



# RARE STRIDES®

## **Rare STRIDES Website Privacy Policy Purpose**

Rare STRIDES LLC is committed to protecting your privacy. Rare STRIDES will make efforts to protect your Personal Data in accordance with the following Website Privacy Notice (“Notice”) which applies to the personal data that it collects and processes about visitors to this website. This privacy policy describes how Rare STRIDES subsidiaries and affiliated companies, may collect, use, and share information about you that we obtain through [www.rarestrides.com](http://www.rarestrides.com). This Policy does not apply to other Rare STRIDES platforms or Rare STRIDES products, to other websites that we operate, to information that we obtain outside of the Website, or websites of third parties to which we provide links. We do not control and are not responsible for the privacy practices of, or the data available on, the websites of third parties. You are encouraged to evaluate the policies of each third-party website you visit.

## **What is Rare STRIDES?**

Rare STRIDES is Strategic Technology for Rapid Identification of Diseases and Disorders Evaluation System that connects healthcare providers and patients to support, care, and services for rare diseases worldwide; headquartered in the United States. For more information about Rare STRIDES please see the “What We Do” and “Who We Are” section of the website at [www.rarestrides.com](http://www.rarestrides.com)

## **What Information Do We Collect?**

The following types of information may be collected on the website:

We may collect information you provide us if you access, sign up for, or request certain services from us on our website. For example, if you are interested in learning more about Rare STRIDES and the services and products we offer, we may ask for personal information, such as your name, practice name and size, email address, telephone number, and city/state. We do not collect or process any sensitive data such as: race or ethnic origin, political opinions, religious

beliefs, or sexual orientation in connection with this website. When you visit our website, we may gather certain information about your visit and your device automatically. This information may, for example, reflect how you found, were directed to, or used this website. Similarly, we may collect your IP address, browser type and version, and other data about the equipment used to visit Rare STRIDES, the website, as well as the patterns of searching and browsing that preceded access to the website, and the patterns of searching and browsing on the website.

### **How Do We Use Your Information?**

We use information collected through cookies to improve the functionality of the website. Examples may include the following: We track the popularity of features on the website to guide development of new ones; We identify the types of devices our visitors use to improve our systems; We track the number of visitors using certain features of the website to make changes that may be needed to improve the functionality of the website. By continuing to use our website you consent to the use of cookies. We evaluate how users find our website to improve methods of our advertising. Personally Identifiable Information is defined as any information that can be used to distinguish or trace an individual's identity. Examples include name, social security number, and date of birth. If you choose to provide Rare STRIDES with Personally Identifiable Information, we will use that information for purposes explained at the time of collection; as described in this Policy and our Terms; and for our business purposes. For example: If you provide Rare STRIDES with your email address, we may use it for our own marketing, promotional, and informational purposes, including new release updates, invitations, newsletters, awareness campaigns, and announcements. We will not retain your information, whether obtained through tracking technologies or provided by you longer than necessary to fulfill the purposes for which it was collected or as required by applicable laws or regulations. Wherever your PII may be held by Rare STRIDES or on its behalf, Rare STRIDES takes reasonable and appropriate steps to protect the PII that you share with us from unauthorized access or disclosure. Rare STRIDES provides mandatory training to its employees on data handling practices. In addition, Rare STRIDES and its service providers enter into agreements which require that care and precautions be taken to prevent loss, misuse, or disclosure of your PII.

### **Sharing Your Information**

Rare STRIDES will only share your information in adherence with this Privacy Policy, except in the following situations: We are required by law to disclose information; You have provided consent to share or use information about you; We believe that we need to share information about you to provide a service you requested from us or from others; To an actual or potential buyer (and its agents and advisors) in connection with any actual or proposed purchase, merger or acquisition of any part of our business, provided that we inform the buyer it must use your Personal Information only for the purposes disclosed in this Policy; We believe that it is necessary to avoid violations of the law, avoid liability, or to protect our rights.

### **Updates to this Privacy Policy**

We reserve the right to make periodic updates and revisions to the Policy. Please check this page to review whether any changes have been made to the Policy. The policy will be reviewed and approved by our board on an annual basis.

### **Contact Information for Questions about this Privacy Policy**

Rare STRIDES Board has appointed a Data Protection Officer to address any inquiries:

*Andy Halsema*

*Data Protection Officer Rare STRIDES, LLC*

*195 West Pike Street*

*Lawrenceville, GA 30046*

You may contact the Data Protection Officer to submit a written request to review information you submitted, how it was used, and to whom it was disclosed. Subject to legal exemptions and once your identity can be authenticated you will receive a response within 30 business days. You have the right to challenge any information provided and request an amendment.

**Rare STRIDES Website Privacy Policy Effective January 1, 2023**

**Approved by Rare STRIDES Executive Board**