



Hero Highlight - Debbie DeLoach

This month, we are honored to spotlight **Debbie DeLoach**, a dedicated member of the Early Detection & Diagnosis Committee and one of our Regional Coordinators. Debbie also serves on the Executive Board of the International 22q Foundation, where she continues her commitment to supporting and advocating for rare disease communities.

Debbie has been involved with the TANGO2 Research Foundation since 2018, volunteering in memory of her son, Robert, who passed away in 2015 due to complications from TANGO2 Deficiency Disorder (TDD). Robert was diagnosed with both 22q11.2 Deletion Syndrome and TDD. A proud mother and passionate advocate, Debbie shares Robert's story to raise awareness, support families, and honor his legacy. We are deeply grateful for her leadership, compassion, and steadfast dedication to the TANGO2 community.

HERO HIGHLIGHT

Debbie DeLoach

"My hope is that the Foundation will continue raising awareness about TANGO2 & sharing treatments that have shown to be helpful. I am especially eager to see greater recognition & understanding within the 22q community."




**Introducing Our Newest Board Member: Dr.
Samuel Mackenzie!**

We are very excited to welcome Samuel Mackenzie, MD, PhD to the TANGO2 Research Foundation’s Board of Directors! Since April of 2020, Dr. Mackenzie has been a vital part of our community, serving as a research committee member and now the Scientific Advisory Board chair.


As a clinician researcher, he has been at the forefront of advancing knowledge about TANGO2 Deficiency Disorder, leading studies that are helping to unlock answers and guide future therapies. Beyond his research, Dr. Mackenzie has been a consistent advocate for families, sharing insights at scientific and family conferences, supporting T2RF awareness initiatives, and lending his voice to the urgent call for more research and collaboration. His commitment to both scientific progress and improved health outcomes for our TDD warriors makes him an invaluable addition to our leadership team and member of the TANGO2 “family”.

We are thrilled to have his guidance on the Board as we continue to drive our mission and vision forward!


BOARD OF DIRECTORS




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TANGO2 Research Foundation requires 100% board giving from all current board members. We are proud to share that each of our board members meets or exceeds this expectation through both personal contributions and gifts from their extended families, businesses, and personal networks. All board member positions are volunteer. Board members are not compensated for their board duties.




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Call for Presenters: 2025 TANGO2 Virtual Research Symposium

Interested in presenting your TANGO2 research at the **2025 Virtual TANGO2 Research Symposium** on **October 24, 2025 (9 AM–1 PM EST)**?

Apply by September 5, 2025 to be considered. [👉 Apply to Present](#)

This all-virtual event brings together leading scientists, clinicians, and advocates to share timely findings related to **TANGO2 Deficiency Disorder** and rare disease research.

Why Present?

- Elevate your work and connect with a dedicated, multidisciplinary audience.
- Contribute to patient-centered education and research direction.
- Strengthen your visibility in peer-network and advocacy communities.

We welcome 25–30 minute presentations on TDD topics, including (but not limited to): natural history and outcome data, preclinical approaches (iPSc, animals, modeling), metabolic crisis and cardiac management, patient-


centered research, comparative effectiveness research, registry-based findings and cross-disease implications and emerging therapies.

*Selected speakers will be notified via email by **September 12, 2025**.

Apply to Present

LAST CALL: Want to receive a copy of the TDD Parent & Caregiver Guidebook in the mail?


We’re proud to support our community by providing helpful resources like this guide for TDD parents and caregivers. Fill out [this form](#) to receive a physical or digital copy!



TANGO2

DEFICIENCY DISORDER

PARENT & CAREGIVER GUIDEBOOK



VERSION 1 - MARCH 2025

Fill Form

Join the Conversation

There are many helpful and informative conversations happening in our TDD Research Learning Network. With input from families, researchers, clinicians, and other community members, we are paving the way for a brighter tomorrow for our TDD warriors! From B vitamin dosage to speech and language therapy suggestions, there’s topics for everyone!

Topic	Replies	Activity
<p>Families and clinicians, please share with us what dose of vitamin B5 is helping your children/young adults and/or patients the most?</p> <p>■ General</p> <p>What is the appropriate daily B5 dose for TDD to manage symptoms better?</p>	30	Feb 20
<p>Is TDD a degenerative disease?</p> <p>■ General</p> <p>The topic has been raised repeatedly, and since I noticed there wasn't a discussion thread on the learning network, I decided to create one and share my insights. We have been living with TDD for 30 years, with my daugh... read more</p>	4	Jan 7
<p>Need for Coenzyme Q10?</p> <p>■ Outcomes of Interest</p> <p>We were diagnosed three years ago, and since then we have started taking Coenzyme Q 10. I wonder if there is really a need to continue giving it daily. Together with our doctors, a geneticist, cardiologist and neurologi... read more</p>	2	Apr 27
<p>Families and clinicians, do you have any recommendations for therapies that have been helpful in improving the speech and language issues impacting our TDD children/young adults?</p> <p>■ General</p> <p>The questions I am most interested in discussing (but not limited to) are as follows: The tonal nature of</p>	4	Sep 2024

Click to Join

Upcoming Events

Don't miss out on these exciting upcoming events!

2nd Annual

Jim Wilson Memorial

All proceeds go to
Tango2 Research
Foundation



September 6, 2025
10 am Shotgun Start
Maple Hills Golf Course
Marathon, NY

75\$ Per person
Food served after
Door Prize included

20\$ Per Team for Skins
Closest to the pin
Longest Drive

Contact :
Roger Gates

(607) 765-6163

Join us for a day of golf, celebration, and giving back!
Come enjoy some golf fun as we celebrate Jim and support a great cause—the
TANGO2 Research Foundation. Your participation helps make a difference!

BIG RIVERS SPLASH & DASH

SEPTEMBER 20TH 2025

Proceeds Go To  TANGO2RESEARCH
FOUNDATION



5k | 10k | Kid's Dash



[Signup & Learn More](#)

RSVP on Facebook

SAVE THE DATE



2025 TANGO2

RESEARCH SYMPOSIUM

FRIDAY, OCTOBER 24TH

9:00 AM - 1:00 PM EST



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United States

<http://tango2research.org>

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Every dollar counts

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