

## **CVR PRIVACY POLICY**

**Last Updated 7/30/2020**

This CVR Privacy Policy (“**Privacy Policy**”) describes how The National Hemophilia Foundation (“**NHF**”, “**Foundation**”, “**we**”, “**our**” or “**us**”) uses personal information that we collect in connection with your use of or interaction with the Community Voices in Research database (“**CVR**”) hosted by its technology vendor, ArborMetrix and on the Foundation website and any other website we operate that links to this Privacy Policy (collectively, our “**Sites**”), and all other products or services available through our Sites (collectively, our “**Service**”).

Please read this Privacy Policy carefully to better understand how we collect, use, and disclose personal information about you as you use our Service. Any changes to this Privacy Policy will appear on this page, so we encourage you to review it periodically.

**PLEASE REVIEW SECTION 7 OF THIS PRIVACY POLICY FOR INFORMATION ON OUR ADDITIONAL OBLIGATIONS UNDER THE CHILDREN’S ONLINE PRIVACY AND PROTECTION ACT (“COPPA”) AND OUR PRACTICES FOR HANDLING PERSONAL INFORMATION COLLECTED FROM CHILDREN UNDER THE AGE OF 13.**

### **ABOUT CVR**

CVR is a partnership between the bleeding disorder community and NHF. CVR is an initiative through which NHF gathers information through electronic surveys from people with inherited bleeding disorders and their immediate family members over several years (referred to as a longitudinal research registry). Asking the bleeding disorder community members about their specific experiences living with a bleeding disorder versus having it relayed by others, such as healthcare providers, will offer researchers a valuable perspective. CVR’s ultimate goals are to understand the experience of living with an inherited bleeding disorder from the perspective of those affected as well as their immediate family members.

Through the data collected by CVR, NHF will advocate for the community on multiple levels including focused education, legislative and payor issues, and identifying research questions important to them. Then through funding focused research initiatives, contribute to improving quality of life or those affected and their families and finding a cure. We have provided this Privacy Policy to you to describe information collection and use practices at CVR.

### **THE INFORMATION WE COLLECT.**

The information we collect from you varies, depending on the way you use the CVR Services. We collect information from or about you in the ways described below.

#### **1. INFORMATION COLLECTED DIRECTLY FROM YOU.**

We collect information that you provide to us directly when, for example, you create a CVR account, participate in a survey, or communicate with us. The types of personal information we may collect through CVR includes, but is not limited to the following:

- Name
- Email address
- ZIP Code
- Healthcare provider
- Financial information (e.g., household income)
- Race
- Ethnicity

- Disorder and information related to the evaluation, diagnosis, and management of that disorder
- Limited medical information including other disorders, etc.
- Quality of life information including psychosocial information (mental health)
- Insurance information

## **2. INFORMATION COLLECTED AUTOMATICALLY.**

Certain information on our Service is collected automatically by means of various software tools. We have a legitimate interest in using such information to assist in systems administration, information security and abuse prevention, to track user trends, and to analyze the effectiveness of our Service.

### **(a) Log Files.**

Log files refers to the information that is automatically sent by your web browser or device (or otherwise automatically collected) each time you view or interact with our online Service. The information inside the log files may include IP addresses, type of browser, internet service provider, date/time stamp, referring/exit pages, clicked pages and any other information your browser may send to us.

### **(b) Device and Online Usage.**

We may collect information about your computer, browser, mobile or other device that you use to access our Service. We may use cookies, pixels, log files and other techniques to collect such information, including IP address, device identifiers and other unique identifiers, browser type, browser language, operating system name and version, device name and model, version, referring and exit pages, dates and times of Service access, links clicked, features uses, crash reports and session identification information.

### **(c) Cookies.**

We use cookies to make interactions with our Service easy and meaningful. When you visit our Service, our servers may send a cookie to your computer. We may use cookies that are session-based or persistent. Session cookies exist only during one session. They disappear from your computer when you close your browser software or turn off your computer. Persistent cookies remain on your computer after you close your browser or turn off your computer. We use cookies that enable you to navigate our Service and use its features, such as accessing secure areas of our Service. Because required cookies are essential to operate our Service, there is no option to opt out of these cookies. We use cookies to provide features and services such as:

- Remembering your preferences and allowing you to enter your information less frequently;
- Presenting information that's targeted to your interests, which may include our content presented on another website;
- Measuring the effectiveness of our sites, services, content, and advertising;
- Providing other services and features that are only available through the use of cookies;

The Options/Settings section of most internet browsers will tell you how to manage cookies and other technologies that may be transferred to your device, including how to disable such technologies. You can disable our cookies or all cookies through your browser settings, but please note that disabling cookies may impact some of our Service features and prevent the Service from operating properly.

