

# Epilepsy Queensland Inc.

## PRIVACY POLICY

### 1. PURPOSE

Epilepsy Queensland recognises the essential right of individuals to have their information administered in ways which they would reasonably expect – protected on one hand, and made accessible to them on the other. The purpose of this privacy policy is to:

- clearly communicate the personal information handling practices of Epilepsy Queensland
- enhance the transparency of Epilepsy Queensland operations, and
- give individuals a better and more complete understanding of the sort of personal information that Epilepsy Queensland holds, and the way we handle that information.

### 2. OUR OBLIGATIONS UNDER THE PRIVACY ACT

This privacy policy sets out how we comply with our obligations under the Privacy Act 1988 (Privacy Act). We are bound by the Australian Privacy Principles (APPs) in the Privacy Act which regulate how organisations may collect, use, disclose and store personal information, and how individuals may access and correct personal information held about them.

### 3. SCOPE

This policy and procedure applies to all Epilepsy Queensland members, volunteers, clients, donors, business partners and online users.

*NOTE:* The Privacy Act and this Privacy Policy do not apply to acts or practices which directly relate to an employment relationship between a current or former employee and Epilepsy Queensland; or employee records of Epilepsy Queensland's current or former employees.

### 4. POLICY STATEMENT

Epilepsy Queensland respects the privacy of all Epilepsy Queensland people including members, employees, volunteers, our clients/beneficiaries, donors, business partners and online users. EQI will take reasonable steps to secure personal information and protect that information from misuse, interference and loss, and from unauthorised access, modification or disclosure.

### 5. DEFINITIONS

- **Online users** refers to anyone that accesses the Epilepsy Queensland websites and social media sites and any relevant third party websites
- **Electronic Communications** includes communications via email, fax, text, social media, website or other electronic means
- **Personal information** as defined by the *Privacy Act 1988* (as amended) is information or an opinion about an identified individual, or an individual who is reasonably identifiable, whether true or not, and whether recorded in a material form or not.
- **Sensitive information** as defined by the *Privacy Act 1988* (as amended) is information or opinion (that is also personal information) about an individual's racial or ethnic origin, political opinions, membership of a political association, religious beliefs or affiliations, philosophical beliefs, membership of a professional or trade association, membership of a trade union, sexual preferences or practices or criminal record or health, genetic, biometric information or biometric templates, that is also personal information.
- **The website** means Epilepsy Queensland websites

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### 6. OVERVIEW OF EPILEPSY QUEENSLAND PROGRAMS AND SERVICES

Epilepsy Queensland provides services and programs for people with epilepsy, their families, friends, carers, service providers and employers throughout Queensland. These services include a range of counselling therapies, information through a wide range sources and newsletters, children's and family support programs, advocacy, home and hospital visits, community education and specialised training programs and research.

In carrying out this mission Epilepsy Queensland engages volunteers and employees, and receives donations, funding and support from members of the community, corporations, groups and governments.

In addition to the services which we provide from funds donated by the public, Epilepsy Queensland also holds Agreements to deliver State government programs. In providing such services, we comply with the relevant state or national privacy principles and any additional obligations under the contract.

### 7. OUTLINE OF THIS POLICY

'**Part A — Personal Information Handling Practices**' explains our general information handling practices across Epilepsy Queensland including information about how we collect, use, disclose and store your personal information.

'**Part B — Files**' offers further detail by explaining our personal information handling practices in relation to specific Epilepsy Queensland functions or activities. Here you can find out what sort of records we keep and why. You may find this section helpful if, for example, you have made an enquiry to Epilepsy Queensland and wish to know how we manage our enquiries files.

## **PART A — OUR PERSONAL INFORMATION HANDLING PRACTICES**

### **Part A 1 - Collection of Personal and Sensitive Information**

If you would like to access any Epilepsy Queensland Services on an anonymous basis or using a pseudonym, please tell us. If this is possible and lawful, we will take all reasonable steps to comply with your request. However, we may not be able to provide the services in question if we are not provided with the personal information requested.

The nature and extent of personal and sensitive information collected by Epilepsy Queensland varies depending on your particular interaction with Epilepsy Queensland.

Epilepsy Queensland may collect personal and sensitive information from clients, members, donors, business partners, online users, applicants, volunteers, supporters and event attendees. Information about the kind of information we may collect from you and the usage of such information is below. Please contact us if you would like to discuss the information that you provide to us.

