

Privacy Policy

Heart Valve Voice US (“HVV”) is a nonprofit patient advocacy organization that provides patients with a united voice to improve health for people living with heart valve disease. We advocate for early detection, meaningful support, and timely access to appropriate treatment for all people affected by heart valve disease. We work with people living with heart valve disease, clinicians, experts, researchers, industry partners, and other patient service and advocacy organizations.

This Privacy Policy describes how HVV collects, uses, or discloses personal information we receive through our website (at heartvalvevoice-us.org) and through our patient community (My Valve My Voice), and any mobile applications or other related services we may offer (collectively, the “Services”). This policy also describes your choices about the collection and use of your information.

Please read the Privacy Policy carefully before you start to use our Services. By using the Services, you agree to be bound and abide by our posted Terms of Use and Privacy Policy. If you do not agree to both the Terms of Use and our Privacy Policy, or if you violate them in any way, your right to access or use the Services is terminated. *Please see Sections 11-14 of our Terms of Use regarding your legal rights in any dispute involving our Services.*

NOTICE: Although the Services may include health-related information, HVV is not a medical referral service, does not provide healthcare services or medical advice, and does not recommend or endorse any particular provider or medical treatment. HVV does not handle any personal information pursuant to healthcare-specific laws, such as the Health Insurance Portability and Accountability Act (“HIPAA”). Information provided through the Services by HVV or other users is for general informational purposes only and should never be construed as applicable medical or health advice. Please consult your doctor concerning any medical questions or issues, including with respect to the diagnosis or treatment of heart valve disease. If you have a medical emergency, go to the emergency room of a local hospital or dial 911 immediately.

1. How We Collect Information

We may collect information about you by various means, including:

- Directly from you, both online and offline (e.g., phone, postal mail);
- Through our websites, mobile apps, and other connected devices and services;
- From other third party sources and social media platforms that you may use to engage with us, as well as from partners or third parties we work with, in order to supplement information we already possess; and
- By combining information from different sources.

2. Types of Information We Collect

In order to better provide you with our Services, we may collect the following categories of information:

- *Profile and subscription information*, such as a username and password, your name, mailing address, e-mail address, phone number and profile preferences, which may include signing up to specific services or communications from us or selected third parties;
- *Survey information* in response to questions we may send you through the Services, including for research purposes and possibly in connection with a contest or promotion (HOWEVER, WE MAY CONDUCT HEALTH-RELATED SURVEYS WHERE ALL RESPONSES ARE KEPT ANONYMOUS IN ORDER TO PROTECT YOUR PRIVACY AND PREVENT ANY SENSITIVE HEALTH INFORMATION FROM BEING ASSOCIATED WITH YOU);
- *User Content* may be posted through the Services if we permit (e.g., personal comments, photos, and other materials)—this may also include metadata associated with your content (such as location and date/time information embedded in pictures);
- *Communications* between you and us, such as via e-mail, mail, phone, text or other channels;
- *Offline activity* you engage in with us, if and where applicable; and
- *Online User Activity* described in the next section.

If you provide us with information regarding another individual, you represent that you have that person's consent to give us their information and to permit us to use the information in accordance with this policy.

3. Online User Activity, Cookies and Information Collected by Other Automated Means

Cookies are a commonly-used web technology that allow websites to store and retrieve certain information on a user's system, and track users' online activities. We and our service providers may collect information about your use of our Services by such automated means, including but not limited to cookies, pixels, SDKs and other similar technologies.

Cookies and similar technologies can help us automatically identify you when you return to our website or app. Cookies help us review website traffic patterns and improve the website, such as determining the popularity of various Services. We can also use such information to deliver customized content and advertising to users of the Services whose behavior indicates that they are interested in a particular subject area.

When you use the Services, the information we may collect by automated means includes, for example:

- *Usage Details* about your interaction with our Services (such as the date, time, and length of visits, and specific pages or content accessed during the visits, search terms, frequency of the visits, referring website addresses);
- *Device Information* including the IP address and other details of a device that you use to connect with our Services (such as device type and unique device identifier, operating system, browser type, mobile network information, and the device's telephone number)
- *Stored information* you affirmatively provide the Services with access to, such as pictures, video and contacts stored on your device; and

- *Location information* where you choose to provide the website or app with access to real-time information about your device's location.

If a user does not want information collected through the use of cookies, most browsers allow the visitor to reject cookies, but if you choose to decline cookies, you may not be able to fully experience the interactive features our Services provide. We may share non-personal information obtained via cookies with our advertisers and affiliates. Because there is not yet a consensus on how companies should respond to web browser-based do-not-track ("DNT") mechanisms, we do not respond to web browser-based DNT signals at this time, but we do not collect information about users' online activities across third-party websites. While disabling cookies may impact your user experience for technical reasons, your participation will not be limited in any other way by HVV.

4. How We Use Information We Collect

We may use the information we obtain about you for purposes allowed by applicable laws, including:

- Provide our Services to you, including to establish and maintain any account you create for our Services;
- Respond to your requests, questions and comments and provide customer support;
- For marketing or promotional activities, and to personalize the content we may display to you in our Services and communications, including advertising of products or services that may be of interest to you;
- Operate, evaluate and improve our programs, our websites and other products and services we offer (including to develop new services), and to diagnose or fix technology problems;
- Analyze and enhance our communications and strategies (including by identifying when emails sent to you have been received and read);
- Inform you about changes to this Privacy Policy and our Terms of Use and other policies;
- Comply with and enforce as needed applicable legal requirements, industry standards, our policies and our contractual rights; and
- Monitor the performance of our Services including metrics such as total number of visitors, traffic, and demographic patterns.

