FARA PRIVACY POLICY

Effective Date: September 24, 2026

Friedreich's Ataxia Research Alliance ("FARA," "we" or "our") maintains this website to provide information about our organization, our work, and Friedreich ataxia. We take your privacy very seriously. This Privacy Policy describes how we collect, process, store, protect, use, and share personal information when you interact with us, including through our website, https://curefa.org/,the Clinical Management Guidelines for FA website, https://frdaguidelines.org/, (collectively, the "Websites"), our social media presence, our newsletters, and FARA-hosted events. For information on how we use Personal Information collected from donors, please see the "**Donor Privacy**" section below.

CHANGES TO THIS NOTICE

We reserve the right to amend this Notice at our discretion and at any time. When we make material changes, we will notify you in a manner in which we regularly interact with you, such as by email, or through a notice on our Website's homepage. You will also be able to determine the date that our current Notice has become effective, by viewing the Effective Date at the top of this document.

WHY WE COLLECT PERSONAL INFORMATION

FARA's mission is to marshal and focus the resources and relationships needed to cure Friedreich's Ataxia by raising funds for research, promoting public awareness, and aligning scientists, patients, clinicians, government agencies, pharmaceutical companies and other organizations. We may collect Personal Information in furtherance of these objectives for the following purposes:

- To provide the services and programs you request from us and products you purchase from our online store, which is operated on our behalf by our service provider;
- To process donations;
- To communicate with you and/or your authorized representatives about the requested products or services and programs;
- To personalize, troubleshoot or improve our online content and experiences;
- To market and inform you about FARA's programs;
- To comply with our legal obligations and to enforce our rights;
- To combat fraud and prosecute bad actors.

We will not use the Personal Information we collected for materially different, unrelated, or incompatible purposes without providing you with an advance notice, including by updating this Notice.

INFORMATION WE MAY COLLECT AND USE

We may collect, use, and/or share some or all of the following Personal Information categories:

- **Identifiers**, such as your name, preferred alias, address, email address, telephone number, e-contact, account name and similar identifiers, age, t-shirt size;
- **Transactional history**, such as records of transactions; donations; event registration; and emails intended for FARA;
- **Internet activity**, such as browsing history, IP address, search history, cookies and similar technologies, information about your browser and operating system, information on a consumer's interaction with a website, application, or advertisement.
- **Financial information,** such as partial debit or credit card information to facilitate transactions and donations made to FARA.
- **Sensitive information,** such as diagnosis of ataxia which is self-reported by individuals or parents when registering for, or participating in, FARA programs and events such as Ambassador program, advocacy events, educational events, or other programs. Visitors to curefa.org may choose to use an AI chat bot to assist them in finding information and answering questions. Users are instructed to not provide personal or sensitive information however if they do this, information will be recorded and saved by a third party provider and available to FARA. This information is mainly used to train the AI bot and inform FARA on topics and questions most queried by visitors to our website.

This Personal Information is required to provide services to you and information that may be of interest to you, such as research to reach treatments and cures for FA, as well as to provide education, raise funds for research, and promote public awareness. If you do not provide the Personal Information we ask for, it may delay or prevent us from providing services to you.

We will not collect additional categories of Personal Information without providing you with an advance notice, including by updating this Notice.

HOW YOUR PERSONAL INFORMATION IS COLLECTED

We collect your Personal Information directly from you when you interact with us through our Websites, including when you use the chat bot feature on the Websites, if you provide information to us on social media, by telephone, or at in-person or virtual events. We also collect information about you through our service providers, such as our web store provider, e-newsletter provider, event registration and donor software companies, and chat bot provider. FARA has data sharing agreements in place with these service providers. We may also supplement the data collected through our Websites with Personal Information from data analytics providers in order to understand how our Website visitors engage with our content and to improve our content.

NO SALE OF PERSONAL INFORMATION

We do not sell your Personal Information and have not sold your Personal Information to any third party in a traditional sense of that term. However, as some laws broadly interpret the term "sale" to include any sharing of personal information to third parties in exchange for any valuable consideration, please note that we may allow certain third parties, such as data analytics or online advertising service providers, to collect information about your browsing activity on our Website. For more information about these practices and how to limit information-sharing with third parties, see Cookies and Similar Technologies section below.

DISCLOSURE OF YOUR INFORMATION TO OUR SERVICE PROVIDERS

We may 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 the edicts of the law or comply with legal process served on us, (b) protect and defend our rights or property or our customers or users, or (c) under exigent circumstances to protect the personal safety of our users, customers, or the general public.

