



Hero Highlight: TANGO2 Banquet Committee

This month, we're celebrating the TANGO2 Banquet Committee, a dedicated group of volunteers who have been involved with the Foundation since its beginning in 2018.

This incredible team, Cindy Schaller, Joanne Barmasse, Lynn MacDonald, Sharon Owen, Jodi & London Brazal, Beth Kelpen, Stacey Gibson, Chris Miller, Jo Schultz, Kaitlyn Morris, Joyce Lombardi, and Cary & Carl Provencher, work tirelessly for months leading up to the TANGO2 Banquet & Auction. From selecting venues and decorations to organizing sponsorships, auctions, raffles, and more, their creativity and teamwork bring the banquet to life.

Thanks to their hard work, passion, and countless volunteer hours, the TANGO2 Banquets have raised more than \$150,000 to support life-saving research for Ryan and TANGO2 warriors around the world!

HERO HIGHLIGHT

TANGO2 Banquet Committee

"This amazing group of volunteers are the heart and hard work behind the successful TANGO2 Banquet fundraising events."



We're grateful for two incredible community supporters making a global impact for TANGO2 families! The **Newcastle 50's Rock and Roll Club** generously donated \$1,050 AUD to the Foundation in honor of Harrison, with research updates being shared during the event.

In Italy, **Giuseppe Pochettino**, grandfather of Edoardo, marked his 80th birthday by inviting friends and family to give in support of TANGO2 research, raising an amazing \$2,770 (€2,413).



IMPACT INVESTORS

*Thank you to the **Newcastle 50's Rock and Roll Club** for donating \$1,050 AUD in honor of Harrison, and to **Giuseppe Pochettino** for raising €2,413 through his 80th birthday celebration. Your generosity fuels TANGO2 research and brings hope to families worldwide.*



Together, their generosity helps advance life-changing research and brings hope to families worldwide.

Exciting News from the NORD Rare Diseases and Orphan Products Breakthrough Summit!

Our Director of Research Engagement, Deena Chisholm, proudly represented the TANGO2 Research Foundation as a poster presenter at this year's NORD Rare Diseases and Orphan Products Breakthrough Summit in Washington, D.C.

This event brought together patient advocates, researchers, clinicians, and industry leaders to share progress and collaborate on improving the lives of people living with rare diseases. Presenting our work at NORD highlights our commitment to advancing research, building partnerships, and amplifying the TANGO2 community's voice in the broader rare disease field.

We're grateful to NORD for this opportunity to connect and learn alongside so many inspiring rare disease leaders!



In the News

CBS Pittsburgh recently featured the story of John Martinez, one of our inspiring TANGO2 Warriors. The segment shared John and his family’s journey since his diagnosis and the care and support that have helped him thrive. As the story beautifully stated, **“John has TANGO2, but thanks to UPMC and the TANGO2 Research Foundation, it doesn’t have him.”**



Living with TANGO2



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LOOKING FOR TANGO2 HEALTHCARE HEROES!

We want to honor a health care or research professional who inspires, supports, and fights alongside you. We know so many doctors, nurses, therapists, and researchers go above and beyond for our TANGO2 community—and we want to celebrate them! Nominate your hero today for a chance to be featured as a TANGO2 Healthcare Hero in our upcoming newsletters.

Nominate a Hero 🖱️ <https://form.jotform.com/25266...>

New Committee Member Welcomes

We are thrilled to welcome our newest committee members!

Welcome **Catie Hedrick** to the Early Detection & Diagnosis (ED&D) Committee. As a registered nurse, and parent navigating both 22q and a possible TDD diagnosis, Catie brings invaluable insight and heart to the team.

We also warmly welcome **Tyson Swetek** to the Research Committee! Tyson is the father of Thea, and his family was our 2025 Ambassador Family. Tyson brings both passion and dedication to advancing our mission.





Upcoming Events:

We are very excited for the following upcoming events, you can stay up to date on Foundation events at: <https://tango2research.org/eve...>

TANGO2 TALK: SIBLING ROUNDTABLE

Saturday, December 6th, 2025 10:00 AM – 11:00 AM ET

What is it like to be a sibling of someone living with a rare disease? We invite all members of our community — parents, caregivers, siblings, and loved ones — to join us for an open conversation as we listen to sibling voices, learn from their unique perspectives, and explore ways to support them as an essential part of the TANGO2 community.



Siblings Roundtable

Saturday, December 6th, 2025 10:00 – 11:00 am ET USA

What is it like to be a sibling of someone living with a rare disease?



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