We may also use or share information *in an anonymized or aggregate manner* for many purposes such as research, analysis, modeling, marketing, and advertising, as well as improvement of our Services.

5. Online Advertising

We may in the future serve advertisements, and allow third parties to serve advertisements, through our Services. These advertisements are sometimes targeted and served to particular users and may come from third party organizations called "ad networks." Ad networks can include a number of third party ad servers, ad agencies, ad technology vendors and research firms. Advertisements served through our Services may be targeted to users who fit a certain general profile category, which may be

inferred from information you provide to us or, based on your website or mobile app usage patterns, or based on your activity on other website or online services as may be available to the ad networks.

6. How We Share Your Information

We will not disclose your personal information to third parties without your consent, except in the following circumstances.

- We may share your information as permitted by law, including, for example, with service providers that we believe need the information to perform a technology, business, or other professional function for us (examples include IT services, maintenance and hosting of our Services, payment processors (if applicable), marketing partners, and other vendors). We only provide such vendors with information so they can perform their required functions on our behalf.
- If you voluntarily share or submit any User Content including contact information (e.g., name) or content (e.g., picture), or commentary (e.g., forums, message boards, chats) for posting through our Services, or link it to any social media platforms, that post and any information associated with it may become available to the public. See our Terms of Use for more information about how we may use User Content.
- We also may disclose information about you (i) if we are required to do so by law or legal process, (ii) when we believe disclosure is necessary to prevent harm or financial loss, (iii) in connection with an investigation of suspected or actual fraudulent or illegal activity; or (iv) under exigent circumstances to protect the personal safety of our staff, users or the public.
- We reserve the right to transfer the information we maintain in the event we sell or transfer all or a portion of our organization or assets. If we engage in such a sale or transfer, we will make reasonable efforts to direct the recipient to use your personal information in a manner that is consistent with this Privacy Policy.
- We may, from time to time, contact you on behalf of external partners about a particular offering that may be of interest to you. In those cases, your information (e.g., e-mail, name, address, telephone number) is not transferred to the third party. Instead, we may share anonymous data with trusted partners to help perform statistical analysis, and then we would send you an email, postal mail, or other communication on their behalf.

Where appropriate, we will limit sharing of your information in accordance with the choices you have provided us and applicable law.

7. Your Privacy Choices

We offer you certain choices about what information we collect from you, how we use and disclose the information, and how we communicate with you.

- *Marketing Emails:* From time to time, we may contact you via email for the purpose of providing announcements, promotional offers, alerts, confirmations, surveys, and/or other general communication. In order to improve our Services, we may be notified when you open an email from us or click on a link therein. You may choose not to receive marketing emails from us by

clicking on the unsubscribe link in the marketing emails you receive from us. Even if you opt out of receiving such communications, we will continue sending you non-marketing email communications, such as administrative or transaction alerts, or information about changes to our terms of service.

- *Text messages:* You may opt-out of receiving text messages by replying “STOP” to any text message received.
- *Cookies:* Web browsers may offer users the ability to disable receiving certain types of cookies; however, if cookies are disabled, some features or functionality of our websites and mobile apps may not function correctly.
- *User Account:* You may terminate your user account or any loyalty program you participate in by contacting us as provided below. We may retain any account information or User Content for internal purposes or as otherwise provided in this Privacy Policy and our Terms of Use.

8. Links to Other Websites and Third Party Content

Our Services may contain links to other websites or apps. This can include social media integrations. Please be aware that we are not responsible for the content or privacy practices of such other websites or apps, and we encourage you to be aware when you leave our Services and to read the privacy statements of any other website or app that collects personal information.

9. How We Protect Information

We endeavor to maintain reasonable administrative, technical and physical safeguards designed to protect the personal information we maintain against accidental, unlawful or unauthorized destruction, loss, alteration, access, disclosure or use. However, we cannot ensure the security of any information you transmit to us, or guarantee that this information will not be accessed, disclosed, altered, or destroyed. We will make any legally required disclosures in the event of any compromise of personal information. To the extent the law allows us to provide such notification via e-mail or conspicuous posting on the Services, you agree to accept notice in that form.

10. Children

We do not knowingly collect personal data from children under the age of 13 on our Services. If you have reason to believe that a child under the age of 13 has provided personal information to us through our Services, please contact us, and we will endeavor to delete that information from our systems. In the event that we learn that we have collected personal information from a child under age 13 without parental consent, we will endeavor to delete that information as quickly as possible. If you believe that we might have any information from or about a child under 13, please contact us as directed below.

If you are a California resident under the age of 18, do not share any personal information on any public content channel we may offer (e.g., User Content). If you do post any such information, you can request removal by contacting us as directed below.

11. International Considerations

Our Services are controlled and operated by us from the United States and are not intended to subject us to the laws or jurisdiction of any state, country or territory other than those of the United States.

12. Updates to Our Privacy Policy

We may revise or update this Privacy Policy at any time. We will post the updated version on our Services, and may notify you of any significant changes to our Privacy Policy. We will indicate on our Privacy Policy when it was most recently updated. Your continued use of our Services after such updates will constitute an acknowledgment of the change and agreement to abide and be bound by the updated Privacy Policy.

13. Contacting Us

If you have any questions, concerns or comments about this Privacy Policy, our privacy practices, or if you would like us to update information or preferences you provided to us, please contact us at: 100 M ST, SE, Ste 600, Washington, DC 20003, via email at info@heartvalvevoice-us.org.

This Privacy Policy was last updated June 1, 2020.