TANGO2RESEARCH
FOUNDATION

ANNUAL REPORT 2024

PHOEBE

WWW.TANGO2RESEARCH.ORG

OUR MISSION

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

OUR VISION

Accelerate research and therapeutic discoveries

Advocate and promote awareness

Support and connect families

Drive early and accurate diagnosis

Table of Contents

TANGO2RESEARCH
FOUNDATION

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 Foundation in 2024.

The year was highlighted by the foundation's third TANGO2 Family Conference, held in Orlando at the end of June. The conference brought together over 150 attendees including families, clinicians, researchers, staff, and volunteers. We also introduced the TDD (TANGO2 Deficiency Disorder) Learning Network, a shared discussion platform that brings together all TDD stakeholders to foster communication and accelerate learning. Additionally, 48 new family members joined the community and our growing network now connects 210 families, 30-plus researchers and clinicians, and 60-plus active volunteers across the globe.

The foundation continues to push forward on the science front and funded several new projects under Grant Cycle 4 that bring our total research investment to date to over $860,000 in support of 21 researchers representing 16 different international institutions. Grant Cycle 5 is currently underway and we will surpass the $1 million mark in 2025. Additionally, we have underwritten much needed personnel support for the TDD Baylor College of Medicine natural history study.

Thank you to all the dedicated families, clinicians, researchers, staff, and volunteers who make this community such a special place! We're very optimistic that through our collective efforts, 2025 will bring new scientific understanding to TDD, expand on the amazing B-vitamin story, and continue down the path of helping all TDD patients live their best lives!

With gratitude,

Mike & Kasha Morris

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ORION

OUR COMMITTEES

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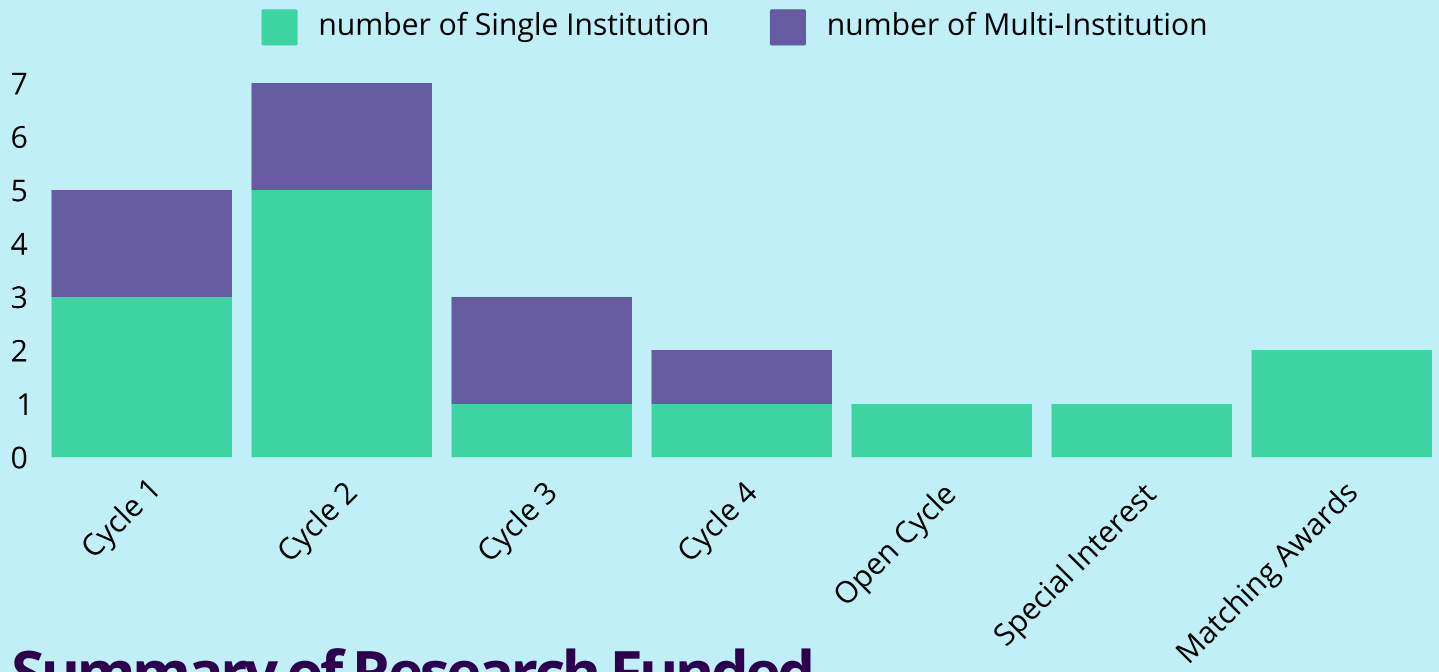
- LINA GHALOUL GONZALEZ, MD

