

CONQUER CHIARI

Privacy Policy

Effective date: September 25, 2023

This Privacy Policy describes how Conquer Chiari, including its affiliates (together referred to as “Conquer Chiari” or “we” or “us” or “our”), collects, uses, and shares information from and about people who visit us online at one of our websites at www.conquerchiari.org, walk.conquerchiari.org, or chiariacademy.getlearnworlds.com (collectively, the “Sites”), who communicate with us, or whose information we receive in other ways (“you” or “your”).

Please review this Privacy Policy carefully. By visiting our Sites or communicating with us in other ways, you agree to the collection, use and processing of your personal information as described in this Privacy Policy. If you do not agree to the terms of this Privacy Policy, please do not access our Sites or provide personal information to us.

SCOPE OF THIS PRIVACY POLICY

Conquer Chiari is dedicated to improving the experiences and outcome of Chiari & syringomyelia patients by providing accurate information, raising awareness, and sponsoring research in the field.

This Privacy Policy describes how Conquer Chiari collects, uses, shares, and protects personal information and your choices regarding use, access, and correction of your personal information. We use the term “personal information” in this Privacy Policy to refer to information that identifies, relates to, describes, or is reasonably capable of being associated or linked, directly or indirectly, to an identifiable individual.

We collect personal information that you submit to us directly, that is gathered automatically online by cookies and similar internet technologies, and that we receive from social media and other sources. For example, we collect information about you when you:

- Visit our Sites and any other website, online portal that we operate and displays a link to this Privacy Policy;
- Set up an account on our Sites;
- Join our various events, including the annual walk program, whether as a participant, volunteer, organizer, sponsor, fundraiser, or in any other capacity;
- Sign up for our mailing list to receive information about our educational, marketing, or fundraising events;
- Shop online at our online store;
- Participate in research initiatives conducted by third-party independent organization working in this field; or

- Communicate or interact with us in other ways, including through attending our in-person events .

This Privacy Policy does not apply to:

Collection by third party websites. Our Sites may contain links to third-party websites that we do not operate or control, such as various links to research institutes or the independent third-party service providers engaged by us for hosting/processing our online store. The information practices and the content of these third-party websites are governed by their own privacy practices. We encourage you to review the privacy statements posted by these third-party websites to understand how they will manage your information.

Business to business communications. Information we obtain about our employees, job applicants, and other personnel or the employees and representatives of business customers, service providers, suppliers, and business partners.

PERSONAL INFORMATION YOU PROVIDE TO US

Account Registration. When you set up a Conquer Chiari online account, join our email list, donate to Conquer Chiari through our website or by sending a check, register to be a walk organizer, register to participate in a walk, or sponsor a walker, we ask you for some or all of the following information as applicable:

Account Registration

- Name
- E-mail address
- Phone number
- Fundraiser idea

Walk Fundraising Page:

- Name
- Address
- E-mail address
- Phone number
- Geographical location (e.g., walk location)
- Number of people in your group
- Identify the walker type (e.g., Chiari patient, family member, supporter, etc.)
- Address
- T-Shirt size (optional)
- Username and password for walker fundraising page
- Donation amount
- Fundraising goal
- Fundraising page information (e.g., account information, address, etc.)

- Your message, name, or picture on the donation page or walker group (optional)
- Conquer Chiari name and contact for corporate sponsors
- Background and experience (e.g., professional background, volunteer experience, availability of organizers)
- Information about the scale of your presence and the number of your connections in social media platforms (e.g., how many people in your network, how many businesses in your network, payment for incidental costs, etc.) (optional)
- Skills & Traits (e.g., handling conflict, overcoming obstacles, etc.) (optional)
- Waivers and Release (e.g., confirm your age verification (or parents/guardian consent if a walk participant is under the age of 18) at the time of registration.)

Donations:

- Name
- Address
- E-mail address
- Phone number
- Date and time donation made
- Purpose of donation (optional)
- Any message that is included with the donation (e.g., if the donation is in honor/memory of anyone, etc.)

Your credit card information is processed through a payment gateway, a transaction processing technology that process your credit card information when you make a donation online. Your personal information collected by gateway payment is subject to such service provider's privacy policy and practices. We do not receive or store your credit card information.

