



EARLY DETECTION AND DIAGNOSIS COMMITTEE

Purpose:

The Early Detection and Diagnosis Committee's purpose is to develop and pursue novel strategies that will ultimately improve the TANGO2-related disorders diagnostic odyssey and strengthen T2RF's position as the leading patient authority on TANGO2 disease. It will do this by employing collaborative and innovative approaches to committee specific outreach, education and awareness activities, while 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 diagnostics, medical, basic, and clinical outcomes, stakeholder and community engagement & outreach

Committee Roles and Responsibilities:

- Promote and encourage early detection and diagnosis in TANGO2-related disorder by developing and maintaining an awareness, outreach and education agenda
- Review all previous year activities and make recommendations for future outreach, education and awareness activities
- Develop an annual calendar for this committee's activities, including critical dates, milestones and required Board of Directors' actions
- Work with foundation committees to share developments in the field as it relates to rare disease diagnostics and collaborate as needed to carry out committee activities
- Identify candidates for the early detection and diagnosis committee
- Monitor, advise and provide assurance to the Board of Directors on the quality of the early detection and diagnosis outreach, education, and awareness activities of the foundation
- Track and report progress toward goals to the Board of Directors

Committee Members Expectations:

- Attend and participate in 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 key internal and external stakeholders
- Participate in the development and implementation of the committee goals

Time Commitment:

- 2-4 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 at deena.chisholm@tango2research.org