



The policies below are applicable to the website located at [www.caudaequinafoundation.org](http://www.caudaequinafoundation.org) and any other websites under the control of the Cauda Equina Foundation (the “Website”), however the Website is accessed and/or used, whether via personal computers, mobile devices, or otherwise, and other interactive features, applications (including mobile applications), or downloads that are operated by the Cauda Equina Foundation (“we” and “us”) that are made available by us. Please be advised that the practices described in this Privacy Policy apply only to information gathered online at our Website. They do not apply to information that you may submit to us offline or to websites maintained by other companies or organizations to which we may link.

## What information we collect

As a general matter, you can browse the Website without submitting your personal information to us. However, there are a number of circumstances in which you may need to provide us with your personal information. The following lists the most common ways in which we collect your personal information.

- When you register for an account on the Website;
- When you sign up to receive email newsletters from us;
- When you participate in surveys, panels, or research;
- When you register for and participate in our programs, activities, initiatives, and events;
- When you request information or assistance;
- In conjunction with processing your grant applications;
- In conjunction with your employment inquiries or applications;
- When you participate with social media accounts involving Foundation properties;
- When you participate in communities, chat rooms, and other interactive services;
- In conjunction with any verification of your account information;
- In conjunction with investigations into any activity that may violate the law or the Website’s terms and conditions;
- When you communicate with us through the Website;
- When you provide user-generated content on any part of the Website that permits it; and
- In conjunction with any other place on the Website where you knowingly volunteer personal information.

When you interact with any Cauda Equina Foundation page or account on a social media platform, such as Facebook, Twitter, Google+, LinkedIn, Tumblr, YouTube, or Pinterest, or Instagram, or when you use your social media account or credentials to log in to the Website, we may also collect the personal information that you make available to us on that page or through that account, including your account ID or “handle.”

In addition, when you interact with the Website, our servers may keep an activity log that does not identify you individually (“Non-Personal Information”). Generally, we collect the following categories of Non-Personal Information:

- We may collect certain demographic data such as age, gender, and five-digit zip code as part of collecting personal information;
- We collect and store certain device information about your computer, mobile device, or other device that you use to access the Website. This information may include IP address, geolocation information, unique device identifiers, browser type, browser language, and other transactional information;
- We automatically log certain usage information about your use of the Website. This information includes a reading history of the pages you view. We use this information to provide you with a more customized experience on the Website;
- We collect and store additional “traffic data” such as time of access, date of access, software crash reports, session identification number, access times, and referring website addresses; and
- We collect and store your search terms and search results.

We also collect and store certain other information regarding our users’ use of the Website so that third parties may provide us with reports and analysis regarding usage and browsing patterns of the Website.

## How we combine your information

We may combine information gathered from the Website and information that we have received, gathered, acquired, or stored from other sources, both information collected offline by the Foundation and information received from third parties—including information that currently exists in our files—into a single customer record. We also use and/or combine information that we collect offline or receive from third-party sources (e.g., contact information from government funders or grantor information) to edit, enhance, and/or check the accuracy of your customer record.

## How we use your information

We use the information we learn from you to help us personalize and continually improve your experience on the Website. We use your Personal and Non-Personal Information in the following ways:

### General Uses

- For editorial purposes;
- Responding to your inquiries;
- Communicating with you about your account or transactions with us and sending you information about features on our Website or about the Foundation;

- Communicating with you about changes to our policies;
- Personalizing content and experiences on our Website, including providing you with recommendations based on your preferences;
- Sending you newsletters, mailings, and information about programs, initiatives, activities, and events by e-mail or another medium;
- Processing your grant application or employment application;
- Event or program registration;
- Optimizing or improving our programs, services, and operations;
- Research and development;
- Verifying your account and account activities;
- Detecting, investigating, and preventing activities that may violate our policies or be illegal;
- Performing statistical, demographic, and marketing analyses of users of the Website and their usage patterns; and

## How we share your information

The Cauda Equina Foundation adheres to the highest standards of ethical practices in all our operations and is dedicated to protecting the privacy of all visitors to our Website. *Except as disclosed below, we don't sell, barter, give away, rent, or permit anyone outside the Cauda Equina Foundation to use or access your personal information.*

We occasionally use independent contractors and third-party agents, affiliates, and partners to perform functions such as marketing, analytics, providing customer service, etc., on our behalf. These entities have access to the personal information needed to perform their functions and are contractually obligated to maintain the confidentiality and security of any personal information collected from the Website. They are restricted from using, selling, distributing, or altering this data in any way other than to provide the requested services to the Cauda Equina Foundation. Inspire™ is an independent contractor that we are partnered with that provides our online group support forum, we encourage our members to read their privacy policy before participation.

Cauda Equina Foundation conducts and supports research, and may promote external research on cauda equina syndrome, all research is voluntary and is based off informed consent. You may share as much information as you are comfortable with for research purposes. When presenting research results patient identifiers will be kept confidential by all parties involved.

