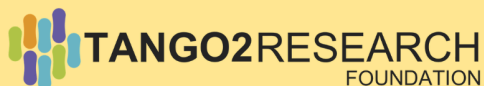


January Newsletter



Monthly Updates



Hero Highlight: Maria Jose (Majo) Arredondo—A Passionate Advocate for TANGO2 Families

This month, we're thrilled to highlight Maria Jose (Majo) Arredondo, a dedicated clinician at Baylor College of Medicine and Project Coordinator for the TANGO2 Natural History Study. Majo's tireless commitment to TANGO2 research and her deep care for families affected by TANGO2 Deficiency Disorder have made a lasting impact.

After graduating from medical school, Majo shared, "I decided to focus on researching TANGO2, as it is an area that greatly interests me. Shortly after getting to know this incredible community, I realized I wanted to be more involved." Her passion and achievements, including being one of this year's Emerging Researchers, make her an inspiration to us all.

HERO HIGHLIGHT



Maria Jose Arredondo Researcher

"The TANGO2 community is amazing, with families from all over the world coming together to support each other...it feels so rewarding to know that my work can make a difference for them in any way."



[Read More](#)

Exciting NIH Grant Announcement for TANGO2 Research

We're excited to share that Dr. Christina Miyake, a TANGO2 clinical research collaborator, has received a prestigious NIH grant from the National Heart, Lung, and Blood Institute (NHLBI). This funding will advance research into life-threatening arrhythmias in TANGO2 Deficiency Disorder (TDD) and explore the potential of vitamin B9 (folate) as a treatment.

Dr. Miyake's study will combine patient data, mouse models, and stem cell technology to uncover the mechanisms behind arrhythmias in TDD and develop evidence-based therapies. This groundbreaking research brings us closer to improving outcomes for TDD patients and families.

Thank you to the NHLBI and our dedicated community for making this progress possible. Together, we're paving the way for a brighter future for the TANGO2 community.

[Read More](#)

Campfires and Community- Raising Awareness for TANGO2 in Italy

A remarkable group of friends in Italy recently came together to support the TANGO2 Research Foundation, inspired by Anna and Paolo, parents of TANGO2 Warrior Lorenzo. For over a decade, this group has hosted festive gatherings to fund meaningful causes, and this year, they chose to raise awareness and support research for TANGO2 Deficiency Disorder (TDD).

Their event was a uniquely Italian experience—an open-air celebration with delicious food, live music, and a warm sense of community. Guests arrived by bike or on foot, gathering around campfires to share stories, laughter, and a commitment to making a difference. The TANGO2 Research Foundation extends heartfelt thanks to La Ciminiera Cycling Team and Giro di Amari Party friends for their generosity and dedication, proving the incredible impact a united community can have on TANGO2 warriors worldwide.



[Read More](#)

[Upcoming Foundation Events](#)

TDD PCOR Workshop #4: Join us for the next PCOR workshop, "Connecting the Dots: Developing a PCOR/CER TDD Research Proposal," on Friday, February 7th, from 12 to 1:30 PM EST via Zoom. Families and researchers will collaborate to shape research ideas focused on TANGO2 Deficiency Disorder.

REGISTER TODAY

**TDD PCOR Workshop #4:
Connecting the Dots: Developing a
PCOR/CER TDD Research Proposal**

Friday, February 7th from 12 to 1:30 PM EST

 **Via Zoom**

This workshop brings together families affected by TANGO2 Deficiency Disorder (TDD) and researchers to work on creating research ideas focused on TDD. The goal is to develop studies that prioritize the needs and experiences of patients.



[Register](#)

Join us for the **Shine a Light on TANGO2 Kickoff** on March 1st at 10 AM ET. Don't miss out on this opportunity to hear from our Ambassador Family Veronica Jones and Tyson Swetek, learn about new TANGO2 families, and hear about our new Shine a Light fundraising platform!

If your family has received a TANGO2 deficiency disorder diagnosis in the past 2-3 years, we'd love to officially welcome and introduce you to our community during the Shine a Light on TANGO2 Kickoff. To have your loved one featured during the event, please fill out [this form](#).

You're Invited!

SHINE A LIGHT ON TANGO2

Kickoff

SATURDAY, MARCH 1, 2025 10:00 AM ET

Be inspired and learn how you can have fun while making a difference!

**With special guests:
Veronica Jones & Tyson Swetek**

Zoom Meeting ID: 878 6421 8634

[Fill Out Welcome Form](#)

We are excited to announce that we will be hosting a virtual **TANGO2 Show & Tell** on Saturday, February 15th at 9-10 AM ET.

Due to a scheduling conflict for the Baylor team, we have changed the topic for the next TANGO2 Talk. The TANGO2 Natural History Study updates will be postponed until spring and instead the TANGO2 Talk Topic will be a fun post-Valentine's Day Show and Tell - What You Love!

We hope to see you there!

TANGO2 TALKS

TANGO2 SHOW & TELL

Saturday, February 15 | 9:00 AM - 10:00 AM ET

Zoom Meeting ID: 884 0823 0063 Passcode: 2222

This will be an informal, interactive and fun show and tell discussion where we are encouraging families to join with their children/young adults who can share a toy or pet or something they love! Siblings are welcome to join, too! And we would love parents to join and share something they love about their child.

Join the Discussion

Curious about vitamin b5 dosage? It's a trending topic on the Research Learning Network right now! Check out the thread to see what others are saying and add your voice to the conversation.



Families and clinicians, please share with us what dose of vitamin B5 is helping your children/young adults and/or patients the most?

Research General



seemal

Aug 2024

What is the appropriate daily B5 dose for TDD to manage symptoms better?

Like, share, bookmark, and Reply icons

2024: The Year in Review

238 views, 34 likes, 12 users



KMorris24

Aug 2024

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Join the Conversation



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