



FAMILY OUTREACH & SUPPORT COMMITTEE

Purpose:

Our mission is to connect TANGO2 families from around the world by providing access to information and firsthand experiences with TANGO2 Disease from parents and professionals. We strive to link families connected by this isolating, rare disease because we believe that together we can provide comfort, strength, and combined knowledge for each other when we are able to join with others who can understand our unique journey.

Committee Composition:

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

- Board members (Committee Chair will be a Board member)
- Medical professionals who will serve on a consult basis such as metabolic physicians, genetic counselors, etc.
- At large people who are interested or have experience in patient advocacy and support.

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 milestones and required board actions
- Work to develop and maintain a "welcome packet" for all new families that join the foundation
- Each new member who joins the foundation or the TANGO2 Disease facebook group will be assigned to one committee member. That committee member will be the new member's main point of contact and serve as their support person through the foundation
- Administer the TANGO2 Disease Facebook group
- Develop and initiate an international program that will include committee member volunteers that will serve as regional, state and/or country liaisons that will give families access to resources and support
- 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:

- 3-5 hours per month
- Attend Monthly Committee meetings