

## Vice President, Clinical Development

The International Rett Syndrome Foundation (IRSF) is a 501(c)(3) nonprofit, founded in 2007 with the mission of funding research that promises to rapidly advance life-changing treatments and therapies for Rett syndrome. IRSF makes strategic investments in basic, translational, and clinical research to bolster the fundamental understanding of the disease mechanism, pursue novel drugs and genetic approaches for treatment, support clinical initiatives, and develop guidelines for clinical care.

### **Position Summary:**

Reporting to the Chief Executive Officer and working in collaboration with the Vice President of Research, the Vice President of Clinical Development directs the strategic growth and management of the Foundation's clinical research investments, convenes and coordinates the pre-competitive consortium in the development of meaningful outcomes measures, engages actively with industry and regulatory agencies, including the FDA, during the clinical development process, and oversees the strategic development and expansion of the clinical network, including the growth of the Rett syndrome clinical registry. The VP of Clinical Development will also represent IRSF at relevant professional and scientific meetings and may serve as the voice of IRSF at those meetings.

### **Specific Responsibilities:**

- Fosters engagement, and relationship development, and serves as the liaison with governmental and regulatory bodies, especially NIH and FDA.
- Oversees strategic development and supervision of the clinical research network, including strategic oversight of the clinical data registry and the development of clinical research projects evolving from the clinical network.
- Establishes and leads the Rett syndrome pre-competitive consortium, consisting of members of industry, clinical researchers, and regulatory agencies, with the goal of accelerating the development and adoption of clinical outcome measures that are considered clinically meaningful and relevant to both families living with Rett syndrome and regulatory agencies.
- Supports the VP of Research as they plan and execute the Annual IRSF Scientific Meeting and represents IRSF at national and international scientific meetings.
- Works closely with the VP of Research, who has responsibility for strategic development, oversight, and execution of IRSF-funded basic and translational annual grants program.
- Represents IRSF in meetings that involve stakeholders from other rare disease communities that are relevant to Rett syndrome.
- Some travel is required to present at IRSF Education Days and community events.

**Required Education and Experience:**

- Ph.D. or M.D. degree and extensive experience working on neurodevelopmental disorders (or related basic, translational, or drug development science).
- Ten (10) years or more of prior related work experience in drug development, industry, and/or a regulatory environment in neurodevelopmental disorders, ideally in the rare disease research space, with specific knowledge of regulatory practices as they pertain to therapeutic development and industry.
- Demonstrated ability to develop and maintain collaborative relationships with key stakeholders.
- Track record of effective leadership, with success in rare disease drug development preferred.

**Additional Position Details:**

It is expected that this is a remote, U.S.-based position, requiring approximately 50% effort. Compensation will be commensurate with experience.

Please contact Melissa Kennedy, CEO, at [mkennedy@rettsyndrome.org](mailto:mkennedy@rettsyndrome.org) if you are interested in discussing this opportunity.