



SHINE A LIGHT

ON  **TANGO2**

VIRTUAL CAMPAIGN PARTICIPANT HANDBOOK

ABOUT THE CAUSE



What is TANGO2?

TANGO2 is a gene on chromosome 22 (22q11.21) that stands for "Transport And Golgi Organization". This gene plays an important role in protein secretion from cells.

What is TANGO2 Disease?

In 2016, problems in the TANGO2 gene were found to cause recurrent episodes of muscle and nerve breakdown that are associated with life-threatening heart rhythm problems and neurological changes. Problems manifest when children inherit the recessive trait even though the father and mother show no symptoms.

Our Mission

Our mission is to lead the way in finding a cure for TANGO2 related disease. We will do this by helping to fund, coordinate and guide scientific research that leads to a better understanding of how TANGO2 mutations affect people at the most basic cellular and biochemical pathway levels.

OUR IMPACT

SINCE OUR INCEPTION IN 2017, WE'VE MADE GREAT STRIDES TOWARD FINDING TREATMENTS AND A CURE FOR TANGO2 DISEASE.

YOU HELPED...

FUND **6**
RESEARCH GRANTS TO
UNDERSTAND TANGO2
TOTALING

\$290,000



CONDUCT A VIRTUAL
SYMPOSIUM TO
SHARE LATEST
RESEARCH PROGRESS

LAUNCH A
REGIONAL SUPPORT
PROGRAM WITH

11

COORDINATORS TO
SUPPORT FAMILIES
WORLDWIDE



FACILITATE ACCESS
TO PATIENT DATA
FOR RESEARCH

RAISE OVER

\$80,000

AT OUR INAUGURAL
VIRTUAL FUNDRAISING CAMPAIGN



ENHANCE
EDUCATIONAL AND
AWARENESS VIDEOS
FOR FAMILIES



SECURE BRAND NEW
PARTNERSHIPS WITH INDUSTRY
EXPERTS, AND MANY OTHER
ACCOMPLISHMENTS...

ADVOCATE FOR
EARLIER GENETIC
TESTING TO
SHORTEN
THE PATH
TO DIAGNOSIS



FUND **2**
FAMILY
CONFERENCES

RECOGNIZE US AS
A CHAN
ZUCKERBERG
INSTITUTE RARE
AS ONE NETWORK
GRANTEE



JOIN US



- Fund scientific research
- Increase studies to manage critical symptoms
- Raise awareness for accurate diagnosis
- Provide support to families

