ORLANDO2026
TANGO2 FAMILY CONFERENCE

June 28 - 30th 2026

Disney's Coronado Springs Resort
Orlando, Florida

Conference Program

CONTENTS

TANGO2RESEARCH FOUNDATION

WELCOME

We are pleased to bring the global TANGO2 community together in Orlando, Florida for the 4th biennial TANGO2 Family Conference, three days of learning, connection, and collaboration. Together, we will...

SHARE
the latest advances in TANGO2 Deficiency Disorder (TDD)

STRENGTHEN
community connnections

LEARN
from leading experts

SHAPE
the future of TDD research & treatment

We are grateful for your participation and look forward to a meaningful and impactful conference experience.

The 2026 Conference Planning Committee & PCOR Convening Advisory Board (CAB),

Ann Geffen, JD, MA
Deena Chisholm, MPH, CHES
Kasha Morris, MS
Seema Lalani, MD
Destiny Braden

A MESSAGE FROM OUR FOUNDERS

We'd like to welcome everyone to the 2026 TANGO2 Family Conference. We've entered our eighth year as patient advocacy organization and this is our fourth family conference. We're grateful and inspired by the progress made so far. But, like many of you, as parents to an individual with TDD, we still have many questions about the future and the impact of this disease on our child's quality of life.

This event is always a highlight for our community, providing an opportunity to share new knowledge, celebrate progress, and showcase the outstanding work being led by researchers and healthcare professionals in partnership with the TANGO2 Research Foundation. It reflects the collaborative spirit that drives meaningful advances in rare disease research, bringing together families, clinicians, scientists, donors, volunteers, and Foundation leadership around a shared mission.

This collaboration is essential to advancing the science and improving the lives of individuals living with TANGO2 Deficiency Disorder. By the end of this year, we anticipate awarding more than $1.3 million in research funding since the Foundation's inception. This remarkable milestone would not be possible without the dedication, generosity, and partnership of our entire TANGO2 community.

This is how the best science works and how we will help our children live their best lives.

Together, we continue to make a difference!
Mike and Kasha Morris

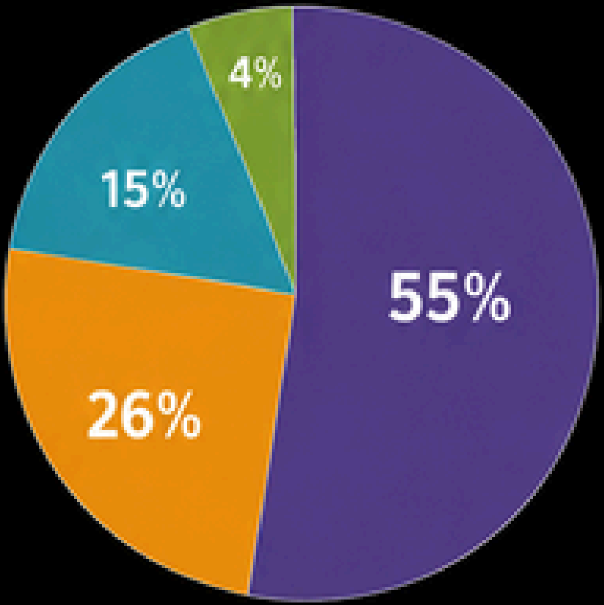
Our Community. Our Foundation. Our Future.

REVENUE: WHERE DOES IT COME FROM?

67%	**Personal Donations from Families & the greater TANGO2 Community** The generosity of families, friends, and supporters fuels our mission every day.
15%	**Grassroots Fundraising from the Community** (Shine a Light on TANGO2 campaign/TANGO2 Banquet)
12%	**Institutional Grant Support**
6%	**Corporate Sponsorship/Matching**

EXPENDITURES: WHERE DOES IT ALL GO?

55%	**T2RF Events:** The TANGO2 Family Conference & Innovation Summit
26%	**Family Support, Programs:** To facilitate all activities that support the foundation's mission and vision
15%	**Research Initiatives:** Foundation grant awards, Special Interest Research Projects & PCORI
4%	**Infrastructure Support:** Costs ensuring our foundation operates efficiently, enabling us to maximize impact and sustain our mission



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FOUNDATION STAFF

Ann Geffen, JD, MA serves as the TANGO2 Research Foundation's Executive Director. With a strategic vision, she directs the Foundation's goals and oversees its daily functions, including marketing, operations, programs, and financial management. Ann plays a pivotal role in both the recruitment and engagement of international key stakeholders and volunteers to serve families located in over 30 countries. She spearheads the Foundation's fundraising initiatives and propels the foundation's research-funding mission.

Deena Chisholm, MPH, CHES serves as the T2RF's Research Director. Deena plays a pivotal role in developing and implementing the foundation's strategic plans for research and grant activities, ensuring alignment with the Foundation's objectives. She also builds and maintains relationships with a diverse array of stakeholders, such as researchers, clinicians, patient families, and the broader research community. Deena oversees the continuous evaluation and refinement of the foundation's research operations ensuring that the Foundation consistently operates at the forefront of the field.

Destiny Braden is the Development & Operations Manager at TANGO2 Research Foundation. Destiny plays a critical role in ensuring smooth and efficient operation of various T2RF activities, with an emphasis on development-related duties. Prior to joining the Foundation, Destiny spent nearly three years working in nonprofit development, supporting immigrants and refugees from over 60 different countries. She also completed a year of national service through AmeriCorps.

FOUNDATION FOUNDERS

Kasha Morris is the mother of Ryan, a TANGO2 warrior, and Co-Founder and Secretary of the TANGO2 Research Foundation. She serves on the Foundation's Research Committee and plays a leading role in family engagement and community support initiatives. Through her advocacy, Kasha works to bridge the gap between scientific research and the everyday experiences of families affected by TANGO2 Deficiency Disorder (TDD), helping to advance awareness, collaboration, and hope for the global TDD community.

Mike Morris is dad to TANGO2 warrior Ryan and Co-founder of the TANGO2 Research Foundation. His background is in technology and entrepreneurship. Mike currently serves as the T2RF President and is a member of the Board of Directors and Research Committee.

SPECIAL ACKNOWLEDGEMENTS

This conference was partially funded through a Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington Engagement Award (EASCS-41293). Funding from this award will support the development of a TDD globally connected, patient-centered, research-engaged community of families, researchers, clinicians, and stakeholders actively involved throughout the research process, from concept development to dissemination.

The TANGO2 Research Foundation remains committed to supporting TANGO2 families, raising awareness, promoting earlier diagnosis, and advancing innovative TDD research.

We extend our sincere gratitude to the T2RF PCOR Convening Advisory Board (CAB) members for generously contributing their time, expertise, and leadership to this initiative.


