



The CTX Alliance is a non-profit charitable organization whose mission is to provide education, support, advocacy, and promoting research for CTX patients, their families, and medical professionals who treat and study this rare disease. The CTX Alliance's (CTXA) 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 order to ensure a civil, respectful discussion that adds to the richness of CTXA's publications and communications dialogue. This privacy statement discloses the privacy practices for the CTX Alliance and for those people who utilize any of the CTX Alliance publications and communications including but not limited to the following: the CTX Alliance Websites, Facebook, Twitter, Pinterest, YouTube, Online Communities, Other (Emerging), Mobile Applications, Educational Materials, Conferences & Meetings, Fundraising Events, and Story Campaigns. The CTX Alliance 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 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 on our website and in our databases. We use this data to tailor your experience at the CTX Alliance 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 with our information, our programs, and our services. Part of our mission is to support our community, 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

CTXA, unlike many other non-profit organizations, does not make available the names and addresses of our contributors to other companies or organizations, although the CTX Alliance does offer programs in which members must consent in advance before a member's name is disseminated.

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 CTX Alliance 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 CTXA. (If you use more than one email address, postal address, or telephone number, please identify each one.)

We use cookies to enhance your online experience by storing preferences and personalizing content. Cookies do not provide us with your personal information unless you choose to share it. They help us save time, improve site offerings, and remember your details for future visits. You can opt to reject cookies, but this may require re-registering each time you visit. This policy does not apply to third-party cookies.

If you are visiting the website from outside of the United States, your connection will be through and to servers located in the United States, all information you provide will be processed and securely maintained in our web servers and internal systems located within the United States. By using the website, you authorize the export of personal information to the USA and its storage and use as specified above when you provide such information to us. This policy and our legal obligations are subject to the laws of the State of Illinois and the USA, regardless of the location of any user.

Changes to Privacy Policy

We may update this Privacy Policy at any time and, if so, we will post the new effective date. Your continued use of the Site after the effective date of the new Privacy Policy constitutes your consent to the new Privacy Policy.

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 CTXA's social media presences which contain nudity will be deleted.

Links to Other Sites

This site links to other websites unrelated to the CTX Alliance that are owned and operated by third parties. The CTX Alliance 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 endorsement or affiliation by CTXA. The CTX Alliance 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.

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

E-mail Guidelines

The CTX Alliance 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 CTX Alliance also provides all e-mail recipients with a clear, easy and effective method to unsubscribe to any and all online communications.

The CTX Alliance is not responsible for information or advice provided by others, including information on the CTXA's social media sites, websites that link to Association sites, and on third party sites to which the CTX Alliance links. Fan-produced content on CTXA's social media does not necessarily reflect the opinions of CTXA.

CTX Alliance Website Terms of Use

Permission to use material from this website/reprints/copyright

The CTX Alliance 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 CTX Alliance.

Translations and adaptations

Translations or adaptations of the CTXA's content must be reviewed and approved by CTXA. Please send an email describing intended use, duration, and contact information to CTXA.

Using content from the CTXA's communications

Reprint of the CTXA's content or references to the CTXA's contact information in an organization's communications must be approved by a person of authority at CTXA. Please send queries to CTXA.

Logos

Using any of the CTXA's logos or registered trademarks without the CTXA's prior consent is strictly prohibited. Please send written requests describing intended use, duration, and contact information to CTXA.

Photographs and graphics

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

Linking policy

When linking to the CTXA's website, web managers should be aware that the CTX Alliance trademarks are not available for posting or replication on third party websites without a written agreement with CTXA. 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 CTXA's website: *Linking Disclaimer: "This site links to other websites unrelated to the CTX Alliance that are owned and operated by third parties. The CTX Alliance 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 endorsement or affiliation by CTXA. The CTX Alliance 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

Hubspot, Constant Contact, Fundraise Up and Network for Good, the database software and donor processing companies used by the CTX Alliance are PCI compliant. They have been validated as either a level 1 or level 2 PCI Compliant Service Provider. "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 CTX Alliance works to ensure that the information provided on its authorized website is accurate, timely and useful. However, the information contained on the CTX Alliance website should not be considered medical guidance or professional advice. The CTX Alliance 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.

The CTX Alliance, its affiliates or agents, or any other parties involved in the preparation or publication of this site are not responsible for errors or omissions in information provided on this site or any actions resulting from the use of such information. Visitors are encouraged to confirm the information contained herein with other reliable sources and to direct any questions concerning their personal health to licensed physicians or other appropriate health care professionals. Corrections and additions to this site will be made when necessary or as time permits.

How to Correct or Update Information

To change or modify information previously provided, e-mail the CTX Alliance at info@ctxalliance.org or send a letter to the office at 1586 Sumneytown Pike #1322, Kulpsville, PA 19443.

Tell us What you Think

The CTX Alliance welcomes your questions and comments about this privacy statement, about the practices of CTXA, and about your dealings with our website. Please send e-mail to the CTX Alliance at info@ctxalliance.org or send a letter to the office at 1586 Sumneytown Pike #1322, Kulpsville, PA 19443.