Epilepsy Smart Australia Privacy Statement

The Epilepsy Smart Australia Program ('ESAP') is a national program, providing high quality epilepsy services that are based on the latest evidence and will improve the quality of life for people living with epilepsy and those who support them. ESAP is a collaboration of four state-based epilepsy service providers, coordinated by the Epilepsy Foundation. The four epilepsy organisations involved in ESAP are:

- Epilepsy ACT
- Epilepsy Foundation (VIC & NSW)
- Epilepsy Queensland
- Epilepsy Tasmania

ESAP is strongly committed to protecting your privacy and safeguarding your personal information. This Privacy Statement applies to all six of the epilepsy organisations involved in the ESA Program.

This Privacy Statement relates to ESAP's collection and handling of personal information that is covered by the Australian Privacy Act 1988 (Cth) ('Privacy Act'). It is not intended to cover categories of information not covered by the Privacy Act.

ESAP may, from time to time, review and update our Privacy Statement, including to take into account new laws, regulations, practices and technology. All personal information held by ESAP will be governed by our most recent Privacy Statement. Our website will always contain the most up to date version of our Privacy Statement.

The following topics are covered in our Privacy Statement:

1. Use of Personal Information
2. Collection of Personal Information
3. Marketing Communications
4. Disclosure of Personal Information
5. Security of Personal Information
6. Privacy on our Websites
7. Access to Your Personal Information
8. Contacts, Complaints and Further Information

1. Use of Personal Information

The main purposes for which we collect, hold and use personal information are to:

- provide support services;
- evaluate and improve our services;
- conduct research and / or to produce reports on our activities and impact;
- inform individuals about ESAP developments, services and opportunities and share relevant information;
- comply with legal obligations and government contracts funding our services;
- facilitate on-going fundraising and marketing activities;
- obtain and respond to feedback, queries or analyse survey responses;
- communicate with you about donations, products, services, campaigns, causes and events; and
- enable you to assist us with volunteering, community fundraising, advocacy and other activities where we seek the community's assistance.

If you choose not to provide us with personal information, we may be unable to undertake some of the activities described above.

2. Collection of Personal Information

Personal information means information or an opinion about an identified individual, or an individual who is reasonably identifiable:

- whether the information or opinion is true or not; and
- whether the information or opinion is recorded in a material form or not.

ESAP may collect personal information such as:

- name, including the name of an authorised parent, guardian, carer or other representative who you have nominated as your representative,
- date of birth and gender,
- the name, address and contact details of your organisation or business (if applicable),
- contact information (such as a home address, email address and phone number),
- credit/debit card and bank account information,
- signatures,
- employment details,
- details of service and product preferences,
- details of products or services purchased or received from ESAP and ESAP suppliers (such as counselling and support services, professional development events, training programs, fundraising activities, education, peer support and networking and information services),
- details of the products or services purchased, received or in which individuals have participated (such as the name and date of the fundraising activity or professional development/training program),
- health information and other sensitive information (as set out in further detail under 'Health information and other sensitive information', below), and
- other information about your history with, or relationship to epilepsy.

Health information and other sensitive information

As part of administering ESAP services, to comply with our legal obligations, and depending on who you are, we may collect health information and other sensitive information about you. For example, we may collect medical history information from you, if you are participating in an epilepsy program or research study. Sensitive information is defined by law as the following type of information:

- racial or ethnic origin;
- political opinions;
- membership of a political association;
- religious beliefs or associations;
- philosophical beliefs;
- memberships of a professional or trade association, or of a trade union;
- sexual orientation;
- criminal record;
- health information;
- genetic information;
- biometric information; or
- biometric templates.

We will only collect these types of information if it is necessary to deliver a service to you, or where it is required for research purposes and you have specifically consented to the collection of that information or where we are otherwise permitted by applicable privacy laws to do so.

COVID-19: given the impacts of COVID-19, the nature of the services that ESAP provides, its role as an employer and the mandatory vaccination orders and directions that are issued from time to time, we may

request evidence and collect the vaccination status of all individuals who work or attend at our premises or attend events, functions or fundraisers organised by us, including employees, contractors, and volunteers.

What happens if you don't provide all the information requested?

You are free to provide (or not provide) any information you choose. However, if you do not provide some or all of the personal information requested, we may not be able to offer you services or products, allow you to participate in ESAP's events or fundraisers, or provide you with information about our cause, events, programs and projects.

Collection of your COVID-19 vaccination status: if you do not provide the information we request about your status we may not be able to ensure that we remain compliant with the mandatory vaccination orders and directions that are issued from time to time and meet our obligation to maintain a safe workplace, which may affect your ability to access services through ESAP.

Anonymity or Pseudonymity

You may choose to remain anonymous or to use a pseudonym when dealing with ESAP. We may be limited in the supports and services we can provide if you choose to remain anonymous or use a pseudonym. We will notify you at the time of contact if this is the case.

A donor may request to remain anonymous for publication or recognition purposes, however, a tax receipt that can be used for tax deduction can only be issued when the donor is identified.

How does ESAP collect your personal information?