Kasha Morris


Debbie DeLoach


Amanda Hull, PhD


Seema Lalani, MD


Mathew Edick, PhD


Lina Gonzalez, MD


Jonathan Scaccia, PhD


Alison Bell, MPH

EVERYLIFE FOUNDATION FOR RARE DISEASES

Tango2 RARE DISEASE FOUNDATION


KATIE “DJ ICECAT” CLAY

ultragenyx

SHARE YOUR TANGO2 JOURNEY

Here are some things we would like to know:

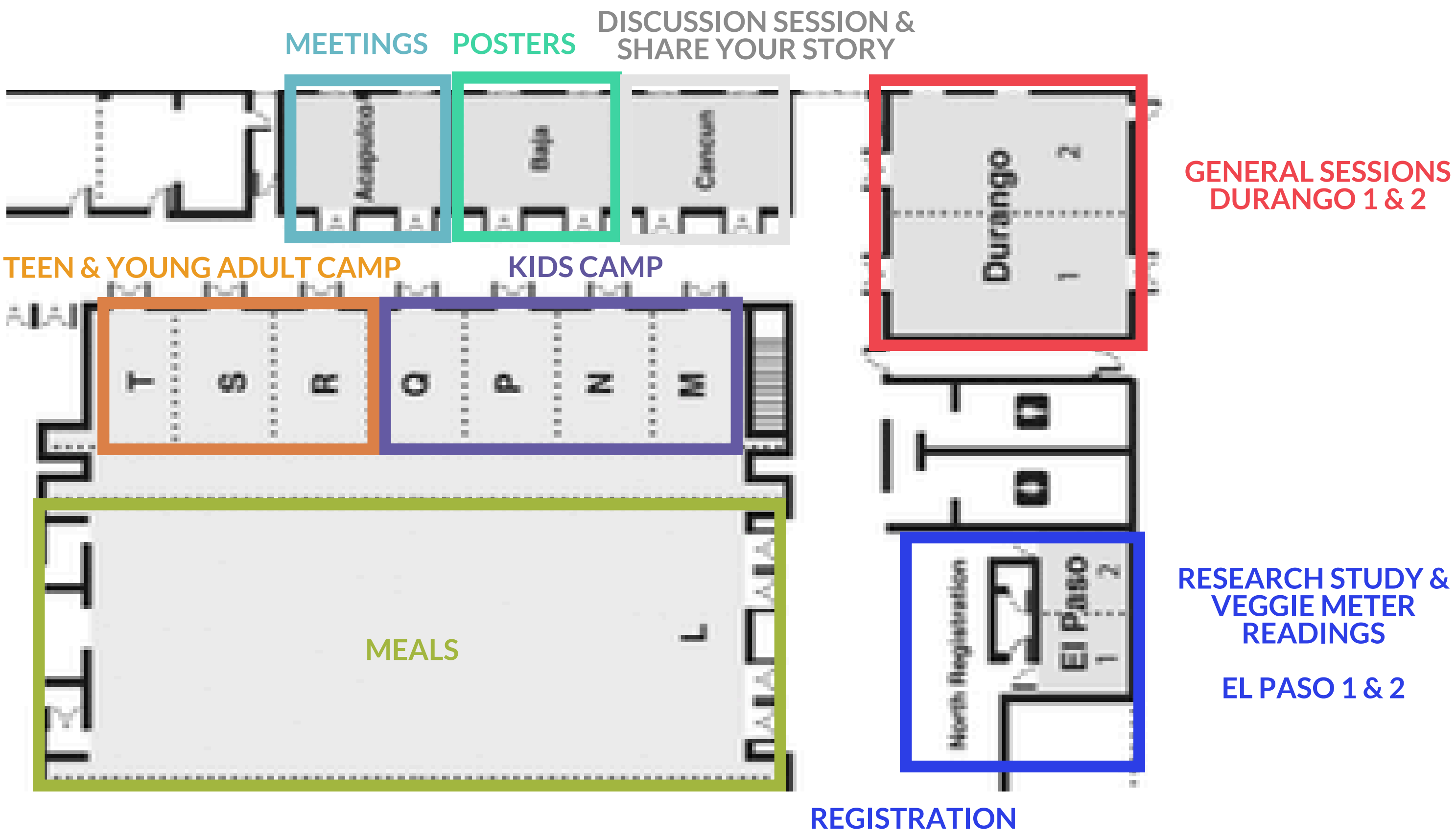
1. How has participating in TANGO2 research impacted you or your family?
2. How has your life changed since joining the TANGO2 community?
3. What are your hopes for the future of TANGO2 deficiency disorder?
4. What do you enjoy most about attending the TANGO2 Family Conference?

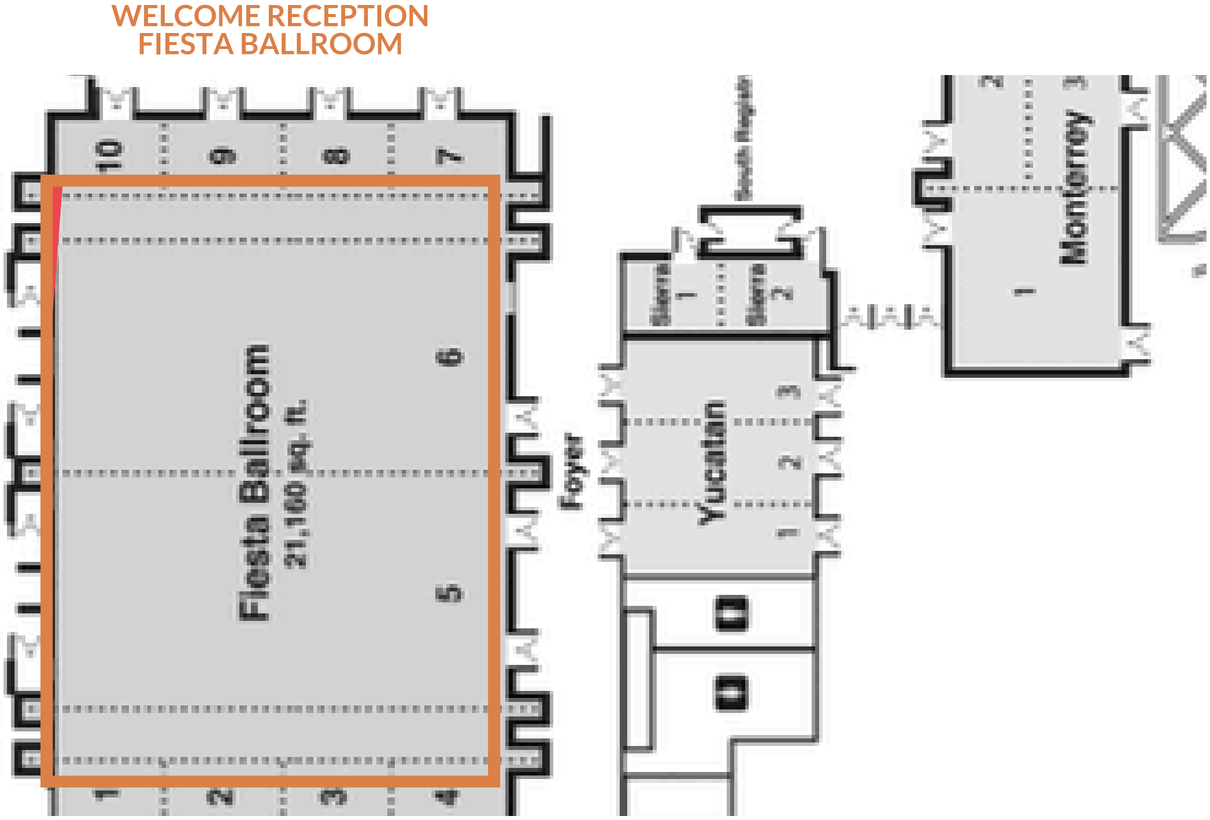
SCAN TO SCHEDULE TIME WITH KAHLIN:

