

# PRIVACY POLICY DISCLAIMER

*Produced by the National Organization for Rare Disorders (NORD®)*

Whether your organization already has a privacy policy or has yet to develop one, the following is sample copy from NORD for your consideration to excerpt and add to existing policy or to adapt and use as a basis for your privacy policy statement. The language is written appropriately for posting to your organizational website; please keep in mind that the language is for use on your website's desktop browser interface and would require additional language for your website's mobile interface. Because state, national and international privacy regulations are complex and compliance will vary depending upon the unique way each organization collects and utilizes its member data, it is the responsibility of NORD member organizations to review, assess and amend this policy template to achieve full compliance with state, national and international regulations.

If you are collecting personal data for the purposes of research, fundraising or member communication, we encourage you to review the websites below\* for more information regarding compliance with the General Data Protection Regulation 2016/679 ("GDPR"), a complex regulation governing the privacy rights of European Union (EU) residents impacting all organizations internationally.

1. EU GDPR\*
  - a. <https://www.eugdpr.org/>
  - b. <https://eur-lex.europa.eu/legal-content/en/TXT/?uri=CELEX%3A32016R0679>
2. BDO: Effective Data Governance and GDPR Compliance for the Nonprofit cfo\*
  - a. [https://university.learnlive.com/Content/Podcast/2139/BDO\\_115617\\_3-22-18.mp3](https://university.learnlive.com/Content/Podcast/2139/BDO_115617_3-22-18.mp3)
3. Community Brands: Let's talk about GDPR\*
  - a. <https://www.communitybrands.com/resource-library/webinars/lets-talk-gdpr/>
4. IMPERVA: Does the GDPR Apply to You?\*
  - a. <https://www.imperva.com/blog/2017/02/gdpr-series-part-1-gdpr-apply/>
5. IMPERVA: 72 Hours: Understanding the GDPR Data Breach Reporting Timeline\*
  - a. <https://www.imperva.com/blog/2018/05/72-hours-understanding-the-gdpr-data-breach-reporting-timeline/>

*\*NORD does not endorse or recommend any of these processes or services. The views and opinions expressed in these resources do not state or reflect those of NORD.*

## PRIVACY POLICY

Effective date: Month DD, YYYY

### PRIVACY POLICY TERMS

[ORGANIZATION NAME] (“us”, “we”, or “our”) operates the [INSERT ORGANIZATION URL] website (hereinafter referred to as the “Service”).

This webpage informs you of our policies regarding the collection, use, and disclosure of personal data when you use our Service and the choices you have associated with that data.

We use your data to provide and improve the Service. By using the Service, you agree to the collection and use of information in accordance with this policy. Unless otherwise defined in this Privacy Policy, the terms used in this Privacy Policy have the same meanings as in our Terms and Conditions, accessible from [INSERT ORGANIZATION URL].

### WE RESPECT YOUR CONFIDENTIALITY

Your personal information will 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

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 about [ORGANIZATION NAME]. You may notify us via email if you wish to discontinue electronic communication.

### 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 it to us. Upon written request 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). You may request a copy of your information, request to delete your information, or request to remove yourself from our databases by communicating with us via the contact information listed at the very end of this policy.

### DEFINITIONS

- **Service**  
Service is the [INSERT ORGANIZATION URL] website operated by Organization
- **Personal Data**  
Personal Data means data about a living individual who can be identified from that data (or from other information either in our possession or likely to come into our possession).
- **Usage Data**  
Usage Data is data collected automatically and either generated by the use of the Service or from the Service infrastructure itself (for example, the duration of a page visit).
- **Cookies**  
Cookies are small files stored on your device (computer or mobile device).

## **INFORMATION COLLECTION AND USE**

We collect several different types of information for various purposes to provide and improve our Service to you.

### **PERSONAL DATA**

While using our Service, we may ask you to provide us with certain personally identifiable information that can be used to contact or identify you ("Personal Data"). Personally identifiable information may include, but is not limited to:

- Email address
- First name and last name
- Phone number
- Address, city, state, ZIP/postal code, province
- Cookies and Usage Data

### **USAGE DATA**

We may also collect information on how the Service is accessed and used ("Usage Data"). This Usage Data may include information such as your computer's Internet Protocol address (e.g. IP address), browser type, browser version, the pages of our Service that you visit, the time and date of your visit, the time spent on those pages, unique device identifiers and other diagnostic data.

### **TRACKING AND COOKIES DATA**

We use cookies and similar tracking technologies to track the activity on our Service and we hold certain information.

