



## Privacy Policy

Policy Version Control			
Policy Number	SCLA-VOL-POL-003-v1.0	Version	1.0
Drafted by	Kelly Johnston Rachel Smith Amy Lee Corr	Approved by Board of Directors on	19/12/2025
Responsible Person(s)	Kelly Johnston/ Rachel Smith	Scheduled review date	December 2027, or as per legislation changes

### 1. Introduction

Spinal CSF Leak Australia is committed to protecting the privacy and confidentiality of personal information. This Privacy Policy outlines how we collect, use, store, and disclose personal information in compliance with the Privacy Act 1988 (Cth) and the Australian Privacy Principles (APPs).

By engaging with our services, volunteering, or providing information to us, you consent to the collection, use, and disclosure of your personal information as described in this policy.

### 2. What Information We Collect

We may collect and hold the following types of personal information:

1. Personal Details: Name, contact details (email, phone number, address), and demographic information.
2. Medical Information (if applicable): Health conditions, medical history, symptoms, and treatment details if shared with us voluntarily.
3. Volunteer or Donor Information: Records of participation, donations, and communication with us.
4. Digital Information: Website interactions, IP addresses, and online preferences (if applicable).

### 3. How We Collect Personal Information

We may collect information through:

1. Direct communication (e.g., phone, email, forms, or social media).
2. Participation in events, programs, research, or surveys.
3. Online interactions, including website visits and social media engagement.

Where possible, we will collect personal information directly from the individual. If information is provided by a third party, we will take reasonable steps to ensure consent has been obtained.

## 4. How We Use Personal Information

We may use personal information for purposes including, but not limited to:

1. Providing support, information, and resources related to Spinal CSF Leak Australia.
2. Managing volunteer and donor engagement.
3. Conducting research, advocacy, and awareness activities (with consent).
4. Complying with legal obligations.
5. Communicating updates, newsletters, and event details (where consent is given).

We will not use personal information for purposes unrelated to our work without consent.

## 5. Disclosure of Personal Information

We may disclose personal information only when necessary and in accordance with the Privacy Act 1988 (Cth), including:

1. With medical professionals, researchers, or partner organisations (with explicit consent).
2. To comply with legal or regulatory obligations.
3. With service providers who assist in our operations (e.g., IT or fundraising platforms), under strict confidentiality agreements.

We will not sell, rent, or trade personal information.

## 6. Storage and Security of Information

We take reasonable steps to ensure personal information is stored securely, protected from misuse, loss, unauthorized access, or disclosure. This includes:

- Secure digital and physical storage systems.
- Restricted access to sensitive information.
- Encryption and secure transmission where applicable.

If personal information is no longer required, we will securely destroy or de-identify it in accordance with legal requirements.

## 7. Access and Correction of Personal Information

Individuals may request access to their personal information and request corrections if it is inaccurate or incomplete. Requests can be made by contacting us (see details below). We will respond within a reasonable timeframe and may require verification of identity.

## 8. Data Breach Notification

In the event of a data breach that is likely to result in serious harm, we will comply with the Notifiable Data Breaches (NDB) Scheme, including notifying affected individuals and the Office of the Australian Information Commissioner (OAIC).

## 9. Privacy Complaints and Contact Information

If you have concerns about how we handle personal information, you can contact us at:

Spinal CSF Leak Australia

[directors@spinalcsfleakaustralia.org](mailto:directors@spinalcsfleakaustralia.org)

PO Box 1005, MILTON, QLD, 4064, Australia.

If you are not satisfied with our response, you may lodge a complaint with the Office of the Australian Information Commissioner (OAIC) at [www.oaic.gov.au](http://www.oaic.gov.au).

## 10. Policy Updates

We may update this Privacy Policy to reflect changes in legislation or our practices. Any updates will be published on our website.

Last Updated: December 2025