ORLANDO2026
TANGO2 FAMILY CONFERENCE

MAP

↑ TO RESTAURANTS & LOBBY





WORDLY TRANSLATION & CLOSED CAPTIONING

Vertaling en Geslote Ondertiteling | Përkthimi dhe Titrat e Mbyllur | الترجمة والترجمة المغلقة | অনুবাদ এবং বন্ধ ক্যাপশনিং | Превод и Затворен Субтитър | 翻译和闭幕字幕 | 翻译和字幕 | 翻譯和封閉字幕 | Prijevod i Zatvoreno Titlovanje | Překlad a uzavřené titulky | Oversættelse og Lukket Tekstning | Vertaling en Gesloten Ondertiteling | Tõlge ja Suletud Subtiitrid | Käännös ja Suljetut Tekstit | Traduction et Sous-titrage | Traduction et Sous-titrage | Übersetzung und Untertitelung | Μετάφραση και Κλειστή Υποτιτλισμός | અનુવાદ અને બંધ કેપ્શનિંગ | תרגום וכיתובים סגורים | अनुवाद और बंद कैप्शनिंग | Fordítás és Zárt Felirat | Terjemahan dan Teks Tertutup | Aistriúchán agus Foirmeacha Dúnta | Traduzione e Sottotitolazione | 翻訳とクローズドキャプション | 번역 및 폐쇄 자막 | Tulkojums un Aizvērtie Subtitri | Vertimas ir Uždaryti Subtitrai | Terjemahan dan Sari Tertutup | Terjemahan dan Sari Tertutup | Oversettelse og Lukkede Tekster | ترجمه و زیرنویس بسته | Tłumaczenie i Napisy | Tradução e Legendagem | Tradução e Legendagem | ਅਨੁਵਾਦ ਅਤੇ ਬੰਦ ਕੈਪਸ਼ਨਿੰਗ | Traducere și Subtitrare | Перевод и Закрытые Субтитры | Превод и Затворени Титлови | Preklad a uzavreté titulky | Prevod in Zaprti Podnapisi | Traducción y Subtitulación | Traducción y Subtitulación | Tafsiri na Maandishi ya Sauti | Översättning och Slutna Texter | Pagsasalin at Saradong Subtitles | மொழிபெயர்ப்பு மற்றும் மூடப்பட்ட கப்ஷனிங் | การแปลและคำบรรยายที่ปิด | Çeviri ve Kapalı Altyazı | Переклад і Закриті субтитри | ترجمہ اور بند کیپشننگ | Dịch và Phụ Đề | Cyfieithu a Chyfandir Cau

SCAN THE QR CODE

slido

AUDIENCE Q&A

Use Slido to participate in live audience Q&A sessions throughout the conference. Submit questions in real time, vote for the questions you would most like answered, and help shape discussions around the topics that matter most to the TDD community. Questions may be submitted anonymously. Simply scan the QR code to join the session and participate.

To view TANGO2 Research Foundation resources, scan the QR codes below:

Glossary of Terms

Family Resources

YouTube Channel

TDD Mental Health Toolkit

Funding Portfolio

Featured Conference Activités

Poster Presentations

Located in Baja

We invite you to explore poster presentations highlighting TANGO2 research conducted by students, clinicians, healthcare professionals, and researchers attending the conference. This year's poster session also features patient experience presentations submitted by TANGO2 family members, offering valuable community perspectives.

SCAN TO VIEW PUBLISHED FAMILY AND SCIENTIFIC POSTER ABSTRACTS

Natural History Study Enrollment

Located behind North Registration in El Paso 1 & 2

Individuals with TANGO2 Deficiency Disorder (TDD) and/or 22q11.2 Deletion Syndrome are invited to participate in the TANGO2 Natural History Study (NHS), led by Dr. Christina Miyake at Baylor College of Medicine and funded by the TANGO2 Research Foundation. Participation in the study plays a vital role in advancing scientific understanding of TDD and helping drive future research, treatments, and improved patient care. We strongly encourage families to learn more and consider participating. Additional information about the study can be found at the end of this conference program.

Veggie Meter Readings

Located behind North Registration in El Paso 1 & 2

Stop by the North Registration area to complete a quick, noninvasive Veggie Meter reading with Dr. Mousumi Bose as part of the TANGO2 Natural History Study. Your participation supports ongoing nutrition & health research and contributes valuable data that may help advance our understanding of TDD and the role of B vitamins. If you have not yet participated or would like additional information, please visit the North Registration area or refer to the information provided at the end of this conference program.

SCAN TO SIGN YOUR WARRIOR UP FOR A VEGGIE METER READING

Merchandise

Located at the North Registration Area

Support the TANGO2 Research Foundation by purchasing branded merchandise. Proceeds support the T2RF's mission and vision.

Share Your TANGO2 Story

Located in Cancun

Come share your story and be featured in future marketing & communications for the Foundation. *Hosted by Kahlin Grant of Kapow Social Branding.*

Conference Agenda

Mini Scientific Symposium *

Sunday, June 28, 2026

All times are listed in Eastern Standard Time (EST)

1:00 PM	**Welcome**	**Deena Chisholm, MPH, CHES**
1:05 PM	**TANGO2: From Mitochondrial Lumen Localization to Lipid-Chain Interactions**	**Agustin Lujan, MD, PhD**
1:35 PM	**Unveiling Novel Insights into the Pathophysiology of TANGO2 Deficiency Disorder Using Integrated Functional and Multiomic Studies**	**Lina Ghaloul-Gonzalez, MD**
2:05 PM	**Metabolic Crisis Causes QT Prolongation in TANGO2 Deficiency Disorder**	**Lili Wang, PhD**
2:35 PM	**Special Research Update**	
3:05 PM	**Break & Poster Session**	
3:20 PM	**Understanding TANGO2 Deficiency Disorder via Genotype-Phenotype Correlations in 22q11.2 Deletion Syndrome**	**Donna McDonald-McGinn, MS, CGC** **Beata Nowakowska, MD**
3:50 PM	**The Future of TDD Gene Therapy - AAV Development**	**Vandana Gupta, PhD, MSC**
4:20 PM	**Higher-ordered Organization of TANGO2 May Be a Prerequisite for Its Function**	**Michael Sacher, PhD**
4:50 PM	**Final Audience Question & Answer Session and Adjournment**	**Samuel Mackenzie, MD, PhD**
6:15 PM	**Welcome Reception**	**Fiesta Ballroom**

Posters will be available to view in Baja starting at 3 PM

*This mini scientific symposium is primarily designed for healthcare professionals and researchers, and the presentations may include detailed and technical information. While the content is not specifically tailored for a general audience, all are welcome to attend.

