

## **Privacy Policy**

The Spina Bifida Association (SBA) is committed to protecting your privacy. This Privacy Policy 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 information and resources. 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.

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

The following services are among those SBA provides 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 visits to 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.

### **How We Secure Your Information**

SBA has implemented security measures designed to secure your personally identifiable information from unauthorized access, use, alteration, and disclosure. Access to data and technology relating to user information is password-protected and limited to authorized personnel and those vendors that require access to the information in order to furnish services to SBA.

When you provide personally identifiable information and credit card information for e-commerce transactions, this information is encrypted using industry-standard SSL Encryption technology. We submit to the appropriate credit card clearinghouse only the information necessary to collect payment.

SBA's donor database is protected with a secured login with authentication, assignment of a unique ID to each person with authorized access (development staff only), quarterly pass code changes, and user IDs are deactivated or terminated as needed.

The safety and security of your information also depends on you. Where we have given you (or where you have chosen) a password for access to certain parts of our website, you are responsible for keeping this password confidential. We ask you not to share your password with anyone.

### **Removing Name from Our Mailing Lists**

SBA honors preferences with regard to the method and frequency of communication. You may contact us at any time to request removal from our mailing list(s) and your wish will be promptly followed.

### **Social Media**

You may share Personal Information with your friends associated with your social media account(s), 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 Children's Privacy**

Protecting the privacy of the very young is especially important. We adhere to the 1998 Children's Online Privacy Protection Act (COPPA). (For more information, visit the Federal Trade Commission's [COPPA site](#).)

### **External Use**

Your information is privileged and confidential and will not be shared or release to any organization or business entity.

**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

National Resource Center

1600 Wilson Boulevard, Suite 800

Arlington, VA 22209