

PRIVACY & COOKIE NOTICE

Last updated December 2, 2021

Thank you for choosing to be part of our community at International Spinal Cord Injury Biobank, doing business as ISCIB ("ISCIB," "we," "us," or "our"). We are committed to protecting your personal information and your right to privacy. If you have any questions or concerns about this privacy notice or our practices with regard to your personal information, please contact us at iscib.info@icord.org.

This privacy notice describes how we might use your information if you:

- Visit our website at <https://www.sci-biobank.org>
- Engage with us in other related ways — including any sales, marketing, or events

In this privacy notice, if we refer to:

- **"Website,"** we are referring to any website of ours that references or links to this policy
- **"Services,"** we are referring to our Website, and other related services, including any sales, marketing, or events

The purpose of this privacy notice is to explain to you in the clearest way possible what information we collect, how we use it, and what rights you have in relation to it. If there are any terms in this privacy notice that you do not agree with, please discontinue use of our Services immediately.

Please read this privacy notice carefully, as it will help you understand what we do with the information that we collect.

1. WHAT INFORMATION DO WE COLLECT?

Personal information you disclose to us

In Short: We only collect personal information that you provide to us.

We collect personal information that you voluntarily provide to us when you express an interest in obtaining information about us or our products and Services, when you participate in activities on the Website or otherwise when you contact us.

This website is not intended for individuals under the legal age of their jurisdiction. We also do not knowingly collect personal information from minors. If we learn we have collected or

received personal information from a minor, without verifiable consent of a parent or legal guardian, we will delete that information.

The personal information that we collect depends on the context of your interactions with us and the Website, the choices you make and the products and features you use. The personal information we collect may include the following:

Personal Information Provided by You. We collect names; email addresses; phone numbers; contact preferences; and other similar information.

All personal information that you provide to us must be true, complete and accurate, and you must notify us of any changes to such personal information.

2. HOW DO WE USE YOUR INFORMATION?

***In Short:** We process your information for purposes based on legitimate business interests, the fulfillment of our contract with you, compliance with our legal obligations, and/or your consent.*

We use personal information collected via our Website for a variety of business purposes described below. We process your personal information for these purposes in reliance on our legitimate business interests, in order to enter into or perform a contract with you, with your consent, and/or for compliance with our legal obligations. We indicate the specific processing grounds we rely on next to each purpose listed below.

We use the information we collect or receive:

- **To post testimonials.** We may post testimonials on our Website that may contain personal information. Prior to posting a testimonial, we will obtain your consent to use your name and the content of the testimonial. If you wish to update, or delete your testimonial, please contact us at iscib.info@icord.org and be sure to include your name, testimonial location, and contact information.
- **Request feedback.** We may use your information to request feedback and to contact you about your use of our Website.
- **To send administrative information to you.** We may use your personal information to send you product, service and new feature information and/or information about changes to our terms, conditions, and policies.
- **To protect our Services.** We may use your information as part of our efforts to keep our Website safe and secure (for example, for fraud monitoring and prevention).
- **To enforce our terms, conditions and policies for business purposes, to comply with legal and regulatory requirements or in connection with our contract.**

- **To respond to legal requests and prevent harm.** If we receive a subpoena or other legal request, we may need to inspect the data we hold to determine how to respond.
- **Fulfill and manage your inquiries.** We may use your information to fulfill and manage your inquiries made through the Website.
- **Administer prize draws and competitions.** We may use your information to administer prize draws and competitions when you elect to participate in our competitions.
- **To deliver and facilitate delivery of services to the user.** We may use your information to provide you with the requested service.
- **To respond to user inquiries/offer support to users.** We may use your information to respond to your inquiries.
- **To send you marketing and promotional communications.** We and/or our third-party marketing partners may use the personal information you send to us for our marketing purposes, if this is in accordance with your marketing preferences. For example, when expressing an interest in obtaining information about us or our Website, subscribing to marketing or otherwise contacting us, we will collect personal information from you. You can opt-out of our marketing emails at any time (see the "[WHAT ARE YOUR PRIVACY RIGHTS?](#)" below).
- **Deliver targeted advertising to you.** We and/or our third-party marketing partners may use your information to develop and display personalized content and advertising (and work with third parties who do so) tailored to your interests and/or location and to measure its effectiveness. For more information see our Cookies Policy (Section 4).
- **For other business purposes.** We may use your information for other business purposes, such as data analysis, identifying usage trends, determining the effectiveness of our promotional campaigns and to evaluate and improve our Website, products, marketing and your experience. We may use and store this information in aggregated and anonymized form so that it is not associated with individual end users and does not include personal information. We will not use identifiable personal information without your consent.