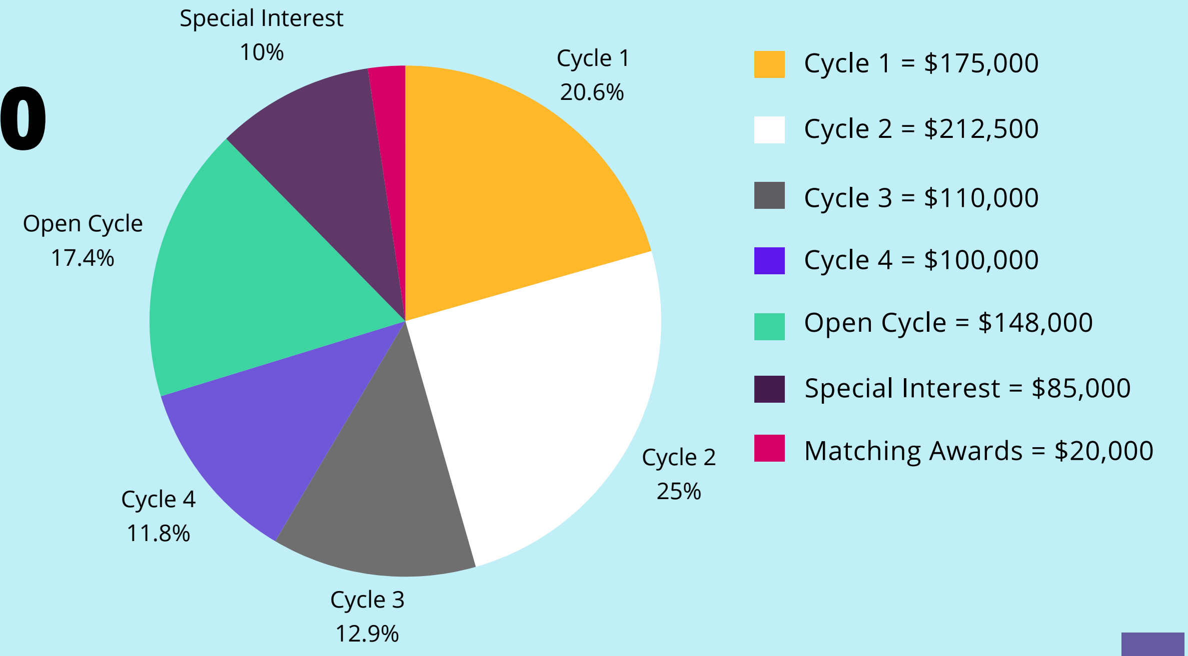
OUR IMPACT

Research Initiatives Funded (2017-2024)



Summary of Research Funded (2017-2024)

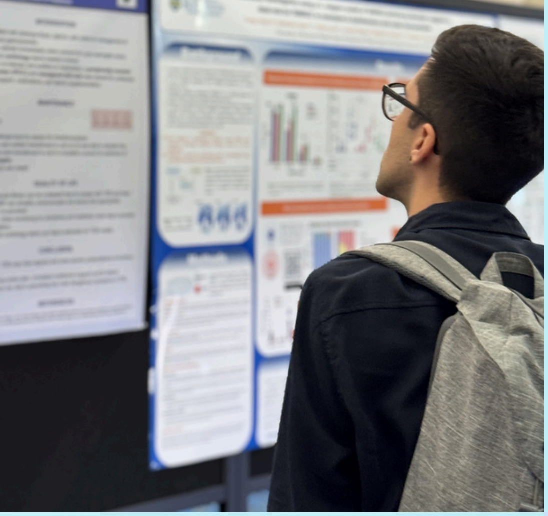
$850,500



Other Research Expenditures (2017-2024)

$50,000

- Researcher equipment and materials
- Strategic Investments: monoclonal antibody development



SHINE A LIGHT

Our annual community-wide Shine a Light on TANGO2 campaign raised **$113,000**. The biennial Connecticut TDD benefit banquet raised **$55,000**.

$400,000

Raised since 2020

FAMILY CONFERENCE

This year, T2RF hosted its **3rd** Biennial Family Conference at Disney's Coronado Springs in Orlando, FL, bringing together families, TDD warriors, and healthcare professionals to connect and collaborate.

150 Attendees

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 **8** wellness podcasts and **43** YouTube videos.

117,851 Views

TDD RESEARCH LEARNING NETWORK

In June, T2RF launched the TDD Research Learning Network, providing a shared virtual platform to connect our global TDD community of families and healthcare providers. The RLN has **50** members & counting.

29 Conversations

COMMUNITY GROWTH

The larger our community, the stronger we become. We're thrilled to see our global network expanding, now connecting with **210** families, **30** healthcare professionals & over **60** active volunteers.

48

New Family Members

FUELING RESEARCH

The Foundation has funded **21** TANGO2 Deficiency Disorder research initiatives, driving innovation & discoveries bringing us closer to fulfilling our mission of finding a cure.

$860,000

Invested in TDD research

HERO HIGHLIGHTS

In 2024, we began highlighting the many heroes in our community, from researchers and clinicians, to volunteers, family members and more. This year, we highlighted: Robin Mitchell, Joanne Barmasse, and the Driffill family.

A SEASON OF GIVING

Thanks to incredible generosity, we surpassed our $10,000 goal during the holiday season, bringing hope and support to the TANGO2 community. Together, we made an extraordinary impact!

$13,077 Raised

BUILDING A GLOBAL COMMUNITY

Our impact reaches across the globe! This year, generous contributions from supporters in over **14** countries have demonstrated the unity of our global community.

More than **1000** donations

ADVANCING RESEARCH

Dr. Christina Miyake, a T2RF research collaborator, received an NHLBI grant to study life-threatening arrhythmias in TDD and the potential of vitamin B9 (folate) supplementation as a therapy.

$800,951 awarded

BUILDING CAPACITY

The TANGO2 Research Foundation is growing! With the addition of a full-time staff member, along with many new volunteers and committee members, we're expanding our reach and increasing our impact to better serve the TANGO2 community.

IN THE NEWS

Endpoints News recognized the foundation in an article highlighting the power of patient-driven organizations in advancing research and improving outcomes. This recognition underscores the vital role our community plays in uniting families, researchers, and clinicians to drive progress and hope for TDD.

