

Chief Science Officer

Position Description

April 2019

The International Rett Syndrome Foundation is a 501(c)(3) nonprofit doing business as Rettsyndrome.org

With the mission of transforming the lives of individuals and families living with Rett syndrome, Rettsyndrome.org makes strategic, meaningful investments in research toward all aspects (T0-T4) of potentially life altering treatments and curative therapies. The Foundation not only funds the highest quality research but also empowers families through advocacy and education. Rettsyndrome.org has invested \$48 million dollars in support of a full-spectrum research strategy through December 2018.

Position summary:

The Rettsyndrome.org Chief Science Officer serves as the primary advocate and liaison on science issues to all relevant stakeholders. The reach of this full-time position is international in scope. Using a network of professional and scientific advisors, the CSO develops and executes a compelling research investment strategy, advising the Executive Director and the Board of Directors on strategy, tactics, and opportunities to make the best use of the Foundation's research funding. A successful CSO develops and maintains professional relationships and partnerships with key federal officials, actively participating in the regulatory process through communication and advocacy. In addition, the CSO serves as the Foundations spokesperson in responding to the needs of the organization and community regarding scientific inquiries, and policies that are relevant to those affected by Rett syndrome.

Specific Responsibilities:

- Identify, evaluate and monitor science trends and opportunities of strategic scientific importance to Rettsyndrome.org (RSO).
- Identify and cultivate high-quality scientific opportunities that have the prospect of improving, on both a short-term and long-term basis, the treatment and quality of life for individuals affected by Rett syndrome.

- Build and engage with the RSO Scientific Advisory Committee, and the broader scientific community, to establish expert consensus recommendations regarding care and treatment for people of all ages with Rett syndrome.
- Work closely with the SAC Chair, as needed, in recruiting and identifying appropriate reviewers for grant proposals in areas such as medical research, psychopharmacology, and clinical trials.
- Develop and manage relationships with key external stakeholders' communities (NIH [NINDS, NICHD], CDC, DoD, NSF); regulatory agencies (FDA); academic research institutions, private hospitals and organizations, and other non-profit organizations that are germane to the broader effort.
- Review Federal opportunities and analyze the impact of those opportunities with regard to potential research concerning Rett syndrome.
- Represent the Foundation in international initiatives focused on progressing the science and the therapeutic options for individuals affected by Rett syndrome.
- Develop, maintain, and enhance supportive, but appropriately impartial working relationships with biotechnology and pharmaceutical companies to promote the development and registration of better treatments for Rett syndrome.
- Represent the Foundation at FDA/regulatory meetings in concert with industry representatives.
- Establish and maintain connections with internal staff on science developments.
- Develop, promote and maintain a transparent programmatic research grant process, including review of grant applications. Track impact of funded applications.
- Organize, plan and manage all scientific meetings including the RSO Annual Scientific Symposium.
- Ability to build on existing Rett syndrome clinical trial sites, foster the development of additional sites, as well as broad scientific endeavors such as natural history, clinical trial readiness, and other elements needed for the community to be ready for disease modifying therapies.
- Work with the Foundation's communications team to develop content and shape strategy for communicating the Foundation's activities in the areas of preclinical, medical, neuropharmacology, and translational research to internal and external stakeholder communities, as well as responding to media requests providing specific expert opinion and comment on topics of contemporary importance to the Rett syndrome community.
- Work with the Foundation's leadership to develop and manage budgets.

Required Education and Experience:

- Ph.D. or M.D. degree and extensive knowledge and principles of the theories and principals surrounding the biology and treatment of Rett syndrome.
- Five years or more of prior related work experience and is recognized as a subject matter expert in their field/discipline.

- Specific and significant experience with the design, conduct and management of proof-of-concept through registration-enabling clinical trials. A solid understanding of the key aspects of translational medicine endeavors is essential.
- Solid grounding in preclinical science and preclinical methodologies that are relevant to understanding the biology of Rett syndrome, and an ability to parlay into successful clinical development of high-quality treatments for Rett syndrome.
- Strong track record of peer-review publications, participation in professional societies, and presentation at scientific meetings/conferences

SPECIALIZED SKILLS AND KNOWLEDGE:

- Significant experience relevant to Phase I through IV clinical development projects, including a sophisticated understanding of drug discovery, clinical development planning, and the importance of relevant regulatory guidance.
- Strong scientific skills and expertise relevant to pharmacological/biological product development and clinical trials. Solid understanding of the key concepts of translational medicine.
- Solid scientific understanding of medical genetics.
- Ability to think broadly across scientific disciplines
- Forward thinking and able to proactively identify key areas of investment, on behalf of the Foundation, for scientific and clinical discovery and development
- Ability to communicate complex scientific concepts to the lay public and media
- Genuine comfort with public speaking
- Flexibility to travel up to 4 days per month.

CORE COMPETENCIES:

- Stakeholder focus
- Results driven
- Confident problem-solver
- Manages change in a fluid, efficient manner
- Team focus
- Highly skilled in building effective, collaborative relationships
- High emotional intelligence
- Adept at building and preserving trust

Please submit letter of interest and CV to Melissa Kennedy, Executive Director
mkennedy@rettsyndrome.org