We may use or engage a third party that uses Local Stored Objects (LSOs), sometimes referred to as "Flash Cookies", and other technologies to collect and store information about your use of our Service. A flash cookie is a small data file placed on your device using Adobe Flash technology. Flash cookies are different from the cookies described above because cookie management tools provided in your browser will not remove them. To limit the websites that can store information in flash cookies on your device, you must visit the Adobe website:

[http://www.macromedia.com/support/documentation/en/flashplayer/help/settings\\_manager07.html](http://www.macromedia.com/support/documentation/en/flashplayer/help/settings_manager07.html)

#### **(d) Do Not Track Signals.**

We do not currently respond or take any action with respect to web browser "do not track" signals or other mechanisms that provide consumers the ability to exercise choice regarding the collection of information about an individual consumer's online activities over time and across third-party websites or online services.

#### **(e) Analytics Services.**

We may use certain third party analytics services to improve the functionality, features, or delivery of our Service. We may also use these analytics services to record mouse clicks, mouse movements, scrolling activity, as well as any text that you type into our Service. For example, we use Google Analytics on our Service to track user trends and usage. For more information on Google Analytics' processing of your information as it relates to our Service, please see <http://www.google.com/policies/privacy/partners/>. By using a [browser plugin](#) provided by Google, you can opt out of Google Analytics.

#### **(f) Web Beacons and Similar Tracking Technologies.**

When you visit our Service, we may collect your IP address for certain purposes such as, for example, to monitor the regions from which you navigate our Service. We may also use web beacons alone or in conjunction with cookies to compile information about your usage of our Service and interaction with emails from us. Web beacons are clear electronic images that can recognize certain types of information on your computer, such as cookies, when you viewed a particular site tied to the web beacon. We may use web beacons to operate and improve our Service.

### **3. HOW WE USE YOUR INFORMATION.**

If you submit or we collect Information through our Service, then such Information may be used to:

- Conduct research studies or for educational purposes. Any information used in studies will be de-identified or aggregated so that participants cannot be personally identified;
- Advance advocacy efforts
- Improve access to care and treatment and to help people better manage their care;
- Fundraise or acquire contributions from sponsors or donors
- Provide, analyze, administer, improve, and personalize the Service;
- Provide you with the Service and any information, product or order fulfillment;
- Contact you in connection with the Service, notifications, events, programs or offerings;
- Send you updates and educational materials;
- Provide personalized advertising to you;
- Protect our rights or our property and to ensure the technical functionality and security of the Service; and
- Comply with applicable law, assist law enforcement, and to respond to regulatory or other legal inquiries.
- Fulfill any purpose to which you consent or for which you direct us to use your information.

### **4. HOW WE SHARE OR DISCLOSE YOUR INFORMATION.**

We do not sell, lease, rent or otherwise disclose the information collected from our Service to third parties unless otherwise stated below or with your consent.

#### **(a) Our Third Party Service Providers.**

We transfer information to our third party service providers to perform tasks on our behalf and to assist us in providing our Service. For example, we may share your information with service providers who assist us in performing core functions (such as hosting, data storage, and security) related to our operation of the Service and/or by making certain interactive tools available to you as a user. We also use third parties for technical and customer support, application development, tracking and reporting functions, quality assurance, and other services. In the performance of our Service, we may share information from or about you with these third parties so that we can deliver the highest quality user experience.

**(b) Aggregated or Deidentified Information.**

To better serve our users and community, business and research partners, and to improve our Service, we may conduct surveys and research based on personal information that we aggregate or de-identify. Aggregated or de-identified information is not considered personal information and does not identify a user personally. We may share this aggregated or de-identified information with our users and community, affiliates, agents, business partners, and/or other third parties and in providing Services and for any other purpose not prohibited by applicable law.

**(c) Sponsored Surveys.**

From time to time, we may work with other companies or organizations to conduct surveys. We would share only de-identified and aggregated information collected in connection with your participation. You can decline to participate at any time.

**(d) In the Event of Merger, Sale, or Change of Control.**

We may transfer or assign this Privacy Policy and any information to a third party entity that acquires or is merged with us as part of the evaluation of an entry into such transactions, or in the course of a merger, acquisition, sale, or other change of control (such as the result of a bankruptcy proceeding).

**(e) With Your Consent.**

At your direction or request, or when you otherwise consent, we may share your information.

**(f) Other Disclosures.**

We may disclose information about you if we have a good faith belief that disclosure of such information is helpful or reasonably necessary to comply with any applicable law, regulation, legal process or governmental request, provided that such disclosures are permissible under our Certificate of Confidentiality, granted by the National Institutes of Health, Office of Extramural Research.

**5. RETENTION.**

You may stop participation at any time. We will retain any information previously utilized for projects in which you participated and cannot be deleted in order to: (i) fulfill the purposes for which we collected the information, and (ii) comply with applicable law.

**6. DATA SECURITY.**

We take the protection of your information seriously and take reasonable and appropriate physical, administrative, and technical measures to protect the information collected through our Site. While we implement commercially reasonable security measures to protect your privacy, please keep in mind that the Internet is not a 100% secure medium for communication, and we cannot guarantee that the information collected about you will always remain private when using our Site and/or Services. As a result, while we strive to protect your personal information, we cannot guarantee the security of any information you transmit to us, and you do so at your own risk.