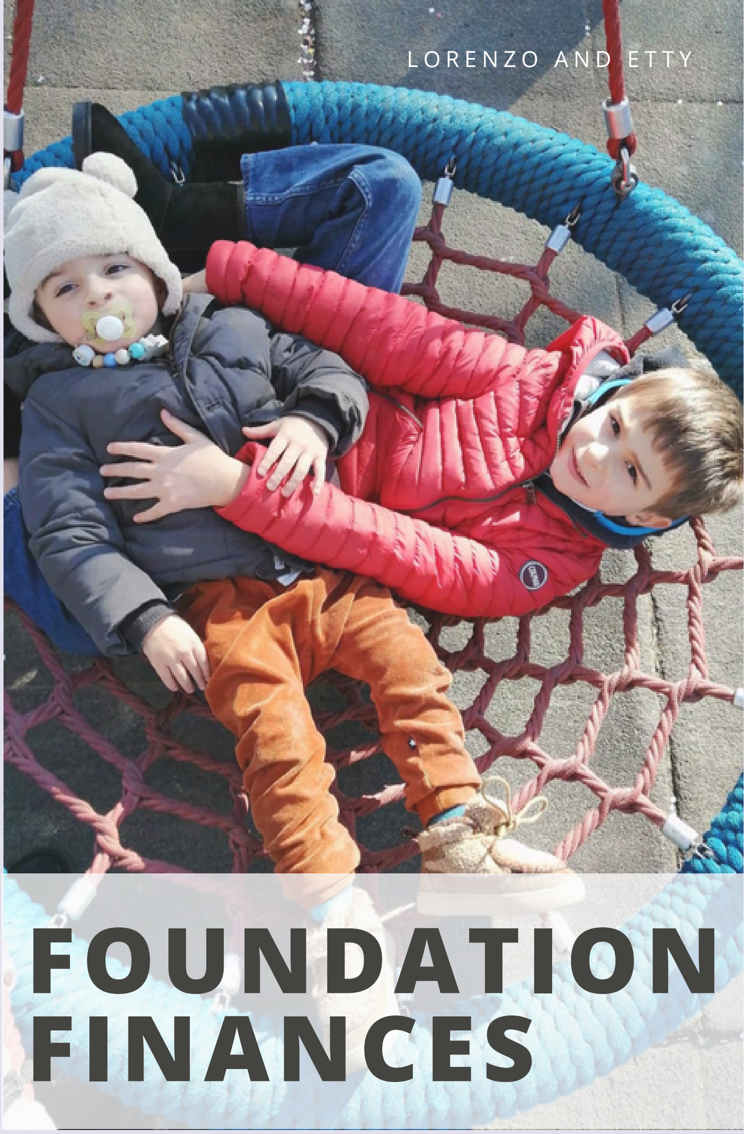
TREASURER'S MESSAGE

Inspired by the strength of our TANGO2 warriors, our community has shown extraordinary dedication and perseverance. We are proud to celebrate another year of unwavering donor support, which empowers us to provide critical assistance to families and drive impactful research forward.

We expanded our Shine a Light on TANGO2 campaign with incredible success, welcoming **354** new donors to our community. This year, we received over **1,000** individual donations from **14** countries, surpassing our previous milestones and demonstrating the growing global support for our mission.

The foundation continued to thrive thanks to the dedication of our supporters. Every donation has played a crucial role in advancing our work and connecting families to essential resources. Our mission, our progress, and every success story are all made possible because of you—our generous donors and supporters.

Kara Cameron

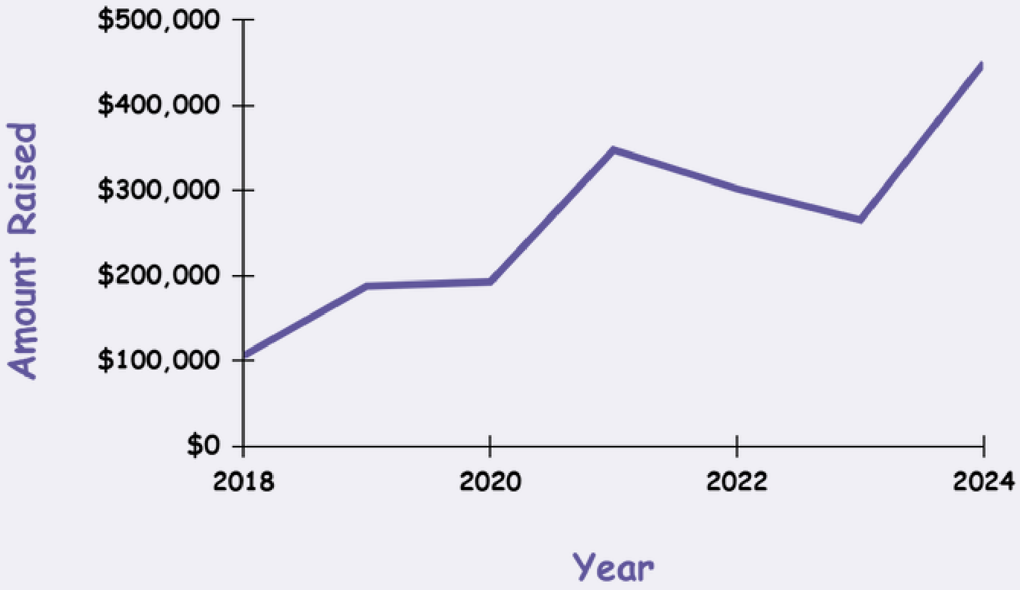


LORENZO AND ETTY

FOUNDATION FINANCES

With over 1,000 donations this year, our community has helped bring hope and resources to TANGO2 warriors and their families worldwide.