3. WILL YOUR INFORMATION BE SHARED WITH ANYONE?

In Short: We only share information with your consent, to comply with laws, to provide you with services, to protect your rights, or to fulfill business obligations.

We may process or share your data that we hold based on the following legal basis:

- **Consent:** We may process your data if you have given us specific consent to use your personal information for a specific purpose.
- **Legitimate Interests:** We may process your data when it is reasonably necessary to achieve our legitimate business interests.
- **Performance of a Contract:** Where we have entered into a contract with you, we may process your personal information to fulfill the terms of our contract.
- **Legal Obligations:** We may disclose your information where we are legally required to do so in order to comply with applicable law, governmental requests, a judicial proceeding, court order, or legal process, such as in response to a court order or a subpoena (including in response to public authorities to meet national security or law enforcement requirements).
- **Vital Interests:** We may disclose your information where we believe it is necessary to investigate, prevent, or take action regarding potential violations of our policies, suspected fraud, situations involving potential threats to the safety of any person and illegal activities, or as evidence in litigation in which we are involved.

More specifically, we may need to process your data or share your personal information in the following situations:

- **Business Transfers.** We may share or transfer your information in connection with, or during negotiations of, any merger, sale of company assets, financing, or acquisition of all or a portion of our business to another company.
- **Affiliates.** We may share your information with our affiliates, in which case we will require those affiliates to honor this privacy notice. Affiliates include our parent company and any subsidiaries, joint venture partners or other companies that we control or that are under common control with us.

4. DO WE USE COOKIES AND OTHER TRACKING TECHNOLOGIES?

***In Short:** We may use cookies and other tracking technologies to collect and store your information.*

We may use cookies and similar tracking technologies (like web beacons and pixels) to access or store information.

Cookies Policy

International Spinal Cord Injury Biobank ("ISCIB", "us", "we", or "our") uses cookies on the ISCIB Site (the "Site"). By using the Site, you consent to the use of cookies.

Our Cookies Policy explains what cookies are, how we use cookies, how third-parties we may partner with may use cookies on the Site, your choices regarding cookies and further information about cookies.

What are cookies

Cookies are small pieces of text sent by your web browser by a website you visit. A cookie file is stored in your web browser and allows the Site or a third-party to recognize you and make your next visit easier and the Site more useful to you.

Cookies can be "persistent" or "session" cookies.

How ISCIB uses cookies

When you use and access the Site, we may place a number of cookies files in your web browser.

We use cookies for the following purposes: to enable certain functions of the Site, to provide analytics, to store your preferences, to enable advertisements delivery, including behavioral advertising.

We use both session and persistent cookies on the Site and we use different types of cookies to run the Site:

- Essential cookies. We may use essential cookies to authenticate users and prevent fraudulent use of user accounts.

Third-party cookies

In addition to our own cookies, we may also use various third-parties cookies to report usage statistics of the Site.

We host our through Squarespace, which may collect traffic data, location-based data, communication data for analytics purposes. By visiting our website, you are also agreeing to Squarespace [cookie policy](#) and [privacy policy](#).

Our site is registered through Google Domains, therefore you may also be bound Google Analytics [policies](#) and [privacy policy](#).