TO START YOUR VIRTUAL TEAM, GO TO:
www.shinealightontango2.com

SAVE THE DATES

KICKOFF: FEBRUARY 26TH

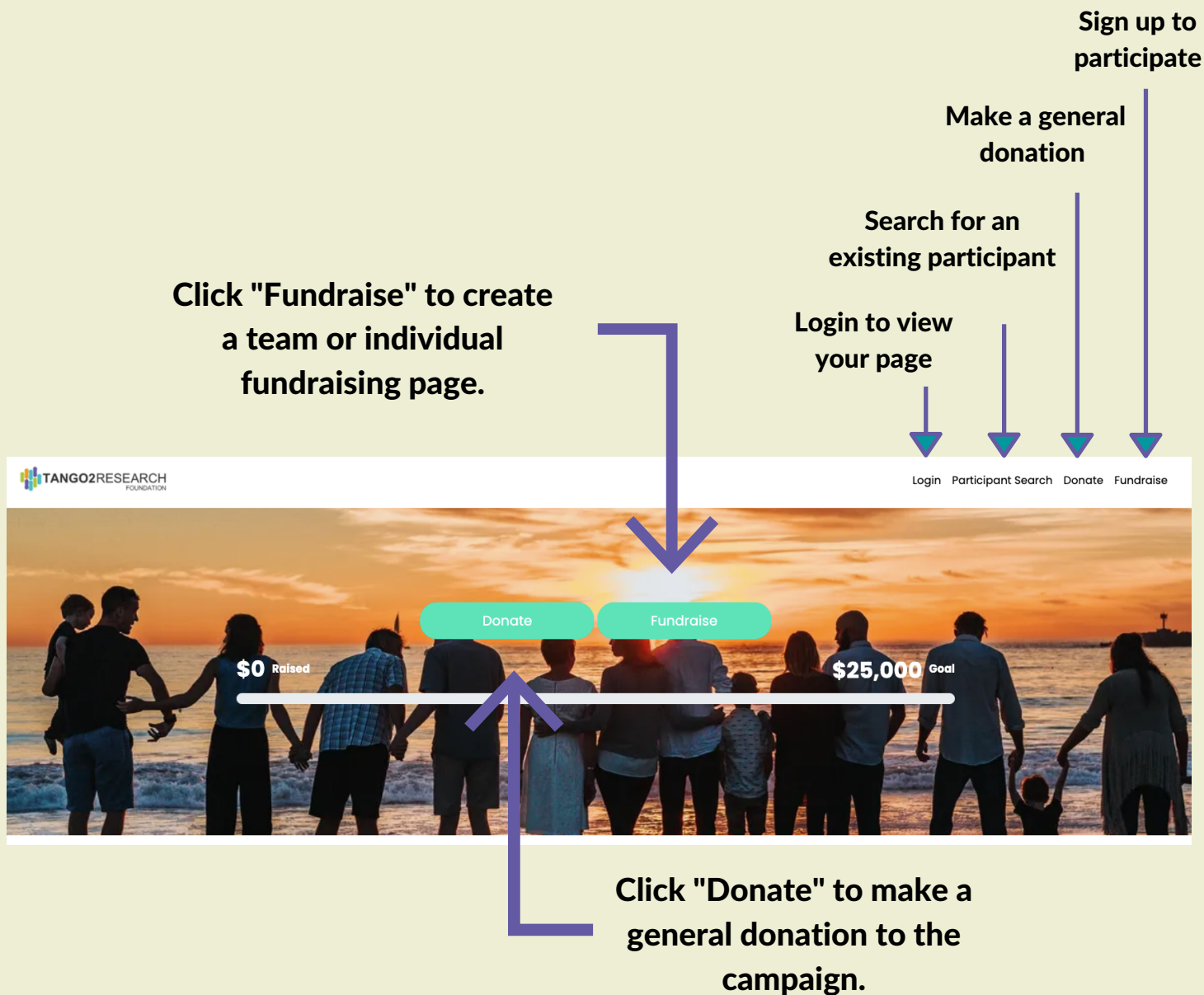
Join us on Saturday, February 26th at 11 AM EST/8 AM PST (Zoom ID: 843 7332 3190) right after Rare Disease Day to kick off the campaign. Hear inspirational stories from families, learn about what the foundation is doing, and get motivated to fundraise.

CELEBRATE: JUNE 28TH

On Tuesday, June 28th, we are celebrating our participants in-person at the TANGO2 Family Conference in Orlando, Florida! You are invited to join us to share fundraising successes, celebrate the campaign, and hear about foundation accomplishments.



TO START



We encourage you to sign up as a team captain and recruit participants to fundraise together or individually.

TO NAVIGATE

Post your page on
social media or
email friends &
family

Fundraising
progress bar

TANGO2RESEARCH FOUNDATION

Ann Geffen
Profile

- Dashboard
- Participant Page
- Emails
- Cash and Checks
- Logout

Virtual Fundraising

[Donate](#)

\$50 raised \$500 Goal

Update goal

Invite Supporters

Invite your supporters to donate! Let your family and friends know why this matters to you. We've put together an email template to get you started.

[Skip](#) [Add](#)

Participant

1 donations	\$50 average donation	\$50 average donation for event
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Activity Feed

10/07/20 Thien-Vu Hogan donated \$50.00 to you.

Registration

Name: Ann Geffen reg id: 4789937
Registration Status: Registered

Team

You are not currently on a team.
[Create](#) a team.

Page Navigation:
Personalize your page, email friends & family to ask for support, or enter offline donations to increase your progress bar.

This page allows you to manage your fundraising campaign as a team captain and individual.

RESOURCES

1.EVENT FLYER

2.SHARE YOUR STORY

3.TEAM CAPTAIN ACTION PLAN AND TIPS

4.KNOW YOUR NETWORKS

5.FOUNDATION INFORMATION

TO FUNDRAISE

There are several ways you can fundraise. Here are just a few ideas.

Send creative emails and/or post on social media: Offer a prize, donation match or special video message if you hit your goal.

Have a fundraising sale: hold a bake sale, lemonade stand, neighborhood yard sale, etc.

Birthday fundraiser: instead of gifts, ask for donations.

Fundraise with a local business: ask them to donate a percentage of proceeds to the foundation.

Fundraising competition: have a virtual (or in-person) cooking or singing competition where viewers make donation "bets" on the potential winner.

Fundraising baskets: have team members divide up in pairs to create themed baskets. Hold a raffle or silent auction for donations to win the basket.

Have a party: throw a party in your favorite theme and ask for "admission" as a donation to the foundation.

Conduct a letter writing campaign: write a personal letter and include a self-address stamped envelope asking for donations to the foundation.



JOIN US

THE DISEASE

TANGO2 disease is a very rare genetic condition that causes muscle breakdown, seizures, or even life-threatening heart problems. There is currently no cure or treatment.