Online Shopping. You may choose to purchase goods or services from Conquer Chiari using a payment card. Typically, payment card information is provided directly by you, via a third-party website, into the PCI compliant payment processing service to which Chiari subscribes, and Conquer Chiari does not, itself, process or store the card information. When you place an order online, you will be directed to the website of our third-party shopping site platform to view our merchandise, place your order, process your payment, and ship your order to you. Your order information, including PayPal account or credit/debit card information will be collected by the shopping site platform—not by us—and will be subject to platform's privacy policy, rather than this Privacy Policy. The shopping site will share information with us about your purchase (e.g., name, shipping address, items, date, and amount of purchase), but will not share your payment information.

Register for Courses with Chiari Academy. When you register to participate in our online education program, we ask for your name, email address, username and password, your account information such as your last log in information, date and time of registration, the courses taken, etc.

Requests for Information. When you ask us for information about our services, events, or products, we may ask for your name, e-mail address, phone, and information you're interested in.

Message Boards/Community Forums: The Sites may offer publicly accessible blogs, community forums, comments sections, discussion forums, or other interactive features, such as fundraising messages, or stories ("Community Forums"). You should be aware that any information that you post on a Community Forum will be read, collected, and used by others who access it. To request removal of your personal information from a Community Forum, contact us. In some cases, we may not be able to remove your personal information, in which case we will let you know if we are unable to do so and why. See "How to Contact Us" below.

Events and Workshops. If you register for a walk, or other event sponsored by Conquer Chiari, we may ask for your name, phone number, email address, and information relating to the specific event when you register or attend.

AUTOMATED ONLINE DATA COLLECTION

We (and our third-party service providers) may place cookies, web beacons, scripts, and similar tracking technologies and device identifiers on your web browser or mobile device when you visit our Sites. (In this Privacy Policy we use the term "cookies" to refer generally to cookies, tracking technologies, and other internet tools.) You can use the settings or tools offered on your browser to refuse or restrict certain cookies or to delete cookies that have already been stored. (See "How You Can Restrict Cookies and Targeted Advertising" below.)

Log in and identification—to recognize and verify you and your device when you log in to access your account and use the Sites by storing data including, for example, your password, device and browser type, Internet Service Provider (ISP) and Internet Protocol (IP) addresses, device and browser identifiers and information (including device, application, or browser type, version, plug-in type and version, operating system, and other technical data).

Features and performance—to provide functionality for the features and options you select to use on our Site; deliver consistent performance; recognize and implement your preferences; and enable information sharing with third-party providers. For example, Chiari Academy may use a third-party online learning platform such as Get Learn Worlds to operate our course offerings. We also use payment processing providers to process credit card payments for donations and merchandise.

Location—if you visit our Sites using a mobile device, we obtain geolocation data from device sensors, GPS signals, WiFi access points, and cell towers, unless you disable location information in your device setting. We can also more generally identify your location through the IP address of your computer or mobile device identifier.

Data analytics—track and log web usage data about your interactions with our Sites and online activities including, for example, browsing history, usage rates, settings preferences, content interactions (including searches, page views, downloads, and prints), and user journey history (including clickstreams and page navigation, URLs, timestamps, content viewed or searched for, page interactions, and similar data).

Email Interconnectivity—if you receive email from us, we use internet tools to capture data related to when you open our message and click on any links or banners it contained. We use this information to track the effectiveness of our communications with you.

HOW WE USE PERSONAL INFORMATION WE COLLECT

We use personal information to conduct our services, stay in contact with you, and meet your expectations, including to:

- Register new user accounts;
- Process and complete registrations and requests, and send you related information, including registration confirmations;
- Provide accurate, up-to-date, and easy to understand information to patients, the medical community, and the general public about Chiari;
- Raise awareness about Chiari in family and friends of a Chiari patient, in the general public, and the medical community;
- Sponsoring research activities and initiatives to advance the understanding of Chiari;
- Organize community events, fundraisers, and walks to raise awareness and financial support;
- Offer courses and educational materials to provide information to educate about Chiari;
- Send transactional messages, including responses to your comments, questions, and requests; provide user service and support; and send you technical notices, updates, security alerts, and support and administrative messages;
- Provide, operate, maintain, improve, and promote the Sites;
- Enable you to access and use the Sites efficiently;
- Send communications about Chiari medical developments, and Conquer Chiari activities and services including features, newsletters, contests, and events; and provide other news or information about us and our research, third-party independent organization working in this field (you can opt-out of receiving marketing communications as explained under How You Can Restrict Online Data Collection and Marketing Communications);
- Protect our Sites and users by investigating suspicious activity and unauthorized access;
- Comply with valid legal process and respond to governmental requests.

