TANGO2RESEARCH
FOUNDATION

ANNUAL REPORT 2025

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Our Mission

to lead the way in finding a cure for TANGO2 deficiency disorder

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ANNIE

Our Vision

- Accelerate research and therapeutic discoveries
- Advocate and promote awareness
- Support and connect families
- Drive early and accurate diagnosis

Dear Friends & Supporters,

On behalf of the Board of Directors, Foundation staff, and volunteers, we are proud to share some of the highlights and successes of the TANGO2 Research in 2025.

This year marks the Foundation's eighth anniversary as well as a milestone moment in our journey. We are thrilled to announce that we have surpassed $1.1 million in direct research funding, supporting more than 30 researchers across 23 institutions in 9 countries.

But the real story, the one that humbles and motivates us, is that these efforts are working. They are making a tangible difference in the lives of families around the world!

Our progress demonstrates the power of a small but deeply committed community. Families, researchers, clinicians, staff, volunteers, and supporters have come together to drive change measured not in decades, but in just a few short years. The B-vitamin story continues to lead the way as we explore new therapeutic options, raise awareness, promote earlier diagnosis, and deepen global understanding of TANGO2 Deficiency Disorder (TDD).

In 2025, the Foundation expanded financial support for the TANGO2 Natural History Study, launched the TANGO2 Clinician Consult Hotline in partnership with Baylor College of Medicine, continued with Cycle Five Grant Funding and hosted the TANGO2 Innovation Summit in Houston, Texas. The Summit was a particularly meaningful milestone, marking the first time leading TANGO2 experts from around the world gathered in person to collaborate on advancing care and research.

As we look ahead to 2026, we are inspired by what this dedicated community continues to accomplish in pursuit of helping every TDD warrior live their best possible life!

With gratitude,

Mike & Kasha Morris

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SHINE A LIGHT

Our annual community-wide Shine a Light on TANGO2 campaign raised **$107,000**. The biennial Connecticut TDD Banquet raised **$38,000**.

$720,534

Raised since 2017

FUELING RESEARCH

The Foundation has funded **26** investigator led TANGO2 Deficiency Disorder research initiatives, driving innovation & discoveries, bringing us closer to fulfilling our mission of finding a cure.

>$1,100,000

Invested in TDD Research

IN THE NEWS

TDD warrior, John Martinez was featured on KDKA-TV Talk Pittsburgh, where he shared his journey living with TDD. He is cared for by **Dr. Lina Ghaloul-Gonzalez**, a valued T2RF clinician researcher and Research committee member at University of Pittsburgh Medical Center.

TDD RESEARCH LEARNING NETWORK

Our Research Learning Network is a shared virtual platform to connect our global TDD community of families and healthcare providers. The RLN has **97** members from **12** countries & counting.

75 **Conversations**

COMMUNITY GROWTH

The larger our community, the stronger we become. Our global network now connects around **240** families, along with many healthcare professionals and volunteers.

>40

New Family Members

INNOVATION SUMMIT

The Foundation hosted a group of TANGO2 clinican-researchers in Houston, TX to collaborate, develop & standardize best practices and ultimately publish evidence-based TDD acute care clinical guidelines.

25

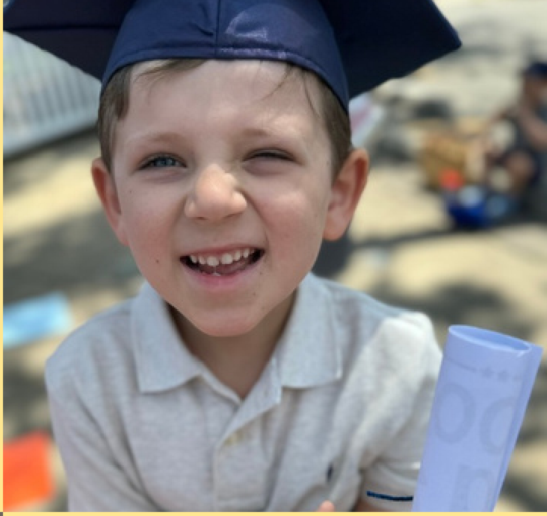
Innovators Engaged

BUILDING A GLOBAL COMMUNITY

Our work is powered by a global TDD community, with support from donors across more than **14** countries.

>1,100

Donations



A SEASON OF GIVING

Thanks to your incredible generosity, we surpassed and tripled our **$10,000** goal during the holiday season, to fuel research and innovation. Together, we made an extraordinary impact!

$34,764 **Raised**

DIGITAL CONTENT

The TANGO2 Research Foundation is proud to offer an array of resources to our TDD community. This year, we released a series of **5** genetic explainer videos and **26** YouTube videos.

508,000

Views

EARLY AND ACCURATE DIAGNOSIS

As our community continues to spread awareness, educate and provide support we are shortening the diagnostic odyssey for new families, significantly improving warrior outcomes.

44 **New Diagnoses**

BUILDING CAPACITY

The TANGO2 Research Foundation is growing! With the addition of many new volunteers & committee members, we're expanding our reach and increasing our impact to better serve the TANGO2 community.

12

New Committee Members

LEADING THE CONVERSATION

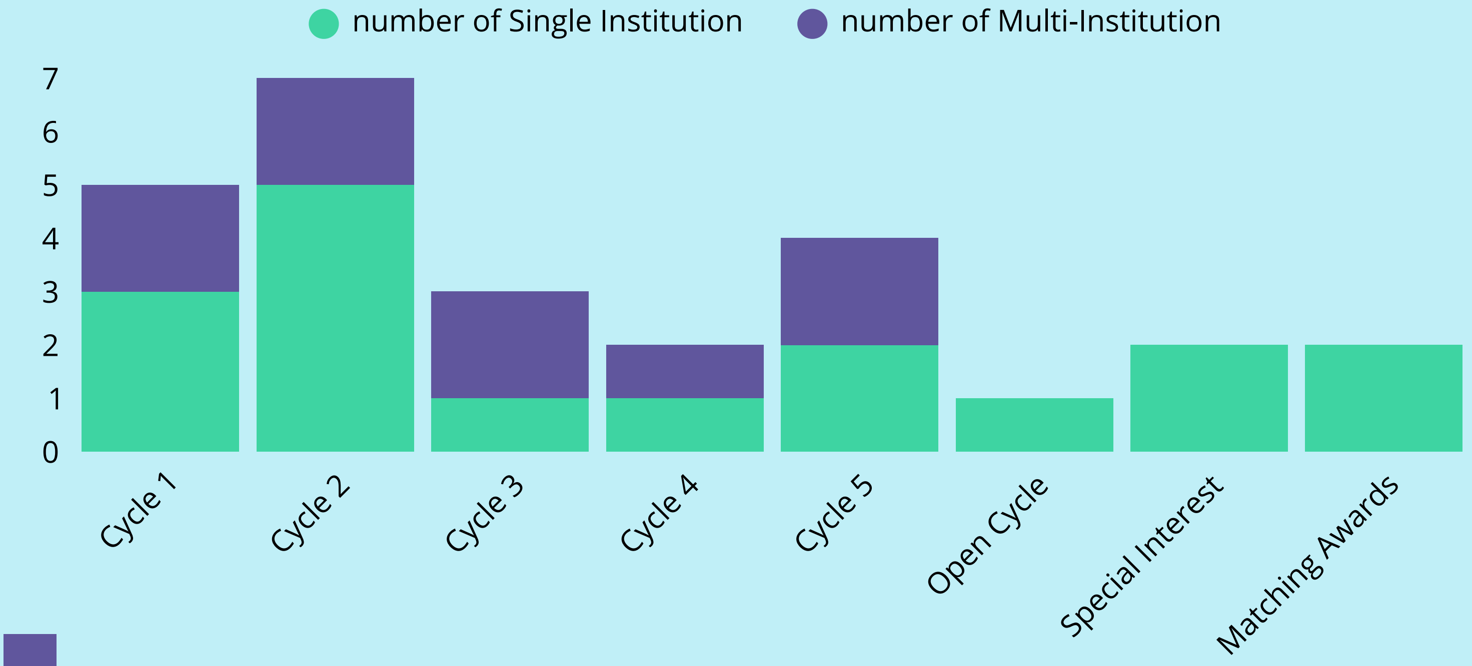
Our conference engagement nationwide helps accelerate learning, collaboration, and progress in TANGO2 research and care.

