



Scientific Director Job Description

General Overview:

Phelan-McDermid syndrome (PMS) is a rare genetic condition associated with Autism Spectrum Disorder, seizure disorders, and intellectual disability. Phelan-McDermid Syndrome Foundation (PMSF) is a 501(c)(3) nonprofit organization based in Osprey, Florida. Founded in 2003 by a group of parents, PMSF's mission is to accelerate research, provide family support, and advance awareness of PMS.

Description of Duties:

Reporting to the Executive Director, the Scientific Director will lead efforts to build a strong and dynamic program with input from the scientific and medical advisory boards. The Scientific Director will be responsible for developing and producing the scientific and medical content for all PMSF educational programs and ensuring that the scientific mission of PMSF is delivered.

In addition, the Scientific Director will:

- Encourage collaboration and build relationships with key stakeholders in PMS research and serve as a liaison to key organizations as appropriate;
- Support the Executive Director as needed in developing and maintaining relationships with key stakeholders in industry, sister organizations, and in the medical community;
- Identify opportunities for PMSF to significantly impact scientific progress as related to PMS;
- Engage with families and others in the PMSF community to communicate and explain scientific findings; and
- Represent PMSF at national and international meetings and perform other duties on an ad hoc basis as is required to fulfill the aforementioned roles and responsibilities.

Requirements:

- Minimum 2 years experience in rare disease or not-for-profit setting
- PhD or other graduate degree in biology, genetics, or related field
- Excellent demonstrated oral and written communications skills
- Strong strategic thinking and analysis
- Ability to translate basic science and technical terminology to a lay audience
- Existing relationships with alliances and volunteers
- Self-motivated, ability to exercise independent judgment and manage multiple priorities in a dynamic and challenging environment with minimal supervision
- Extremely detail-oriented with excellent and timely follow-through
- Experience communicating with patients and families
- Strong project management skills
- Well organized with special attention to detail
- Comfortable interacting with team members virtually