



## **PRIVACY POLICY and TERMS OF USE (CURRENT APRIL 2021)**

Spina Bifida Wisconsin, LLC (SBWIS) is Wisconsin's only nonprofit 501©3 organization serving the unique needs of our families impacted by this neural tube birth defect throughout the lifespan of the individual. Our mission is to change the lives of those we serve.

Here at SBWIS, we understand the value of your personal information and we respect your right to privacy. We are committed to earning and maintaining your confidence and trust. We will only use your personal information to administer our programs and services and we will protect the personal information we obtain from you.

Your agreement with us includes our Privacy Policy and the Terms of Use. You acknowledge that you have read and understood the agreements, accept these agreements, and agree to be bound by them. If you do not agree with (or cannot comply with) the Privacy Policy and the Terms of Use, then you may not use SBWIS's services or consume any content on our website or social media sites.

By using [www.sbwis.org](http://www.sbwis.org), you signify your acceptance of this policy, as amended from time to time in accordance with previously stated guidelines. If you do not agree with the terms and conditions contained in this policy, please do not use the SBWIS website or social media sites.

## **IDEMNIFICATION**

By using this site, you agree to indemnify, defend, hold harmless Spina Bifida Wisconsin, Ltd and its affiliates, partners, third party content providers and licensors and each of their respective directors, officers, employees and agents from and against any and all claims, actions, suits, proceedings, judgments, damages, losses, liabilities, costs and expenses arising directly or indirectly out of or in connection with your breach of these Terms of Use, any content uploaded, posted or transmitted by you on or through the site, and/or your activities in connection with this site.

## VISITORS USE OF SITE INFORMATION

You are permitted to view, copy, download and print materials from this site provided that:

- you use the materials for informational, personal and non-commercial purposes only
- you do not modify or alter materials in any way
- you do not copy or distribute graphics from this site
- you do not quote materials out of context
- you display and retain SBWIS logo and proprietary notices on every copy of materials from our site that you make
- for permission to use third party materials appearing on our site, please contact the owner of such materials

## INFORMATION COLLECTED AND HOW IT IS USED

Users of this website are cautioned that the collection of personal information volunteered by children online or by email will be treated the same as information given by an adult, including the safe rights to erasure subject to Wisconsin public records law.

**Website usage information:** Our SBWIS website is hosted on Squarespace's web design platform. If you do nothing during your visit to the SBWIS website and social media but browse, click on external links, or download information, Squarespace automatically collects and stores the following information about your visit:

- The Internet Protocol Address and domain used but not the email address.
- The type of browser and operating system used and your connection speed.
- The date and time you visited.
- The webpages or services you accessed.

This information is used to improve the content of our web services and helps us understand how people are accessing our services. Most devices allow you to prevent location data from being sent to us through your device settings. We analyze our website logs to continually improve the value of the materials available on our site.

**Personal data:** If during your visit to the SBWIS website or social media profiles, you voluntarily provide information through an online submitted form, direct message, online post, survey or email, the following information will be collected:

- Your home mailing address. We maintain a database of people engaged in our services and organization. You may occasionally receive post mail from us.
- Your name and/or screenname (if provided), name and age of person with spina bifida, and the contents of your message.
- Any information you volunteer in response to a survey, message, or form.

- The information collected is not limited to text characters and may include audio, video, and graphic information formats you share with us.

How we use your personal information will depend on which services you request, how you use those services, and the choices you make in your device settings. We use your email to respond to you appropriately (answer your questions, acknowledge financial assistance submissions, provide event information, communicate details or changes to activities, request your input, to provide relevant messages or to forward information from another agency). By submitting your information, you consent to the collection and use of your personal data under this privacy policy.

You acknowledge and consent to the application of Wisconsin laws related to the information and documents.

SBWIS may modify this Privacy Policy, and if we make material changes to it, we will provide notice through our services, or by other means, to provide you the opportunity to review the changes.

## **PERSONAL INFORMATION AND CHOICE**

“Personal information” is any information relating to an identified or identifiable natural person. Personal information includes personal identifiers such as an individual’s name, address, and phone number. The electronic interaction logs are not considered personal information.

We collect no personal information about you unless you voluntarily provide information (complete and submit a form, request information, join SBWIS). If you choose not to participate in these activities, your choice will in no way affect your ability to use any other feature of the SBWIS website.

If personal information is volunteered by you, the user, then that information may be protected by law. You recognize that any information provided to SBWIS will be governed by Wisconsin laws which mandate record retention and disclosure requirements that may subject your information to public inspection and copying if not otherwise protected.