8

Events Attended

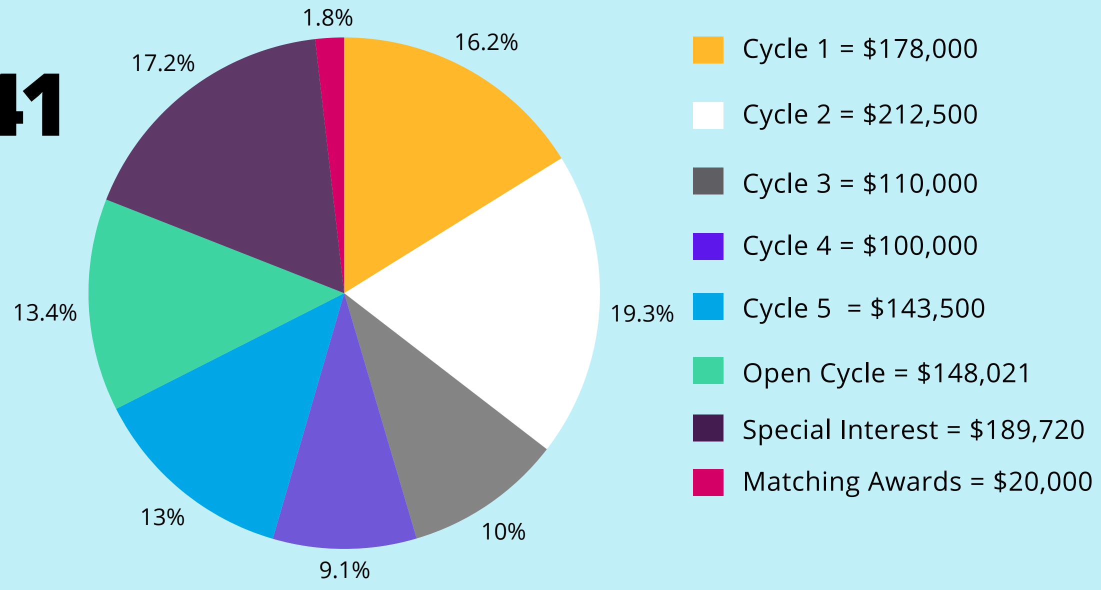
OUR IMPACT

Research Initiatives Funded (2017-2025)



Summary of Research Funded (2017-2025)

$1,101,741



Other Research Expenditures (2017-2025)

$39,584

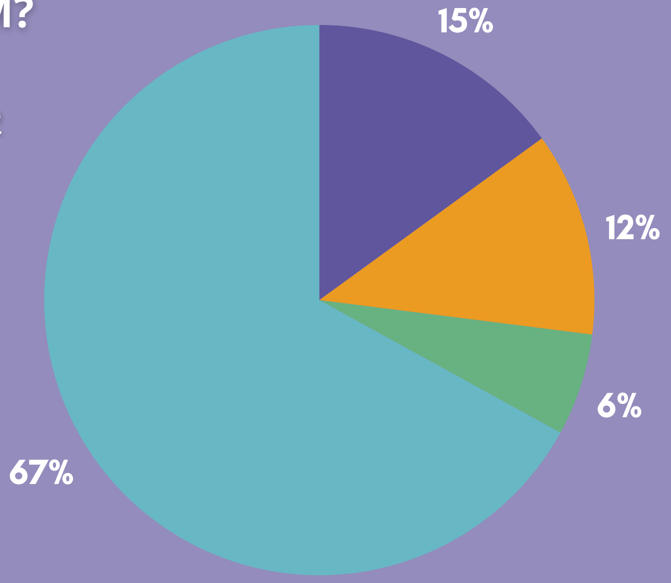
- Researcher equipment, materials, publications, and travel
- Strategic Investments

FOUNDATION FINANCES

The TANGO2 Research Foundation is dedicated to financial transparency and ensuring that every dollar supports our mission to **advance research, empower families, and foster meaningful connections** within our community. These percentages reflect our steadfast commitment to impactful programming, sustainable operations, and direct support for families.

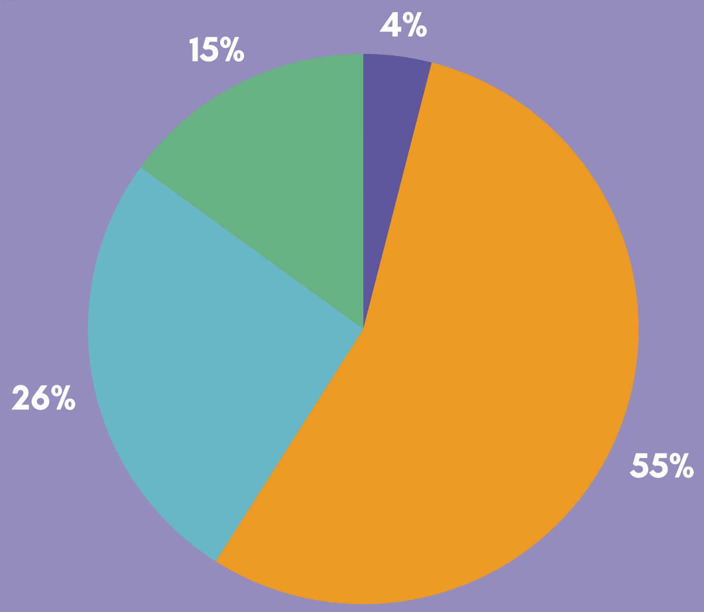
REVENUE: WHERE DOES IT COME FROM?