Charting Generosity: Total Gifts by Year

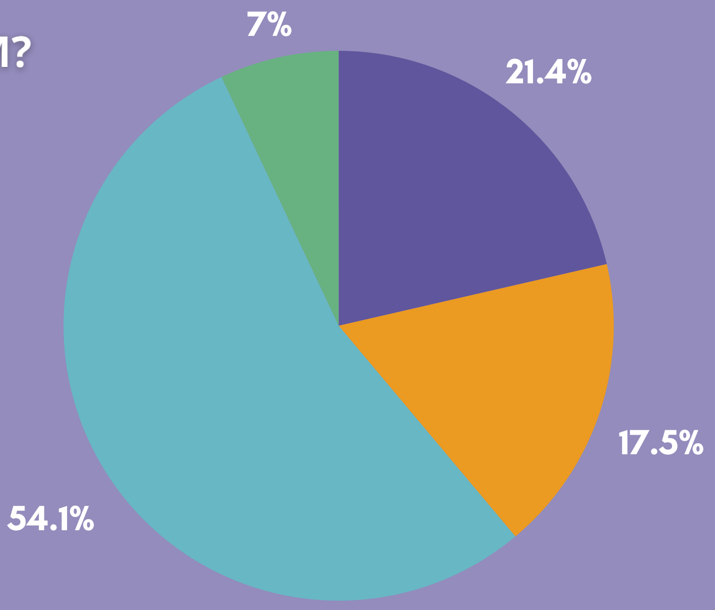


FOUNDATION FINANCES

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.

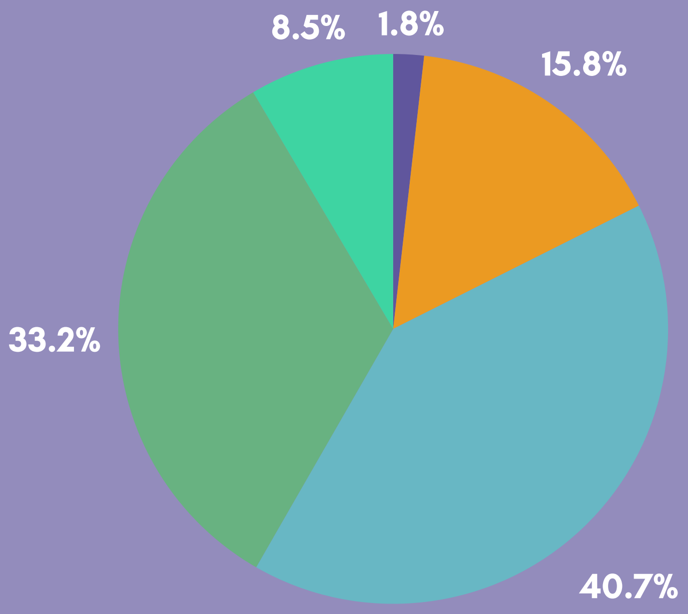
REVENUE: WHERE DOES IT COME FROM?

- 🟪 Grassroots Fundraising from the Community (Shine a Light on TANGO2 campaign)
- 🟧 PCORI Eugene Washington Engagement Award
- 🟦 Personal Donations from Families & the greater TANGO2 Community
- 🟩 Corporate Sponsorship/Matching



EXPENDITURES: WHERE DOES IT ALL GO?

- 🟪 **T2RF Family Grants**: The RP Murray Memorial Travel Grant
- 🟧 **T2RF Events**: The TANGO2 Family Conference & Research Symposium
- 🟦 **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
- 🟩 **Administrative & Operational Support** Essential costs ensuring our foundation operates efficiently, enabling us to maximize impact and support the community



THE MORRIS FAMILY ANNOUNCES $2.5 MILLION GIFT TO THE TANGO2 RESEARCH FOUNDATION

Open Letter to the TANGO2 Community and Board - August 27, 2024

The $2.5M will be distributed over the next 3-5 years to accelerate strategic initiatives and help support ongoing operations.

Dear TANGO2 Community and Board Members,

We're excited to share that we will be donating $2.5 million to the TANGO2 Research Foundation to support the vital work of advancing research and making a difference in the lives of those impacted by TANGO2 Deficiency Disorder (TDD). Our plan is to distribute these funds to the foundation over the next 3-5 years to accelerate strategic initiatives and help support ongoing operations as we collectively work towards shared goals.

We are deeply committed to the success of the TANGO2 Research Foundation and it has been a profoundly rewarding experience to be part of this community and witness the progress made in such a short period of time. This demonstrates how a relatively small but dedicated group of families, researchers, clinicians, foundation staff and volunteers can come together and effect change that is measured in months, not decades. The B-vitamin story is nothing short of amazing and has had a significant impact on Ryan's life – he's generally healthy, happy and no longer experiences episodes of weakness and fatigue. We hear similar heartwarming stories from other families every week.

With that said, there is still much more to learn and crucial work that lies ahead. The underlying mechanism of the TANGO2 protein is still not fully understood. We need to focus on early diagnosis and detection as we now know early intervention is key to saving lives and improving outcomes for those living with TDD. For families, how can we ensure that our children thrive not only for the next one, five to ten years – but are healthy and vibrant for a lifetime with improved cognition, free of seizures and able to regain some lost physical function? This will require not only optimizing the B-vitamin treatment while actively exploring other therapeutics, but also careful study and observation of TDD patients over time through a prospective natural history study.