In the state of Wisconsin, laws exist to ensure that the public has a right to access specific records and information possessed by the state government and public-private entities, such as SBWIS. At the same time, there are exceptions to the public’s right to access public records that serve various needs; the privacy of individuals is included among these exceptions. Exceptions are provided by both state and federal laws. We strive to protect identified or identifiable information by collecting only information necessary to deliver our services. All information collected at this site and on social media becomes public record that may be subject to inspection and copying by the public unless an exemption law exists. In the event of a conflict between this Privacy

Policy, and the Wisconsin Open Records Law or other law governing the disclosure of records, the Wisconsin Open Records Law or other applicable law will control.

## **ONLINE FORMS**

SBWIS provides several online forms, some of which request personal information. These online forms are secure, we commit to upholding your privacy. Only select SBWIS staff members will have access to the information you provide. SBWIS will not intentionally share the contents of online forms with any third party.

SBWIS does not rent or sell visitors' personal information to third parties, such as marketers.

It is possible that SBWIS could be required to disclose personally identifiable user information in response to a search warrant, subpoena, court order or pursuant to applicable law; this can happen to any organization keeping records. We may also disclose personally identifiable user information to protect our legal rights and the security or integrity of our website, or to avoid liability. These kinds of disclosures are highly unlikely, but possible.

## **DATA SECURITY**

SBWIS makes reasonable efforts to ensure that all the transactions that occur on our website are secure. We store personally identifiable data with Secure Socket Layer (SSL) encryption to protect information you may submit on our site. SSL is the industry standard protocol.

## **DONATIONS**

When you decide to donate to Spina Bifida Wisconsin via our website, "Stripe" is the secure third-party involved in processing credit card transactions. For information about "Stripe" and their security, privacy policies and terms of use, please visit:

<https://stripe.com/docs/security/stripe>

When completing your online donation, SBWIS asks you to voluntarily provide your name, address, email and nature of your donation (in honor of or in memory of someone with spina bifida). When you make a donation on our site, your information goes into our post mail data base for future mailings and opportunities to support SBWIS. You always have the option to opt-out and be removed from our mailing data base by emailing [adminassist@sbwis.org](mailto:adminassist@sbwis.org) . Please use subject "remove from mailing data base".

When you make a donation designating “in memory of” or “in honor of”, upon request, your name (not the amount of the donation) may be disclosed to an individual requesting it. For example, if your donation is in memory of “John Doe”, someone who recently passed away, John’s family may contact SBWIS asking if donations were made in his memory so they can appropriately acknowledge and thank you for your kind donation. Donors can grant or deny permission for SBWIS to do this at the time of making the online donation.

## **ACCESS, CORRECTION AND ERASURE OF PERSONAL INFORMATION**

Only designated staff of SBWIS have access to records that obtain personal information.

We will take all reasonable steps to verify your identity before granting access or making corrections to your personal information.

You recognize that the information that you voluntarily submit to SBWIS is subject to Wisconsin record retention laws which mandate how long public records are kept and what happens to public records at the end of that time frame. SBWIS may retain data for differing periods of time for different purposes as required by statute or best practices. Other statutory obligations, legal processes and inquired may also necessitate the retention of certain data. When data held in accordance with this policy is destroyed, it will be destroyed securely in accordance with the best practice at the time of destruction.

By providing personal information to SBWIS, including those who live outside of the United States, you agree that the laws of the state of Wisconsin shall exclusively govern any dispute. We both agree that all claims can only be litigated in the federal or state courts in Milwaukee County, Wisconsin, USA, and we each agree to personal jurisdiction in those courts.

## **THIRD-PARTY SERVICE EMAIL BLASTS**

SBWIS uses the third-party service Mail Chimp for group email blasts of updates, announcements, and information. Your email is secure and private in this database. Messages sent electronically do not reveal recipients’ email addresses or any other personal information. SBWIS will only send Mail Chimp messages to individuals who have opted in and have provided their emails to us directly. At any time, you may “unsubscribe” or “opt out” by using the link at the bottom of any Mail Chimp email.

## **OPT OUT PROCESS**

At any time you can “opt out” of receiving post mail, letters and materials from SBWIS. You can “opt out” by sending an email to our Administrative Assistant: [adminassist@sbwis.org](mailto:adminassist@sbwis.org) . Please use the subject line “Opt out of post mail” and you will be removed from our database and post mailings.

To opt out or unsubscribe to our email blasts through Mail Chimp, you can click “unsubscribe” at the bottom of any email. Additionally, you can contact our Administrative Assistant: [adminassist@sbwis.org](mailto:adminassist@sbwis.org) . Please use the subject line “Opt out of email” and you will be unsubscribed from our email blasts.