- 🟪 Grassroots Fundraising from the Community (Shine a Light on TANGO2 campaign/TANGO2 Banquet)
- 🟧 Institutional Grant Support
- 🟦 Personal Donations from Families & the greater TANGO2 Community
- 🟩 Corporate Sponsorship/Matching

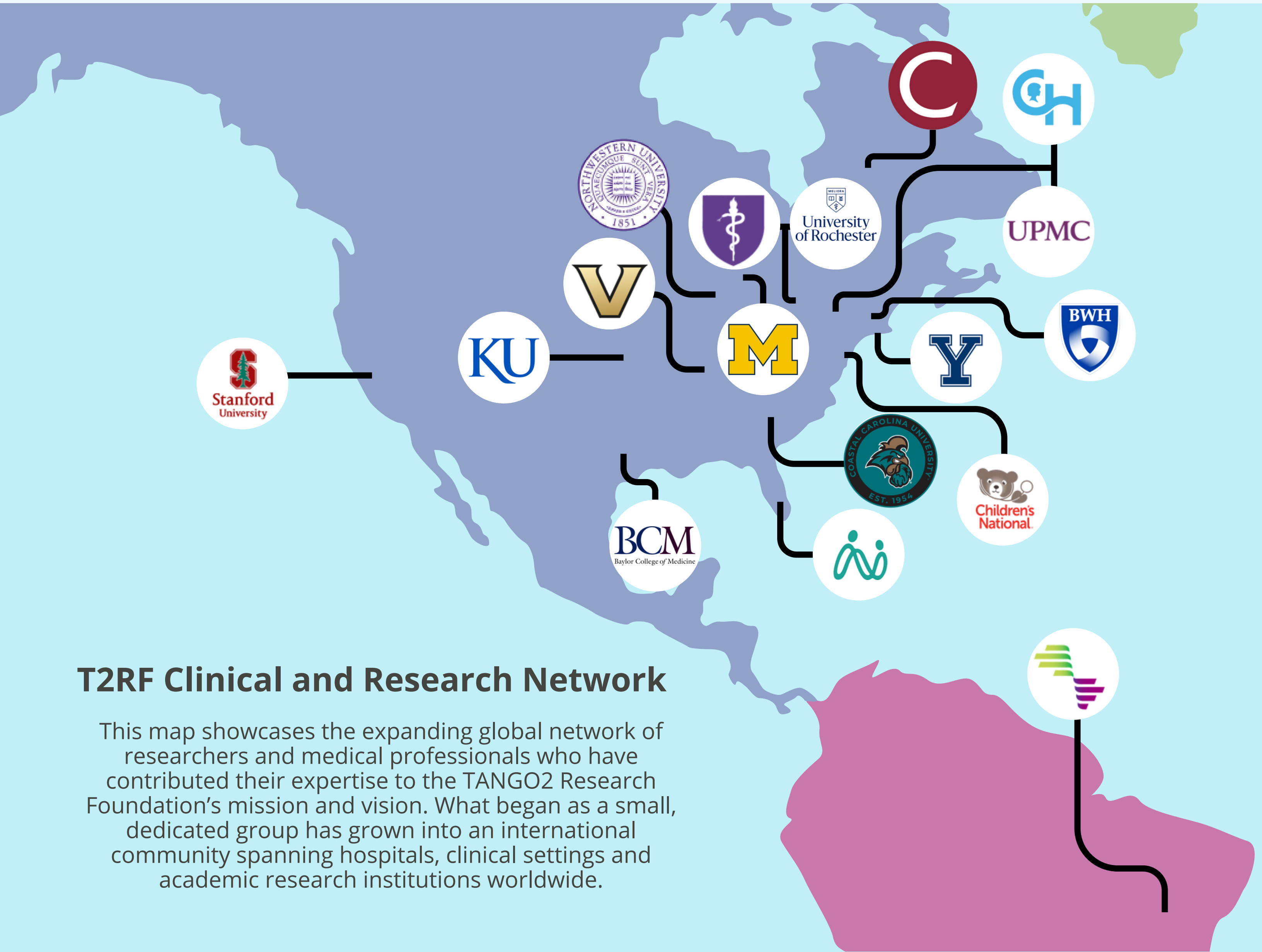


EXPENDITURES: WHERE DOES IT ALL GO?

- 🟪 **T2RF Events**: The TANGO2 Family Conference & Innovation Summit
- 🟧 **Family Support, Programs:** To facilitate all activities that support the foundation's mission and vision
- 🟦 **Research Initiatives**: Foundation grant awards, Special Interest Projects (Natural History Study & Uplifting Athletes) & PCORI
- 🟩 **Infrastructure and Operational Support** Essential costs ensuring our foundation operates efficiently, enabling us to maximize impact and sustain our mission



