



PRIVACY NOTICE

Last update: February 2024

This privacy notice informs you how we collect, use, and disclose your personal data. It also describes the choices that you have with regard to your personal data.

Please read this privacy notice carefully before submitting your personal data to us.

1. ABOUT EMILY'S ENTOURAGE AND THIS PRIVACY NOTICE

The following section provides general information about Emily's Entourage (EE) and this privacy notice.

1.1 About the Notice. This Privacy Notice (the "Notice") governs the processing of personal data collected from individual users ("you" and "your") through the Emily's Entourage Patient Registry website <https://emilysentourage.my.site.com/registry/s/login/> (the "Website"), online and physical forms, and our clinical trial matchmaking services (collectively, the "EE Services"). This Notice does not cover any third-party websites, applications, software, or services that integrate with EE Services or any other third-party products and services.

1.2 Data controller. EE Services are provided by Cystic Fibrosis Research Fund, Inc. (DBA Emily's Entourage) having an address at PO Box 71, Merion Station, PA 19066, USA ("we," "us," and "our"). We act in the capacity of a data controller with regard to the personal data that you provide to us.

1.3 Children. Some of the personal data that you provide us with may belong to children. We collect such data only with explicit written consent of the child's parents or legal guardians. If you become aware a child's personal data has been provided to us without such valid consent and you are a parent or a legal guardian of that child, please contact us immediately at admin@emilysentourage.org.

1.4 Term and termination. This Notice enters into force on the effective date indicated at the top of the Notice and remains valid until terminated or updated by us.

1.5 Amendments. We may change this Notice from time to time, if necessary to address the changes in our business practices, the EE Services, the Website, or laws, regulations, and standards applicable to us. The amended version of the Notice will be posted on this page and, if we have your email address, we will send you information about all the changes implemented by us. We encourage you to review our Notice regularly to stay informed.

2. WHAT DATA DO WE COLLECT?

The following section provides an overview on what personal data we collect from you or the persons you represent, for what purposes we use it, what technical data is collected automatically when you use the Website, and how we communicate with you.

2.1 We comply with data minimization principles and use personal data for limited purposes, as explained in this Notice. Below, you can find an overview of the types of personal data that we collect, the purposes for which we use it, and the legal bases on which we rely when processing it.

2.2 **Sources of personal data.** We obtain your personal data from the following categories of sources:

- **Directly from you.** For example, if you submit your personal data when completing our forms or contacting us;
- **Directly or indirectly through your activity on the Website.** When you use the Website, we automatically collect analytics information about your use of the Website.

2.3 **What personal data do we collect directly from you?**

- **Patient registration form.** When you complete our patient registration form available on the Website, we collect the following data: registrant's first and last names, date of birth, address, email address, and phone number. In addition, we collect the patient's cystic fibrosis ("CF")-related data (e.g., mutations and bacteria the patient chronically colonizes, transplant status, and modulator status), and any additional comments that you may provide. We use such data to contact the registrant, maintain our patient registry and other records, inform the registrant about relevant research, clinical advances, and drug trials, and send the registrant information about the EE Services. For more information on how we process health-related data, please refer to section 2.5 "Sensitive Data". The legal bases on which we rely are 'consent' and 'pursuing our legitimate interests' (i.e., administer our organization). We store such data in our systems for no longer than 10 years, unless you (i) permit us to store it longer or (ii) request us to delete such data earlier.

2.4 **What personal data do we automatically collect while you are using the Website?**

- **Analytics data.** While you are browsing on the Website, we collect analytics data that allows us to see what kind of users access and use the Website, which parts of the Website you find interesting, improve our content, improve our services and develop new ones, and investigate and prevent security issues and abuse. When we process your analytics data that is personal data, we rely on the 'legitimate interest' (i.e., to analyze, improve, and protect our Website) and 'your consent' bases. The analytics data that we collect includes:
 - URL addresses from which you access our Website;
 - Your device type;
 - Your operating system;
 - Your browser name and version;
 - IP address; and
 - Your other online behavior.
- **Cookies.** While you are browsing on the Website, we also collect your cookie-related data. We use such information to analyze the technical aspects of your use of the Website, analyze your use of the Website, prevent fraud and abuse, and ensure the security of the Website. For more

information on our use of cookies, please read the [Salesforce Cookie Policy](#). The legal bases on which we rely are ‘pursuing our legitimate interests’ (i.e., analyze our content and protect the Website) and ‘your consent’. We will store this data as long as analytics records are necessary for our activities or you withdraw your consent.

2.5 Sensitive data. When you, as a person with CF or a representative fills out the patient registry form, we collect your health-related (“sensitive data”), namely, information regarding your CF (e.g., mutations, bacteria you chronically colonize, transplant status, and modulator status). Such data is necessary for informing you about medical research, clinical advances and drug trials that may be relevant to you, as well as maintaining our records. We keep such data in strict confidentiality and do not disclose it to third parties, unless you or your representative authorizes us to do so via our consent form or personally in writing, including electronic means. The legal basis on which we rely when processing such data is ‘consent’ and, more particularly, ‘written explicit consent.’

2.6 Refusal to provide personal data. If you refuse to provide us with your personal data when we ask for it, we may not be able to perform the requested operation and you may not be able to use the EE Services, receive the requested information, or get our response. Please contact us immediately if you think that any personal data that we collect is excessive or not necessary for the intended purpose.

2.7 Your feedback and de-identified data. If you contact us, we may keep records of any questions, complaints, recommendations, or compliments made by you and the response. Where possible, we will remove all personal data that is not necessary for keeping such records. Also, we may use and share with third parties de-identified data for the purpose of facilitating research. Such data does not allow users to identify you as a natural person and, therefore, is not considered to be personal data.

