



PREVENTION AND EARLY DIAGNOSIS COMMITTEE

Purpose:

This committee is working on prevention and early diagnosis in TANGO2 Disease. This was reported as important to families who attended the TANGO2 conference in Houston based on completed parent surveys. The goal of this committee is to communicate with genetic testing labs with the intent of advocating for TANGO2 Disease to be added to their expanded carrier screening panels.

Committee Composition:

4 volunteer members comprised of the following:

- Board members (Committee Chair will be a Board member)
- Metabolic physician, genetic counselors

Committee Roles and Responsibilities:

- Review all previous year activities and make recommendations for improvements
- Review short and long term committee goals
- 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 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:

- 1-3 hours per month
- Attend Committee meetings