



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
- As a committee member affirm a commitment to maintaining the confidentiality of all research materials which includes but aren't limited to letters of intent (LOI), research proposals, special interest applications etc.. and abstain from using, disclosing, or sharing any information, concepts, or ideas contained within committee meetings for personal or professional gain.
- 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 or Giorgio Pochettino at giorgio.pochettino@gmail.com