Why Should I Participate in the TANGO2 Natural History Study?

1. A natural history is the **single best avenue** to study traits of TANGO2 and how these traits progress over time.
2. With so little currently known about TANGO2, the collective data in a natural history study provides a resource to physicians that can potentially **help treat children in crisis today**
3. A natural history study can help identify and **prioritize areas of focus for future research**
4. The natural history study provides the beginning of a centralized patient registry - **critical for future clinical trials** around treatment and management of the disease
5. A natural history study provides the environment to establish both tissue and blood repositories (biorepositories). This biorepository is the **basis for researchers studying the disease** at the cellular or molecular level.

What do I need to do to participate in the Natural History Study?

- [ ] Email **tango2.research@bcm.edu** Let them know that you are interested in participating in the natural history study for TANGO2
- [ ] Review, Sign and Return the consent form that you will receive from the doctors
- [ ] Request that your child's medical records be sent to Baylor either by fax **713-798-5950**: (*ATTN: Dr. Mahshid Azamian*) or by mail: *ATTN Dr. Azamian* 6621 Fannin Street Suite 19345-C Houston, TX 77030 *(See page 2 for a list of records to request and tips to help you get it done)*
- [ ] Write a written summary of your own account of your child's medical history including first symptoms, triggers, how long symptoms last, signs of crisis, admissions for crisis
- [ ] If you have any pictures or videos of symptoms, they would also be welcomed by the research team

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As we move forward with research unraveling the molecular and cellular events associated with TANGO2, the role of the natural history will only increase. It will provide the vehicle for us to translate our basic discovery work into new clinical treatments to modify the pathology associated with TANGO2.

Key medical records include:

- Medical office visits (specialty consults or visits, ex. neurologist) prior to diagnosis
- Any notes from a genetics visit or counselor
- Records of all emergency room visits or admission for “crisis” events (events with low blood sugar, dark urine, elevated CK rhabdomyolysis, and elevated liver enzymes)
- Any lab values particularly CK, AST, ALT, troponin, lactate, urine, blood gas pH, chemistry (sodium, potassium, glucose, bicarb, creatinine, magnesium, calcium, phosphate)
- Any imaging such as head MRI or muscle testing or biopsy, echocardiogram
- Any cardiac testing of the heart rhythm (ECG, Holter reports)
- Medications: a list of medications and when they were taken or stopped

Tips for requesting medical records:

- Hospitals have medical record request forms on their websites that you can print and complete.
- Hospitals have medical record departments that you can visit in person to request medical records.
- Your child’s pediatrician usually receives a summary from visits to specialists like neurologist, and heart doctors. They can be a great resource.
- Some specialists and hospitals have online patient portals where you can access test results yourself to print and send in.
- You can have records sent directly to Briana or you can request copies go to you so you can compile and organize before mailing them to Briana yourself.

Don’t hesitate to ask for help! We are in this together and need each other to succeed in this process. Help is always available.

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