

RESEARCH COMMITTEE

Purpose:

The Research Committee is the TANGO2 Research Foundation's primary working committee responsible for planning, implementing, and advancing the Foundation's research initiatives. Working collaboratively with Foundation leadership, the committee develops and executes research-related activities, supports the Foundation's research funding programs, fosters scientific collaboration, engages key stakeholders, and helps implement the Foundation's strategic research priorities. Through these efforts, the committee works to accelerate research that improves the understanding, treatment, and ultimately a cure for TANGO2 deficiency disorder (TDD).

Committee Composition:

The committee consists of **6–12 members** appointed by the Foundation and may include:

- Director of Research (Committee Chair)
- Members of the Board of Directors
- Researchers and clinicians with expertise in rare diseases, metabolism, genetics, neurology, cardiology, translational science, clinical research, patient-centered outcomes research, or related disciplines
- Individuals with expertise in research funding, research administration, regulatory affairs, or scientific collaboration
- Other subject matter experts, as appropriate

Committee Roles and Responsibilities:

- Advise the Foundation on short- and long-term research priorities aligned with the T2RF Strategic Plan.
- Develop and periodically update the Foundation's research roadmap and strategic research agenda.
- Identify emerging scientific opportunities, technologies, and collaborative initiatives relevant to TDD.
- Promote multidisciplinary and international research collaborations.
- Support the development, implementation, and continuous improvement of the Foundation's research funding programs.
- Assist in developing research policies, funding mechanisms, review procedures, and programmatic initiatives.
- Monitor the progress and impact of Foundation-supported research and provide recommendations for future investments.
- Review committee accomplishments annually and recommend priorities for the upcoming year.
- Provide strategic guidance for scientific meetings, research workshops, investigator networking opportunities, and educational initiatives.
- Assist with identifying and recruiting qualified researchers, advisors, reviewers, and future committee members.

- Serve as ambassadors for the Foundation by promoting awareness of TDD research opportunities within the scientific and clinical communities.
- Report committee recommendations and progress to the Board of Directors.

Committee Member Expectations:

- Attend and actively participate in at least **80%** of scheduled committee meetings.
- Review meeting materials in advance and provide thoughtful scientific and strategic input.
- Participate in committee projects, subcommittees, and working groups as appropriate.
- Maintain strict confidentiality regarding all non-public Foundation information, including grant applications, letters of intent, reviewer discussions, committee deliberations, and proprietary research information.
- Disclose any actual, potential, or perceived conflicts of interest and recuse themselves from discussions or decisions when appropriate.
- Act in the best interests of the Foundation and uphold the highest standards of scientific integrity, professionalism, and ethical conduct.
- Foster collaboration and respectful dialogue among committee members and external stakeholders.
- Support the Foundation's mission through professional engagement, outreach, and advocacy whenever appropriate.

Time Commitment:

- 4-8 hours per month (includes meeting, committee activities/tasks and outreach events)
- Committee members are appointed annually by the TANGO2 Research Foundation and may be reappointed based on continued engagement, contributions, and Foundation needs.

For more information please contact Deena Chisholm deena.chisholm@tango2research.org