Together, we can and will reach these goals – but achieving them will take all of us. Our hope is that our gift, along with the critical fundraising efforts of the entire TANGO2 community, will enable the foundation and its partners to get started on key initiatives sooner rather than later and help bridge the gap to larger institutional funding (NIH, FDA and similar organizations) in the near future.

Sincerely,

Mike & Kasha Morris

OUR PROGRESS

ADELAIDE & HUNTER

TANGO2 TALKS

To support our community, the Foundation hosts "TANGO2 Talks," a virtual gathering that connects families affected by TANGO2 deficiency disorder. These sessions foster a supportive community and keep attendees updated on the Foundation's latest initiatives.

In 2024, the Foundation welcomed Behavior Coach Leah Engbrecht to speak with our families, offering them valuable insights and tips on behavior management. In addition, we had a family share session where three families affected by TANGO2 Deficiency Disorder shared their inspiring TANGO2 journeys and the unique challenges they have faced.

Feedback from the family sharing session highlighted the powerful benefits that sharing experiences have on building a strong and supportive community. To view recordings of our TANGO2 Talks, visit the TANGO2 Research Foundation's YouTube channel.

ORLANDO2024
TANGO2 FAMILY CONFERENCE

This year, T2RF hosted its 3rd Biennial Family Conference at Disney's Coronado Springs in Orlando, Florida. The two and a half day event offered a unique opportunity for families, affected individuals, and healthcare professionals to connect and collaborate. Gathering our global TDD community together has proven to be an impactful and inspirational experience for all involved. For some families it was the first time meeting other TDD parents and children and many attending researchers were inspired by getting to see the faces of those that benefit from their work in the lab.

Visit our website (www.tango2research.org) or YouTube channel to view conference proceedings and watch recorded presentations.

SHINE A LIGHT
ON TANGO2

COMMUNITY-WIDE CAMPAIGNS

The TANGO2 Research Foundation's fourth annual Shine a Light on TANGO2 campaign raised $113,000 for TANGO2 Deficiency Disorder research. From February to June, teams supported T2RF Cycle 4 Research Grantees, funding studies at Brigham and Women's Hospital, Baylor College of Medicine, and Concordia University. Special thanks to top fundraisers **Veronica Jones, Matt Dort, Blake Moore, Mike Morris,** and **Ines Carreira**. T2RF thanks all participants and looks forward to continued support!

This year, with support from the **Hull Family**, we introduced the **TANGO2 Trailblazer Challenge**. A total of **121** individuals participated or supported the initiative, showcasing participants of all ages and abilities going the distance for hope!

OUR PROGRESS

In 2024, our community celebrated **19 birthday fundraisers**, collectively raising **over $3,000** to support our mission. These heartfelt efforts highlight the power of coming together to fund critical research and provide resources for families impacted by TANGO2 deficiency disorder. Each birthday fundraiser is a step closer to hope, progress, and finding a cure.

MOVING THE NEEDLE IN THERAPEUTICS

Throughout our TANGO2 journey, new discoveries often lead to new questions. Many families now ask, *"How much B vitamins should I give my TDD warrior*?" This question is a key focus for researchers, including the team at Baylor College of Medicine leading the TDD Natural History Study (NHS).

As researchers work to gather evidence-based data, families play a crucial role in collaborating and using current information to support the development of optimal dosage recommendations.

B-Vitamin Quick Facts

- Research is clear that B5 (Pantothenic Acid) is very important for those who have TDD.
- Multiple animal models and information reported from families in the NHS show that B5 specifically helps prevent metabolic crisis and in some can help improve energy & reduce the TDD "spells".
- B9 has corrected heart arrhythmias in TANGO2 animal models and heart cells.
- It is unknown if there are other B vitamins that serve a critical role in the health of individuals with TDD.
- The T2RF Clinical Advisory Board recommends a multivitamin or B complex with all 8 B vitamins at least meeting the FDA's RDA, though many warriors benefit from higher doses.

For more information about TDD & B-vitamins visit our website and/or YouTube channel. Also join in on this important conversation via the TDD Research Learning Network (www.forum.tango2research.org).

B-Vitamin Testimony: Highlighting the Cohen Family

Rebecca fondly referred to as Bec is a 30 year old, inspiring TDD warrior—beautiful, adventurous, and full of life. She's a sailor who embraces wild, windy rides, a music lover, and a source of joy to everyone around her, truly embodying the TANGO2 warrior spirit.

Before increasing her B vitamin intake above the RDA, Bec experienced significant muscle weakness, weight gain, and lethargy. Following the adjustment, her family noticed immediate improvements in strength, energy, & alertness. Her therapists, unaware of the change, observed that she walked farther with her frame and displayed enhanced strength and stamina.

- Historical Dosage: RDA - resulted in muscle weakness, and lethargy.
- Current Dosage: As of July 2024, 1000 mg of B5 daily. Higher dose is safe due to B5's water-soluble nature.
- Bec thrives on higher B5 dosage and is more alert and stronger.

TDD NHS Study Site: Baylor College of Medicine and Texas Children's Hospital, Houston, Texas
Contacts: Drs. Christina Miyake & Maria Arredondo
Email: tango2.research@bcm.edu or info@tango2research.org

BEC COHEN

OUR PROGRESS

OUR RESEARCH


RASHID

RESEARCH IS AT THE EPICENTER OF FINDING A CURE

We envision our foundation as the vehicle committed to driving the research forward: funding grants, enhancing communication and coordinating efforts among those invested in conquering TANGO2 deficency disorder.