Wherever possible, we collect personal information directly from individuals when we deal with them. The personal information we collect may be provided in telephone conversations, email messages, in forms filled out by individuals, face to face meetings, when you use our websites or our social media, or by third parties, such as treating doctors.

In some circumstances, we may take photographs or videos of individuals, such as at events we run, sponsor or are otherwise involved in.

Where it is unreasonable or impracticable to collect personal information about you directly from you, we may also collect your personal information from third parties such as:

- parent/carer
- health professionals, and
- social and community workers.

Where we engage with you multiple times over a short period in relation to the same matter, we may not provide you with a separate notice about privacy each time we engage with you.

Research studies with ethics approval from an Australian Human Research Ethics Committee (HREC) may have additional obligations in relation to collection of personal information. Such projects will comply with the conditions of the ethics approval by the relevant HREC. In particular, collection of health information from health professionals and health record databases must be provided for in a peer-reviewed protocol that is approved by the relevant HREC, and consent must be obtained from the relevant individuals.

3. Marketing Communications

We may collect, hold and use your personal information to send you marketing communications, including to keep you informed of ESAP developments, products and services, fundraising activities and other events that we believe may be of interest to you. These communications may be sent in various ways, including electronic communication, direct mail or phone.

Like many organisations, and as is permitted under relevant laws, we often rely upon the implied consent of individuals to send them marketing communications.

Individuals always have the opportunity to elect not to receive further marketing communications from us. If you do not wish to receive or if you wish to modify how you receive or how much direct marketing communication you receive from us, please contact us in any of the ways set out under 'Contact, complaints and further information', below.

If you wish to modify the type or frequency of direct marketing communication you receive from us, please contact us in any of the ways set out under "Contact, complaints and further information", below.

Please note that if you opt out of receiving all marketing communications, we may still contact you for the other purposes described in the 'Use of personal information' section above.

If you would like to change any consents you previously provided us with, or you have any questions about how we use and disclose your personal information, please contact ESAP using any of the details set out at the end of this Privacy Statement.

4. Disclosure of Personal Information

We may need to disclose your personal information to others in order to carry out our activities and comply with our legal obligations, including in connection with the purposes described in this Privacy Statement. Depending on the nature of your engagement with us, ESAP may disclose your personal information to:

- External support services: to health care professionals, lawyers, other professionals, counsellors, funders, financiers, coordinators, volunteers, service providers, agencies and not-for-profits that provide support services;
- Researchers: to conduct research studies on the psycho-social issues of living with epilepsy;
- Contractors and service providers located within Australian and offshore who perform services on our behalf, such as mailing houses, printers, information technology services providers, database contractors and telemarketing agencies; and
- Corporate partners: who may wish to provide special offers to ESAP supporters.

We may also be required to share non-personal or de-identified information in order to comply with legal obligations and government contracts funding our services

5. Security of Personal Information

ESAP will endeavour to take all reasonable steps to keep secure any information which we hold about you, whether electronically or in hard-copy, and to keep this information accurate and up to date. While we take reasonable precautions against possible loss, misuse, or unauthorised access, no storage system or transmission of data over the Internet can be guaranteed to be secure.

We require our employees and data processors to respect the confidentiality of any personal information held by ESAP. Your personal information will stay on the database indefinitely until you advise you would like it removed, unless we de-identify it or destroy it earlier in accordance with privacy law requirements.

ESAP utilise servers owned and managed by a third parties to store our data. These servers are located in Australia. Your information may be accessible to the managers and owners of these servers, but not in an identifiable format. Your information is stored on third party servers for the purposes of storage only. We have arrangements which require those third parties to maintain the security of the information they store. We take reasonable steps to protect the privacy and security of that information, but we are not liable for any unauthorised access or use of that information.

We comply with the Payment Card Industry standards when handling payment card transactions. This means that we handle payment card information extremely securely while transactions are made. Your financial information is encrypted on our servers and access to this information is restricted to authorised staff.

6. Privacy on Our Websites

This Privacy Statement also applies to any personal information we collect via our websites, electronic forms and social media channels.

Use of cookies on websites

Cookies are used on the ESAP website. Cookies are small text files that are placed on your computer by the websites that you visit. They are widely used in order to make websites work, or work more efficiently, as well as to provide information to the owners of the site. Cookies do not identify individuals personally, but they

identify computers. If you are uncomfortable with the use of cookies, you can manage and control them through your browser, including removing cookies by deleting them from your 'browser history' (cache) when you leave the site. In most cases, you can refuse a cookie and still fully navigate the ESAP websites.

We may gather your IP address as part of our business activities and to assist with any operational difficulties or support issues with our services. This information does not identify you personally.

How we handle email and "Contact us" forms and messages

ESAP may preserve the content of any email, completed "Contact us" form or other electronic message or form that we receive. Any personal information contained in those messages will only be used or disclosed in accordance with this ESAP Privacy Statement. The message content may be monitored by our service providers or employees for purposes including trouble shooting, compliance, auditing and maintenance, or where email abuse is suspected, which means that your personal information may be disclosed to third party service providers.

