



## PRIVACY POLICY

The Spina Bifida Association (SBA) is committed to protecting your privacy. This Privacy Statement explains the types of personal information we may collect from website visitors and other individuals with whom we interact, whether online or offline, why we collect it, and with whom we may share it. It also describes how we protect your personal information and how you can contact us with any questions. This notice explains our information practices and the choices you can make about the way your information is used.

We collect information so that we may advance SBA's mission: to promote the prevention of Spina Bifida (SB) and enhance the lives of all affected. The information you provide allows us to help you on a more personal level so we can better respond to your requests, understand your needs, and provide you the information and resources you need. If you provide a mailing address, email address or phone number, our intention is to send correspondence only to those who have chosen to receive such communications. At any time, you have the right to decline receiving future communications in any manner, including email, fax, phone, and postal mail.

### **How Your Information May Be Used**

The following services are among those SBA is providing or may provide:

- send e-mail alerts
- answer requests for information
- provide information about SB, including educational information
- connect the SB community with platforms that foster communications between persons with SB, clinicians, those caring for someone with SB and others
- help individuals find clinics
- engage in fundraising through avenues including website, email, mail and other solicitations
- enable you to sign up for events, like "Walk N Roll" and other activities
- communicate with volunteers

You may choose to opt out at any time, which will cease all communications from us.

### **Non-Personal Information We Collect**

We may also use your information to track visitors of our website. This lets us see which of our features are the most popular so we can better serve our users' needs. It also lets us

provide aggregate data about our traffic (not identifying you personally, but showing how many visitors used which features, for example) to outside parties. We may also use cookies and third-party web analytic tools to analyze traffic.

### **Cookies**

Cookies are small text files or data placed by your web browser on your hard drive to store information that allow a website to recognize whether a certain computer or device has been used to visit the site in the past. Cookies enable websites to keep track of online patterns and preferences and make the personalization of web experiences possible. We may make use of session-based and/or "persistent or memory based" cookies, which remain on your computer's hard drive until you delete them. You can adjust your browser settings to remove or block cookies, although if you do so, it may not be possible to utilize all of our services if you reject cookies.

### **Collection and Use of Personal Information**

When you request information, order a product or service, register using one of our forms, donate, or contact us offline, we may need your specific information in order to process your registration/request and reply promptly.

We may ask you for contact information (such as your name, email and address) and demographic information (such as your zip code or age). We also collect demographic and profile data at our site and in our databases. We ask for health-related data to help us help you with information on our programs, services or other work. We use data you provide to tailor your experience at the SBA and develop and distribute content that we think you might be interested in.

### **Social Media**

You may share personal information with your friends associated with your social media account, to other website users and to your social media account provider, in connection with your social sharing activity. Please note that any information you post within these public forums or social media pages may become public and may be read, collected, and used by anyone. Please exercise caution when deciding whether to disclose your Personal Information in these forums.

### **Our Commitment to Donors**

We will not sell, share or trade our donors' names or personal information with any other entity. To the extent any donations are processed through a third-party service provider, our donors' information will only be used for purposes necessary to process the donation.

### **External Use**

Your information is privileged and confidential. It will remain with SBA and/or chapter organizations governed by an affiliation agreement and will not be shared or release to any other outside organization or business entity.

### **Links to Other Sites**

This site may provide links to other World Wide Web sites or resources. You acknowledge and agree that the SBA has no control over such sites and resources and is not responsible for the availability of such external sites or resources and does not endorse and is not responsible or liable for any advertising, products, or other materials on or available from such sites or resources. You further acknowledge and agree that the SBA shall not be responsible or liable, directly or indirectly, for any damage or loss caused or alleged to be caused by or in connection with use of or reliance on any such materials or goods available on or through any such site or resource.

### **How We Protect Your Data**

Your personal data is incredibly important to us. SBA collects and stores contact information in a database that is protected by multi-factor authentication and does not share that data with any outside parties. All SBA database software is regularly updated with the latest security updates. SBA does not keep any individual credit card data; all credit card transactions are managed by a third-party resource.

### **How to Correct or Update Information**

Below are options for changing and modifying information:

Email: [webmaster@sbaa.org](mailto:webmaster@sbaa.org)

Or Mail:

Spina Bifida Association  
1600 Wilson Boulevard, Suite 800  
Arlington, VA 22209

### **POLICY HISTORY**

<b>Date</b>	<b>Description</b>
March 11, 2018	Board approved policy
Dec. 10, 2022	Board approved updates to policy
Oct. 7, 2023	Board approved updates to policy