



## **Privacy Policy**

**Approved Date: August 12, 2021**

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The TANGO2 Research Foundation is a non-profit charitable organization devoted 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. The TANGO2 Research Foundation's website is an important tool in carrying out our mission, and we want all its users to be comfortable and confident when you use the website and/or contact our office. For that reason, we have adopted this privacy policy.

The following are basic guidelines in place to ensure a civil, respectful discussion that adds to the richness of TANGO2 Research Foundation's publications and communications dialogue. This privacy statement discloses the privacy practices for the TANGO2 Research Foundation and for those persons who utilize any TANGO2 Research Foundation's publications and communications including but not limited to the following: TANGO2 Research Foundation Websites, Facebook, Twitter, YouTube, Online Communities, Other (Emerging), Mobile Applications, Educational Materials, Conferences & Meetings, Fundraising Events, and Story Campaigns. The TANGO2 Research Foundation is dedicated to protecting the privacy of all involved and ensuring their ability to use our publications and communications with confidence.

### **Our Commitment to Privacy**

Your privacy is important to us. To protect your privacy, we provide this notice explaining our information practices and the choices you can make about the way your information is collected and used.

### **Collection and Use of Personal Information**

When you request information online, register using one of our forms, or contact us offline, we may need your specific information in order to process your registration/request and reply to your needs promptly. We may ask you for contact information (such as your name, email and address) and demographic information (such as your zip code or age). We also collect demographic and profile data at our website and in our databases. We use this data to tailor your experience at the TANGO2 Research Foundation and to develop and distribute content that we think you might be interested in.

In general, we only use identifiable information to complete the transactions described in this Privacy Policy. In addition, we use any health-related data you provide to us to help us help you through our information, our programs and our services. Part of our mission is to

lead the way in finding a cure for TANGO2 related disease, and we do that by providing appropriate health information to you based upon information you personally provide. We maintain health-related data and do not provide your name and address to outside parties, except as described here.

### **Policies Regarding Disclosure of Personal Information**

TANGO2 Research Foundation, unlike many other non-profit organizations, does not make available the names and addresses of our contributors to other companies or organizations, although the TANGO2 Research Foundation does offer programs in which members must consent in advance before a member's name is disseminated. In addition, the TANGO2 Research Foundation will periodically distribute sample products from carefully selected vendors to its members. All such mailings are prepared by the TANGO2 Research Foundation, and members' names and addresses are never provided to the manufacturers.

Member names are provided to a credit card vendor to process credit card transactions. These practices help us reduce the costs of providing more individuals with the TANGO2 Research Foundation's information. The companies with which your name may be shared are carefully screened. Names/addresses are provided on a one-time basis; therefore, these companies will not have continued access to your name and address unless you respond to them directly, which you are free to do or not to do. You can request that we do not share your information by emailing us at [info@tango2research.org](mailto:info@tango2research.org).

### **Our Commitment to Children's Privacy**

Protecting the privacy of the very young is especially important. For that reason, we adhere to the 1998 Children's Online Privacy Protection Act (COPPA). (For more information, visit the Federal Trade Commission's COPPA site at <http://www.ftc.gov/ogc/coppa1.htm>). Any user-generated content shared to the TANGO2 Research Foundation's social media presences which contains nudity will be deleted.

### **Links to Other Sites**

This site links to other websites unrelated to the TANGO2 Research Foundation that are owned and operated by third parties. The TANGO2 Research Foundation does not make any representations or warranties about any third-party sites you may access through this website. These links are provided solely as a convenience to you and do not constitute an endorsement or affiliation by the TANGO2 Research Foundation. The TANGO2 Research Foundation is not responsible for the privacy practices, contents of, or any products or services offered on, any third-party sites. You must make your own independent decisions regarding your use of any third-party website. We will not pass your information along to the linked site; however, we cannot protect the information you provide to that site.

When an advertisement appears in our monthly e-news, which provides live links directly to an advertiser's website, the words "paid advertisement" are placed underneath the ad so that our members, donors and the general public know that the TANGO2 Research Foundation is not endorsing the product. Other notifications may be added from time to time.

