

#### **Hero Highlight: Lynn MacDonald**

This month, we are proud to highlight Lynn MacDonald, a longtime supporter and dedicated volunteer of the TANGO2 Research Foundation. Since the very beginning in 2018, Lynn has been an integral part of our community, serving as a Volunteer and Fundraising Committee Member.

Lynn first got involved through her close friendship with co-founder Kasha Morris and quickly became a driving force behind our events. She played a vital role in planning the very first TANGO2 Banquet and Auction and continues to lend her energy and heart as we prepare for our 5th banquet season. Beyond fundraising, Lynn has attended and volunteered at our TANGO2 Banquets and Family Conferences, always ready to step in wherever help is needed.

Her kindness, generosity, and steadfast commitment make her not only a treasured friend to the Morris family but also a true champion for the entire TANGO2 community.



We are so grateful to our amazing supporters who continue to make a difference for the TANGO2 Research Foundation!

On September 20, 2025, the Galland family hosted the 1st Annual Big Rivers Splash & Dash in New Caney, TX, in honor of their daughter Megan, a true TANGO2 warrior. A total of 247 participants ran the 10K, 5K, Kids Dash, or joined virtually, racing through Big Rivers Waterpark to raise funds and awareness for TANGO2 Deficiency Disorder. Thanks to the Galland family's dedication, this event raised \$11,000 to support vital research and treatments.

Earlier in the month, on September 6, 2025, the Wilson family and Roger Gates organized the 2nd Annual Jim Wilson Memorial Golf Outing, which brought in over \$5,000 in support of our mission.



Thank you to **the Galland family** for hosting the Splash & Dash 5K and to **Roger Gates and the Wilson family** for hosting their second annual Jim Wilson memorial golf outing. Your efforts advance TANGO2 research and offer hope for longer, healthier lives.



# T2RF at the 22q Scientific & Family Conference – September 4-6, 2025

The TANGO2 Research Foundation (T2RF) was honored to participate and attend this year's 22q Scientific & Family Conference September 4-6, 2025. This event brings together a robust clinical audience & family caregiver community dedicated to advancing care and research in rare diseases.

Representing T2RF, Dr. Samuel Mackenzie, Board Member and SAB Chair, presented on TANGO2 Deficiency Disorder (TDD) and its importance for the 22q community. In addition, T2RF SAB member Dr. Madeline Chadehumbe, Cycle 5 awardees Donna McDonald-McGinn and Dr. Beata Nowakowska presented, along with 22q and TDD mom Debbie Deloach. Deena Chisholm, T2RF Director of Research Engagement was also in attendance.

T2RF's presence at this important meeting reflects our commitment to expanding our reach across overlapping rare diseases, fostering collaboration, and ensuring that insights from the TDD community inform and strengthen broader rare disease research and clinical care.



## **Strengthening the Rare Disease Community: T2RF Leaders Selected as Mentors**

Ann Geffen, Executive Director of the TANGO2 Research Foundation (T2RF), will mentor in the FasterCures & Chan Zuckerberg Initiative (CZI) Rare As One program, guiding capacity building, governance, and patient-community engagement for Michaelle Jinnette (Cure KCNH1 Foundation). This reflects Ann's nonprofit leadership and commitment to peer collaboration.

Deena Chisholm, T2RF's Director of Research Engagement, will mentor Eszter Hars (Shwachman-Diamond Syndrome Alliance) through PCORI's Eugene Washington Engagement Award (BCSO), advising on partner engagement, patient-centered CER capacity, and culture change so advocacy groups are recognized as true research partners.

Kasha Morris, T2RF co-founder and mom to TANGO2 warrior Ryan, will mentor the next BCSO cohort for PCORI, sharing T2RF tools—the TDD <u>Research Learning Network</u>, <u>Research Engagement Roadmap</u>, and <u>Research Toolbox</u>—as models for sustainable, high-impact engagement.

Together, these mentorships affirm T2RF's leadership in patient-centered research and strengthen a more collaborative rare-disease ecosystem.



