timing:

- GRANT APPLICATION DUE: OCT 7, 2014
- GRANT AWARD: DEC 2014
- FUNDING OF GRANT: As soon as all IRB documents are obtained and completed as well as meeting other requirements.

Proposal Submission:

Applications must be submitted as *a single electronic pdf package* to: Janalee Heinemann, MSW, at jheinemann@pwsausa.org and to Merlin G. Butler, M.D., Ph.D., at mbutler4@kumc.edu. Please send a separate email to confirm that the file has been received. Questions regarding the research topics to be addressed in this request for applications (RFA) or suitability of the proposed project may be addressed via email to either party. One signed hard copy should be mailed to:

Janalee Heinemann, Director of Research & Medical Affairs
The Prader-Willi Syndrome Association (USA)
8588 Potter Park Drive, Suite 500
Sarasota, FL 34238

The face page should be signed, scanned and included in the pdf file. Alternatively, the application can be accompanied by an email from the administrative official authorized to sign for the Institution stating that the grant has been reviewed and approved by the institution's grant administration office.

Maximum Single Grant Allowed: \$75,000

Maximum Length of Grant: 2 years (the grant proportion for the second year is contingent on the timely receipt of the first year's progress report and status at the end of the first year).

GRANT APPLICATIONS SHOULD INCLUDE: THE FOLLOWING ITEMS:

The required font is Arial, 11 point.

1. Face Page

The face page should include the following information:

- * Title of the Project
- * Principal Investigator
- * Principal Investigator's Contact Information:
 - * Institutional Contact Information: Name; Mailing Address; Phone Number; Fax Number; E-mail Address
- * Signatures: The principal investigator should sign

2. Abstract

Technical Abstract - An abstract of not more than 400 words should be provided with an overview of the proposed studies. The abstract should include background, objective/hypothesis, specific aims and study design.

Lay Abstract and Relevance Statement (250 words maximum) - Provide an abstract in non-technical terms for an informed lay person. The goal of this abstract is to communicate the rationale and scientific objectives of the study to the non-scientific community. The potential relevance of the proposed work to the mission of PWSA(USA) should be stated. Explain how the completion of the proposed study will significantly advance our understanding of Prader-Willi syndrome and/or develop a potential new therapeutic approach for the treatment of symptoms associated with PWS.

3. Budget and Justification

Budget: Provide the amount requested, broken down by categories: personnel, supplies, equipment, patient costs, travel, and other expenses. In the Budget Justification, provide a brief explanation of the costs in each category. Include under 'Personnel' a list of all of the key personnel involved in the project, the percent of their time to be spent on the project, and a brief description of their role. Salary for the principal investigator is permitted, but should not exceed \$12,500. Travel expenses up to \$1,750 are allowed. Equipment expenses may not exceed \$3,000. PWSA(USA) requests that institutions allow indirect costs to be at or under 8% in order to maximize the impact of these small grants.

Period of Support:

4. Qualifications of the Investigators (Biosketch) -- NIH style biosketch (2-4 pages) of primary investigators of the Project

5. Research Plan (5 page limit)

- **Specific Aims:** Concisely state the specific research goals of the proposal.
- **Background and Significance:** Explain the goals of the research in the context of the field, emphasizing the significance of the hypothesis to be addressed and for translational application.

- **Preliminary Studies:** Preliminary data are welcomed, but because PWSA(USA) is particularly interested in new, innovative translational research, preliminary data are not required.
- **Experimental Design and Methods:** Provide the details of the experimental plan that will be used to accomplish the specific aims. Routinely used methods do not need to be described in detail; however, new or unusual methods should be described in enough detail to allow evaluation. Identify potential limitations/pitfalls and alternative approaches.

An email will be sent within three working days after submission confirming that the application has been received. If you do not receive confirmation of receipt, please contact us via email or call 800-926-4797 and ask for Janalee Heinemann.

Grant will be judged on:

- The ability of the Principal Investigator and the research institution to complete the project successfully.
- The potential for the project to provide valuable and accurate insight into an important topic area which would fulfill PWSA(USA) goals outlined above.
- The potential of the project to impact rapidly and translate to the PWS community.
- The reasonableness of the time and budget required given the scope of the research and its potential significance.
- The likelihood that the project could not and would not receive funding from alternative sources (NIH, pharmaceuticals, foundations) without pilot data and likelihood of additional funding if the objectives of the study are successfully met.