#### **Kind of information we may collect:**

- contact details, emergency contacts, personal details including: date of birth, gender,
- information on client personal issues and experiences, relationships, family background, community supports, areas of interest, health information and/or history, other information to assist with supports
- communication preferences
- financial information
- business, donor, support information/history
- for EQI roles, current/previous employment or volunteer activities, skills and experience, languages spoken and written, qualifications, drivers licence details, referee information and opinions, police checks, Blue card information, residency status
- non-identified data for statistical reporting
- communication source information

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Epilepsy Queensland Inc. uses remarketing tracking cookies and conversion pixels from vendors such as Google and Facebook to present special offers and information to users on our fundraising and awareness campaigns as well as our products or services over the Google Content Network and via social networks. This means users may see an ad for one of our campaigns, products or services as a result of visiting our website. In addition, Epilepsy Queensland Inc. uses custom audiences based on e-mails and phone numbers of subscribers, service users and customers. This allows us to present special offers and information on our campaigns, products and services to users via Facebook and Google. However, any personally identifiable information is not used by any remarketing service other than to present the user information and special offers from Epilepsy Queensland. We use the following third-party service providers for remarketing:

Facebook: Should you wish to opt-out of Facebook remarketing visit <https://www.facebook.com/help/568137493302217>

Google: Should you wish to opt-out of Google remarketing visit <https://support.google.com/ads/answer/2662922>

**Please note:** The Epilepsy Queensland website may, from time to time, contain links to other websites. Epilepsy Queensland stresses that when an online user accesses a website that is not a Epilepsy Queensland website, it may have a different privacy policy. To verify how that website collects and uses information, the user should check that particular website's policy.

To the extent that this Privacy Policy applies to online privacy issues, it is to be read as forming part of the terms and conditions of use for Epilepsy Queensland websites and social media sites and any third party platforms used to facilitate this purpose.

### How the information is collected:

- contact sheets, registration forms for events/ training, purchase orders / donations, membership applications
- electronic communications and telephone
- Customer Relationship Management system
- surveys, email, flyers, donation response coupons

### Purpose for which Epilepsy Queensland uses the information:

- to provide Epilepsy Queensland services and monitor and evaluate existing services and plan for future services
- to conduct research (including through third party organisation) and / or to produce reports on our activities and impact.
- to inform individuals about Epilepsy Queensland developments, services and opportunities and share relevant information in a variety of electronic and non-electronic forms
- to comply with legal obligations and government contracts funding our services
- to facilitate on-going fundraising and marketing activities
- to provide transparency relating to donated funds, particularly for Appeals for public donations
- to obtain and respond to feedback, queries or analyse surveys responses
- to facilitate a placement in an appropriate service or position
- to facilitate further involvements with Epilepsy Queensland (eg. disability supports, membership, donor)
- to process an application to become a member, volunteer or employee of our organisation
- to process bookings, payments, donations, purchases, transactions and provide accurate receipts
- to analyse website usage to improve website

Epilepsy Queensland does not match the personal information collected with the non-personal information

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### Part A 2 – How We Collect Information

Where possible, we collect your personal and sensitive information directly from you. We collect information through various means, including telephone and in-person interviews, appointments, forms and questionnaires. If you feel that the information that we are requesting, either on our forms or in our discussions with you, is not information that you wish to provide, please feel free to raise this with us.

In some situations we may also obtain personal information about you from a third party source. If we collect information about you in this way, we will take reasonable steps to contact you and ensure that you are aware of the purposes for which we are collecting your personal information and the organisations to which we may disclose your information, subject to any exceptions under the Act. For example, subject to normal permission requirements under the Act a health professional, such as your doctor, may provide us with information about you.

### Part A 3 – Health Information

As part of administering Epilepsy Queensland services, Epilepsy Queensland may collect health information. For example, Epilepsy Queensland collects health information (such as medical history) from some clients/beneficiaries participating in Epilepsy Queensland programs. When collecting health information from you, Epilepsy Queensland will obtain your consent to such collection and explain how the information will be used and disclosed.

As stated above, if health information is collected from a third party (such as your doctor), Epilepsy Queensland will inform you that this information has been collected and will explain how this information will be used and disclosed.