Conference Agenda

Monday, June 29, 2026

All times are listed in Eastern Standard Time (EST)
Posters will be available to view in Baja starting at 8 AM

8:00 AM	**Breakfast**	
9:00 AM	**Welcome**	**Mike & Kasha Morris**
9:10 AM	**Opening Keynote**	**Pat Furlong, BSN, MS**
9:30 AM	**From Observation to Impact: TANGO2 Natural History Study Updates - Developing Acute Care Clinical Guidelines**	**Samuel Mackenzie, MD, PhD & Jonathan Scaccia, PhD**
10:00 AM	**From Observation to Impact: TANGO2 Natural History Study Updates - Nutrition Matters: Supporting Health Day to Day**	**Mousumi Bose, PhD**
10:30 AM	**Break & Poster Session**	
10:50 AM	**From Observation to Impact: TANGO2 Natural History Study Updates - Looking Ahead: What Long-Term Follow-Up Tells Us**	**Christina Miyake, MD, MS, MPH**
11:35 AM	**Audience Question & Answer Session**	**Seema Lalani, MD**
12:00 PM	**Lunch**	
1:30 PM	**You Spoke, We Listened: Community Priorities and a Transparent Look at Rare Disease Research Funding**	**Deena Chisholm, MPH, CHES & Courtney Clyatt, MPH**
2:00 PM	**TDD PCOR Workshop Part 1 - Researching the Core: Unveiling What the Community Values Most**	**Breakout Group Workshop**
3:05 PM	**Bridging the Gap Between TDD Community Needs, Research and Regulatory Agendas**	**Elizabeth Long, PhD** (Moderator) **Dylan Simon, MS** **Ron Bartek, MA** **Julie Tierney, JD**
3:50 PM	**Break & Poster Session**	
4:10 PM	**Giving Voice to TANGO2: Speech Challenges, Strategies, and Hope**	**Erin Kaiser, MA, CCC-SLP** **Amy Clay,** **Kasha Morris,** **Laura Moore**
4:55 PM	**Audience Question & Answer Session**	**Seema Lalani, MD**
5:05	**Adjournment**	**Ann Geffen, JD, MA**

Child/Teen/Young Adult Camp Daily Sign in/out 8:30 AM & 5:30 PM

Conference Agenda

Tuesday, June 30, 2026

8:00 AM	**Breakfast**	
9:00 AM	**Welcome**	**Michael Sacher, PhD**
9:05 AM	**From Lab Discoveries to Warrior Impact: The Latest in TDD Research**	**Sarah Sandkuhler, MD, PhD** **Vandana Gupta, PhD** **Agustin Lujan, MD, PhD** **Weiyi Xu, PhD** **Lauren Peacoe, PhD Cand** **Mike Morris**
10:35 AM	**Understanding the TANGO2 Brain: Development, Injury, & Lived Experience**	**Kuntal Sen, MD** **Kimberly Houck, MD** **Robin Mitchell**
11:20 AM	**Audience Question & Answer Session**	**Seema Lalani, MD**
11:30 AM	**Break & Poster Session**	
11:50 AM	**Lunch & “Shine a Light” On You Celebration**	
1:15 PM	**Advocating for Your Warrior: A Panel Perspective**	**Chaya Murali, MD** (Moderator) **Amanda Hull, PhD** **Cheyenne Beach, MD** **Tyson & Veronica Swetek**
2:00 PM	**Behind Every TDD Warrior Is a Caregiver, Rare and Resilient: Tools & Strategies to Cultivate Hope, Community, & Well-Being**	**Julie Wells & Kasha Morris**
2:35 PM	**Audience Question & Answer Session**	**Seema Lalani, MD**
2:50 PM	**Group Discussions: Family Experiences Through the Years** **Option 1:** Tips for Managing Your Warrior's Challenging Behaviors (Birth - 12 yrs) **Option 2:** Pre-teens & Beyond: Adapting to Your Warriors Changing Needs (13 - 19) **Option 3:** Transitioning Your Warrior into Adulthood (20+ yrs), **Option 4:** "Get it Write" for TANGO2 (all ages) **Option 5:** Angel & Family Support Circle	**Moderators** **Option 1: Amanda Hull, PhD** **Option 2: Sam Mackenzie, MD, PhD** **Option 3: Farah Ladha, MS, CGC** **Option 4: Chaya Murali, MD** **Option 5: Julie Wells**
3:50 PM	**Break & Poster Session**	
4:10 PM	**TDD PCOR Workshop Part 2 - Researching the Core: Unveiling What the Community Values Most**	**Breakout Group Workshop**
5:00 PM	**Group Report Out - PCORI Activitiy**	
5:20 PM	**Closing Remarks**	**Ann Geffen, JD, MA**

KEYNOTE SPEAKER

Patricia (Pat) Furlong, BSN, MS is the Founding President of Parent Project Muscular Dystrophy (PPMD), the leading U.S. nonprofit dedicated to ending Duchenne muscular dystrophy. Following the diagnosis of her two sons with Duchenne in 1984, Pat transformed personal tragedy into a lifelong mission to accelerate research, improve care, and advance treatments for individuals living with rare diseases.

Under her leadership, PPMD has become an internationally recognized force in patient advocacy, research collaboration, and public policy. Pat is widely regarded as a pioneering leader in the rare disease community and has served on numerous national advisory boards and committees, including the National Organization for Rare Disorders (NORD). A frequent speaker at scientific, regulatory, and patient-focused conferences worldwide, Pat continues to champion the role of patients and families in driving meaningful progress in research and therapeutic development.

SPEAKERS

Courtney Clyatt, MPH is a Senior Program Officer for Engagement at the Patient-Centered Outcomes Research Institute (PCORI). She came to PCORI with more than 10 years of experience in public health and project management. In her position, she has played a vital role in the Engagement Awards program and, specifically, the Pipeline to Proposal Awards, which funded community-building and engagement projects. Currently, her work has been focused on helping smaller organizations to build capacity to engage in patient-centered comparative effectiveness research.

Samuel Mackenzie, MD, PhD is an assistant professor at the University of Rochester where he focuses on developing gene-targeted therapeutics for pediatric neuromuscular conditions. He has been a long-standing advocate for the TANGO2 community and currently serves as chair of the T2RF Scientific Advisory Board (SAB) and as a member of the Board of Directors.

Agustín Luján, MD, PhD is a physician-scientist dedicated to advancing research in pediatric rare diseases, including conditions like TANGO2 deficiency. He holds a PhD in biological sciences and postdoctoral training in cell and molecular biology. At Hospital Sant Joan de Déu, he works as a researcher in the neuromuscular and arrhythmia/sudden death units, serving as a bridge between basic and clinical research in this field. Agu currently serves as a T2RF Research Committee member.

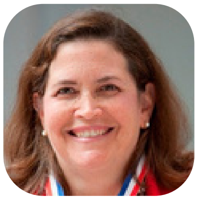
Lina Ghaloul-Gonzalez, MD, is a clinical and metabolic geneticist and Mellon Scholar at UPMC Children's Hospital of Pittsburgh. She co-founded the Plain Community Translational Medicine Program at UPMC in 2016, which provides clinical care and research opportunities for patients from the Plain communities (Amish and Mennonite), primarily in western Pennsylvania. Dr. Ghaloul-Gonzalez leads multiple clinical and research initiatives within this population. She also serves on the Research Committee of the TANGO2 Research Foundation, and her laboratory is dedicated to understanding the function of TANGO2 and the pathophysiology of TDD.

Michael Sacher, PhD attended McGill University in Biochemistry where he focused on neurofilament dynamics. He then was a postdoctoral associate and research associate at Yale University in the Cell Biology department studying the mechanism of membrane trafficking in the early secretory pathway where he discovered and characterized the TRAPP complexes. In his independent laboratory at Concordia University in Montreal he continued working on TRAPP and linked mutations in the proteins to rare disease. More recently, his laboratory has focused on TANGO2 function and TDD where they discovered that vitamin B5 had beneficial effects in both a fruit fly model system and in human cells. His laboratory continues to make progress on the function of TANGO2 in the hopes of identifying further beneficial treatments for TDD.

Vandana Gupta, PhD works on neuromuscular disorders, with a particular focus on the molecular mechanisms underlying genetic muscle diseases, gene discovery, and therapeutic development. Her research integrates genetics, developmental biology, and translational approaches to uncover disease mechanisms and develop targeted therapies for rare neuromuscular disorders. Vandana currently serves on T2RF's SAB.