OUR GLOBAL SCIENCE,DISCOVERY

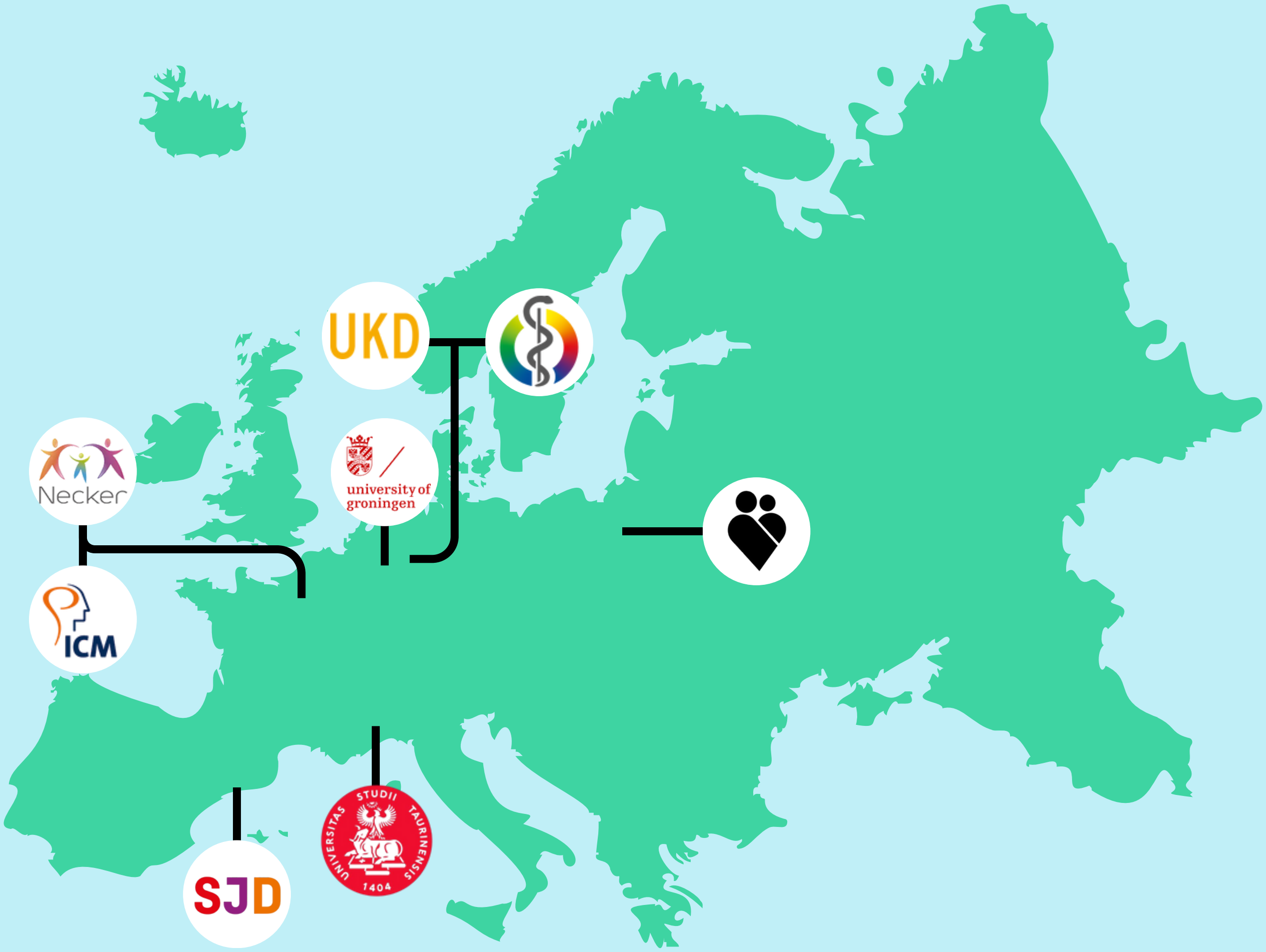


T2RF Clinical and Research Network

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.

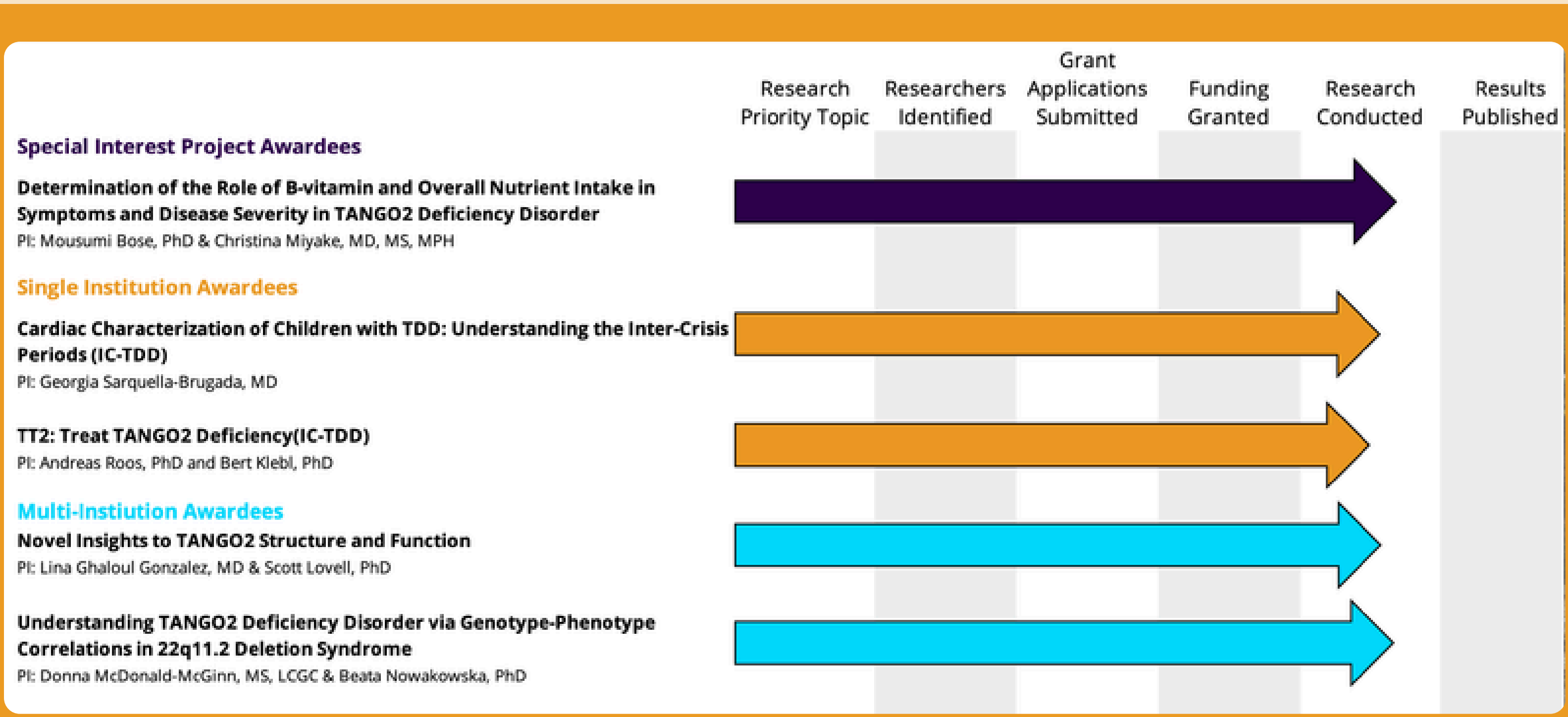
- We are rapidly expanding our international network of TDD clinicians and researchers, enhancing awareness, improving clinical outcomes, strengthening collaboration and expediting progress.
- Currently, there are about 150 TDD publications on cardiac risk, metabolic crises & natural history that has 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. 13 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 million in TDD research, directly supporting 26 projects led by 30 researchers across 23 academic institutions in 9 countries.