### **E-mail Guidelines**

The TANGO2 Research Foundation does not send unsolicited commercial e-mail to individuals with whom it does not have consent/permission or a pre-existing or current business relationship. The TANGO2 Research Foundation also provides all e-mail recipients with a clear, easy and effective method to unsubscribe to any and all online communications. We do not offer any online mass communications, only individual direct e-mails.

The TANGO2 Research Foundation is not responsible for information or advice provided by others, including information on the TANGO2 Research Foundation's social media sites, websites that link to association sites, and on third party sites to which the TANGO2 Research Foundation links. Fan-produced content on the TANGO2 Research Foundation Facebook Group page does not necessarily reflect the opinions of the TANGO2 Research Foundation.

### **Permission to use material from this website/reprints/copyright**

The TANGO2 Research Foundation retains copyright on the content of this site, unless otherwise noted.

### **Reprint or reuse of information from this site without change**

To request permission to use information from this website for other than personal use, send an email describing intended use, duration and contact information to the TANGO2 Research Foundation.

### **Translations and adaptations**

Translations or adaptations of the TANGO2 Research Foundation content must be reviewed and approved by the TANGO2 Research Foundation. Please send an email describing intended use, duration and contact information to the TANGO2 Research Foundation at [info@tango2research.org](mailto:info@tango2research.org).

### **Using content from the TANGO2 Research Foundation's press releases**

Reprint of the TANGO2 Research Foundation's content or references to the TANGO2 Research Foundation's contact information in an organization's press release must be approved by a person of authority at the TANGO2 Research Foundation. Please send queries to [info@tango2research.org](mailto:info@tango2research.org).

### **Logos**

Using any of the TANGO2 Research Foundation registered trademarks (logos) without the TANGO2 Research Foundation's prior consent is strictly prohibited. Please send written requests describing intended use, duration, and contact information to [info@tango2research.org](mailto:info@tango2research.org).

### **Photographs and graphics**

The photographs and graphics on our website are not available for reproduction by third parties.

## **Linking policy**

When linking to the TANGO2 Research Foundation's website, web managers should be aware that the TANGO2 Research Foundation trademarks are not available for posting or replication on third party websites without a written agreement with the TANGO2 Research Foundation. As part of the permission agreement for web linking, third parties must post the following with any logo, trademark, URL, or content used from the TANGO2 Research Foundation website - Linking Disclaimer: *"This site links to other websites unrelated to the TANGO2 Research Foundation that are owned and operated by third parties. The TANGO2 Research Foundation does not make any representations or warranties about any third-party sites you may access through this website. These links are provided solely as a convenience to you and do not constitute an endorsement or affiliation by the TANGO2 Research Foundation. The TANGO2 Research Foundation is not responsible for the privacy practices, contents of, or any products or services offered on any third-party sites. You must make your own independent decisions regarding your use of any third-party website."*

## **Database Privacy Policy**

Frontstream and Donorbox database software and donor processing companies used by the TANGO2 Research Foundation is PCI compliant. "PCI Compliance" means compliance with the Payment Card Industry Data Security Standard (PCI DSS), an information security standard defined by the Payment Card Industry Security Standards Council. The overall objectives of the PCI DSS are to build and maintain a secure network, protect cardholder data, maintain a vulnerability management program, implement strong access control measures, regularly monitor and test networks, and maintain an information security policy.

## **Disclaimer**

The TANGO2 Research Foundation works to ensure that the information provided on its authorized website is accurate, timely and useful. However, the information contained on the TANGO2 Research Foundation's website should not be considered medical guidance or professional advice. The TANGO2 Research Foundation does not give medical advice or engage in the practice of medicine and recommends that you consult with your physician or local treatment center before beginning any form of treatment.

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## **How to Correct or Update Information**

To change or modify information previously provided, e-mail [info@tango2research.org](mailto:info@tango2research.org) or send a letter to:

TANGO2 Research Foundation

*Attention: Privacy Policy*  
300 Plaza Middlesex, Middletown, CT 06457

**Tell us what you think**

The TANGO2 Research Foundation welcomes your questions and comments about this privacy statement, about the practices of the TANGO2 Research Foundation, and about your dealings with our website. Please send e-mail to [info@tango2research.org](mailto:info@tango2research.org) or write to:  
TANGO2 Research Foundation

*Attention: Online Services*  
300 Plaza Middlesex, Middletown, CT 06457