SPEAKERS

Christina Miyake, MD, MS, MPH is a pediatric cardiologist and Director of the Cardiovascular Genetics Arrhythmia Program at Baylor College of Medicine. She is a member of the T2RF Scientific Advisory Board and lead investigator of the TANGO2 Natural History Study. She discovered the role of B vitamins and TANGO2 deficiency disorder. Dr. Miyake's ultimate goal is to improve TDD management and outcomes while working toward effective treatments and a cure.

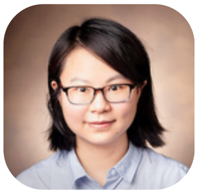


Donna McDonald-McGinn, MS, LCGC is the Director of the 22q Center and Chief of the Genetic Counseling Section at Children's Hospital of Philadelphia, also serving as Professor of Clinical Pediatrics at the Perelman School of Medicine of the University of Pennsylvania. As Chair of the 22q11.2 Society and a Founding Board member of the International 22q11.2 Foundation, she leads global initiatives, focusing on chromosome 22q11.2 copy number variants. With over 380 original articles, as well as a textbook on 22q11.2 deletion syndrome, she specializes in understanding outcomes in patients with chromosome 22q11.2 deletions and variants, including the subset of patients with a chromosome 22q11.2 deletion and TANGO2 Deficiency Disorder. Donna currently serves as a member of the T2RF's Scientific Advisory Board.

Jonathan Scaccia, PhD, is a community psychologist and implementation scientist specializing in systems change, health equity, and AI-enhanced dissemination. He is the founder of PubTrawlr and This Week in Public Health, where he develops innovative tools that translate complex research into accessible, actionable insights for practitioners and communities. His work focuses on bridging research, practice, and policy to improve health outcomes and strengthen community-driven systems.

Sarah Sandkuhler, MD/PhD candidate is a student in the Pathology department at the University of Rochester School of Medicine and Dentistry. She is working on her thesis in the lab of Samuel Mackenzie, studying TANGO2 Deficiency Disorder in a C. elegans (worm) model. Her clinical interests include neurogenetics and the development of improved gene replacement therapeutic strategies. She currently serves on the T2RF Early Detection and Diagnostic Committee and was a recipient of the 2024 T2RF Emerging Researcher Award. When not in the lab, she can be found swing dancing, singing in choir, and spending time with her cat, Beatrice.

Mousumi Bose, PhD is the mother of Ilan Betzer (2010-2011), who was born with Zellweger spectrum disorder, a rare genetic disorder of peroxisome biogenesis. As a result of her personal experience with her son, Dr. Bose re-focused her career goals to study rare disease. Over the last decade, Dr. Bose has conducted research and published multiple papers on the role of the family caregiver in the management of rare pediatric disorders. Currently, Dr. Bose holds a faculty position in the Department of Nutrition and Food Studies at Montclair State University in New Jersey, studying quality of life, patient-focused drug development, dietary assessments, and health equity issues in rare disease communities. Dr. Bose is passionate about learning what is important to rare disease families and using that information to improve their lives.



Lili Wang, PhD is a Research Instructor in the Department of Medicine at Vanderbilt University Medical Center, where she investigates the arrhythmia mechanisms underlying genetic cardiac disorders. Her research centers on how metabolic stress disrupts cardiac electrophysiology, using hiPSC-derived cardiomyocyte models to dissect disease mechanisms at the cellular level. She will be presenting her work on how metabolic crisis drives QT prolongation in TANGO2 deficiency disorder convening.

Beata Nowakowska, PhD is researcher in the Department of Medical Genetics at the Institute of Mother and Child in Warsaw, Poland. She has also served as a Trustee of the 22q11.2 Society and 2024 Program Chair. Dr. Nowakowska has published research exploring pre- and post-natal diagnosis of TANGO2 Deficiency Disorder (TDD) and genotype-phenotype correlations with TDD and 22q11.2 Deletion Syndrome. Her research aims to uncover how genetic links could offer key insights into the biology of TDD, bringing us closer to better understanding, earlier diagnosis, and smarter treatment strategies.

PANELISTS

Kimberly Houck, MD is a Pediatric Neurologist at Texas Children's Hospital and Assistant Professor in the Department of Pediatrics, Division of Neurology and Developmental Neuroscience at Baylor College of Medicine (BCM) in Houston. Her clinical practice focuses on medical and surgical management of refractory epilepsy, with special interest in genetic and structural causes. She is a member of the multidisciplinary TANGO2 research team at BCM and has contributed to natural history study publications, review articles, and practice guidelines.

Julie Wells has spent over 32 years in the non-profit sector working on community-based issues, centering marginalized populations and access to opportunities as the focal point of her impact. In 2024, she joined Give an Hour, a national mental health nonprofit, as Director of Strategic Relationships. In this role, she travels nationwide providing training and support to diverse communities, including military personnel, individuals affected by rare diseases, and survivors of crime. She also has a personal connection to the rare disease community through her own experience with genetic heart failure, which similarly affects her sister, nieces, and nephew.

Cheyenne Beach, MD directs the Pediatric Electrophysiology program at Yale New Haven Children's Hospital. In addition to seeing patients in both inpatient and outpatient settings, she performs procedures to restore more normal heart rhythms for children with arrhythmias and adults with congenital heart disease. She cares for patients with TDD and other rare diseases and wants to help patients, families, and other providers in their rare disease journeys. Cheyenne currently serves as a T2RF SAB member.

Weiyi Xu, PhD 2024 T2RF Emerging Researcher awardee is an instructor in the Molecular and Human Genetics Department at Baylor College of Medicine (BCM). He did his PhD in electrophysiology at University of Hong Kong, and then received postdoctoral training specialized in cardiology and genetics in BCM. He is pursing an academic career path in genetic cardiac arrhythmias, and enjoys conducting translational research where findings in the laboratory can have an immediate impact on patient care in the clinic. Outside the lab, he enjoys playing basketball and hanging out with his 2-year-old son.

Lauren Peacoe, BS, PhD Candidate is a Neuroscience PhD student at Baylor College of Medicine in Houston, Texas. Growing up alongside two brothers with a rare disorder, Lauren has always been passionate about understanding how genetic variations can disrupt brain development and activity. She conducts her thesis work in the Sillitoe Lab, where discoveries continue to establish the cerebellum, a brain region that coordinates movement and balance, as an origin of diseases like dystonia, ataxia, and tremor. Using a mouse model, Lauren studies how loss of TANGO2 alters cerebellar structure and function to influence movement, with the goal of identifying ways to improve the lives of those with TDD. Beyond her research, Lauren enjoys sharing her love of science through teaching, and she volunteers with children and families affected by special needs in her community.

Dylan Simon currently serves as the Senior Director of Policy for the EveryLife Foundation for Rare Diseases. Since joining the EveryLife Foundation, he has focused on newborn screening and diagnostic policy issues, as well as annual appropriations efforts for the rare disease community. Dylan's work includes leadership with the community on the passage of landmark state legislation providing for expedient implementation of RUSP conditions. Prior to joining EveryLife, Dylan interned for the Senate HELP Committee and worked at advocacy organizations.

Erin Kaiser, MA, CCC-SLP has two decades of experience in school-based speech-language pathology and specializes in treating complex disabilities, including autism, intellectual disabilities, and other genetic disorders. Her clinical focus centers on implementing multimodal communication strategies, including comprehensive AAC evaluations, as well as staff and parent training. Driven by a personal connection to the TANGO2 community formed early in her career, Erin is a fierce advocate for neurodiverse learners in Colchester, CT, where she works to educate families and community members about multimodal communication and acceptance for all forms of communication. Every child deserves a voice!