CURRENTLY FUNDED RESEARCH



Special Interest Project Awardees

Determination of the Role of B-vitamin and Overall Nutrient Intake in Symptoms and Disease Severity in TANGO2 Deficiency Disorder
PI: Mousumi Bose, PhD & Christina Miyake, MD, MS, MPH

Single Institution Awardees

Cardiac Characterization of Children with TDD: Understanding the Inter-Crisis Periods (IC-TDD)
PI: Georgia Sarquella-Brugada, MD

TT2: Treat TANGO2 Deficiency(IC-TDD)
PI: Andreas Roos, PhD and Bert Klebl, PhD

Multi-Instiution Awardees

Novel Insights to TANGO2 Structure and Function
PI: Lina Ghaloul Gonzalez, MD & Scott Lovell, PhD

Understanding TANGO2 Deficiency Disorder via Genotype-Phenotype Correlations in 22q11.2 Deletion Syndrome
PI: Donna McDonald-McGinn, MS, LCGC & Beata Nowakowska, PhD

RESEARCHER'S CORNER:
UPDATE ON PREVIOUSLY FUNDED T2RF RESEARCH

Project Name: Remote Assessment of Abnormal Movements in TANGO2 Deficiency Disorder
Project Principal Investigators: Samuel Mackenzie, MD, PhD, Jennifer Vermilion, MD, Angela Hewitt, MD, PhD and Jonathan Mink, MD, PhD
Funding Cycle: 2
Project Duration: 2022 - 2023
Project's Results: The teams at the University of Rochester and Baylor College of Medicine have been finalizing their project on characterizing movement disorders in TANGO2 deficiency disorder, as part of the ongoing TDD natural history study. A total of 26 participants were enrolled (thank you to those who participated!), and 23 caregivers completed follow-up interviews. They found that dystonia, ataxia, and "TANGO2 spells" are common, early manifestations of TDD and frequently occur before metabolic crisis, offering a potential opportunity for early diagnosis. They also looked at the effects of vitamin supplementation based on caregiver report and found that most patients experienced improvements or outright cessation of movement symptoms with supplementation. They are hoping to submit a manuscript for publication in early 2026, so stay tuned for these results!


OTIS

Visit our website at www.tango2research.org to learn more about T2RF funded research and upcoming grant opportunities.

ADVANCING TOMORROW'S DISCOVERIES: EMERGING RESEARCH INNOVATORS


HELOISA

OUR RESEARCH

Vandana Gupta, PhD, of Brigham and Women's Hospital, Inc., T2RF Scientific Advisory Board member & past T2RF grantee is working on developing therapies for neuromuscular diseases using small-molecule-based approaches and gene-targeting strategies. Her team is working on identifying small molecules in TDD to prevent and reverse the disease in affected warriors. Dr. Gupta has recently been awarded a grant, *Genetic and Extrinsic Mechanisms in Metabolic Myopathies,* from the Muscular Dystrophy Association. This project will define how genetic vulnerabilities and extrinsic stressors converge to drive metabolic dysfunction and will identify key biomarkers and therapeutic targets in TDD and related disorders. The work will also evaluate TANGO2 gene-replacement therapy using AAV-based vectors as a preclinical therapeutic strategy for TDD. Together, these efforts aim to accelerate treatment development and improve disease management for individuals living with TDD and related disorders.

What is AAV (Adeno-Associated Virus) therapy? A type of gene therapy that uses a harmless virus to deliver a healthy copy of a gene into a patient's cells. The virus acts as a carrier, helping the body produce a missing or faulty protein that is needed for normal function. This approach aims to treat the underlying cause of a genetic condition rather than just managing symptoms.

This approach aims to treat the underlying cause of a genetic condition rather than just managing symptoms.


DR. VANDANA GUPTA

> ***"My motivation for this work comes from close interactions with TDD families. I'm deeply committed to translating basic discoveries into therapies. My hope is that this work will not only identify actionable therapeutic strategies but also provide families & clinicians with clearer guidance for disease management and long-term care."***
>
> ***- Vandana Gupta, PhD***


LAUREN PEACOE

Lauren Peacoe, is a Neuroscience PhD student at Baylor College of Medicine in Houston, Texas. She conducts her research in the Sillitoe Lab, where discoveries continue to establish the cerebellum, a part of the brain that controls movement, as an origin of diseases including dystonia, tremor, and ataxia.

TANGO2 Deficiency Disorder causes serious movement challenges, including muscle stiffness, tremors, poor balance, and seizures, which can worsen suddenly during "TANGO2 spells." Driven by a commitment to rare neurodevelopmental research, Lauren's work uses a TANGO2 knockout mouse model to identify when and how these brain disruptions begin and how harmful signaling may be reversed. By combining brain recording techniques, behavioral studies, and targeted interventions such as deep brain stimulation, her research aims to uncover the neural mechanisms behind motor dysfunction and explore potential therapeutic strategies for individuals living with TDD.

RESEARCH DIRECTOR'S MESSAGE

This year marks a pivotal moment in the history of the TANGO2 Research Foundation. Since our inception in 2018, we have remained deeply committed to our mission: to accelerate scientific discovery, improve patient care, and ultimately find a cure for TDD. Today, we are proud to share that we have crossed an extraordinary milestone, more than **one million dollars** invested directly into TDD research! Reaching this milestone reflects not only the urgency of our work, but the strength and unity of our global TDD community. In just a few short years, the landscape of TDD research has transformed. What was once an unexplored and poorly understood condition now has a growing body of high-quality, diverse scientific studies supporting it. Our funded projects span a wide range of critical areas, including basic science, clinical characterization, neurology, cardiology, metabolic research, natural history development, biobank expansion, and cutting-edge therapeutic exploration. This diversity has ensured that progress is not limited to a single path, but instead advances across the entire spectrum of what TDD warriors and families need. Because of these investments, we have:

- Improved understanding of metabolic crises, movement disorders, and cardiac risks.
- Strengthened diagnostic tools and clinical awareness across multiple specialties.
- Advanced preclinical studies that move us closer to future treatments.
- Built the early infrastructure needed for clinical trials, including data, biospecimens, and expert collaboration.
- Fostered a global network of scientists, clinicians, and families who are aligned and commited to driving solutions forward.

I am deeply grateful for the opportunity to lead the Foundation's strategic vision and research activities over the last three and a half years. Thank you to the TDD community for your trust and for believing in the direction needed to move this work forward. Your support has made this progress possible. The impact of this work can already be felt among clinicians, researchers, and most importantly, families. Yet our progress is also a reminder: we are just getting started!

As we look ahead, the path to better treatments, and ultimately a cure, relies on continued partnership with our community. Your involvement, your advocacy and your financial support are what makes this momentum possible. Every donation, every shared story, and every act of engagement fuels the next breakthrough. Your belief in this mission is what brings us closer to the cure our community deserves.

The next phase of TDD research is about building on our momentum and pushing forward with urgency and purpose. By accelerating high-impact studies across science, clinical care, and therapeutic development, we are laying the groundwork for real breakthroughs. Hope is no longer abstract, we are actively shaping it through the research we drive every day.