Cookies are files with a small amount of data which may include an anonymous unique identifier. Cookies are sent to your browser from a website and stored on your device. Other tracking technologies are also used such as beacons, tags and scripts to collect and track information and to improve and analyze our Service.

You can instruct your browser to refuse all cookies or to indicate when a cookie is being sent. However, if you do not accept cookies, you may not be able to use some portions of our Service.

Examples of Cookies we use:

- Session Cookies. We use Session Cookies to operate our Service.
- Preference Cookies. We use Preference Cookies to remember your preferences and various settings.
- Security Cookies. We use Security Cookies for security purposes.

### **USE OF DATA**

ORGANIZATION NAME uses the collected data for various purposes:

- To provide and maintain the Service
- To notify you about changes to our Service
- To allow you to participate in interactive features of our Service when you choose to do so
- To provide customer care and support

- To provide analysis or valuable information so that we can improve the service
- To monitor the usage of the Service
- To detect, prevent and address technical issues

## **TRANSFER OF DATA**

Your information, including Personal Data, may be transferred to and maintained on, computers located outside of your state, province, country or other governmental jurisdiction where the data protection laws may differ than those in your jurisdiction.

If you are located outside United States and choose to provide information to us, please note that we transfer the data, including Personal Data, to the United States and process it there.

Your consent to this Privacy Policy followed by your submission of such information represents your agreement to the transfer of that information.

ORGANIZATION NAME will take all steps reasonably necessary to ensure that your data is treated securely and in accordance with this Privacy Policy and no transfer of your Personal Data will take place to an organization or a country unless there are adequate controls in place, including the security of your data and other personal information.

## **DISCLOSURE OF DATA**

The ORGANIZATION NAME shall provide you with the recipients or categories of recipients of your personal data, if any.

## **LEGAL REQUIREMENTS**

ORGANIZATION NAME may disclose your Personal Data in the good faith belief that such action is necessary to:

- To comply with a legal obligation
- To protect and defend the rights or property of ORGANIZATION NAME
- To prevent or investigate possible wrongdoing in connection with the Service
- To protect the personal safety of users of the Service or the public
- To protect against legal liability

## **SECURITY OF DATA**

The security of your data is important to us but remember that no method of transmission over the Internet or method of electronic storage is 100% secure. While we strive to use commercially acceptable means to protect your Personal Data, we cannot guarantee its absolute security.

## **DATA BREACH**

ORGANIZATION NAME will work within 72 hours of a data breach to gather all related information, conduct a thorough investigation, inform regulators and impacted individuals of the breach, identify what personal data has been impacted and how; and draft a comprehensive containment plan, reporting data breaches to the relevant regulator.

If we are unable to provide a notification within the 72-hour window, we will provide reasonable justification for the delay; which may be caused by potentially adding additional disruption to regular business operations and exasperating administrative hassle.

## **SERVICE PROVIDERS**

We may employ third party companies and individuals to facilitate our Service (“Service Providers”), to provide the Service on our behalf, to perform Service-related services or to assist us in analyzing how our Service is used.

These third parties have access to your Personal Data only to perform these tasks on our behalf and are obligated not to disclose or use it for any other purpose.

## **ANALYTICS**

We may use third-party Service Providers to monitor and analyze the use of our Service.

- Google Analytics a web analytics service. You can visit their Privacy Policy page here: <https://policies.google.com/privacy?hl=en&gl=ZZ>
- Piwik or Matomo is a web analytics service. You can visit their Privacy Policy page here: <https://matomo.org/privacy-policy>
- Clicky is a web analytics service. Read the Privacy Policy for Clicky here: <https://clicky.com/terms>

## **LINKS TO OTHER SITES**

Our Service may contain links to other sites that are not operated by us. If you click a third party link, you will be directed to that third party’s site. We strongly advise you to review the Privacy Policy of every site you visit. We have no control over and assume no responsibility for the content, privacy policies or practices of any third party sites or services.

## **CHANGES TO THIS PRIVACY POLICY**

We may update our Privacy Policy from time to time. We will notify you of any changes by posting the new Privacy Policy on this page.

We will let you know via email and/or a prominent notice on our Service, prior to the change becoming effective and update the “effective date” at the top of this Privacy Policy.

You are advised to review this Privacy Policy periodically for any changes. Changes to this Privacy Policy are effective when they are posted on this page.

## **CONTACT US**

If you have any questions about this Privacy Policy, please contact us:

- By email: [\[yourmail@organizationname.org\]](mailto:[yourmail@organizationname.org])
- By visiting this page on our website: [www.yourorganization.org/contactus](http://www.yourorganization.org/contactus)
- By phone number: xxx-xxx-xxxx
- By mail: [insert your address]