



## RESEARCH COMMITTEE

### **Purpose:**

The Research Committee's purpose is to pursue activities that will improve the understanding of TANGO2 disorder with a goal of finding treatments and ultimately a cure for this disease. It will do this by helping to identify opportunities for collaborative research, spearheading foundation grantor research activities and engaging key stakeholders in the process.

### **Committee Composition:**

At least 3-6 staff and volunteer members comprised of the following:

- Research Engagement Director
- Board members
- At large members who have expertise, experience or an interest in rare disease medical, basic, clinical and/or translational research

### **Committee Roles and Responsibilities:**

- Promote and encourage research in certain thematic areas identified by the foundation. Develop and maintain a medium- and long-term research agenda and strategy.
- Review all previous year activities and make recommendations for future research roadmaps
- Work toward completion of research goals outlined in the foundation's strategic goals
- Develop an annual calendar for the committee's activities, including critical dates, milestones and required Board of Directors actions
- Share developments in the field as it relates to research
- Participate in foundation grantor activities during interval funding cycles
- Identify candidates for the research committee in addition to volunteers who can assist T2RF in awareness and research efforts
- Monitor, advise and provide assurance to the Board of Directors on the quality of the research projects and activities of the Foundation
- Track and report progress toward goals to the Board of Directors

### **Committee Member Expectations:**

- Attend and participate in regular and sub-committee meetings and activities, attending 80% of yearly meetings
- Review materials and provide input

- Serve as a resource and ambassador for the TANGO2 Research Foundation to further the organization's mission and vision
- Provide a connection to an ongoing exchange of information and ideas with practitioners, researchers and scientists, in the field and other external contacts
- Participate in the development and implementation of the committee goals

**Time Commitment:**

- 4-8 hours per month (includes meeting, committee activities/tasks and outreach events)
- Appointment terms are annual, and volunteer members can be reappointed

For more information or to join the committee, please contact Deena Chisholm [deena.chisholm@tango2research.org](mailto:deena.chisholm@tango2research.org) or Giorgio Pochettino at [giorgio.pochettino@gmail.com](mailto:giorgio.pochettino@gmail.com)