"As we enter the next phase of TDD research, our work is accelerating faster than ever. Every study we fund brings us closer to the answers families urgently need, & each new discovery strengthens our optimism for meaningful treatments, and ultimately a cure. This momentum is real, & it's carrying us toward a future where TDD no longer defines what is possible for our loved ones."

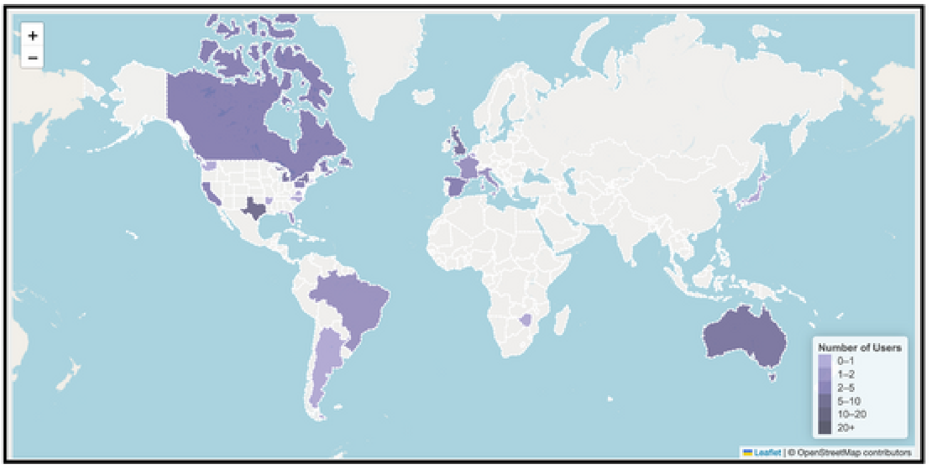
- Deena Chisholm

A GLOBAL HUB FOR COLLABORATION: THE TANGO2 DEFICIENCY DISORDER RESEARCH LEARNING NETWORK

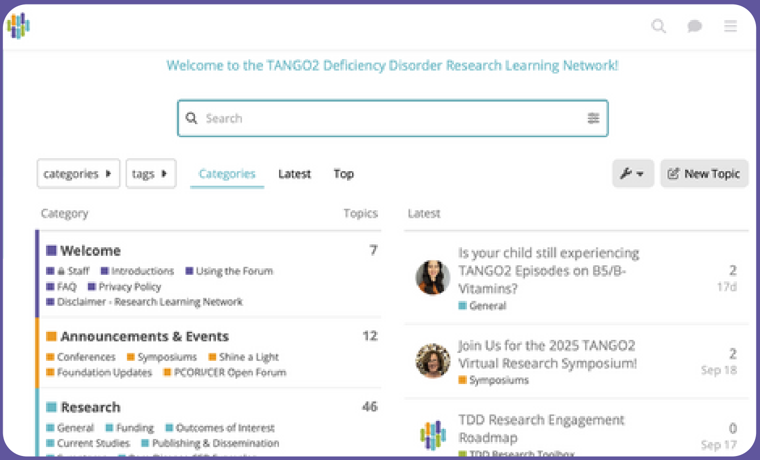
Every new discovery in TANGO2 research brings new questions, like the one many families now ask: “How much B vitamins should my TDD warrior take?” The Research Learning Network (RLN) has become the heart of our community, uniting researchers, clinicians, families, and warriors from around the world. More than a forum, it’s a living network where ideas are shared, questions spark breakthroughs, and collaboration drives hope forward.

A centerpiece of the RLN is its interactive global heat map, a live tool that showcases the diverse and growing network of members. By visually connecting participants across continents, the heat map highlights both the breadth of our community and the shared commitment to advancing care and research. Members can easily connect with others in their region, spark collaborations, and see firsthand the worldwide impact of this effort.

Learn more and join the TDD RLN by scanning the QR code



Together, the RLN and its global network demonstrate the power of community in advancing TANGO2 research and care. By connecting families, clinicians, and researchers across the world, we are accelerating discoveries, fostering collaboration, and most importantly, bringing hope and improved outcomes to every TDD warrior.



Welcome to the TANGO2 Deficiency Disorder Research Learning Network!

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REEM

OUR PROGRESS

JOSEPH

OUR PROGRESS

IS YOUR TANGO2 WARRIOR TAKING THE RIGHT B VITAMINS?

In 2025, one of our ongoing challenges remains helping families understand the importance of ensuring their TANGO2 warrior receives the right B-vitamin formulation.

Since the publication of the TANGO2 Research Foundation funded B-vitamin breakthrough, we have continued to hear firsthand accounts of TANGO2 warriors experiencing preventable symptom complications. Unfortunately, many in our community are still not taking the correct B-vitamin complex. B-vitamin complexes are, by nature, complex. Understanding product labels, formulations, and dosages can be confusing and overwhelming.

Families often ask: *How do I know if my TANGO2 warrior is getting the right amount of vitamin B5 and B9? Are all B-vitamin complexes the same? Can these vitamins be given separately?*

To help answer these important questions, the next section offers a simple guide on how to read a vitamin label and ensure your TANGO2 warrior is receiving the optimal support:

- **Check the ingredient list.** Look for vitamin B5 (pantothenic acid) and vitamin B9 (folate) not “folic acid.” Folate is the natural, more active form that the body can use effectively.
- **Review the dosage amounts.** Compare the label’s dosage (usually listed in milligrams or micrograms) to the recommendations provided by your clinician. Too much or too little can impact effectiveness and safety. Data from the TANGO2 Natural History Study suggest that many TDD warriors benefit from a B-complex supplement containing at **least 400 mcg (0.4 mg) of folic acid (B9)**, with some safely taking up to **1 mg daily**. **Vitamin B5 doses also vary widely**, with TDD warriors showing improvement at amounts from **10 mg up to 500 mg or more, tailored to individual needs**. Always make sure to take the serving size listed in the nutritional information into account, as **one serving does not always equal one unit (gummy or capsule)**, and may actually mean two.
- **Check for quality and certification.** Choose vitamins that are third-party tested or certified for purity and potency (for example, NSF, USP, or GMP labels). This ensures you’re getting what’s on the label, and nothing extra your TANGO2 warrior doesn’t need
- **Look for “B-complex” formulations that specify individual vitamin amounts.** Not all complexes are created equal. Some brands include only trace amounts of key B vitamins, while others provide balanced, therapeutic doses.
- **When in doubt, ask.** Bring the label to your healthcare provider to confirm that it meets your TANGO2 warrior’s specific needs.

SHIFTING THE CLINICAL LANDSCAPE FOR IMPROVED TANGO2 WARRIOR HEALTH OUTCOMES

OUR PROGRESS

In May 2025, the TANGO2 Research Foundation partnered with Dr. Samuel Mackenzie, Board member and Chair of the TANGO2 Research Foundation Scientific Advisory Board (SAB), to convene leading TDD experts from some of the most prestigious institutions worldwide in a collaborative initiative aimed at improving acute care outcomes for TDD warriors. This effort focuses on developing evidence-based clinical guidelines for managing metabolic crises and other acute complications in the inpatient setting.