PANELISTS

Julie Tierney, JD is a Principal at Leavitt Partners in Washington, D.C., where she advises stakeholders across the life sciences ecosystem, including companies, researchers, and patient organizations, on U.S Food and Drug Administration (FDA) regulatory strategy and policy. Before joining Leavitt Partners, she held a number of senior roles during an almost two decade tenure at the FDA, including FDA Chief of Staff, and Deputy Director of FDA's Center for Biologics Evaluation and Research. While at FDA, Julie advanced cross cutting policy and regulatory initiatives to promote innovation for patients with rare and serious diseases, with a strong focus on cell and gene therapies. She is committed to patient focused regulatory science and partnering with advocacy organizations to help translate scientific advances into meaningful therapies. Julie received her Bachelor of Arts from Johns Hopkins University with a double major in History and Biology and her Juris Doctor from Georgetown University Law Center.

Ron Bartek is Co-Founder and President of the (FARA), a leading rare disease advocacy organization focused on accelerating treatments and cures for Friedreich's ataxia. He is widely recognized as a national leader in rare disease advocacy, patient engagement, and research acceleration. Ron currently serves on the Board of Directors of Critical Path Institute and previously served as Director and Chair of the (NORD). Ron has held numerous leadership and advisory roles across the NIH, FDA, and rare disease ecosystem, including service on the NIH/NCATS National Advisory Council and NIH Neurological Institute National Advisory Council. In recognition of his longstanding impact on the rare disease community, he was named one of the FDA Office of Orphan Products Development's "30 Heroes Changing the Lives of Rare Disease Patients."

Robin Mitchell, MHSA is mom to Hanna (TANGO2 warrior) and Benjamin (TANGO2 sibling) and a 2023 retiree from a large health insurance company in Michigan. Robin's currently a volunteer with the TANGO2 Research Foundation, serving as the chair of the Outreach Committee and the Plymouth Canton Literacy Council.

Veronica Jones-Swetek is a first grade teacher with over 20 years of experience in education. She is also the mother of an 11-year-old daughter who was diagnosed with TANGO2 Deficiency Disorder at age two. Through the TANGO2 Research Foundation, Veronica has served as a former board member and currently helps lead the family community as an administrator of the foundation's Facebook group. She is also an active member of the Outreach committee and a Regional Coordinator where she works to connect and support families navigating a TANGO2 diagnosis.

Tyson Swetek is dad to TANGO2 warrior Thea. Tyson currently serves as a member of the T2RF Research Committee. His family served as the 2025 Shine a Light on TANGO2 Ambassador Family, helping elevate awareness through their story.

Amanda Hull, PhD (DPsych Ed) is from Suffolk in England. She and husband, Daniel, have three boys; Joe, Sebby and Walter. Sebby is a 15-year-old diagnosed with TANGO2 Deficiency Disorder. Amanda has worked as an Educational Psychologist for the past 20 years, and Daniel is a farmer. They live on a farm and have an active lifestyle with all of them enjoying being outdoors and doing adventurous activities.

Kuntal Sen, MD is the co-director of the Neurogenetics Clinic in the Division of Neurogenetics & Neurodevelopmental Pediatrics at Children's National Hospital. He is one of the few physicians in the country with dual training in neurology and clinical genetics which affords him a unique expertise to diagnose and manage patients with complex monogenic neurological disorders. Dr. Sen's clinical expertise is centered on providing long-term, holistic, & family-centered care for patients with mitochondrial diseases and other ultra-rare neuro-metabolic disorders. Dr. Sen's research focus is on multi-modal neuroimaging and neuromonitoring in inborn errors of metabolism.

PANELISTS

Chaya Murali, MD is a pediatric geneticist at Texas Children's Hospital in Houston, Texas. Her research is focused on quality of life and lived experiences in people with genetic diagnoses and their families. Dr. Murali spearheaded a study of quality of life in the TDD community in 2019, and she currently serves as part of the TDD PCOR stakeholders team. In addition to her work as a physician, Dr. Murali is a published personal essayist, and some of her writing can be viewed at www.chayanautiyalmurali.com

Laura Moore wears many hats, as many TANGO2 parents do. She is the mother of three children, including her youngest daughter, Ellie, who was diagnosed with TANGO2 Deficiency Disorder in 2017. A dedicated homeschool parent and caregiver, Laura balances her family's needs with her role as Financial Director for the City of Tahoka, Texas. Laura holds a Bachelor of Science in Accounting Control Systems and a Bachelor of Arts in Interior Design from the University of North Texas. She and her husband, Blake, have been married for 20 years and live in Littlefield, Texas, with their three children: Denton, Reese, and Ellie.

Elizabeth Long, PhD is Director of Research and Evaluation of the Evidence-to-Impact Collaborative's Research Translation Platform where she oversees the evaluation and research activities of research-policy bridging models. These include a science communication model (the SciComm Optimizer for Policy Engagement) and a partnership model (the Research-to-Policy Collaboration model). Her training background is in the etiology and prevention of substance use disorders, which led to her aspirations of informing large-scale impact through evidence-based policies.

Amy Clay resides in Rochester, NY, with her husband Stan, daughter Katie, and dog Cody. She serves as a T2RF Regional Coordinator and actively participates in the Outreach and Fundraising Committees. Professionally, she is an IT Director for the Catholic Health System and also serves as a board member and Treasurer for the Rochester Special Hockey Icecats. In her spare time, she supports her daughter's DJ endeavors as a chauffeur and groupie for DJ IceCat.

Seema Lalani, MD is a Professor & clinical geneticist at Baylor College of Medicine & sees patients at Texas Children's Hospital. As a T2RF Research Committee & Board of Directors member, she is dedicated to advancing research, education, & equitable access to genetic care. She co-leads the TDD Natural History Study.

Farah Ladha, MS, CGC is a certified genetic counselor at Baylor College of Medicine and Texas Children's Hospital. Along with seeing patients in clinic to discuss genetic testing and provide support, she has been the Chair of the T2RF Early Detection & Diagnosis Committee since 2023. She has led several studies and community outreach initiatives focusing on the pediatric to adult healthcare transition for individuals with rare genetic conditions.

MAKE AN IMPACT TODAY

Join Our Global Community

BECOME A TANGO2 MONTHLY HERO

Thank You Current Monthly Heroes:

Jim and Tina Adams
Steven Brown
Kara Cameron
Diego Da Silva Lima
Robbie Haug
Traci Waxman Huber
Marsha Jones
Hadzire Likovic
Peter Morris
Seelin Naidoo
Giorgio Stefanelli
Aubrey Swetek

Become a Monthly Hero

Provide ongoing support for TANGO2 research through a monthly donation and receive a limited-edition pin today!

Questions? Ask a T2RF team member!

Scan to Join

Earn a TDD Rare Stripes Shine T-shirt!
Register, Raise or Donate $50 Online

scan to earn your T-shirt

SHINE A LIGHT
ON TANGO2

WWW.SHINEALIGHTONTANGO2.COM

POLL: DESCRIBE YOUR 2026 TANGO2 FAMILY CONFERENCE EXPERIENCE

Scan to tell us in a few words about your conference experience.