Epilepsy Queensland will not use health information beyond the consent provided by you, unless your further consent is obtained or in accordance with one of the exceptions under the Privacy Act or in compliance with another law. If Epilepsy Queensland uses your health information for research or statistical purposes, it will be de-identified if practicable to do so.

### Part A 4 - Use and Disclosure of Personal Information

We only use personal information for the purposes for which it was given to us, or for purposes which are related to one of our functions or activities.

For the purposes referred to in this Privacy Policy (discussed above under '*Collection of Personal and Sensitive Information*'), we may also disclose your personal information to other external organisations including:

- Government departments/agencies who provide funding for Epilepsy Queensland services
- Contractors who manage some of the services we offer to you, such as distribution centres who may send information to you on behalf of Epilepsy Queensland. Steps are taken to ensure they comply with the APPs when they handle personal information and are authorized only to use personal information in order to provide the services or to perform the functions required by Epilepsy Queensland;
- Doctors and health care professionals, who assist us to deliver our services;
- Other regulatory bodies, such as WorkSafe;
- Referees and former employers of Epilepsy Queensland employees and volunteers, and candidates for Epilepsy Queensland employee and volunteer positions; and
- Our professional advisors, including our accountants, auditors and lawyers.

Except as set out above, Epilepsy Queensland will not disclose an individual's personal information to a third party unless one of the following applies:

- the individual has consented
- the individual would reasonably expect us to use or give that information for another purpose related to the purpose for which it was collected (or in the case of sensitive information – directly related to the purpose for which it was collected)

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- it is otherwise required or authorised by law
- it will prevent or lessen a serious threat to somebody's life, health or safety or to public health or safety
- it is reasonably necessary for us to take appropriate action in relation to suspected unlawful activity, or misconduct of a serious nature that relates to our functions or activities
- it is reasonably necessary to assist in locating a missing person
- it is reasonably necessary to establish, exercise or defend a claim at law
- it is reasonably necessary for a confidential dispute resolution process
- it is necessary to provide a health service
- it is necessary for the management, funding or monitoring of a health service relevant to public health or public safety
- it is necessary for research or the compilation or analysis of statistics relevant to public health or public safety
- it is reasonably necessary for the enforcement of a law conducted by an enforcement body.

### Use and Disclosure to Overseas Recipients

We do not usually send personal information out of Australia and unlikely to do so. However, if we are otherwise required to send information overseas we will take measures to protect your personal information. We will protect your personal information either by ensuring that the country of destination has similar protections in relation to privacy or that we enter into contractual arrangements with the recipient of your personal information that safeguards your privacy.

### Part A 5 - Security of Personal and Sensitive Information

Epilepsy Queensland takes reasonable steps to protect the personal and sensitive information we hold against misuse, interference, loss, unauthorised access, modification and disclosure. These steps include password protection for accessing our electronic IT system, securing paper files in locked cabinets and physical access restrictions. Only authorized personnel are permitted to access these details.

EQI has a policy and response plan to deal with any possible breach of personal information.

All staff and volunteers are required to sign a Confidentiality Agreement and Code of Ethics/Conduct when they commence at our organisation. We make provision for private interview space when interviewing clients or talking with them about matters of a sensitive or personal nature.

When the personal information is no longer required, it is destroyed in a secure manner or deleted in accordance with any legislation and our Policy relating to records disposal.

### Part A 6 - Access to and Correction of Personal Information

If an individual requests access to the personal information we hold about them, or requests that we change that personal information, we will allow access or make the changes unless we consider that there is a sound reason under the Privacy Act or other relevant law to withhold the information, or not make the changes.

Requests for access and/or correction should be made to the Privacy Officer (details of which are set out below). For security reasons, you will be required to put your request in writing and provide proof of your identity. This is necessary to ensure that personal information is provided only to the correct individuals and that the privacy of others is not undermined.

In the first instance, Epilepsy Queensland will generally provide a summary of the information held about the individual. It will be assumed (unless told otherwise) that the request relates to current records. These current records will include personal information which is included in Epilepsy Queensland databases and in paper files, and which may be used on a day to day basis.

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We will provide access by allowing you to inspect, take notes or print outs of personal information that we hold about you. If personal information (for example, your name and address details) is duplicated across different databases, Epilepsy Queensland will generally provide one printout of this information, rather than multiple printouts.