Currently, there is no published literature or established best practices for caring for TDD warriors during acute hospitalizations. The resulting knowledge gaps among healthcare professionals often leave warriors vulnerable, leading to prolonged hospital stays, suboptimal treatment, worsening symptoms, and, in some cases, life-threatening outcomes. Addressing these gaps is critical to ensuring that TDD warriors recieve timely, evidence-based care during medical crises. Healthcare professionals collaborated in focused working groups to review the literature, co-develop clinical care recommendations, and convene at the in-person TANGO2 Innovation Summit at Baylor College of Medicine. The Summit brought together 22 healthcare professionals and TDD family members, fostering rich dialogue, collaboration, and meaningful networking around a shared goal: improving acute care for individuals with TDD. By combining deep clinical expertise, research insight, and lived experience, participants aligned on evidence-informed, practical guidance.

The ultimate aim is to publish these recommendations in a peer-reviewed journal, equipping clinicians worldwide with the confidence and tools needed to deliver timely, life-saving care during critical episodes.

> ***"By establishing consensus guidelines, we're trying to get clinicians on the same page when it comes to treating the acute complications that come with TANGO2. It's exciting to see what we can come up with when we pool everyone's expertise together."***
>
> ***-Sam Mackenzie, MD, PhD***

Visit the our website to access healthcare professional resources under the *For Healthcare Professionals* tab at www.tango2research.org.

A LIFELINE IN CRISIS: HOW THE TANGO2 CLINICAL CONSULT HOTLINE IS SAVING LIVES

When a person with TANGO2 deficiency disorder experiences a medical crisis, every second counts. For families facing the terrifying uncertainty of cardiac arrhythmias, seizures, or metabolic crashes, immediate access to expert guidance can mean the difference between life and death. That is why the TANGO2 Research Foundation established its international 24/7 clinician consult hotline.

The TANGO2 clinician consult hotline, born from the vision of Dr. Christina Miyake, gives families immediate access to life-saving expertise during medical crises. Since its launch in July 2025, it has already saved 13 TDD warriors, turning a bold idea into real-world impact.

One family recently highlighted the vital role of the hotline. Brandi Guillet, mother of 14-year-old Connor, shared how the service helped during a near-fatal emergency. Connor was rushed to the hospital with rhabdomyolysis, ventricular tachycardia, and a metabolic stroke. In the chaos, his care team contacted the TDD clinician consult hotline, and within minutes, a TANGO2 physician expert was on speakerphone, guiding doctors and helping stabilize him. Brandi recalls the moment vividly:

> ***"In those five minutes over speakerphone, it was as if divine intervention had arrived. There was a calm, brilliant force in the chaos, and I will never forget it. It was an angel we needed that moment."***

Against all odds, Connor's recovery was nothing short of miraculous. Just three short weeks after being completely bed-bound with paralysis, he was eating, drinking, walking, and even using his wheelchair to push adults across the room.

Connor recently celebrated his 15th birthday, a milestone his family wasn't sure they would ever see. Conner and his family can now look forward to more birthdays, milestones, and miracles.

Conner's story is one of many reminders that together, with rapid response, research, and collaboration, lives can be saved, and futures can be rewritten.

TANGO2 ☎ HOTLINE

+1 (860) 598-0955

OUR PROGRESS

ROOTS AND REACH: THE EXPANSION OF FOUNDATION AFFILIATES

Our Foundation supports a growing global community with affiliate organizations. Together, we raise awareness, support families, and advance research across borders.

The Canadian TANGO2 Rare Disease Foundation (CT2RDF) founded by **Kara Cameron** is steadily building its presence within Canada's rare disease community. CT2RDF marked a successful start with over $12,000 CAD raised in its inaugural fundraising campaign as part of the global Shine a Light on TANGO2 initiative.

These funds support families in Canada and beyond, including the distribution of the newly developed T2RF TANGO2 Caregiver Guidebook. CT2RDF also advocates for families by providing access to up-to-date research, resources, and personalized guidance, advancing its mission and strengthening the TANGO2 community across Canada.

In 2024, **Tim and Hannah Driffill** founded TANGO2UK, just one year after their daughter Phoebe was diagnosed with TDD following years of health challenges and uncertain diagnoses. Inspired by the T2RF, they recognized the need for a UK-based charity to assist local families, collaborate with clinical teams, and expand fundraising and grant opportunities not accessible to overseas organizations. Within one year of establishment, TANGO2UK raised $15,000, and made a matching contribution to fund innovative research initiatives at the TANGO2 Research Foundation.

OUR COMMUNITY

The founders of TANGO2UK, CT2RDF, and TANGO2 Australia also serve on the T2RF's Board of Directors, as well as the Research and Outreach Committees, strengthening collaboration across organizations & helping advance the Foundation's mission globally.

The TANGO2 Research Foundation welcomes the launch of TANGO2 Australia, a nonprofit founded by Australian families affected by TDD. Its mission is to support individuals and families, advance research, and raise national awareness. With approximately 20 known families in Australia, TANGO2 Australia will serve as a local hub, strengthening global collaboration while providing region-specific support, education, and fundraising efforts.

TANGO2 Australia is currently pursuing national charity accreditation and developing its first website, expected to launch in 2026. The TANGO2 Research Foundation celebrates this milestone and looks forward to collaborating closely with TANGO2 Australia in our shared commitment to improving the lives of those impacted by TDD.

COMMUNITY-WIDE CAMPAIGNS

SHINE A LIGHT ON TANGO2

Special thanks to top fundraisers:

Top Team Captain: Kalee Hanley
Top Fundraiser: Veronica Jones-Swetek
Community Champion: Amanda Hull
TANGO2 Heroes: Carley Way, Matt Dort, & Eileen Hanley
TANGO2 Champions: Kara Cameron, Jordan & Amanda Taggart, Kaitlyn Fryar, & Giorgio Pochettino

The TANGO2 Research Foundation's fifth annual Shine a Light on TANGO2 campaign raised over $107,000 USD to advance TDD research. From February through June, our community came together to generate critical funding that fuels scientific progress and advocacy. T2RF extends its sincere gratitude to all participants and looks forward to continued partnership in driving its mission forward.

The **Wilson family** and **Roger Gates** organized the 2nd Annual **Jim Wilson** Memorial Golf Outing, which brought in $5,000+ USD in support of our mission.

The **Galland family** hosted the 1st Annual Splash & Dash at Big Rivers Waterpark in New Caney, TX, honoring their daughter **Megan.** 247 participants helped raise $11,000 USD.

