

## **PRISMS Professional Advisory Board Guidelines for Approved Research Endeavors**

### **Statement of Purpose**

*PRISMS is dedicated to the ongoing research of Smith-Magenis Syndrome and supports efforts of a diversified approach. Research efforts should be inclusive to address the concerns, challenges, strengths, and legacies of persons with Smith-Magenis syndrome across the lifespan, with the landscape of research embracing all disciplines within basic science, medicine, education, social sciences, and family welfare. The PRISMS Professional Advisory Board, comprised of an interdisciplinary cross-section of leading researchers and clinicians, is responsible for reviewing and recommending research projects that are suitable for funding from PRISMS.*

PRISMS, an acronym for Parents and Researchers Interested In Smith-Magenis Syndrome, is a 501c3 organization dedicated to providing information and support to families of persons with Smith-Magenis Syndrome (SMS), sponsoring research and fostering partnerships with professionals to increase awareness and understanding of SMS. To learn more about PRISMS, visit [www.prisms.org](http://www.prisms.org)

### **Policies and Procedures related to SMS research studies**

The Professional Advisory Board (PAB) is authorized to form a separate ad hoc review committee comprised of PAB members and/or appointed third parties, as required, to assist in the fulfillment of duties outlined below:

1. Establish the procedure for review of research studies that seeks to recruit participants via PRISMS and/or its programs (website, newsletter).
2. Review all submissions in response to RFAs.
3. Provide recommendations to the PRISMS Board on which projects to fund, considering the responsiveness to the RFA, appropriateness of the funding for the project, quality of science, and potential outcomes. The projects funded by PRISMS and the level of funding for each project, remain a Board of Directors' decision. PRISMS Board approval is required before any project receives PRISMS funding.
4. Review all research project requests in which PRISMS and/or PRISMS' members are asked to participate (including but not limited to proof of Institutional Review Board approval).
5. Ensure that proper documentation is obtained for all studies or research programs that are funded by PRISMS, including procedure to monitor progress (i.e. progress reports) if funded.

The PRISMS conflict of interest policy governs the actions of those Boards or Research Committee members seeking funds for projects.