We will take all reasonable steps to provide access or the information requested within 14 days of your request. In situations where the request is complicated or requires access to a large volume of information, we will take all reasonable steps to provide access to the information requested within 30 days.

Epilepsy Queensland may charge you reasonable fees to reimburse us for the cost we incur relating to your request for access to information, including in relation to photocopying and delivery cost of information stored off site. For current fees, please contact the Privacy Officer.

If an individual is able to establish that personal information Epilepsy Queensland holds about her/him is not accurate, complete or up to date, Epilepsy Queensland will take reasonable steps to correct our records.

Access will be denied if:

- the request does not relate to the personal information of the person making the request;
- providing access would pose a serious threat to the life, health or safety of a person or to public health or public safety;
- providing access would create an unreasonable impact on the privacy of others;
- the request is frivolous and vexatious;
- the request relates to existing or anticipated legal proceedings;
- providing access would prejudice negotiations with the individual making the request;
- access would be unlawful;
- denial of access is authorised or required by law;
- access would prejudice law enforcement activities;
- access would prejudice an action in relation to suspected unlawful activity, or misconduct of a serious nature relating to the functions or activities of Epilepsy Queensland
- access discloses a 'commercially sensitive' decision making process or information; or
- any other reason that is provided for in the APP's or in the Privacy Act.

If we deny access to information we will set our reasons for denying access. Where there is a dispute about your right of access to information or forms of access, this will be dealt with in accordance with the complaints procedure set out below.

### **Part A 7 - Complaints Procedure**

If you have provided us with personal and sensitive information, or we have collected and hold your personal and sensitive information, you have a right to make a complaint and have it investigated and dealt with under this complaints procedure. If you have a complaint about Epilepsy Queensland privacy practices or our handling of your personal and sensitive information please contact our Privacy Officer (details of which are set out below).

All complaints will be logged on our database.

A privacy complaint relates to any concern that you may have regarding Epilepsy Queensland privacy practices or our handling of your personal and sensitive information. This could include matters such as how your information is collected or stored, how your information is used or disclosed or how access is provided to your personal and sensitive information.

The goal of this policy is to achieve an effective resolution of your complaint within a reasonable timeframe, usually 30 days or as soon as practicable. However, in some cases, particularly if the matter is complex, the resolution may take longer.

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Once the complaint has been made, we will try to resolve the matter in a number of ways such as:

- Request for further information: We may request further information from you. You should be prepared to provide us with as much information as possible, including details of any relevant dates and documentation. This will enable us to investigate the complaint and determine an appropriate solution. All details provided will be kept confidential.
- Discuss options: We will discuss options for resolution with you and if you have suggestions about how the matter might be resolved you should raise these with our Privacy Officer.
- Investigation: Where necessary, the complaint will be investigated. We will try to do so within a reasonable time frame. It may be necessary to contact others in order to proceed with the investigation. This may be necessary in order to progress your complaint.
- Conduct of our employees: If your complaint involves the conduct of our employees we will raise the matter with the employee concerned and seek their comment and input in the resolution of the complaint.

If your complaint is found to be substantiated, you will be informed of this finding. We will then take appropriate agreed steps to resolve the complaint, address your concerns and prevent the problem from recurring.

If the complaint is not substantiated, or cannot be resolved to your satisfaction, but this Privacy Policy has been followed, Epilepsy Queensland may decide to refer the issue to an appropriate intermediary. For example, this may mean an appropriately qualified lawyer or an agreed third party, to act as a mediator.

At the conclusion of the complaint, if you are still not satisfied with the outcome you are free to take your complaint to the Office of the Australian Information Commissioner at [www.oaic.gov.au](http://www.oaic.gov.au).

We will keep a record of your complaint and the outcome.

We are unable to deal with anonymous complaints about Privacy. This is because we are unable to investigate and follow-up such complaints. However, in the event that an anonymous complaint is received we will note the issues raised and, where appropriate, try and investigate and resolve them appropriately.

### **Part A 8 – Data Breach**

Under the state and federal privacy legislation, Epilepsy Queensland is required to report to affected individuals, the department, and the Office of the Australian Information Commissioner when a data breach has occurred that is likely to result in serious harm to the people whose information is involved in the breach.

Where a breach of personal information has been detected by Epilepsy Queensland, the Data Breach Response Plan will be activated.