TYLER & KATIE

OUR COMMUNITY

This year's TANGO2 Banquet & Auction, hosted by Foundation co-founders **Kasha** and **Mike Morris,** was a resounding success, bringing together 170 guests for an evening defined by connection, generosity, and hope. The event was made possible by an extraordinary team; **Cindy Schaller, Joanne Barmasse, Lynn MacDonald, Sharon Owen, Jodi & London Brazal, Beth Kelpen, Stacey Gibson, Chris Miller, Donna Goodspeed, Jo Schultz, Kaitlyn Morris, Joyce Lombardi,** and **Cary & Carl Provencher**—whose tireless efforts brought every detail to life, from venue selection and décor to sponsorships, auctions, and raffles.

The community responded with overwhelming kindness, raising more than $38,000 USD this year to directly accelerate research and strengthen family support. To date, these banquets have collectively raised over $200,000, providing vital funding for life-saving research for TANGO2 warriors worldwide. We are deeply grateful for the countless volunteer hours and the unwavering spirit of our community that continue to drive meaningful progress for our families.


YUITO

OUR COMMUNITY

RESOURCES FOR EVERY JOURNEY

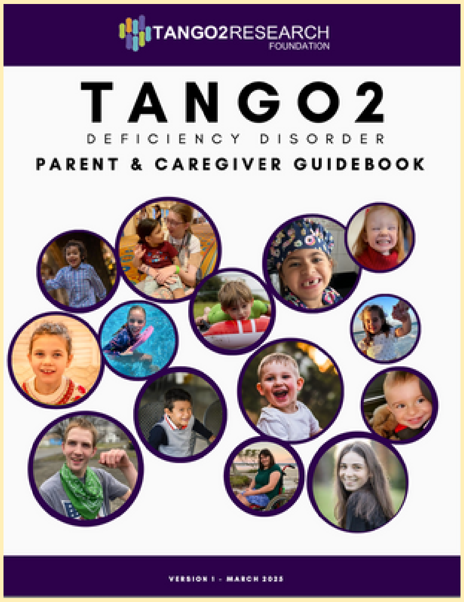
TANGO2 TALKS

In 2025, the Outreach Committee continued to strengthen its commitment to fostering connection,communication, and support within the TANGO2 community. One of the most meaningful initiatives the committee leads is TANGO2 Talks, a virtual gathering that connects families affected by TDD.

These sessions provide a safe and supportive space for sharing experiences keep everyone informed our latest initiatives and research efforts.

In 2025, T2RF hosted three TANGO2 Talks. The talks included; timely updates, creative family sessions, Natural History Study progress and a sibling roundtable amplifying the voices of brothers and sisters of TANGO2 warriors.

In addition to hosting TANGO2 Talks, the Outreach Committee was delighted to welcome two new members: **Sheean Hughes** and **Carmel Murphy**. Their passion and dedication bring fresh energy to the committee, and their contributions will help expand the reach and impact of community programs in the year ahead.


TANGO2RESEARCH FOUNDATION

TANGO2

DEFICIENCY DISORDER

PARENT & CAREGIVER GUIDEBOOK

VERSION 1 - MARCH 2025

The T2RF Outreach Committee is proud to share a resource many families wish they had at diagnosis. A new diagnosis of TANGO2 Deficiency Disorder can feel all-consuming, with many unanswered questions. This guidebook supports newly diagnosed families with clear, accessible information about TDD, caregiver insights, treatment considerations such as B vitamins, and links to trusted resources. Most importantly, it reassures families that they are not alone and connects them to a community that understands their journey.

The T2RF thanks the **Canadian TANGO2 Rare Disease Foundation** for printing and mailing the first 100 copies to new families.

Scan this QR code to get a copy emailed to you

WE EXPRESS OUR GRATITUDE TO THOSE WHO GENEROUSLY CONTRIBUTED DONATIONS IN 2025.

$5,000+

THE GALLAND FAMILY
MATT DORT
MIKE & KASHA MORRIS
GIORGIO & RASHMI POCHETTINO
JUDITH MITCHELL
ARLENE MORRIS
VERONICA & TYSON SWETEK

$2,000+

JOYCE LOMBARDI AND GREG NICHOLSON
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JO MYCOFF-SCHULTZ
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SANDRA E EMILIO BOLZONI
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BIG RIVERS WATERPARK & ADVENTURES

MONTHLY HEROES

MARSHA JONES
SEELIN NAIDOO
JIM AND TINA ADAMS
AUBREY SWETEK
HADZIRE LIKOVIC
ROBBIE HAUG
KARA CAMERON
STEVEN BROWN
TRACI WAXMAN HUBER
PETER MORRIS
GIORGIO STEFANELLI
DIEGO DA SILVA LIMA

OUR SUPPORTERS

EXECUTIVE DIRECTOR'S MESSAGE

Every story has a beginning, and for the TANGO2 community, it begins with Sammy Lopez. As one of the first warriors described in the medical literature with TANGO2 deficiency disorder (TDD), his journey laid the foundation for our current understanding. Without Sammy, there would be no TANGO2 research, no emerging treatments, and no hope for the hundreds of families who have since received a diagnosis.

Sammy's parents, Marcie and Johnny, spent years seeking answers to his unexplained health challenges. With the expertise of Drs. Seema Lalani and Christina Miyake at Baylor College of Medicine, they ultimately received a diagnosis of TDD, a moment that changed everything. Sammy's journey brought TDD to the world's attention and inspired the vision for research, treatments, and a Foundation championed by the Morris family. More than a patient, he was a son, friend, and fighter whose resilience paved the way for discoveries that continue to help TDD warriors today. Though Sammy passed away on October 23, 2018, his legacy endures. Today, many TDD warriors are alive and some are standing, walking, and even running thanks to B-vitamin therapies informed by early discoveries. Families now have hope, hope that seizures can be managed, milestones once thought impossible may be reached, and that children can live fuller, healthier lives.

As I share the story of Sammy, I also pause to remember and recognize all of the TANGO2 angels, warriors whose lives were cut too short, but whose memory drives our urgency and determination to change the future of this rare disease.

In 2025 alone, 44 new families received a TANGO2 deficiency disorder diagnosis, and the Foundation surpassed a major milestone: over $1 million dollars in research funded since its founding. Each discovery honors Sammy's legacy of courage and hope. Looking ahead, the 2026 TANGO2 Family Conference will strengthen community bonds and share the latest research. The Foundation is has expanded globally, with affiliates in the United Kingdom, Spain, Australia, and Canada, united in the mission to bring hope, knowledge, healing and a cure to every TANGO2 family worldwide.

"Sammy's story will forever be a guiding light. His legacy continues to inspire progress as our community continues with hope for a future of new discoveries, new treatments and a cure."

Ann Geffen


BRYNLEE

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