THANK YOU

Richard & Phyllis
MURRAY

Our travel stipend program is made possible by the RP Murray Memorial Fund in memory of **Richard and Phyllis Murray**, grandparents of Ryan Morris. These funds support the global TANGO2 Family in their work to better understand and treat this disease by making it possible for them to attend the TANGO2 Family Conferences.

ultragenyx

Special thanks to Ultragenyx for your commitment and support of our families. Ultragenyx is committed to supporting initiatives that provide impactful resources for the rare disease community, healthcare education, STEAM education, and local community organizations.

UPMC
LIFE CHANGING MEDICINE

Special thanks to UPMC for your commitment and support of our families. UPMC has been a proud sponsor of the TANGO2 Research Foundation since 2022.

JOURNEYS

THAT SHAPE THE FUTURE:

THE TANGO2

NATURAL HISTORY STUDY

TANGO2 RESEARCH
FOUNDATION

In partnership with

Baylor
College of
Medicine

Together, we can deepen our understanding of TANGO2 deficiency disorder and drive progress toward **better treatments and a cure.**

WHY IS PARTICIPATION CRITICAL?

Supported by the TANGO2 Research Foundation, this study aims to enhance our understanding of TANGO2 deficiency disorder progression over time, offer opportunities to improve clinical care, establish comprehensive treatment guidelines and ultimately find a cure.

WHO CAN PARTICIPATE?

Any individual diagnosed with TANGO2 deficiency disorder and/or 22q.11.2 Deletion Syndrome.

WHAT WILL PARTICIPANTS BE ASKED TO DO?

- Parents and guardians of individuals diagnosed with TANGO2 deficiency disorder and/or 22q.11.2 Deletion Syndrome will be asked to complete an in-depth interview about their TDD journey with a clinician researcher.
- Send medical records of the individual diagnosed with TANGO2 deficiency disorder and/or 22q.11.2 Deletion Syndrome to the study team.
- Update the study team annually via survey.

FOR MORE INFORMATION AND TO ENROLL
EMAIL SERGIO ESPINOSA-ALVAREZ & JULISSA CASTRO AT
TANGO2.RESEARCH@BCM.EDU **or Visit El Paso 1 & 2**

TANGO2
VEGGIE METER READINGS

TANGO2 RESEARCH FOUNDATION

In partnership with

MONTCLAIR STATE UNIVERSITY

Baylor College of Medicine

VEGGIE METER INTRODUCTION

What is a Veggie Meter?

The Veggie Meter is a small, portable, noninvasive device that measures skin carotenoid levels, an indicator of fruit and vegetable intake. It works via reflection spectroscopy, shining a white LED light into a person's fingertip to measure carotenoids. Carotenoids are natural pigments found in colorful fruits, vegetables, and leafy greens such as carrots, spinach, and sweet potatoes, that accumulate in the skin with regular consumption.

During the screening, an individual places a sanitized finger into the device for a few seconds while a reading is taken. The measurement is repeated three times to ensure accuracy, and the results are averaged to generate a final Veggie Meter score.

Image source: https://www.louisianafitkids.com/Home/VeggieMeter

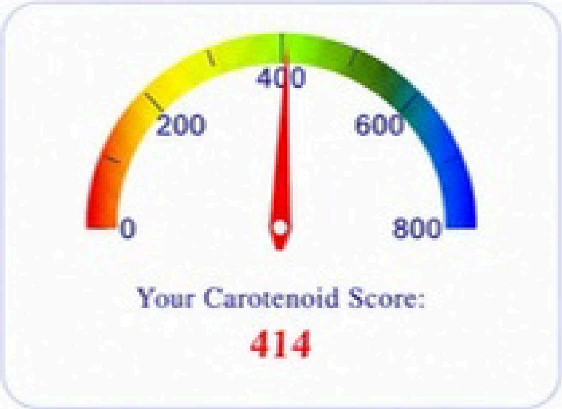
UNDERSTANDING VEGGIE METER SCORES

What does the Veggie Meter score tell us?

Using the Veggie Meter®, three scans will be taken on your non-dominant index finger. After each scan, a dial gauge and a score will appear on the screen. Your final score, calculated as the average of the three scans, will range from 0 to 800.

Research suggests that a veggie meter score between 280 and 480 reflects adequate fruit and vegetable intake. Each 100 unit increase corresponds to about one additional serving (cup)/day of fruits and vegetables consumed.

If your score falls in the red, orange, or yellow areas, you should consider incorporate more fruits and vegetables in your diet. If your score is in the green or blue areas, you are doing a good job of eating a healthy amount of fruits and vegetables.



Your Carotenoid Score:
414

Image source: https://www.louisianafitkids.com/Home/VeggieMeter

TDD NATURAL HISTORY STUDY (NHS) & VEGGIE METER READINGS

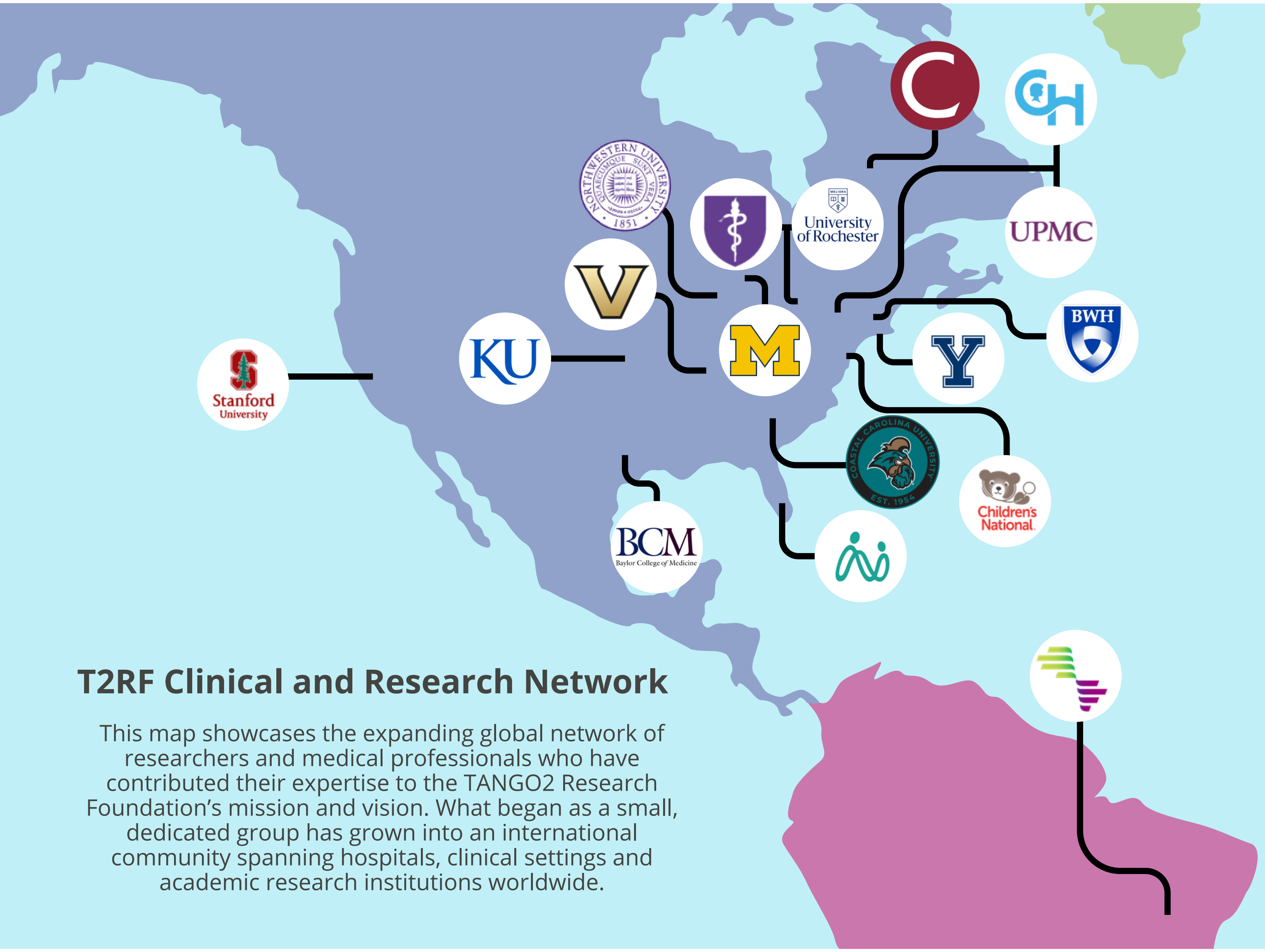
Why are Veggie Meter readings a part of the TDD NHS?