3. HOW LONG DO WE STORE YOUR DATA?

The following section explains how long we keep your data in our systems and how we delete it.

3.1 Storage of personal data. We and our data processors store your personal data only for as long as such personal data is required for the purposes described in this Notice or until you request us to update or delete your personal data, whichever comes first. For more details about the period for which each type of personal data is stored, please refer to section 2. After your personal data is no longer necessary for its purposes and there is no other legal basis for storing it, we will securely delete it from our systems.

3.2 Storage of non-personal data. We retain non-personal data pertaining to you for as long as necessary for the purposes described in this Notice.

3.3 Storage as required by law. When we are obliged by law to store your personal data for a certain period of time (e.g., for keeping accounting records), we will store your personal data for the time period stipulated by the applicable law and delete the personal data as soon as the required retention period expires.

4. HOW DO WE DISCLOSE YOUR DATA?

The following section provides information about third parties that may have access to your personal data.

4.1 Disclosure to data processors. If necessary for the intended purpose of your personal data, we will disclose your personal data to entities that provide services on our behalf (our data processors). Your personal data may be shared with entities that provide technical support services to us, such as hosting and email distribution services.

4.2 List of data processors. The data processors that may have access to your personal data are:

- Our cloud storage, analytics, and mailing service provider Google LLC located in the USA;
- Our Website hosting service provider Salesforce located in USA;
- Our CRM service provider Salesforce located in the USA;
- Our independent contractors and consultants.

4.3 Authorized disclosure. If you authorize us by signing the consent form or personally, we may share your personal data, including health-related data, with third parties that engage in the relevant clinical research. We take reasonable safeguards (e.g., data transfer agreements) to ensure that your data will be further processed in accordance with the strictest data protection standards and the applicable laws.

4.4 International transfers. Some of our data processors may be based outside the country where you reside. For example, if you reside in the UK or a country belonging to the European Economic Area (EEA), we may need to transfer your personal data outside the UK or the EEA. In case it is necessary to make such a transfer, we will make sure that the country in which our data processor is located guarantees an adequate level of protection for your personal data or we implement an agreement with it that ensures such protection.

4.5 Disclosure of non-personal data. Your non-personal data may be disclosed to third parties for any purpose as it does not identify you as a natural person. For example, we may share it for clinical research purposes, for improving the EE Services, responding to lawful requests from public authorities or developing new services.

4.6 Legal requests. If requested by a public authority, we will disclose information about the users of the EE Services to the extent necessary for pursuing a public interest objective, such as national security or law enforcement.

4.7 Sale of personal data. We do not sell your personal data without your consent.

5. HOW DO WE PROTECT YOUR DATA?

The following section provides information on how we protect your data against breaches.

5.1 Security measures. We implement up-to-date industry appropriate technical and organizational information security measures that protect your personal data from loss, misuse, unauthorized access, and disclosure. Our measures include:

- a) Maintaining adequate access control mechanisms (e.g., two-factor authentication, password protection, and limited access);
- b) Encryption;
- c) Distributed Denial-of-Service (DDoS) mitigation;
- d) Limiting access to personal data; and
- e) Conducting regular information security audits, access limitation, encryption, measures against server abuse, and DDoS attack prevention.

5.2 Security breaches. Although we put our best efforts to protect your personal data, given the nature of communication and information processing technology and the Internet, we cannot and

will not be liable for any unlawful destruction, loss, use, copying, modification, leakage, and falsification of your personal data caused by circumstances that are beyond our reasonable control. Our liability will be limited to the highest extent permitted by the applicable law.

6. HOW CAN YOU CONTROL YOUR PERSONAL DATA?

The following section provides detailed information about the rights that you have with regard to your personal data and how to exercise those rights.

6.1 The list of your rights. You have the right to control how we process your personal data. Subject to any exemptions provided by law, you have the following rights:

- **Right of access:** you can get a copy of your personal data that we store in our systems and a list of purposes for which your personal data is processed;
- **Right to rectification:** you can rectify inaccurate personal data that we hold about you;
- **Right to erasure ('right to be forgotten')**: you can ask us to erase your personal data from our systems;
- **Right to restriction:** you can ask us to restrict the processing of your personal data;
- **Right to data portability:** you can ask us to provide you with a copy of your personal data in a structured, commonly used, and machine-readable format and move that personal data to another processor;
- **Right to object:** you can ask us to stop processing your personal data;
- **Right to withdraw consent:** you have the right to withdraw your consent, if you have provided one; or
- **Right to complaint:** you can submit your complaint regarding our processing of your personal data.

6.2 How to exercise your rights? If you would like to exercise any of your legitimate rights, please contact us by using our contact details available at the end of this Notice and explain in detail your request. In order to verify the legitimacy of your request, we may ask you to provide us with an identifying piece of information, so that we can identify you in our system. We will answer your request within a reasonable time frame but no later than 30 days.

6.3 Complaints. If you would like to launch a complaint about the way in which we handle your personal data, we kindly ask you to contact us first and express your concerns. After you contact us, we will investigate your complaint and provide you with our response as soon as possible (no later than 30 days). If you are not satisfied with the outcome of your complaint, you have the right to lodge a complaint with your local data protection authority.

7. CONTACT

If you have any questions about this Notice, your rights, or our data protection practices, please contact us by email: admin@emilysentourage.org. Alternatively, you can send us a letter to the following address: Cystic Fibrosis Research Fund, Inc., PO Box 71, Merion Station, PA 19066, USA.

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