FARA may disclose or share some, or all, of the Personal Information we collect about you to service providers who aid us in processing and protecting your Personal Information to host the Website, send email or other communications, manage our events, generate leads, raise funds, process payments, maintain financial accounting, provide analytics and advertising services. Our service providers are given only that Personal Information they need to perform their designated functions, and we do not authorize them to use or disclose Personal Information for any other purposes.

Additionally, our online store, https://www.bonfire.com/store/curefa/ ("Store"), is operated by Bonfire Funds, Inc. When you make purchases from the Store, including via clicking on the link "Shop the FARA Store" on our Website, your personal information necessary to process the purchase will be collected directly by Bonfire Funds, Inc. subject to their privacy policy, available at https://www.bonfire.com/privacy-policy/. When you make a purchase from the Store, the funds go to Bonfire Funds, Inc. and they fulfill the order. FARA has access to a report on the Bonfire website that lists the purchaser's name, email address, phone number, mailing address, the amount of the purchase and of any applicable fees, and the percentage that FARA will receive from the sale of the merchandise. All merchandise is maintained and supplied by Bonfire Funds, Inc.

We may aggregate data we acquire about our Website visitors. If we aggregate such data and provide it to external parties, our customers' Personal Information will not be attached to or included in such aggregated data.

TERRITORIALITY

FARA's computer systems are based primarily in the United States and the content of our Website is directed to U.S. residents and is not directed to residents of other countries. FARA closely collaborates with FARA Europe in our mission to focus resources and relationships to cure Friedreich's ataxia. While FARA does not market our services to non-U.S. residents, under certain circumstances we may collect or process personal information of non-U.S. residents. If you are a resident of a jurisdiction other than the United States, please be aware that the laws of your

jurisdiction may confer upon you similar or additional rights with respect to your personal information. To learn more about your specific rights and how to exercise them, please contact us at info@curefa.org. Below are the situations in which FARA may collect personal information of non-U.S. residents:

- **Registering for events** – FARA hosts in-person and online educational and advocacy events, conferences, and fundraisers. Individuals participating in these events will be asked to register.

- **FARA grant program** - Researchers throughout the world may apply for FARA grants. As part of their application, researchers share their name, work email, work phone, work address. This information is shared with FARA's Scientific Review Board and the Board of Directors for the purposes of review of the grant applications. Data collection for the FARA grant program is operated by our service provider pursuant to a data sharing agreement with FARA, with data stored in the US.

- **FARA Ambassador program** - This is a voluntary program, where individuals who have FA can become spokespeople for FARA, contributing blogs, speaking at events, thanking donors, and participating in similar engagements. FARA collects the following personal information from Ambassadors: name, address, contact information. Individuals may voluntarily provide their date of birth at their election, in order to receive a greeting card from FARA on their birthday.

- **Chat bot** – Visitors to curefa.org may choose to use an AI chat bot to assist them in finding information and answering questions. Users are instructed to not provide personal or sensitive information however if they do this information will be recorded and saved by a service provider and available to FARA. This information is mainly used to train the AI bot and inform FARA on topics and questions most queried by visitors to our website.

If you visit our Websites or subscribe to our services we will collect and process your personal data in the United States, where data protection and privacy regulations may or may not be equal to the level of protection as in other parts of the world, such as in Canada and the European Union. BY VISITING OUR WEBSITE OR SUBSCRIBING TO OUR SERVICES, YOU UNEQUIVOCALLY AND UNAMBIGUOUSLY ACKNOWLEDGE YOUR UNDERSTANDING AND AGREEMENT TO THE COLLECTION AND PROCESSING IN THE UNITED STATES OF YOUR PERSONAL INFORMATION COLLECTED OR OBTAINED BY US THROUGH YOUR VOLUNTARY SUBMISSIONS, AND THAT UNITED STATES LAW GOVERNS ANY SUCH COLLECTION AND PROCESSING.

DONOR PRIVACY

This section is intended to provide information on how FARA collects and uses Personal Information relating to our donors. FARA takes the protection of integrity and privacy of personal information gathered from our donors very seriously. Please also see FARA's Donor Bill of Rights for a list of your rights as a donor.

