

## National Fabry Disease Foundation's Statement of Privacy.

National Fabry Disease Foundation is committed to protecting your privacy. This Statement of Privacy applies to National Fabry Disease Foundation's [www.ThousandsLikeMe.org](http://www.ThousandsLikeMe.org) web site and governs data collection and usage of information collected for the What's my disease? Contest (The Contest); it does not apply to other online or offline sites, products or services. Please read the National Fabry Disease Foundation's Statement of Privacy. National Fabry Disease Foundation is a general audience web site, intended for adult users of all ages as defined in The Contest rules. Personal information of all users is collected, used and disclosed as described in this Statement of Privacy.

### **Collection of your Personal Information**

As an E-commerce Web site, National Fabry Disease Foundation collects personal information, such as your e-mail address, name, home or work address or telephone number. Information collected by National Fabry Disease Foundation is used solely for the purpose of billing, notification, and prize award as indicated in the Contest Rules and for follow up with individuals who indicate they may have the disease described in The Contest. National Fabry Disease Foundation does not collect any information about your computer hardware and software.

National Fabry Disease Foundation encourages you to review the privacy statements of Web sites you choose to link to from National Fabry Disease Foundation's [www.ThousandsLikeMe.org](http://www.ThousandsLikeMe.org) so that you can understand how those Web sites collect, use and share your information. We are not responsible for the privacy statements or other content on Web sites outside of the National Fabry Disease Foundation's [www.ThousandsLikeMe.org](http://www.ThousandsLikeMe.org) web site.

### **Use of your Personal Information**

National Fabry Disease Foundation's and its operational service partners collect and use your personal information to process Contest Entries and deliver the Prize. It is possible that National Fabry Disease Foundation may also use personal information to contact you about the disease described in the Contest or other products or services available from National Fabry Disease Foundation and its affiliates.

National Fabry Disease Foundation does not sell, rent or lease its customer lists to third parties. We occasionally hire other companies to provide limited services on our behalf, such as handling the processing and delivery of mailings, providing customer support, processing transactions, or performing statistical analysis of our services. We will only provide those companies the personal information they need to deliver the service. They are required to maintain the confidentiality of your information and are prohibited from using that information for any other purpose.

National Fabry Disease Foundation does not use or disclose sensitive personal information, such as race, religion, or political affiliations, without your explicit consent.

National Fabry Disease Foundation may access and/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 the edicts of the law or comply with legal process served on National Fabry Disease Foundation or the [www.ThousandsLikeMe.org](http://www.ThousandsLikeMe.org) web site; (b) protect and defend the rights or property of National Fabry Disease Foundation, including its [www.ThousandsLikeMe.org](http://www.ThousandsLikeMe.org) web site; or (c) act under exigent circumstances to protect the personal safety of users of National Fabry Disease Foundation or the public.

Personal information collected on this site may be stored and processed in the United States or any other country in which National Fabry Disease Foundation or its affiliates, subsidiaries or agents maintain facilities, and by using this site, you consent to any such transfer of information outside of your country. National Fabry Disease Foundation abides by the safe harbor framework as set forth by the U.S. Department of Commerce regarding the collection, use, and retention of data from the European Union.

### **Control your Personal Information**

National Fabry Disease Foundation offers its customers choices for the collection, use and sharing of personal information. You may go notify us of your preferences by emailing [info@thousandslikeme.org](mailto:info@thousandslikeme.org). Please be sure to provide complete account information so we can identify you in our records.

You may also stop the delivery of future promotional e-mail from National Fabry Disease Foundation by responding directly to any email you receive with a request to remove you from the mailing list.

### **Security of your Personal Information**

National Fabry Disease Foundation is committed to protecting the security of your personal information. We use a variety of security technologies and procedures to help protect your personal information from unauthorized access, use, or disclosure. For example, we store the personal information you provide on computer systems with limited access that are located in controlled facilities. When we transmit highly confidential information (such as a credit card number) over the Internet, we use a secure payment gateway so your information is protected.

### **Changes to this Statement**

National Fabry Disease Foundation will occasionally update this Statement of Privacy to reflect company and customer feedback. If there are material changes to this Statement or in how National Fabry Disease Foundation will use your personal information, National Fabry Disease Foundation will prominently post such changes prior to implementing the change. National Fabry Disease Foundation encourages you to periodically review this Statement to be informed of how National Fabry Disease Foundation is protecting your information.