Links to third party sites

The ESAP website and the various social media channels used by its service delivery providers may, from time to time, contain links to the websites and social media sites/profiles of other organisations or individuals which may be of interest to you. These third-party websites or profiles themselves may facilitate collection of information by those third parties, through your interaction with the websites or profiles and sometimes even if you do not interact directly with them. We are not responsible for the technical operation of these websites or profiles or the collection and use practices of the relevant third parties. Linked websites and social media sites/profiles are responsible for their own privacy practices and you should check those websites and social media sites/profiles for their respective privacy policies to understand their privacy practices and options they may make available to you in relation to their collection of your personal information.

Social media

ESAP service delivery providers use a range of social media accounts to inform, engage, communicate with and learn from stakeholders and the world-wide epilepsy community. Our social media teams may choose to follow organisations and individuals involved with, or actively discussing relevant issues. ESAP will only contact individuals who have initiated the communication through social media.

You may request that ESAP stop following you by a request to the account or by blocking the account using the block function in the relevant social media account. You are reminded that social media operates in a public space on the internet and most interactions are publicly viewable and searchable over time. For more information on how best to manage your interactions visit the social media account's host website (e.g. www.facebook.com).

Third party sites or profiles linked from our social media accounts are not controlled, maintained or endorsed by ESAP. To the extent permitted by law, ESAP is not responsible or liable for any content posted on or uploaded to our social media accounts by a user or any content on third party sites linked to by our social media accounts.

7. Access to Your Personal Information

ESAP will, upon your request, and subject to applicable privacy laws, provide you with access to your personal information that is held by us and where possible in the form in which you request it.

When you make a request to access personal information, we will require you to provide some form of identification (such as a driver's licence or passport) so we can verify that you are the person to whom the information relates. In some cases, we may also request an administrative fee to cover the cost of access.

We request that you identify, as clearly as possible, the type/s of information requested. We will endeavour to deal with your request to provide access to your personal information within 30 days. If we refuse your request to access your personal information, we will provide you with reasons for the refusal where required by law.

Your rights to access personal information are not absolute and in certain circumstances, privacy laws dictate that we are not required to grant access such as:

- access would pose a serious threat to the life, safety or health of any individual or to public health or public safety
- access would have an unreasonable impact on the privacy of other individuals
- the request is frivolous or vexatious

- denying access is required or authorised by a law or a court or tribunal order
- access would be unlawful, or
- access may prejudice commercial negotiations, legal proceedings, enforcement activities or appropriate action being taken in respect of a suspected unlawful activity or serious misconduct

Participants in research studies should note that access to personal information is not generally granted. This is notified to participants where applicable, at the time of committing to the research study.

Updating your personal information

You may ask us to update or delete the personal information we hold about you at any time. We will take reasonable steps to verify your identity before granting access or making any corrections to or deletion of your information. We also have obligations to take reasonable steps to correct personal information we hold when we are satisfied that it is inaccurate, out-of-date, incomplete, irrelevant or misleading for the purpose for which it is held. To assist us in this, you need to provide true, accurate, current and complete information about yourself as requested, and promptly update the information provided to us to keep it true, accurate, current and complete.

If you require access to, or wish to update your personal information, please contact us in any of the ways set out under "Contact, complaints and further information", below. We will generally not charge you for obtaining your information in an electronic format, but if you would like a hard copy of your information you may be charged a reasonable fee to cover expenses incurred. We will use all reasonable efforts to correct the information. You may be required to authenticate your identity by providing your personal information or the personal information of others, such as your authorised representative or the person for whom you are an authorised representative.

8. Contact, Complaints and Further Information

If you:

- have any questions in relation to this Privacy Statement, or the information handling procedures of ESAP,
- wish to make a complaint regarding the treatment or a breach of your privacy,
- would like to access your personal information held by us,
- would like to opt out of direct marketing, or
- would like to correct your personal information held by us,

you can contact ESAP directly or your local epilepsy organisation at:

Organisation	Contact Details
ESAP	feedback@epilepsysmart.org.au 1300 761 487
Epilepsy ACT	epilepsy@epilepsyact.org.au (02) 6287 4555
Epilepsy Foundation (VIC & NSW)	feedback@epilepsyfoundation.org.au (03) 8809 0600
Epilepsy Queensland	feedback@epilepsyqueensland.com.au (07) 3435 5000
Epilepsy Tasmania	Nerida.green@epilepsytasmania.org.au (03) 6344 6881

We may need you to provide more information about your concern. If your concern is bona-fide, we will investigate the issue and endeavour to provide you with a written response within 28 days of receipt of your written query. Sometimes we might not be able to provide you with a written response within the timeframe specified. If that is the case, we will contact you and explain the reason for the delay and give you a new timeframe for a written response.

You may also direct your issue to the Office of the Australian Information Commissioner's website at www.oaic.gov.au/privacy/privacy-complaints/

You are entitled to make an anonymous complaint or inquiry in relation to this Privacy Statement or your privacy rights. However, we may require you to identify yourself if required by law or if it is impracticable for ESAP to deal with your matter otherwise.

We may update this privacy statement at any time by publishing an updated version on this website.

This Privacy Statement was last updated October 2024.