What are your choices regarding cookies

If you'd like to delete cookies or instruct your web browser to delete or refuse cookies, please visit the help pages of your web browser.

Please note, however, that if you delete cookies or refuse to accept them, you might not be able to use all of the features we offer, you may not be able to store your preferences, and some of our pages might not display properly.

Where can you find more information about cookies

You can learn more about cookies and the following third-party websites:

- AllAboutCookies: <http://www.allaboutcookies.org/>
- Network Advertising Initiative: <http://www.networkadvertising.org/>

5. HOW LONG DO WE KEEP YOUR INFORMATION?

In Short: We keep your information for as long as necessary to fulfill the purposes outlined in this privacy notice unless otherwise required by law.

We will only keep your personal information for as long as it is necessary for the purposes set out in this privacy notice, unless a longer retention period is required or permitted by law (such as tax, accounting or other legal requirements). No purpose in this notice will require us keeping your personal information for longer than 1 year.

When we have no ongoing legitimate business need to process your personal information, we will either delete or anonymize such information, or, if this is not possible (for example, because your personal information has been stored in backup archives), then we will securely store your personal information and isolate it from any further processing until deletion is possible.

6. HOW DO WE KEEP YOUR INFORMATION SAFE?

In Short: We aim to protect your personal information through a system of organizational and technical security measures.

We have implemented appropriate technical and organizational security measures designed to protect the security of any personal information we process. However, despite our safeguards and efforts to secure your information, no electronic transmission over the Internet or information storage technology can be guaranteed to be 100% secure, so we cannot promise or guarantee that hackers, cybercriminals, or other unauthorized third parties will not be able to defeat our security, and improperly collect, access, steal, or modify your information. Although we will do our best to protect your personal information, transmission of personal information to and from our Website is at your own risk. You should only access the Website within a secure environment.

7. WHAT ARE YOUR PRIVACY RIGHTS?

ISCIB will only collect, use, and disclose personal information for the purposes stated above and in accordance the *Personal Information Protection Act* (BC), the federal *Personal Information Protection and Electronic Documents Act*, and any other applicable privacy regulations. If we do require your personal information for any purposes other than those for which it was originally obtained, we will first ask for your permission to do so.

8. CONTROLS FOR DO-NOT-TRACK FEATURES

Most web browsers and some mobile operating systems and mobile applications include a Do-Not-Track ("DNT") feature or setting you can activate to signal your privacy preference not to have data about your online browsing activities monitored and collected. At this stage no uniform technology standard for recognizing and implementing DNT signals has been finalized. As such, we do not currently respond to DNT browser signals or any other mechanism that automatically communicates your choice not to be tracked online. If a standard for online tracking is adopted that we must follow in the future, we will inform you about that practice in a revised version of this privacy notice.

10. DO WE MAKE UPDATES TO THIS NOTICE?

***In Short:** Yes, we will update this notice as necessary to stay compliant with relevant laws.*

We may update this privacy notice from time to time. The updated version will be indicated by an updated "Revised" date and the updated version will be effective as soon as it is accessible. If we make material changes to this privacy notice, we may notify you either by prominently posting a notice of such changes or by directly sending you a notification. We encourage you to review this privacy notice frequently to be informed of how we are protecting your information.

11. HOW CAN YOU CONTACT US ABOUT THIS NOTICE?

If you have questions or comments about this notice, you may email us at iscib.info@icord.org or by post to:

International Spinal Cord Injury Biobank
5200-818 W 10th Ave
Vancouver, British Columbia V5Z 1M9
Canada

12. HOW CAN YOU REVIEW, UPDATE, OR DELETE THE DATA WE COLLECT FROM YOU?

Based on the applicable laws of your country, you may have the right to request access to the personal information we collect from you, change that information, or delete it in some circumstances. To request to review, update, or delete your personal information, please submit a request by emailing us at iscib.info@icord.org.