

# Privacy Policy

The Spina Bifida Resource Network (SBRN) places a high priority on protecting your privacy. This policy explains what types of information is collected by the SBRN website, [www.thesbrn.org](http://www.thesbrn.org), and how this information is used.

## What Personally Identifiable Information is Collected

Individuals who register for events, sign up for membership, request information or make a donation at [www.thesbrn.org](http://www.thesbrn.org) voluntarily provide us with contact information (such as name, phone number and addresses). We may use this information for specific, limited purposes within the organization.

## Email Privacy

SBRN is the sole owner of the information collected on its website. We do not share, sell, or exchange this information with anyone outside the organization.

## IP addresses

SBRN uses your IP address to help diagnose problems with our server, to administer [www.thesbrn.org](http://www.thesbrn.org), and for statistical metrics used to track website visitor traffic.

## How Your Information May Be Used

SBRN collects information from the users of its website at several different points on the site. We use your personal information to provide you with personalized service; to send e-mail alerts to you; to answer your requests; to process your membership application; etc. You may choose to opt out at any time. We may also use your information to track visitor 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 collect data about our traffic (not identifying you personally, but showing how many visitors used which features, for example.)

It is possible that if you register for a program, event or newsletter that you may receive a fundraising appeal from the SBRN. Only email addresses or regular mail addresses would be used for this purpose. Users may request to be removed from mailing lists at any time. To review or request corrections to your personal information collected by SBRN or preferences for communication, please contact us at [info@thesbrn.org](mailto:info@thesbrn.org).

## Online Donations

Visitors to [www.thesbrn.org](http://www.thesbrn.org) who make monetary contributions through the website are asked to provide information, which is kept on a proprietary secure database. We will not share, sell or exchange donor's information for third party's fundraising or marketing purposes.

## Security Measures

SBRN takes appropriate precautions to protect our site visitors' information. [www.thesbrn.org](http://www.thesbrn.org) uses industry-standard 256-bit Secure Sockets Layer (SSL) encryption on all web pages where personal or sensitive information is required. This encryption allows your data to be safely

transmitted over the Internet without being intercepted, read, altered, or deleted by a malicious third party. The encrypted data goes to a physically secure location where your information is stored on restricted-access computers located at restricted-access sites.

### **External Links**

[www.thesbrn.org](http://www.thesbrn.org) provides hyperlinks to other sites which are not under the control of SBRN. These links are provided for your convenience and for your reference only. These links are not intended as an endorsement by SBRN of the information contained on these websites or of the individuals operating these websites.

SBRN is not responsible for the privacy practices of websites hyperlinked to its website. We encourage you to be aware when you leave [www.thesbrn.org](http://www.thesbrn.org) and to read the privacy statements of each website that collects personally identifiable information. This privacy statement applies solely to information collected on [www.thesbrn.org](http://www.thesbrn.org).

### **Medical Disclaimer**

The information provided by SBRN through [www.thesbrn.org](http://www.thesbrn.org) is for your general information only. It is not intended as medical advice, and should not be relied upon as a substitute for consultations with qualified health professionals. We encourage you to take information and questions back to your individual health care provider.

### **Modifications**

SBRN may amend this privacy policy from time to time; please review it periodically. We maintain the option to modify this privacy at any time by electronic notice posted on our website. Your continued use of our website after the date that such notices are posted will be deemed to be your agreement to the changed terms.