HOW WE SHARE PERSONAL INFORMATION

We do not sell personal information, nor do we share personal information for targeted advertising purposes.

Our Organizers: We share limited walkers' information, such as name, shirt size, amount raised, type of walker and corporate sponsor information with our volunteer organizers.

Third-Party Service Providers: We share information, including personal information, with third-party service providers we use to provide hosting for and maintenance of our Sites, e-mail marketing, backup, storage, payment processing, analytics and other services for us. These third-party service providers may have access to or process your personal information for the purpose of providing these services for us. We do not permit our third-party service providers to use the personal information that we share with them for their own commercial purposes.

Site Analytics: We may collect, and we may engage third-party analytics providers to collect, metrics and information regarding your use of the Site, including evaluating how visitors use our Sites and customer portal ("Usage Data") to develop new features, improve existing features or inform sales and marketing strategies. When we process Usage Data, any personal information is anonymized.

We use Google Analytics to measure and evaluate access to and traffic on the Public Area of the Sites and create user navigation reports for our Site administrators. Google operates independently from us and has its own privacy policy, which we strongly suggest you review. Google may use the information collected through Google Analytics to evaluate Users' and Visitors' activity on our Sites. For more information, see [Google Analytics Privacy and Data Sharing](#).

We take measures to protect the technical information collected by our use of Google Analytics. The data collected will only be used on a need-to-know basis to resolve technical issues, administer the Sites and identify visitor preferences; but in this case, the data will be in non-identifiable form. We do not use any of this information to identify Visitors or Users.

With Your Consent: We may also share personal information with third parties when we have your consent to do so.

Law Enforcement, Legal Process and Compliance: We may disclose personal information or other information if required to do so by law or in the good-faith belief that such action is necessary to comply with applicable laws, in response to a facially valid court order, judicial or other government subpoena or warrant, or to otherwise cooperate with law enforcement or other governmental agencies.

Security and Protection: We also reserve the right to disclose personal information or other information that we believe, in good faith, is appropriate or necessary to (i) take precautions against liability, (ii) protect ourselves or others from fraudulent, abusive, or unlawful uses or activity, (iii) investigate and defend ourselves against any third-party claims or allegations, (iv) protect the security or integrity of the Service and any facilities or equipment used to make the Service available, or (v) protect our property or other legal rights, enforce our contracts, or protect the rights, property, or safety of others.

HOW YOU CAN RESTRICT COOKIES

Conquer Chiari does not publish third-party personalized advertisements on the Sites, nor do we publish personalized advertisements on other companies' websites.

Cookies enable Conquer Chiari to measure and analyze the visits to the Sites and collect data on the activities of users of the Sites and our online portal. We use Google Analytics and/or other third-party data analytics services to place the cookies, track Site usage data, and provide reports to us. Conquer Chiari does not disclose any directly identifying personal information to a third-party data analytics service. However, the service may monitor a user's visits to the Sites and combine this data with data from other websites monitored by the same service provider and then use the aggregated findings for its own commercial purposes. The service provider may have means of correlating data from our Sites to an identifiable individual, in which case the processing of personal information will be the responsibility of the service provider.

By using the Sites, you consent to the processing of your personal information by both Conquer Chiari and the Site analytics services providers, including Google Analytics. You can restrict how cookies and other internet technologies are used to track and log data about your computer and mobile device usage of our Sites by managing the preference settings on your browser or device. You can learn how Google collects data on its partner sites and how to restrict that data collection at <https://policies.google.com/technologies/partner-sites?hl=en-US>.

Note that if you restrict the use of cookies some of the features on our Sites may not be fully functional.

