



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, coordinating foundation research grants and engaging key stakeholders in the process.

Committee Composition:

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

- Board members (Committee Chair will be a Board member)
- At Large members who have an interest in or experience in rare disease medical research

Committee Roles and Responsibilities:

- Review all previous year activities and make recommendations for improvements
- Review short and long term committee goals
- Develop an annual calendar for the committee's activities, including critical dates, milestones and required board actions
- Work to develop and maintain a Research Road Map
- Coordinate open calls for research and facilitate the selection process via subcommittee of key stakeholders
- To serve on or provide oversight to specific activity task forces
- Track and report progress toward goals to the Board

Committee Members Expectations:

- Attend and participate in regular Committee meetings
- Review materials and provide input for improvement
- Serve as an internal/external link for the TANGO2 Research Foundation to open doors to further the organization's mission and vision.
- Participate in the development and implementation of the committee goals.

Time Commitment:

- 4-8 hours per month (includes meeting and outreach events)
- Attend Monthly or Bi-monthly Committee meetings