## **OTHER SITES**

This site has links to other sites we think may be of interest to our visitors. Their purpose is to provide visitors with convenient access to other sites and resources of interest. A link to another site does not imply an endorsement of that site’s content or services. SBWIS is not responsible for the content or for the privacy practices of sites not owned by SBWIS. We encourage you to be aware of other site’s privacy statements indicating collection and use of personally identifiable data.

## **DELETION AND REMOVAL OF INFORMATION**

Non-identifiable information in our aggregate data base will not be deleted. Like all responsible website publishers, SBWIS maintains backup files as protection against natural disasters, equipment failures or other disruptions. Removing a record from our main files does not remove that record from any back up systems.

## **USE OF COOKIES**

A cookie is a small amount of data, which may include an anonymous unique identifier, that is sent to your browser from a website’s computers and may either be used only during your session (a “session” cookie) or may be stored on your computer’s hard drive (a “persistent” cookie). Cookies can contain data about user movement during the visit to the website. If your browser software is set to allow cookies, a website can send its own cookie to you. A website that has set a cookie can only access those cookies it has sent to you; it cannot access cookies sent to you by other sites.

Most browsers now recognize when a cookie is offered and permit users to control how and when they will be accepted. If you are not sure whether your browser has this capability, you should consult the documentation that accompanied your browser or

check with your Internet Service Provider. If you choose to decline cookies, you may not be able to fully experience the interactive features of the SBWIS services and website that you visit.

## **WHY ARE COOKIES USED ON WEBSITE?**

Cookies can be used to recognize you when you visit the SBWIS website, remember your preferences, and give you a personalized experience that is in line with your settings. Cookies also make your interactions with the SBWIS website faster and more secure.

SBWIS uses two types: persistent cookies and session cookies. A persistent cookie helps us recognize you as an existing user, so it's easier to return to our site or interact with our services in the future. A persistent cookie stays in your browser and will be read by SBWIS when you return to our site. Session cookies only last for as long as the session .... Different, so check the "help" menu of your browser to learn how to change your cookie preferences.

SBWIS uses a third-party database, Squarespace, to store your electronic communications preferences; this provider uses its own cookies.

SBWIS also uses a third-party service, Stripe, for donations and financial transactions. This provider uses its own cookies, privacy policies and security.

SBWIS also uses a third-party service, MailChimp, for email group blasts. This provider uses its own cookies, privacy policies and security.

## **SECURITY**

SBWIS is the developer and manager of the SBWIS website and social media accounts. We have taken steps to safeguard the integrity of its telecommunications and computing infrastructure. Security measures have been integrated into the design, implementation, and day to day practices of the entire operating environment as part of our continuing commitment to risk management. This information should not be construed in any way as giving business, legal or other advice. This information should not be construed as warranting as fail-proof the security of information provided through SBWIS-supported websites and online profiles. This system is for authorized use only.

SBWIS stores your personal information in a secure location that is accessible only by designated staff. We make reasonable efforts to protect your personal information from loss, misuse, unauthorized access or disclosure, alteration, or destruction.

## **DISCLAIMER**

The SBWIS internet site and social media accounts have links to other websites. These include links to websites operated by other government agencies, nonprofit organizations, and private businesses. These links are being provided for informational purposes only; they do not constitute accuracy, legality, or content of the external site.

Websites accessed through hyperlinks or links may be governed by privacy policies and practices that differ from this policy and are not covered by this policy. You are encouraged to become familiar with the privacy policies of every website you visit prior to disclosing any personal information. Contact the external site with questions regarding its content and privacy policy.

While we have many security measures to protect electronically transmitted information and frequently review and try to improve the security of our site, in today's computing environment, no organization can completely guarantee that a third party will not gain (illegal or inappropriate) access to information provided via this website.

### **CHANGES TO THE SBWIS PRIVACY POLICY AND TERMS OF USE**

We may modify or amend this policy from time to time. In an effort to keep you informed of changes to this policy, we will indicate the effective date of the current posted policy in the top header of this policy. For substantial changes to this policy, we will notify you by displaying a prominent notice on our home page. Changes to this policy will not affect our use of previously provided personal information. No personal information provided by you under the terms of the policy (or any prior version of this policy) will be used in a manner that is materially inconsistent with it, without your prior written permission.

For questions, thoughts, or suggestions about the SBWIS Privacy Policy or the practices of this site, please contact us at [sbwis@sbwis.org](mailto:sbwis@sbwis.org) .