### **T2RF Grant Cycle 6 Now Open**

The TANGO2 Research Foundation (T2RF) is pleased to announce that Grant Cycle Six is now open. Our research grants provide seed funding to support pilot projects, foster innovative ideas, and build the foundation for larger-scale studies aimed at advancing TANGO2 Deficiency Disorder research. Letters of Intent are due 11/07/2025!





# T2RF RESEARCH GRANT CYCLE 6 NOW OPENI

LETTER OF INTENT DUE 11/07/2025

SINGLE-INSTITUTION AWARDS UP TO \$25,000 USD MULTI-INSTITUTION AWARDS UP TO \$50,000 USD

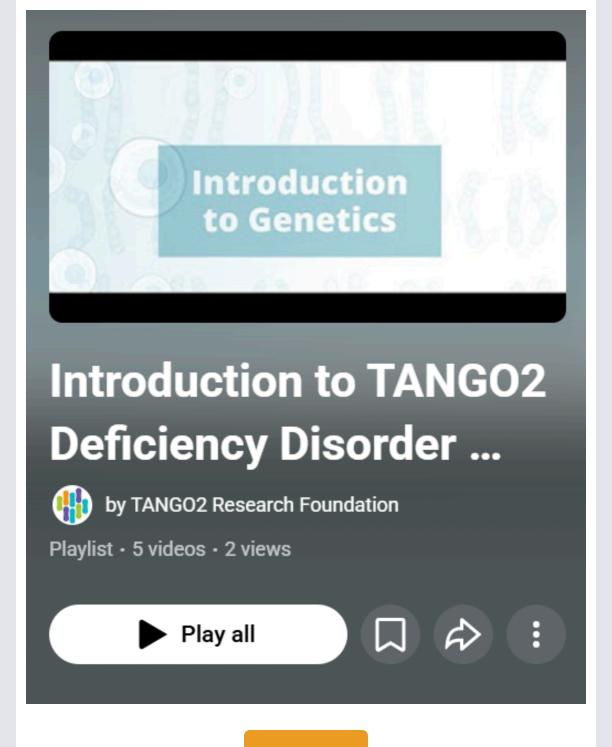
VISIT WWW.TANGO2RESEARCH.ORG/RESEARCH/GRANTS

Learn More

#### New Resource Alert: Introduction to Genetics Explainer Videos

The TANGO2 Research Foundation is excited to share a brand-new video series designed to make understanding TANGO2 Deficiency Disorder genetics simple and accessible. Genetics can often feel overwhelming, especially following a TDD diagnosis, but these short videos break it down into clear, everyday language to help families better understand their loved one's condition.

A special thank you to AMGEN for supporting this project through the 2024 #RAREis Global Advocate Grant—helping us bring valuable resources to our community.



Watch Now

#### **Upcoming Events:**

#### **TANGO2 Research Symposium**

Registration is now open for the 2025 TANGO2 Virtual Research Symposium! Led by leading TDD researchers and healthcare professionals, this symposium provides a program of information-rich sessions designed for researchers, healthcare professionals, caregivers, and advocates of individuals affected by TDD.



You can explore our Research Symposium speakers and agenda here: <a href="https://tango2research.org/202...">https://tango2research.org/202...</a>



#### **TANGO2 Banquet & Auction**

Tickets are now on sale for the 2025 TANGO2 Banquet and Auction! Hosted by Foundation co-founders Kasha and Mike Morris, the biennial event is fun for the entire family and proceeds go to the TANGO2 Research Foundation.

## **TANGO2 Benefit Banquet & Auction**

#### **TPC River Highlands**

Cromwell, Connecticut Saturday · November 1 · 2025 5PM - 9PM



B-lieve in a Cure





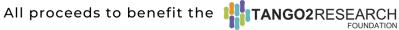
Tickets: \$85 For tickets & information: kasha.morris@tango2research.org

#### JOIN US

Hors d'oeuvres & events begin at 5pm



- Auction
- Themed Basket Raffles
- Restaurant Row
- & so much more!



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**Purchase Tickets** 

Unable to attend? You can still support the TANGO2 Research Foundation by bidding on a trip to Africa through Zulu Nyala. Learn more here or contact kasha.morris@tango2research.org for additional information.







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**Every dollar counts** 

<u>Unsubscribe</u>