In 2024, we invested **$100,000** in research around the world bringing the total planned investment to more than **$860,000** since 2018.

COLLECTIVE RESEARCH IMPACT

26 Researchers

21 Projects

16 Institutions

6 Countries

TDD IN FOCUS: SHARPENING THE LENS FOR STAKEHOLDERS TO ENGAGE IN PATIENT-CENTERED OUTCOMES RESEARCH (PCOR)

In its first year of receiving the $250,000 Eugene Washington Engagement Award from the Patient-Centered Outcomes Research Institute (PCORI), the TANGO2 Research Foundation achieved several significant milestones to advance patient-centered outcomes research for TANGO2 Deficiency Disorder (TDD).

Key accomplishments included the creation of the TDD Research Learning Network, an international platform designed to connect patients, families, researchers, and clinicians. This network fosters collaboration, knowledge-sharing, and engagement in research aimed at improving care and developing treatments for TDD.

The foundation also hosted a four-part workshop series that brought together a diverse group of stakeholders. These workshops provided training and collaborative discussions on patient-centered research methodologies, equipped participants with tools to engage in research effectively, and facilitated dialogue on the challenges and opportunities in TDD research.

Additionally, the TDD PCORI stakeholder project team developed a comprehensive TDD Research Toolkit, which serves as a resource for families, and healthcare professionals. The toolkit includes practical information on TDD, guidelines for managing the condition, and resources to support participation in research initiatives.

These efforts have laid a strong foundation for advancing collaborative patient-centered research, engaging the TDD community, and driving progress toward better treatments and outcomes for those living with this rare genetic disorder.

TDD Research Learning Network

TDD PCOR Research Toolbox

Special Acknowledgements

We would like to thank the 12 project stakeholders who are sacrificing their time and talents to sit on our project team: **Amy & Katie Clay, Cheyenne Beach, MD, Debbie DeLoach, Lina Gonzalez, MD, Dan Hernandez, Amanda Hull, Sam Mackenzie, MD, PHD, Josh Meisner, MD, PHD, Chaya Murali, MD, Ryan Carrier, MD,** and **Bob Mitchell.** In addition, thank you to project leadership team: **Deena Chisholm, Ann Geffen, JD., Seema Lalani, MD,** and **Kasha Morris.**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OUR RESEARCH

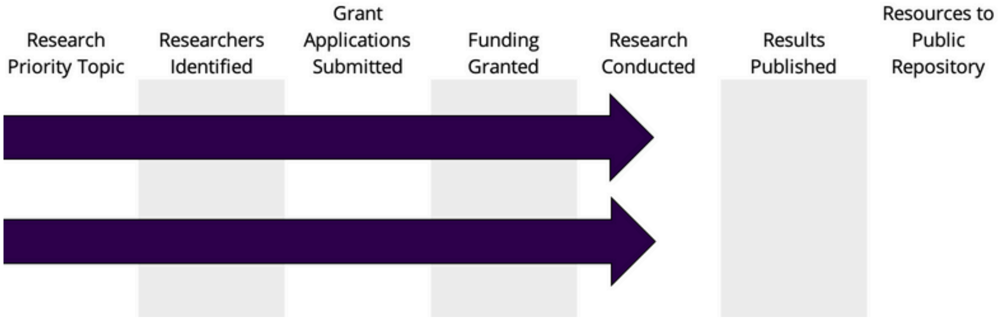
This project was funded through a Patient- Centered Outcomes Research Institute® (PCORI®) Eugene Washington PCORI Engagement Award (30416).

CURRENT FUNDED RESEARCH

Multi-Institution Awardees:

Developing Mechanism-based Therapies for TDD
PI: Vandana Gupta, PhD & Samuel Mackenzie, MD, PhD

Investigating Co-A imbalance, vitamin B5's role, and metabolomics in TANGO2 Deficiency Disorder
PI: Lina Ghaloul-Gonzalez, MD, Ody Sibon, PhD & Barbara Bakker, pro, de, BM



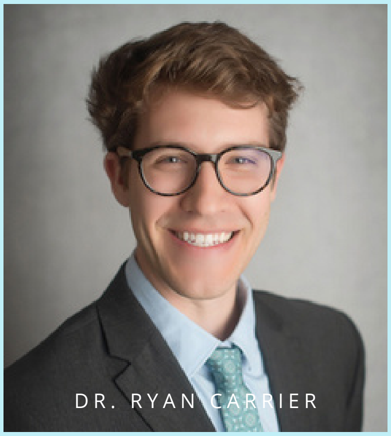
RESEARCHER'S CORNER:
UPDATE ON PREVIOUSLY FUNDED T2RF RESEARCH

Project Name: Exploring a novel TANGO2 interacting partner as a new mechanism for the role of TANGO2 disease & A lipidomic analysis of multiple model systems to better understand the role of TANGO2 in lipid homeostasis.
Project Principal Investigators: Michael Sacher, PhD, & Chiara Gamberi, PhD
Funding Cycle: 2 and 3
Project Duration: 2022 - 2024
Project's Results: Drs. Sacher and Gamberi have uncovered new aspects of the TANGO2 protein, leading to the discovery that vitamin B5 effectively treats the symptoms of TANGO2 Deficiency Disorder (TDD). It all began with the idea that TANGO2 regulates Co-enzyme A, ensuring enough fatty acids are available for cells to use as an energy source. A mutation in the TANGO2 gene can disrupt this balance, causing energy problems within the cells.

