



EDUCATORS' GUIDE: SUPPORTING
STUDENTS WITH THE TANGO2 DISORDER

Contact Information



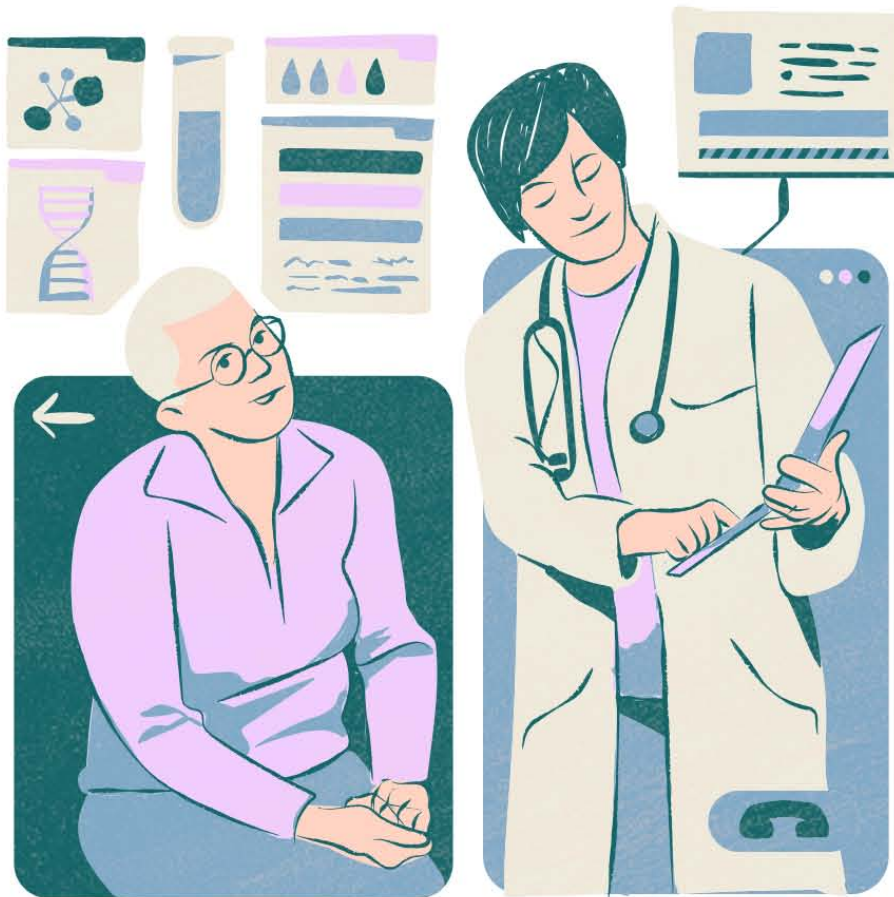
Child's Name:

Parent/Guardian Name:

Parent/Guardian Contact Information:

What is TANGO2 Deficiency Disorder (TDD)?

TANGO2 stands for: transport and Golgi organization 2 homolog - related metabolic encephalopathy and arrhythmias



It is an autosomal recessive disorder caused by pathogenic variants in the TANGO2 gene located on chromosome 22 (Lalani et al., 2016).

What can TDD be characterized by?

- Developmental delay
- Gait incoordination
- Hypothyroidism
- Seizures
- Speech difficulties
- Hearing loss



In more severe cases:

- life-threatening acute metabolic crises such as:
 - rhabdomyolysis
 - cardiac arrhythmias
 - neurodegeneration



Advocacy Card

While certain features of TANGO2 may present similarly, it is essential to recognize that each child is unique, with distinct medical and learning needs. The following page in this document is designated as an advocacy card, where parents and children will communicate their specific learning and medical needs. This information aims to equip you, as the educator, with insights into what to be attentive to and how best to support the individual child in your care.



ALL ABOUT ME

EVERY STUDENT DESERVES A CHANCE TO SHINE!

MY NAME IS: ✨

I AM IN GRADE:



MY STRENGTHS ARE:

[what can you do on your own? What are you really good at? What can you help others with?]

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- -----
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MY MEDICAL NEEDS ARE:

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- -----

MY LEARNING NEEDS ARE: ✨

[what skills do you need help with? What helps you learn best? What do you want teachers to understand about you?]

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- ----- ✨
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ANY ADDITIONAL NOTES: ✨

- ----- ✨
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- -----
- ----- ✨

MY ACCOMMODATIONS ARE:

[How can your teacher help you? What strategies/supports would help you reach your learning goals?]

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WHAT DOES THE RESEARCH SAY?



THIS RESEARCH AIMED TO REVEAL THE EXPERIENCES OF STUDENTS WITH TANGO2 DISORDER AND COLLECT PARENTAL RECOMMENDATIONS TO SUPPORT THEM EFFECTIVELY IN EDUCATIONAL SETTINGS. THE FOLLOWING 4 THEMES WERE REVEALED:

THEME 1: MEDICAL AND CLASSROOM SHARED EXPERIENCES MAY NOT FULLY OVERLAP.

Parents of children with TANGO2 deficiency highlighted shared medical conditions, including metabolic episodes and difficulty walking, emphasizing the importance of nutritional management. In education, challenges such as global developmental delay and struggles in core subjects were noted, but parents also highlighted their children's strengths in empathy, resilience, and a joyful approach to living in the present moment.

THEME 2: EMBRACING CHILDHOOD DESPITE SUBSTANTIAL MEDICAL CONDITIONS.

While parents emphasized the critical priority of addressing medical conditions and ensuring the safety of children with the TANGO2 deficiency, it is noteworthy that these children actively engage in various sports and exhibit strong social skills, highlighting the importance for educators to recognize and support their diverse interests and desire for socialization alongside managing their health challenges.

THEME 3: REQUIREMENT FOR A SYSTEM(S) BUILT ON OPEN COMMUNICATION AND COLLABORATION.

Parents stressed the importance of open communication and collaboration among school stakeholders to understand and address the unique needs of students with TANGO2 deficiency, emphasizing the role of clear communication, daily intake logs, and medical plans in managing both medical and learning requirements. They highlighted the challenge of the recent and complex nature of TANGO2, emphasizing the need for ongoing communication and information sharing to ensure the safety and well-being of students.

THEME 4: ALIGN THE STRATEGY WITH THE INDIVIDUAL STUDENT AND THEIR SPECIFIC NEEDS.

The fourth theme emphasizes the crucial need for personalized strategies in supporting these students, highlighting the importance of educators investing time to build rapport and tailor support based on each child's unique interests, challenges, and strengths.

Medical Plan

Name: _____

Date: _____

Guidelines on Medication and Vitamin Timing:

Vital Information About My Child's Health:

Symptoms to Look out For:

Important Information on Nutrition/Hydration Intake Log:

Enhanced Guidelines for Communication with Parents:

Emergency Contact Information:

FOOD JOURNAL

WEEK: _____

Breakfast _____
Lunch _____
Dinner _____
Snacks _____

Rate your day ○○○○○○

Breakfast _____
Lunch _____
Dinner _____
Snacks _____

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Rate your day ○○○○○○

NOTES:

COMMUNICATION LOG

WEEK

MONDAY

TUESDAY

WEDNESDAY

THURSDAY

FRIDAY

SATURDAY

NOTES:

SUNDAY

For More Information on TANGO2:

You can visit the TANGO2 Research Foundation Website:
<https://tango2research.org/>

and for more information on the research study please
visit:

insert link here to research article