A. Information We May Collect And Use

We may collect, use, and/or share some or all of the following Personal Information categories:

- **Identifiers**, such as your name, preferred alias, address, email address, telephone number, e-contact, account name and similar identifiers.
- **Transactional history**, such as records of transactions; donations; event registration; and emails intended for FARA;
- **Internet activity**, such as browsing history, IP address, search history, cookies and similar technologies, information about your browser and operating system information on a consumer's interaction with a website, application, or advertisement.
- **Financial information,** such as partial debit or credit card information to facilitate transactions and donations made to FARA.
- **Sensitive information** is collected in limited circumstances, such as complete financial account information and connection to FARA or relation to someone with Friedreich ataxia.

B. Purposes Of Collection

FARA's mission is to marshal and focus the resources and relationships needed to cure Friedreich's Ataxia by raising funds for research, promoting public awareness, and aligning scientists, patients, clinicians, government agencies, pharmaceutical companies and other organizations. We may collect Personal Information in furtherance of these objectives for the following purposes:

- To process donations;
- To communicate with you about our programs and your donations, and to provide you with the information you request from us.

C. No Sale Of Personal Information

FARA will not sell or trade your personal information with outside entities. FARA may share your information with service providers (such as but not limited to event coordinator contractors and donor software companies). FARA has data sharing agreements in place with these services providers. Cookies may be collected through FARA event or donation pages, which are operated by a third party, Classy, Inc. To learn more visit: https://www.classy.org/terms/privacy/. Cookies may also be collected through our Websites. Please see the section below, COOKIES AND SIMILAR TECHNOLOGIES.

D. Disclosure of Your Information to Our Service Providers

Solely for the purpose of acknowledging and thanking you for your donation, FARA may share your contact information with volunteer fundraising event hosts or families to whom you've given a tribute gift.

FARA may also share your contact information with volunteer FARA Ambassadors for the purpose of acknowledging your contribution on behalf of the FA community. Donation amounts for a respective campaign may be shared with volunteers acting with FARA to hold a fundraising event or campaign and who sign a non-disclosure agreement.

You have a right to opt out from sharing your information in this manner. If you would like to do so, please contact us at **info@curefa.org** and let us know that you prefer that your contact information should not be shared with the volunteer fundraising event hosts, FARA Ambassadors or families.

COOKIES AND SIMILAR TECHNOLOGIES

Cookies are small text files placed on your device to store data that can be recalled by a web server in the domain that placed the cookie. We may use cookies, web beacons, and other tracking technologies (such as scripts and tags) on our online services. We collect information from cookies via third party technology platforms such as Google Analytics. We also use cookies, web beacons, and other tracking technologies to help our online services function properly, to collect information about how users interact and use our online services, and to ensure the security of our network and related networks.

We classify cookies in the following categories:

- Essential/necessary cookies: These cookies are necessary for the functions of our Website and cannot be switched off as otherwise our Websites will not work.
- Advertisement cookies: These cookies may be set through our Website by advertisers and may be used by them to limit the number of times you see an ad, to mute unwanted ads, and to measure effectiveness of ads. They are based on uniquely identifying your browser and internet device. If you disable or block these cookies, you will experience less targeted advertising.
- Analytics cookies: These cookies collect information about your use of the Websites and enable us to improve the way they work. These cookies give us aggregated information that we use to monitor site performance, count page visits, spot technical errors, see how users reach the Websites, and measure the effectiveness of advertising.
- Other technologies may be used for the same purposes as our cookies, to allow us and third parties to know when you visit the Websites, and to understand how you interact with emails or advertisements.

Through our use of these third-party tools, we may have shared with such third parties the following categories of personal information of our website users:

- Internet or other electronic network activity information, information identifying your browser and device.

You have a variety of tools to control the data collected by cookies and similar technologies. For example, you can use controls in your internet browser to limit how the websites you visit are able to use cookies, alert you about the cookies and to withdraw your consent by clearing or blocking cookies.

LINKS TO OTHER WEBSITES

Our Website may contain links to other sites ("Third Party Websites"). These links are provided solely for the convenience of our Website visitors. We do not necessarily endorse, sanction or verify the accuracy of the information contained on Third Party Websites. Once you access a Third-Party Website through a link on our Website, you are no longer covered by this Notice. Concerns regarding a Third-Party Website should be directed to the Third-Party Website itself. We bear no responsibility for any action associated with any Third-Party Website.