Cauda Equina Foundation provides cauda equina syndrome education to the community, patients, and healthcare providers using information collected from research and demographics. Cauda Equina Foundation also conducts and supports cauda equina syndrome related advocacy initiatives in which we share demographic information with Federal and State Representatives and the public at large. All patient and member identifiers will be kept confidential by all parties involved. Unless the member chooses to engage in the advocacy efforts that include identifiable information.

Cauda Equina Foundation provides patient support services to aid in continuity of care post-hospitalization to improve transition and patient outcomes including patient mentoring. Cauda

Equina Foundation will share patient information with healthcare providers and other care providers to collaborate care coordination with informed consent of patient. All patient confidentiality local, state, and federal laws will be followed by HIPPA standards including all communications, management of electronic and paper records.

We may also use or disclose your personal information if required to do so by law or in the good-faith belief that such action is necessary to (a) conform to applicable law or comply with legal process served on us or the Website; (b) protect and defend our rights or property, the Website, or our users; and (c) act under emergency circumstances to protect the personal safety of us, our affiliates, our agents, or the users of the Website or the public.

## How we use cookies

Like many websites, we use “cookies,” which are small text files that are stored on your computer or equipment when you visit certain online pages that record your preferences. We use cookies to track use of our Websites and online services. We may also use cookies to monitor traffic, improve the Websites, and make it easier and/or relevant for your use. This Website is functional without the retention of cookies. You have the ability to accept or decline cookies. Most web browsers automatically accept cookies, but, if you prefer, you can usually modify your browser setting to decline cookies. For more information on cookies and how to disable them, you can consult the information provided by the Interactive Advertising Bureau at [www.allaboutcookies.org](http://www.allaboutcookies.org).

Like some websites, we may use web beacons or flash cookies. A web beacon or flash cookie (also known as an “action tag” “tracer tag,” or “single-pixel GIF”) is an invisible graphic on a web page or e-mail newsletter that is programmed to collect non-personally identifiable information about your use of a given website or newsletter, e.g., whether you opened the email. Like cookies, web beacons allow the Cauda Equina Foundation and its technology providers to summarize overall usage patterns for our analysis and provide personalized services to you. We do not share or provide personally identifiable information we may collect through such web beacons, such as names or e-mail addresses, without your express permission.

The Cauda Equina Foundation strives to protect the transmission and storage of any information submitted by visitors to the Website. But no transmission and storage of data is completely secure, and submissions are at your sole risk.

This Website may contain links to sites operated by third parties. Please be advised that the practices described in this Privacy Policy do not apply to information gathered through these other websites.

Please remember that any information you share in public areas, such as message boards or feedback sections, becomes public, and therefore this Privacy Policy does not apply to any information you choose to make public. Please be careful about what you disclose, and do not post any personal information that you expect to keep private.

The Website is published in the United States and is subject to laws of the United States. If you are located in a country outside the United States and voluntarily submit personal information to us, you thereby consent to the general use of such information as provided in this Privacy Policy and to the transfer of that information to, and/or storage of that information in, the United States. The Cauda Equina Foundation shall not be liable under any circumstances for damages resulting from use of information collected from visitors to the Website.

We reserve the right to modify or amend the terms of this Privacy Policy from time to time without notice. Your continued use of our Website following the posting of changes to this Privacy Policy will mean you accept those changes.

Questions and comments should be directed to [info@caudaequinafoundation.org](mailto:info@caudaequinafoundation.org).

If you have any questions regarding this policy, if you would like to change your preferences, if you no longer wish to receive email updates from the Cauda Equina Foundation, or if you believe the Cauda Equina Foundation has erroneous or incomplete information about you, please send an email to [info@caudaequinafoundation.org](mailto:info@caudaequinafoundation.org).

### **We respect your confidentiality**

Cauda Equina Foundation requires that your personal information be held in strict confidence. We use your information only for its intended business purpose. We do not sell or trade your information to other organizations or individuals.

### **We protect your information**

Cauda Equina Foundation takes every possible measure to ensure that your information is not compromised in any way. Our privacy promise extends online to our Internet website too.

If you choose to send us email, we may retain the contents of your email message, our reply and your email address as part of our ongoing customer service efforts. We reserve the right to contact you after you have contacted us and may send future email and/or surveys to you. You may notify us via email if you wish to discontinue electronic communication or select "unsubscribe".

### **We keep accurate records**

We keep your personal information as accurate, complete, and up to date as is required to fulfill the purpose(s) for which you provided us with your personal information. Upon request in writing we will remove your personal information from our databases, except where legislation or regulation requires our retention of it (for example, charitable giving history tied to income tax receipts.)

If you have any questions about our website or our Privacy Promise, please contact us at [info@CaudaEquinaFoundation.org](mailto:info@CaudaEquinaFoundation.org)

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