The controls you may be able to use include:

- Managing the settings on your web browser or device
- Installing the Google Analytics opt-out browser add-on, which is described at the [Google Analytics Opt-out Browser Add-on](https://tools.google.com/dlpage/gaoptout) page at <https://tools.google.com/dlpage/gaoptout>
- Communicating directly with third-parties that we authorize to collect data on our Sites as explained at:
 - [Google](https://policies.google.com/privacy): <https://policies.google.com/privacy>
 - [Facebook](https://www.facebook.com/privacy/explanation): <https://www.facebook.com/privacy/explanation>

- Twitter: <https://twitter.com/en/privacy>
- Purchasing a utility from an independent software provider that you install on your computer browsers to limit tracking of your browsing activity.

Do Not Track (DNT) is an optional browser setting that is used by some website operators and third parties. Our Sites do not respond to DNT signals.

YOUR COMMUNICATIONS CHOICES.

E-mail marketing. When you submit your contact information to us, you will be authorizing us and/or our authorized service providers to send you marketing or promotional communications (by mail, e-mail, telephone, text message, or voicemail transmission). We may use an automatic telephone dialing system or automated system to select the telephone number and may play a recorded message when a connection is complete or transmit a pre-recorded voicemail or message. (Message and data rates may apply.)

You can opt-out of receiving marketing communications from us by following the “unsubscribe” instructions included in each of our e-mail marketing communications. You can also opt-out by emailing us at director@conquerchiari.org and providing the names/email address that you want us to remove from our marketing database and add to our ‘Do Not Contact’ list. If you opt-out of marketing messages, we may still send e-mails to you that involve your orders or responses to questions. It may take up to ten days to process your request to unsubscribe from e-mail marketing messages.

RETENTION AND PROTECTION OF PERSONAL INFORMATION

We will retain your personal information as long as we provide services to you, and as necessary to comply with our legal obligations, resolve any disputes, and enforce our agreements.

We maintain commercially reasonable security procedures and practices appropriate to the nature of the categories and specific items of personal information we collect. However, neither people nor systems can operate in a fully secure manner and no method of transmission over the Internet or method of electronic data storage is fully secure. While we use reasonable efforts to protect your personal information and select third-party service providers we believe also use reasonable precautions, we cannot guarantee the security of the personal information you provide to us.

Our Sites permit you to create an account. When you do you will be prompted to create a password. You are responsible for maintaining the confidentiality of your password, and you are responsible for any access to or use of your account by someone else who has obtained your password, even if that person was not authorized by you. You should notify us of any unauthorized use of your password or account, and, if any unauthorized use is suspected, you should immediately reset your password.

If you have reason to believe that your interaction with us is no longer secure (for example, if you feel that the security of any account you have with us has been compromised), please immediately notify us of the problem.

LINKS TO SOCIAL MEDIA AND THIRD-PARTY FEATURES AND WEBSITES

Social Media. Our Sites include social media features and allows you to visit our social media by clicking on the respective icons. Please refer to the privacy settings in your social network account for information about (1) what data is shared with connected applications, (2) how to manage the data that is shared through your social media account settings, and (3) how to disconnect a social media account from our Sites. This Privacy Policy applies solely to information under our control. Conquer Chiari not responsible for the privacy practices of the social media platforms you use in connection with our Sites. We recommend that you review their privacy policies and practices.

Third party Features. Our Sites may use other companies' applications to power some features, for example, to manage online payment processing. Some of these third-party features may be branded with Conquer Chiari logo, even though they are not operated or controlled by us. These third-party applications are able to access and collect data from your use of these features.

Third-Party Websites. Our Sites may include links to websites operated by third parties that have information we think may be of interest to you. If you click on a third-party link, you will be directed away from our Sites to that third-party website and any information you provide to that third party website or is collected from your usage, will be available to the third-party operator. Conquer Chiari is not responsible for the privacy practices of any third-party services. The third-party website operator may collect your IP address or device identifier and other internet browsing data and may set a cookie to enable their features to function and track your usage. We recommend that you review the privacy policies of these websites before sharing any information with them. We have no control over and assume no responsibility for the content, accuracy, privacy policies, or practices of any third-party websites or services.