## **PART B — FILES: HOW WE HANDLE SPECIFIC TYPES OF FILES THAT CONTAIN PERSONAL INFORMATION**

### **Part B 1 - Public Awareness and Education Files**

#### **Purpose**

The purpose of public awareness and education files is to record details of public awareness and educational activities, such as contact with the media, speeches, event management, surveys and publication preparation.

The limited personal information in public awareness and education files relates to organisations, individuals, media representatives, event attendees, service providers and events calendar listings which appear on our website.

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### Collection

It is our usual practice to collect personal information in public awareness and education files directly from individuals. Sometimes we may collect personal information from an individual's representative or from publicly available sources such as websites or telephone directories.

### Use and disclosure

We only use the personal information in public awareness and education files for the purposes of undertaking public awareness and education initiatives and managing public relations and only with permission.

The personal information on public awareness and education files is not disclosed to other organisations or anyone else without consent unless the individual would reasonably expect, or has been told, that information of that kind is usually passed to those organisations or individuals, or the disclosure is otherwise required or authorised by law.

### Data quality

We maintain and update personal information in our public awareness and education files as necessary, or when we are advised by individuals that their personal information has changed.

### Data security

Public awareness and education files are stored in either password protected electronic media or in locked cabinets in paper form. When no longer required, personal information in public awareness and education files is destroyed in a secure manner or deleted in accordance with our Records Disposal Policy.

The following staff members have access to public awareness and education files on a need to know basis:

- Board Members
- Chief Executive Officer
- Fundraising and Marketing staff and any staff responsible for maintaining information on the computer system.
- Services team

### Access and correction

For information about how to access or correct personal information in public awareness and education files see 'Access and correction' in Part A of this document.

## Part B 2 - Contacts Lists

### Purpose

We maintain contacts lists which include contact information about individuals who may have an interest in disability services. We use these contacts lists to distribute information about our activities and publications.

### Collection

It is our usual practice to collect personal information in contacts lists directly from individuals, for example, where they have asked to be added to a contact list.

Sometimes we collect personal information from a third party or from a publicly available source such as a website or telephone directory. We usually only collect personal information in this way if the individual would reasonably expect us to, or has given their consent. For instance, we might collect this information if we thought that the individual (or the organisation they work for) would like to receive information about services we are carrying out, or that they might be likely to consider information about disability care useful in the work they do.

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We would only contact this individual in their work capacity.

### Use and disclosure

We only use personal information in contacts lists for the purpose of managing stakeholder relations.

We do not give personal information about an individual to other organisations or anyone else without consent unless the individual would reasonably expect, or has been told, that information of that kind is usually passed to those organisations or individuals, or the disclosure is otherwise required or authorised by law.

### Data quality

We maintain and update personal information in our contacts lists when we are advised by individuals that their personal information has changed. We also regularly audit contacts lists to check the currency of the contact information. We will remove contact information of individuals who advise us that they no longer wish to be contacted.

### Data security

The personal information in the contacts lists is stored in either password protected electronic media or in locked cabinets in paper form. When no longer required, personal information in contacts lists is destroyed in a secure manner or deleted in accordance with Records Disposal Policy.

Routine access to contacts lists is limited to the database operators who have responsibility for maintaining the contacts lists. Other staff members have access to the personal information in contacts lists on a need to know basis.

### Access and correction

For information about how to access or correct personal information in our contacts lists see 'Access and correction' in Part A of this document.

## 8. CHANGES TO THIS PRIVACY POLICY

Epilepsy Queensland reserves the right to review, amend and/or update this policy from time to time.

We aim to comply with the APPs and other privacy requirements required to be observed under State or Commonwealth Government contracts.

If further privacy legislation and/or self-regulatory codes are introduced or our Privacy Policy is updated, we will summarise any substantial modifications or enhancements in this section of our Privacy Policy.

## 9. HOW TO CONTACT US

For further information, or to provide any comments, please contact us:

- Call 1300 852 853 (local call cost from fixed landlines within Australia) or (07) 3435 5000
- Email [privacy@epilepsyqueensland.com.au](mailto:privacy@epilepsyqueensland.com.au)
- Write to us at Epilepsy Queensland Inc, P.O. Box 1457 Coorparoo BC, Qld. 4151.

(Note: Calls from mobile/pay phones may incur higher charges. Please check with your service provider for call costs)