**7. CHILDREN'S PRIVACY.**

Our Site is generally not intended for or directed to individuals under 13 years of age, and we do not knowingly collect any personal information directly from children under the age of 13 on the publicly available parts of our Site. CVR allows parents or legal guardians to set up individual portal accounts for their children through which Parents provide information about their children. We do, however, occasionally collect information for surveys and other purposes through our Site directly from those with a bleeding disorder, which could include those under 13 years of age. In those circumstances, we comply with the Children's Online Privacy Protection Act of 1998 ("COPPA"). COPPA requires us to inform parents and legal guardians (as used in this section, "**parents**") about our practices for collecting, using, and disclosing personal information from children under the age of 13 ("**children**"). It also requires us to obtain verifiable consent from a child's parent for certain collection, use, and disclosure of the child's personal information. This section only applies to children under the age of 13 and supplements the other provisions of this privacy policy.

## **This Section Notifies Parents of:**

### **The Types of Personal Information We May Collect From Children**

We may collect information from children in connection with a survey, study, or other event, in which case we collect their name, age, address, email address (or parents' email address), and/or responses to various questions about their bleeding disorder, which could include medical information. We limit our collection of personal information from children to no more than is reasonably necessary to fulfill the purpose or activity.

### **How We Use Information Collected From Children**

We use the information we collect from children to administer the survey, study, or event. We de-identify or aggregate information we collect from children to use for research or study purposes or for educational purposes or to provide Services. With respect to the Site, we use personal information for the purpose of website development and maintenance, including but not limited to diagnostic and testing purposes.

### **How We Disclose or Share Personal Information Collected from Children**

We may share or disclose personal information with third parties who act as our service providers in providing our Services but only for the purpose of provided those services. We may also share de-identified or aggregated information with members of CVR, third party researchers or networks, or potential sponsors and donors. A child will not be personally identified, nor will a child's individual, disaggregated information be used as part of any such effort without the express written consent of the child's parent.

To the extent permitted by applicable law, we may also disclose information collected from children (i) in response to a law enforcement or public agency's (including schools or children services) request, (ii) if we believe the disclosure may prevent the instigation of a crime, facilitate the investigation related to public safety, or protect the safety of a child using our Services, (iii) to protect the security or integrity of our Services and technology; or (iv) to enable us to take precautions against liability.

We may also share or disclose information as otherwise permitted or required by COPPA or other applicable laws.

### **Our Practices for Notifying and Obtaining Parents' Consent When We Collect Personal Information from Children, Including How a Parent May Revoke Consent.**

We provide notice of our privacy practices to and collect verifiable consent from parents through a variety of means depending on the context and purpose for which we collect personal information from children. In some instances, we will provide notice through our website or an email and obtain consent from a parent at an email address or phone number that is not provided by a child. In other situations, we may collect consent by obtaining written signed consent from a parent or obtain some other higher form of consent under any circumstances where we collect personal information from children that will be publicly posted. A parent can review his or her child's personal information, direct us to delete it, and refuse to allow any further collection or use of his or her child's information. To exercise any of these rights, please contact us at [research@hemophilia.org](mailto:research@hemophilia.org). The parent must provide us with enough information to verify his or her identity and locate his or her child's account.

### **All operators that collect or maintain information from children through this Website:**

NHF Research Dept may be contacted through email, [research@hemophilia.org](mailto:research@hemophilia.org)

## **8. LINKS TO OTHER SITES.**

Our Site may include links to other third party websites as a convenience to you. If you click on one of those links you will be taken to websites we do not control, and this Privacy Policy does not apply to those third party websites. The inclusion of any link does not imply our endorsement of any other Foundation,

its site(s), or its product(s) and/or service(s). We are not responsible for the privacy practices or content of any other site.

## **9. YOUR CHOICES**

Participants have access to their own information through their individual portal- referred to as the Personalized Dashboard. Participants will also have access to de-identified data that may allow them to benchmark some of their metrics with others. If you lose access to your CVR account, please email [research@hemophilia.org](mailto:research@hemophilia.org).

Participation in CVR is voluntary and you may withdraw at any time. To withdraw from CVR, participants should send an email to [research@hemophilia.org](mailto:research@hemophilia.org). Please keep in mind that information provided prior to receipt and processing of a request cannot be deleted. However, the information will continue to be protected in the same manner as described above.

## **10. CHANGES TO THIS PRIVACY POLICY.**

As our Foundation changes over time, this Privacy Policy may change as well. We reserve the right to amend the Privacy Policy at any time, for any reason, without notice to you, other than the posting of the amended Privacy Policy on our Service. We will provide you notice of material changes by indicating that the Privacy Policy has been updated on our homepage and will indicate the date we made the update above. Your continued use of any of the Services after the changes have been made will constitute your acceptance of the changes. Please therefore make sure you read any such notice carefully. If you do not wish to continue using the Services under the new version of the policy, please cease using the Services.

## **11. CONTACTING US.**

Any comments, concerns, complaints, or questions regarding our Privacy Policy may be addressed to [research@hemophilia.org](mailto:research@hemophilia.org). Please note that email communications may not be secure. Accordingly, you should not include personal or other sensitive information in your email correspondence to the Sites or to CVR.