THE MISSION

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SHINE A LIGHT
ON  TANGO2

HELP US

- FUND SCIENTIFIC RESEARCH
- INCREASE STUDIES TO MANAGE CRITICAL SYMPTOMS
- RAISE AWARENESS FOR ACCURATE DIAGNOSIS
- PROVIDE SUPPORT FOR FAMILIES

REGISTER YOUR VIRTUAL TEAM OR DONATE:
www.shinealightontango2.com

Save the Date for Feb. 26 11 AM EST Zoom ID: 843 7332 3190

TANGO2 Research Foundation is a registered 501(c)(3) | EIN 82-3667557

SHARE YOUR STORY

Sharing your story is a powerful way to advocate for your child or for someone you know that has been touched by TANGO2 disease. As you craft your story, here are some ideas to think about:

- Why are you telling your story and what impact would you like it to have?
- What do you want people to know about your TANGO2 child? Tell what your child loves to do, his/her personality, etc.
- What is your overall experience with TANGO2? The challenges and good things?
- What has the journey to diagnosis been like for your TANGO2 child?
- How has/does TANGO2 Research Foundation help your TANGO2 child? What impact has it made on you?
- What is the call to action? Donate and/or volunteer?

Tips:

- Allow the reader to feel your story. Let them really see what a family who's living with TANGO2 is going through.
- Bring your own personality into the story.
- Explain things in a way that anyone can understand (remember, most people don't have a medical background).
- Include your child's name and a photo.

TEAM CAPTAIN PLAN & TIPS

ACTION PLAN

- Create your team on the website (www.shinealightontango2.com) by clicking "fundraise" and set a team fund-raising goal.
- Recruit 10+ participants to commit to raising money for the TANGO2 Research Foundation.
- Ask each participant to raise a specific amount of money to help achieve the team fundraising goal. For example, a team of 10 can easily raise \$3,000 if each raises \$300.
- Ask one participant to raise \$1,000. This can be the team captain!
- Help all participants to register by sending an e-mail that includes a link for them to register on your team.
- Help each participant achieve their personal fundraising goal.

TIPS

- Ask your participants if their employers have a matching gifts program.
- Identify TANGO2 disease stories on your team and ask them to share their personal story with other participants.
- Recognize participants for progressing towards and achieving their goals.
- Provide updates to your team and celebrate milestones on a weekly basis.

KNOW YOUR NETWORKS

Who can potentially support you?

PERSONAL

FAMILY

Go beyond your immediate family: Who did you see at the last reunion or holiday party?

INCLUDE FRIENDS FROM OTHER PERIODS OF YOUR LIFE:

Grade school, high school, college or graduate programs

FRIENDS FROM GROUPS OR CLUBS:

Book club, exercise groups, poker night or sports groups

DISTANT CONTACTS:

Review your holiday card, wedding and/or shower guest lists.

Were you in a sorority or fraternity?

Anyone in your circle that you recently supported in a charity event of their own?

HOW ARE YOU INVOLVED IN YOUR COMMUNITY:

Volunteer activities/organizations

Your children's activities

Civic or religious organizations

Facebook groups

Connections on social media

WHAT BUSINESSES DO YOU FREQUENT?

Grocery stores, dry cleaners, gyms, salons, financial advisors and/or doctors

PROFESSIONAL

ASK OUTSIDE YOUR DEPARTMENT OR DIRECT CONTACTS:

Outlook contacts, office directory, former co-workers from previous jobs or positions.

WHO DO YOU REGULARLY INTERACT WITH?

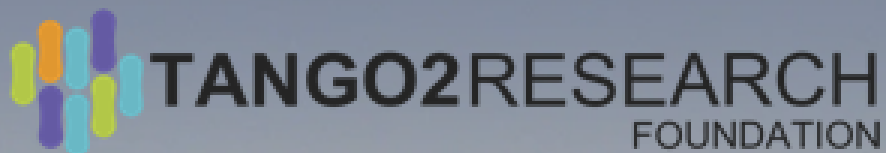
Clients, partners and vendors

WHERE DOES YOUR BUSINESS REGULARLY SPEND MONEY?

LinkedIn network, industry groups, professional development

ORGANIZATIONS WHOSE MEETINGS YOU ATTEND REGULARLY?

Chamber of Commerce, Municipal Meetings, etc.



300 Plaza Middlesex

Middletown, CT 06457

Website: www.tango2research.org

Fundraise: www.shinealightontango2.com

The TANGO2 Research Foundation is a not-for-profit organization recognized as tax-exempt under the internal revenue code section 501(c)(3) and the organization's Federal Identification Number (EIN) is Tax ID: 82-3667557 (US & Canada)