The research teams of Drs. Sacher and Gamberi combined forces, using a range of experimental models, including human and mouse cells, to study molecular interactions. They also utilized fruit flies, which, despite their appearance, have biological functions surprisingly similar to humans. TANGO2 mutant flies exhibited motor problems and stress-induced seizures, mirroring the symptoms seen in humans with TDD. The researchers discovered that mutations in the TANGO2 gene cause an imbalance in how cells process fats, particularly triglycerides, which are crucial for energy storage and release during stress. Their groundbreaking work showed that vitamin B5 restored the lipid balance in both cell and fly models, a finding confirmed in clinical studies. This discovery quickly led to the recommendation of vitamin B5 supplementation as a treatment for TDD symptoms.

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


DR. RYAN CARRIER

Dr. Ryan Carrier completed his Pediatric Neurology Residency at the University of Rochester. Ryan is also a valued and active member of the TANGO2 Research Foundation's PCORI Project Stakeholder Team. Ryan Carrier recently began a Neurogenetics Fellowship at the University of Rochester where he will gain more experience diagnosing and treating genetic diseases with neurologic symptoms. Dr. Carrier has joined Dr. Samuel Mackenzie's lab and has become increasingly interested in clinical research of rare diseases and is lucky to be able to learn from and with the TANGO2 community.

Currently, Dr. Carrier is working on *in silico* modeling of the TANGO2 protein. Ryan's *in silico* modeling research is shedding light on how missense variants in the TANGO2 gene impact the structure and function of the TANGO2 protein, helping to explain the wide range of symptoms seen in patients with TANGO2 Deficiency Disorder (TDD). This work is particularly important for the TDD community, as it provides critical insights into the molecular mechanisms driving the disorder.

By pinpointing how these genetic changes disrupt the protein, Dr. Carrier's research lays the foundation for developing targeted therapies aimed at preventing or reducing the severe metabolic and cardiac crises that are hallmarks of TDD. This innovative approach offers hope for improved treatments and a better quality of life for our TDD warriors.

What is *in silico* modeling? It refers to the use of computer simulations to study biological processes, such as how genetic changes affect proteins. It allows researchers to predict how molecules behave, speeding up discoveries about diseases & potential treatments without needing physical experiments.

> ***"I am truly honored to serve as the coordinator of the TDD NHS. Since I began working with the T2RF, I have felt like a valued member of this incredible community, meeting many inspiring individuals along the way. One of my primary goals is to continue seeking answers that enhance the quality of life for both families and warriors. Although the journey may be long, I am excited about our potential to unite patients, families, doctors, and scientists for a shared cause that has already yielded positive outcomes."***
>
> ***- Maria Jose "MaJo" Arredondo, MD***


DR. MARIA ARREDONDO

Maria Jose Arredondo has earned the Young Investigator Award both at the T2RF & Baylor College of Medicine. She was also nominated for this award at the Heart Rhythm Society Scientific Sessions, a leading conference on arrhythmia. As Project Coordinator for the TDD Natural History Study (NHS), she has contributed significantly to research on TANGO2 Deficiency Disorder (TDD), both in mouse models and clinical studies. Her dedication is evident in her willingness to work beyond expectations, often on weekends, and her deep commitment to supporting affected families. Her passion for finding solutions for our TDD warriors drives her career, making her a committed and impactful researcher.

WE'RE GROWING

As our foundation's agenda grows, so does our need for support. Destiny Braden joined our team as the Development & Operations Associate, leveraging her diverse talents, advocacy passion, and operational management expertise to advance the mission of the TANGO2 Research Foundation for resounding success.

Additionally, we welcomed Dr. Agustin Lujan as the newest member of the T2RF Research Committee. Dr. Lujan is thrilled to bring his expertise as a physician and scientist specializing in cell biology to enhance our understanding of TANGO2 deficiency disorder (TDD). His primary objective is to facilitate international collaborations and advocate for innovative research to improve TDD diagnosis, management, and therapies. His recent work on TANGO2's role in cellular metabolism and lipid homeostasis offers exciting new insights into the disorder's complex pathophysiology.

OUR COMMUNITY

> ***"What truly inspires me about the foundation is the collaborative spirit among families, physicians, and scientists, all working together to make a meaningful difference in TDD patients' lives."***
>
> ***- Agustin "Agu" Lujan, MD, PhD***

TANGO2 DAY IN SPAIN: SHARING KNOWLEDGE, SUPPORTING FAMILIES

On October 17, 2024, **TANGO2 Day in Spain** united 7 families affected by TDD and their clinicians for a day of education, support, and medical care. Organized by Drs. Lujan, Carrera, and Julia at Hospital Sant Joan de Déu in Barcelona, the event offered resources on nutrition, rehabilitation, and new tools on the TANGO2 Research Foundation's website. The morning featured empowering sessions to help families better manage the condition, while the afternoon focused on medical check-ups.

The day also offered a unique opportunity to gather insights and data for ongoing research and the TANGO2 Natural History Study, fostering collaboration between the Spanish medical community and global TANGO2 research efforts. This event marks an important step in supporting affected families and advancing our understanding of TANGO2 deficiency disorder.

To learn more about becoming a TDD Regional Coordinator, contact info@tango2research.org

WE EXPRESS OUR GRATITUDE TO THOSE WHO GENEROUSLY CONTRIBUTED DONATIONS IN 2024.