B-vitamins are important in helping reduce TANGO2 spells, metabolic crisis, cardiac arrhythmia and other symptoms. By collecting Veggie Meter data alongside clinical and nutritional information, researchers hope to better understand whether dietary patterns, nutrient status, and other nutrition-related factors may influence health outcomes in individuals with TDD. These findings may help guide future research and inform evidence-based nutritional recommendations for the TDD community.

Scan to sign-up to complete a Veggie Meter reading at the 2026 TANGO2 Family Conference

FOR MORE INFORMATION AND TO ENROLL IN THE TDD NHS NUTRITION STUDY, EMAIL DR. MOUSUMI BOSE AT BOSEM@MONTCLAIR.EDU or Visit El Paso 1 & 2

OUR GLOBAL SCIENCE, DISCOVERY

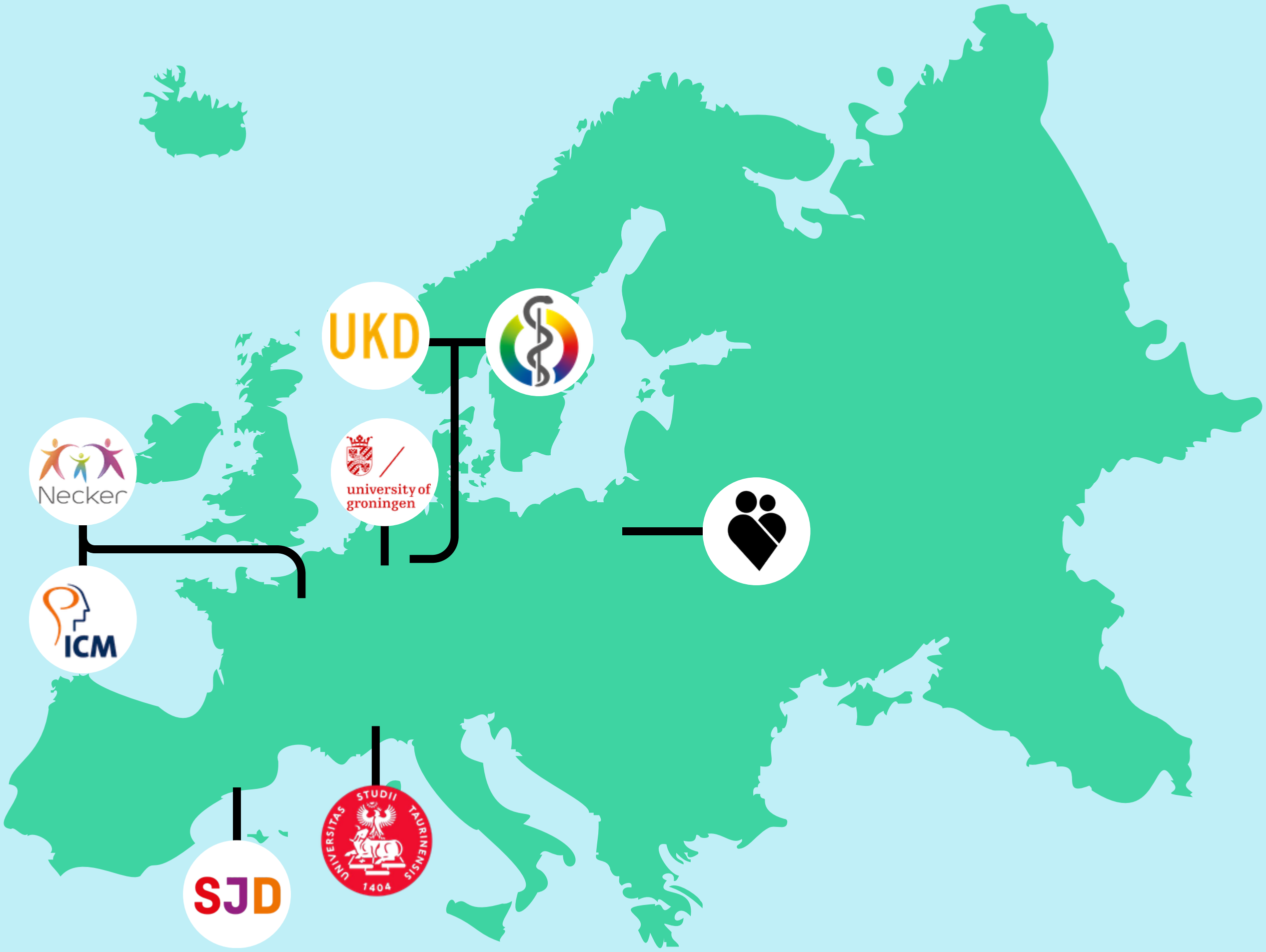


T2RF Clinical and Research Network

This map showcases the expanding global network of researchers and medical professionals who have contributed their expertise to the TANGO2 Research Foundation's mission and vision. What began as a small, dedicated group has grown into an international community spanning hospitals, clinical settings and academic research institutions worldwide.

- We are rapidly expanding our international network of TDD clinicians and researchers, enhancing awareness, improving clinical outcomes, strengthening collaboration and expediting progress.
- Currently, there are about 150 TDD publications on cardiac risk, metabolic crises & natural history that has been supported by T2RF-funded investigators, natural history study data, and/or T2RF facilitated collaborations.
- TDD Natural History Study insights, published in 2023, has been cited over 44 times in peer-reviewed literature.
- First therapeutic insights identified. Folate/B-vitamin supplementation shown to reduce risk of lethal ventricular arrhythmias (JCI Insights, 2024).

AND RESEARCH FOOTPRINT



- T2RF has supported the development of the following preclinical models; C.elegans (worm), zebrafish, drosophila (fruit fly), mouse, and induced pluripotent stem cells (iPSCs) cells.
- In partnership with Baylor College of Medicine the foundation established a global, 24/7, peer-to-peer TDD clinical consult hotline. 15 warrior lives have been saved to date.
- Multidisciplinary working groups, including TDD families, neurologists, cardiologists, geneticists, and other healthcare professionals with direct experience caring for TDD warriors, conducted a structured, modified Delphi consensus process to develop practical TDD acute care clinical guidelines.
- Since its inception, T2RF has invested more than $1.3 million in TDD research, directly supporting 33 projects led by 38 researchers across 29 academic institutions in 9 countries.

WWW.TANGO2RESEARCH.ORG