POLICIES FOR CHILDREN

One of FARA's missions is to inform the discussion about Friedreich's Ataxia. Certain descriptions of medical conditions and their progression may be upsetting to children. Our Websites are not directed to individuals under the age of 13; however, we encourage parents and guardians to monitor and review their children's online activity. For additional tips on how to help children stay safe on the internet, we recommend the following site: https://consumer.ftc.gov/identity-theft-and-online-security/protecting-kids-online.

Our Websites are not directed to individuals under the age of 13. While we will never knowingly request personal information from children, we advise all visitors to Our Website under the age of 13 not to disclose or provide any Personal Information. In the event that we discover that a child under the age of 13 has provided Personal Information to us, we will delete the child's Personal Information in accordance with the Children's Online Privacy Protection Act of 1998. Please see the Federal Trade Commission's website for this Act, available at https://www.ftc.gov/legal-library/browse/rules/childrens-online-privacy-protection-rule-coppa.

Notwithstanding the foregoing, pursuant to 47 U.S.C. Section 230 (d), as amended, we hereby notify you that parental control protections are commercially available to assist you in limiting access to material that is harmful to minors. More information on the availability of such software can be found through publicly available sources. You may wish to contact your Internet Service Provider for more information.

We collect Personal Information on minors, when provided by their parents or legal guardians, or by institutions or government entities that have provided services to the minors, for the purposes of requesting services from us for the benefit of such minors.

HOW LONG YOUR PERSONAL INFORMATION WILL BE KEPT

Consistent with our record retention policy, legal, and contractual obligations, we will keep your Personal Information for the duration of the time necessary to provide the services or products you requested from us.

Thereafter, we may retain your Personal Information only to the extent necessary to:

- Respond to any questions, complaints or claims made by you or on your behalf;
- Provide services to you as contracted for by you;
- Show that we treated you fairly; and/or
- Keep records, as required by law.

We will not retain your Personal Information for longer than necessary for the purposes set out in this Privacy Notice. Different retention periods apply for different types of Personal Information. When it is no longer necessary to retain your Personal Information, we will delete or anonymize it.

KEEPING YOUR PERSONAL INFORMATION SECURE

We have implemented reasonable technical, physical, and administrative security measures to prevent Personal Information from being accidentally lost, used, or accessed in an unauthorized way. These measures offer appropriate reasonable security levels, taking into account the state of the technology, the implementation costs and also the nature, the scale, the context and the processing purposes. We limit access to your Personal Information to those who have a genuine business need to access it. Those processing your information will do so only in an authorized manner and are subject to a duty of confidentiality. The measures are also intended to prevent unnecessary collection and further processing of Personal Information. The Personal Information is contained behind secured networks and is only accessible by a limited number of persons who have special access rights to such systems and are required to keep the information confidential. We also have procedures in place to deal with a suspected data security breach. We will notify you and any applicable regulator of a suspected data security breach where we are legally required to do so.

PLEASE KEEP YOUR DEVICES AND PASSWORDS SECURE

You are also responsible for taking reasonable steps to protect your personal information against unauthorized disclosure or misuse. Please keep your devices secure and do not share devices, logins or passwords to such devices with others as there is a risk that they make access Personal Information that you stored on your device or that you request be transmitted to you from us to your device. If you receive login information, including passwords, to an encrypted account or application, please do not share this information with others. PLEASE SECURE YOUR INFORMATION AND DO NOT DISCLOSE YOUR PASSWORDS AND ANY SENSITIVE INFORMATION TO ANYONE ELSE. If you believe that your Personal Information was compromised while requesting or receiving services from us, or if your device or login and

password have been stolen, please notify us immediately at **info@curefa.org**. We will not be responsible for anyone accessing your information if they use your device or login and password.

YOUR AGREEMENT TO THIS NOTICE

For residents of the United States, to the extent permitted by the laws of your State of residence, by using our online services, you are agreeing to our practices described in this Notice, which includes the collection and use of your Personal Information. Your continued use of our online services following our notification to you of the changes to this Privacy Policy will be deemed your acceptance of those changes. Our Privacy Policy will contain the Effective Date, indicating the date it was last updated. If you have any questions about our Privacy Policy or seek to make any changes, please contact us at the contact information below.

DATA PRIVACY OFFICER CONTACT INFORMATION

FARA's privacy program is managed by FARA's in-house privacy officer. If you have any questions or comments about this Privacy Policy, the ways in which we collect and use your personal information, your choices and rights regarding such use, please do not hesitate to contact us at:

By email: info@curefa.org
By phone: 484 879 6160
By mail: FARA
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