




Over 300
Million

people worldwide are
living with a rare disease.

 TANGO2RESEARCH
FOUNDATION

Join Us Tomorrow for Rare Disease Day!

Over 300 million people worldwide are living with a rare disease — that's about 1 in 17 people globally.

70% of rare diseases begin in childhood, yet most remain under-researched, under-funded, and misunderstood.

This month, we're shining a light on TANGO2 — and the families who face rare disease with strength, hope, and resilience every single day.

Join us tomorrow on Rare Disease Day, **February 28 at 10 AM ET** for our **Shine a Light on TANGO2 Virtual Kickoff & Celebration.**

We will share research updates, the latest news about the 2026 Family Conference, have a special message from this year's Ambassador Family, and more. ✨ **Special Research Spotlight:** Dr. Sam Mackenzie will also be giving us an update on our research efforts at the Foundation.

[Learn More & RSVP](#)

Hero Highlight: Dr. Kuntal Sen

HERO HIGHLIGHT



Kuntal Sen, MD
Clinician-Researcher

"The T2RF has truly been a beacon of hope for families & clinicians alike. The amount of progress in research, awareness, & collaboration has been remarkable. Seeing that level of dedication & partnership gives me genuine optimism that the future of TANGO2 care and research is bright!"



We're excited to spotlight this month's Hero Highlight, **Dr. Kuntal Sen!**

Dr. Sen is the Director of the Mitochondrial Disorders Program and Co-Director of the Neurogenetics Clinic at Children's National Hospital. With specialized training in both neurology and genetics, he brings unique expertise to diagnosing and caring for individuals with complex and ultra-rare neurological conditions.

He is deeply committed to providing long-term, compassionate, family-centered care for patients with mitochondrial and other rare disorders. In addition to his clinical work, Dr. Sen is dedicated to advancing research and improving how physicians are trained in genomic testing.

A pivotal moment for Dr. Sen was leading the neurology work group at the 2025 TANGO2 Innovation Summit in Houston. Bringing together specialists and families in one room created a powerful sense of urgency, collaboration, and hope for the future of this field.

Conference Registration is Now Open

Join Us!

ORLANDO 2026
TANGO2 FAMILY CONFERENCE
June 28 - 30
Disney's Coronado Springs Resort
Orlando, Florida

Registration is now open for the 2026 TANGO2 Family Conference, taking place at Disney's Coronado Springs Resort, June 28-30th 2026! Don't miss this opportunity to connect with families, hear from experts, and be part of an inspiring and impactful event. You can learn more by visiting our [new 2026 Family Conference site!](#)

Conference Deadlines:

[Travel Grant:](#) **March 6th, 2026**

[Poster Abstracts:](#) **March 13th, 2026**

[Emerging Researcher Nomination:](#) **April 3, 2026**

[Conference Registration:](#) **May 8th, 2026**

[Young Adult/Childcare:](#) **May 31st, 2026**




Register

Learn More

Join the Research Learning Network Today!

The TANGO2 Deficiency Disorder Research Learning Network (TDD RLN) is a growing global online community dedicated to advancing research and improving care for individuals living with TANGO2 deficiency disorder. With members in more than 10 countries, and counting, the network brings together researchers, clinicians, families, and patients who are actively collaborating to deepen understanding and accelerate progress.

Join for free and become part of a vibrant, international effort driving meaningful advancements in TANGO2 research and care!

Topic	Replies
<p>Illness duration and increased B5 supplementation - observations wanted</p> <p> General</p> <p>I'd be interested in hearing some anecdotal accounts of whether or not parents here have noticed that increased B-vitamin supplementation (specifically B5) has helped with fighting colds/flu - specifically duration of il... read more</p>	9
<p>Families and clinicians, please share with us what dose of vitamin B5 is helping your children/young adults and/or patients the most?</p> <p> General</p> <p>What is the appropriate daily B5 dose for TDD to manage symptoms better?</p>	31
<p>Increased B9 dosage- noticeable improvements in speech</p> <p> Research research , signs-and-symptoms</p> <p>Hello everyone. My daughter (2.5y/o) recently received her Varicella vaccine and as per her Metabolic doctors recommendation, we increased her B9 from 440mcg per day to 840mcg per day. We did this for about a week follow... read more</p>	19

Join the RLN

In Case You Missed it...
Our 2025 Annual Report is Out

At the TANGO2 Research Foundation, everything we do is driven by a deep commitment to transparency, progress, and impact. Last month, we released our 2025 Annual Report showcasing the incredible strides we've made in our mission to support families, advance research, and fund life-changing treatments for those affected by TANGO2 deficiency disorder.

This year's achievements are a reflection of the power of community, collaboration, and hope. Thanks to the unwavering support of our families, donors, researchers, and advocates, we've made historic progress on every front.

Take a moment to reflect on the impact YOU are making—download our full Annual Report at <https://tango2research.org/ann...> and see how together, we are **changing lives**.



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