CHILDREN'S PERSONAL INFORMATION

The Children's Online Privacy Protection Act of 1998 and its rules (collectively, "COPPA") require us to inform parents and legal guardians (as used in this section, "**parents**") about our practices for collecting, using, and disclosing personal information from children under the age of 13 ("**children**"). It also requires us to obtain verifiable consent from a child's parent for certain collection, use, and disclosure of the child's personal information. If parents wish to revoke their consent as to our practices collecting personal information of their children, please see "How to Contact Us."

This Privacy Policy notifies parents of:

- The types of information we may collect from children when they participate in our community event, and organized walks.
- How we use the information we collect.
- Our practices for disclosing that information.
- Our practices for notifying and obtaining parents' consent when we collect personal information from children, including how a parent may revoke consent.
- All operators that collect or maintain information from children through the Sites, as applicable.

This section only applies to children under the age of 18 and supplements the other provisions of this Policy.

YOUR RIGHTS

When you provide your personal data to us, or we obtain it through your use of our Sites, services, or other means, your information will be transferred to the United States and processed in accordance with the laws of the United States and the guidelines of this Privacy Policy. Depending on your place of residence or citizenship, you may have specific rights with respect to your personal data that we will follow to the extent applicable to our operations.

United States. If you reside in the United States you have certain rights about e-mail and telemarketing messages as explained in the section titled, "How to Opt Out of E-mail and Telemarketing." You also have the right to revoke your consent to any collection or sharing of personal information for which we requested, and you provided, your affirmative consent. Depending on the state where you live and our business activities in your state, you may have other legal rights regarding your personal information.

Canada. If you reside in Canada, you have the right to request access to your data, have your personal information updated or amended to correct inaccuracies or incomplete information, and (where technically feasible) to request a portable copy of your personal data, as defined under and subject to applicable law. You may also have the right to request deletion of your personal data or request that we no longer use it. You are responsible for the accuracy of the information you provide when using our Sites and services. To access, review or update your information for accuracy, please login to your Conquer Chiari account (if applicable) or contact us using the information below. Your right to access or correct your personal data is subject to applicable legal restrictions. We may take reasonable steps to verify your identity before granting access or making corrections.

Europe and United Kingdom. If you are a resident in Europe or the UK, we will process your information in order to fulfill your orders and to otherwise pursue our legitimate business interests as described in this Privacy Policy, subject to your legal rights. If your

personal data is protected under the General Data Protection Regulation, you may be entitled to the following:

The right to access – You have the right to request copies of your personal data. We may charge you a small fee for this service.

The right to rectification – You have the right to request that we correct any information you believe is inaccurate.

The right to erasure – You may have the right to request that we delete your personal data, subject to legally permitted reasons for which we may decline your request in part or in whole.

The right to restrict processing – You may have the right to request that we restrict the processing of your personal data, under certain conditions.

The right to object to processing – You may have the right to object to Conquer Chiari's processing of your personal data, under certain conditions.

The right to data portability – You may have the right to request that we transfer the data that we have collected to another organization, or directly to you, under certain conditions.

If you make a request, we will respond within the timeframe specified by applicable law or within approximately one month from when we receive your request. You can make a request as explained in the section titled "How to Contact Us."]

CHANGES TO THIS PRIVACY POLICY

We reserve the right to amend this Privacy Policy at any time in order to address Conquer Chiari's future developments, changes in industry trends, or changes in legal requirements. If we materially alter the terms of this Privacy Policy, we will post the revised Privacy Policy on the Sites and provide other notification as required by applicable law.

Any changes will become effective upon the posting of the revised Privacy Policy on the Site. You can determine when the Privacy Policy was last revised by referring to the "Effective Date" legend on the top of this Privacy Policy.

By continuing to use the Sites following such changes, you will be deemed to have agreed to such changes. If you do not agree with any or all of the terms of our Privacy Policy as in effect at any time, you should not continue to use the Site.

HOW TO ACCESS AND MANAGE YOUR PERSONAL INFORMATION

You can update or correct your online account information by logging into your account on our Sites.

HOW TO CONTACT US

If you have questions or complaints regarding this Privacy Policy or about Conquer Chiari's privacy practices, please contact us by email at director@conquerchiari.org, or by mail at:

320 Osprey Court
Wexford, PA 15090