



## 2020 GRANT SUBMISSION INFORMATION

### Letter of Intent (LOI) Submission

Celebrating over 40 years as a charitable nonprofit, 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 \$100,000 total per project for a 1-2 year grant support aimed at discovering and developing treatments and technologies benefiting those with Prader-Willi syndrome.

The current focus of PWSA (USA) research is supporting projects that have the potential for immediate and high impact for the PWS community, thus 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.

At PWSA (USA) we work to integrate what we have learned about the needs of our families through our support programs with research that we think will make an important and practical difference in our children's lives, thus the following topics will be the focus area for grants accepted and will receive priority rating for grant funding:

- Alternative methods in the provision of care in PWS i.e.: Continuum of Care, telehealth projects.
- Behavior and Psychiatric issues i.e.; medication management, new treatment therapies.
- Gastrointestinal issues i.e.; constipation, hyperphagia issues.
- Respiratory issues; Sleep and airway evaluation, RSV inoculation.
- Efficacy of growth hormone use in PWS; adults and children
- Skin issues i.e. Picking
- Cardiovascular issues i.e.; Incidence and pathology of thromboemboli and cardiopulmonary failure in adults with PWS.

**Submission of a letter of Intent (LOI):** to the PWSA (USA) Research Committee for review. The letter should be < 250 words. The letter should give an overview of your organization, a brief outline of your project and how your project fits with PWSA (USA)'s research focus and other potential funding sources.

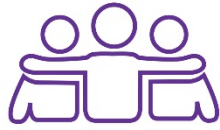
Please send an electronic LOI to Mary Burr at [mburr@pwsausa.org](mailto:mburr@pwsausa.org) and to Rob Lutz at [rob-pws@comcast.net](mailto:rob-pws@comcast.net). Please send a separate email to confirm that the file has been sent and a confirmation email will be sent when it is received.

Grant application requirements can be viewed at <https://www.pwsausa.org/research-funding-opportunities/>

## PWSA (USA) FIVE PILLARS OF SUPPORT



**AWARENESS**



**FAMILY SUPPORT**



**RESEARCH**



**EDUCATION**



**ADVOCACY**

s.research.researchcommittee.grant applicationRFAadvert.1.29.20.



## **PWSA (USA) Grant Application Process**

January 2020

Celebrating over 40 years as a charitable nonprofit, 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 \$100,000 total per project for a 1-2 year grant support aimed at discovering and developing treatments and technologies benefiting those with Prader-Willi syndrome.

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At PWSA (USA) we work to integrate what we have learned about the needs of our families through our support programs — with research that we think will make an important and practical difference in the lives of those affected by PWS, thus the following topics will be the focus area for grants accepted and will receive priority rating for this request for application (RFA):

- Alternative methods in the provision of care in PWS i.e.: Continuum of Care, telehealth projects.
- Behavior and Psychiatric issues i.e.; medication management, new treatment therapies.
- Gastrointestinal issues i.e.; constipation, hyperphagia issues.
- Respiratory issues; Sleep and airway evaluation, RSV inoculation.
- Efficacy of growth hormone use in PWS; adults and children
- Skin issues i.e. Picking
- Cardiovascular issues i.e.; Incidence and pathology of thromboemboli and cardiopulmonary failure in adults with PWS.

## **Grant Award Process**

1. **Submission of a letter of Intent (LOI):** to the PWSA (USA) Research Committee for review. The letter should be < 250 words. The letter should give an overview of your organization, a brief outline of your project and how your project fits with PWSA (USA)’s research focus and other potential funding sources.
2. **Grant Application Due:** Thirty days after notification of LOI acceptance.
3. **Grant Award:** 100,000 total over 1-2 year period

4. **Funding of Grant:** If accepted you will receive the funds after all IRB documents are obtained and completed and all other requirements have been met.

### **Proposal Submission**

Applications must be submitted as *a single electronic pdf package* to: Mary Burr at [mburr@pwsausa.org](mailto:mburr@pwsausa.org) and to Rob Lutz at [rob-pws@comcast.net](mailto:rob-pws@comcast.net). Please send a separate email to confirm that the file has been sent and a confirmation email will be sent when it is received. Questions regarding the research topics to be addressed in this RFA or suitability of the proposed project may be addressed via email to either party.

### **Maximum Single Grant Allowed: \$100,000**

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).

**The required font is Times New Roman 12 point.**

### **Grant applications should include the following items:**

- 1) Face Page, the face page should include the following information
  - a. Title of the Project
  - b. Principal Investigator
  - c. Principal Investigator's Contact Information
  - d. Institutional Contact Information: Name; Mailing Address; Phone Number; E-mail Address
  - e. Signatures: The principal investigator should sign the face page.
- 2) Abstract
- 3) Budget
- 4) Justification
- 5) Period of Support
- 6) NIH style bio sketch (2-4 pages) of primary investigators of the Project
- 7) Research Plan - 5-page limit
- 8) IRB approval documentation

### **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.