$5,000+

MATT DORT
MIKE & KASHA MORRIS
AMERICA ONLINE GIVING (THE POCHETTINO FAMILY)
SEMPRA ENERGY (SWETEK-JONES FAMILY)

$2,000+

JOYCE LOMBARDI
PETER MORRIS
JOSEPH ROMEO
SANDRA & EMILIO BOLZONI

$1,000+

PO'S RICE & SPICE
VERONICA JONES
DAYANE & JOAO RIBEIRO DE OLIVEIRA
MARSHA JONES
THE POCHETTINO FAMILY
DAVID & BETTY SUSTALA
AUBREY SWETEK
JERRY VOCKLEY
ANDY BECK
MAGGIE BURKE
ELLEN DERRIG
JOHN MACKENZIE
RUSSELL FRYAR
VAN AND MANDA GASKINS
JIM HENDREN
SEEMA LALANI
KIMBERLEY NG-MITSUI & CORY MITSUI
WELDON NICHOLS
KEITH SEALOVER
KARA CAMERON
COLLEEN PHIE

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

UPMC
LIFE CHANGING MEDICINE

AMGEN

TOKIO MARINE
HCC

rec desk

TOWN FAIR TIRE
Foundation

EVERYLIFE
FOUNDATION
FOR RARE DISEASES

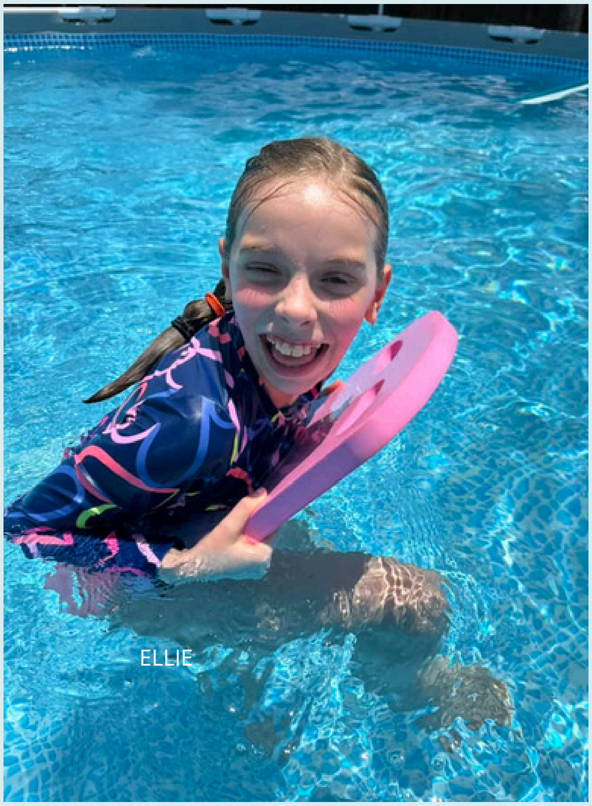
OUR SUPPORTERS

EXECUTIVE DIRECTOR'S MESSAGE

This year has been especially significant for the TANGO2 Research Foundation, as 48 new families affected by TANGO2 deficiency disorder found and connected with us. There were also two new countries added to our community with diagnoses in Japan and India.

Each new family and diagnosis strengthens our community, expanding our understanding of TANGO2 deficiency disorder and empowering us to fund research, support programs, and drive initiatives that fuel progress and innovation. As we move forward, we remain dedicated to work that places our patients at the heart of everything we do.

The highlight of our initiatives this year was the TANGO2 Family Conference, which saw our highest attendance to date. Connecting in person and hearing stories of impact confirmed just how transformative our work and research has been for these families. Additionally, the conference inspired and reinvigorated our team, volunteers, and medical professionals by giving us the opportunity to interact with the very lives we are striving to improve.


ELLIE

Another exciting development for our community-wide fundraiser, Shine a Light on TANGO2, is our 2025 feature of the **Swetek family** and Thea's story, alongside her parents, Veronica and Tyson. Veronica, was the first person to begin connecting TANGO2 families by creating the TANGO2 Disease Facebook group—a vital space that has become a lifeline for families. Her initiative sparked the first connections among families and remains a cherished space of support and hope.

As we approach our fifth grant cycle, we are excited to move closer to surpassing the $1 million mark in research funding. We look forward to welcoming more researchers, institutions, and countries into our network, all dedicated to investigating TANGO2 and advancing research that will profoundly impact the lives of those living with TANGO2 deficiency disorder and their families.

Looking ahead to 2025, your continued support is essential to driving our mission forward. We are deeply grateful for your passion, spirit, and dedication to the TANGO2 Research Foundation.

"Our unwavering determination has driven life-changing breakthroughs in a short time, bringing us closer to a cure. Together with our entire community, we continue to overcome challenges, looking toward a brighter future with optimism and hope."

Ann Geffen

SAVE THE DATES

SHINE A LIGHT ON TANGO2

Saturday, March 1, 2025 10:00 - 11:00 AM ET | Zoom Meeting ID: 878 6421 8634

Our 5th annual Shine a Light on TANGO2 virtual fundraiser is about to begin, with a goal to raise $120,000 for critical research to support children and young adults affected by TANGO2 disease. We need everyone to get involved to help ensure the healthiest and brightest future possible. Join us on March 1st as we kick off this year's campaign.

TANGO2 FAMILY CONFERENCE

Sunday, June 28 - Tuesday June 30, 2026 | Disney's Coronado Springs Resort in Orlando, Florida

Save the date for the 5th biennial TANGO2 Family Conference. This is a special opportunity to connect with experts and families, learn about the latest research updates, and actively contribute to shaping the future of TANGO2 research. Don't miss this chance to engage with the TANGO2 community and make a meaningful impact.

Visit www.tango2research.org/events to stay up-to-date on our upcoming events

WWW.TANGO2RESEARCH.ORG