

Privacy Policy

Policy number	1	Version	2.1
Drafted by	Clare Stuart	Approved by committee	24 th October 2015
Responsible person	General Manager	Scheduled review	November 2016

Background

The committee of Tuberous Sclerosis Australia (TSA) is committed to protecting the privacy of personal information which the organisation collects, holds and administers.

Personal information is information which directly or indirectly identifies a person. TSA collects personal information about individuals, including:

- Information that can identify an individual
- Information that could be considered health information, such as whether the individual is affected by Tuberous Sclerosis

TSA supports the importance the community places on personal and sensitive information. TSA also faces significant challenges caused by a geographically distributed team that is primarily voluntary, with varying degrees of experience in handling personal information.

Purpose

The purpose of this policy is to provide clear principles and guidance about how TSA collects, stores and disposes of information.

Principles

- TSA will attempt to achieve best practice in handling personal information, meeting or exceeding our legal obligations
- TSA will adhere to the Australian Privacy Principles (APP)
- The policy will be implemented in various processes, forms and tools that TSA uses
- The policy will be followed by all TSA staff and volunteers, including management committee members and regional contacts.

The Australian Privacy Principles (APP) can be viewed at www.oaic.gov.au

The Australian Privacy Principles are:

1. Open and transparent management of personal information
2. Anonymity and pseudonymity
3. Collection of solicited personal information
4. Dealing with unsolicited personal information
5. Notification of the collection of personal information
6. Use or disclosure of personal information
7. Direct marketing
8. Cross-border disclosure of personal information
9. Adoption, use or disclosure of government related identifiers
10. Quality of personal information
11. Security of personal information
12. Access to personal information
13. Correction of personal information.

This policy is structured around these principles.

1. Definitions

1.1. How do the privacy regulations apply to TSA?

Privacy regulations define an APP entity, to which the privacy principles apply.

- TSA meets the definition of a small business operator as it has annual turnover of less than \$3,000,000.
- TSA meets the exceptions to this definition “provide a health service and hold health information other than in an employee record”. Through phone, email and internet support, TSA collects health information and might be considered to be providing a health service.

For this reason, the privacy regulations do apply to TSA.

1.2. What is personal information?

- Information or an opinion about an individual whose identity is apparent or can be ascertained from that information or opinion.
- This includes names, addresses, telephone numbers, age and e-mail address.

1.3. What is sensitive information?

This includes information about:

- Racial or ethnic origin;
- Political opinion or association;
- Trade union or professional association membership;
- Religious beliefs or philosophical beliefs;
- Sexual preferences;
- Criminal record;
- Health information;
- Genetic information.

1.4. Volunteers

Volunteers include committee members, regional coordinators and all other people that assist with TSA activities in a voluntary capacity.

2. Privacy Policy

2.1. Open and transparent management of personal information

Under APP 1, TSA will:

- 2.1.1. Maintain a summary privacy policy. See Chapter 3 Public summary privacy policy for this summary.
- 2.1.2. Maintain a detailed privacy policy and procedures (this document).
- 2.1.3. Publish both the summary and detailed privacy policy on the TSA website.
- 2.1.4. Be able to direct people to the policy on the TSA website when the policy is requested.
- 2.1.5. Print a copy of the privacy policy on request.
- 2.1.6. Include details of how to access the policy at the bottom of all correspondence sent to individuals.
- 2.1.7. Review the detailed policy and procedures annually.
- 2.1.8. Nominate one committee member to be jointly responsible with the TSA General Manager for TSAs privacy related procedures.

2.2. Anonymity and pseudonymity

Under APP 2, TSA will:

- 2.2.1. Allow people to not identify themselves when dealing with TSA. This is practicable when TSA staff and volunteers are offering support or advice or in making some financial contributions to TSA. This is not practicable when registering for TSA events or in becoming a member of TSA.
- 2.2.2. Inform people that they may choose to deal anonymously with TSA.
- 2.2.3. When collecting personal stories, feedback and testimonials, allow respondents to contribute anonymously.
- 2.2.4. Provide all publications on the TSA website to enable access without joining TSA or providing name and address information.

2.3. Collection of solicited personal information

Under APP 3, TSA will:

- 2.3.1. Collect the following types of information:

Type of information	Purpose for collection
Contact information for the members of Tuberous Sclerosis Australia (TSA), members of the TSC Professionals Network, people who contact our information and support services, people who attend TSA events and people who make a donation to TSA.	To provide our services, including sending information by post and email, connecting people with TSC to health professionals and holding educational events. We also collect personal information to support our fundraising. We contact previous donors and fundraisers to give them information about our organisation and the people we help and to ask for their ongoing support.
Financial information for people who make a donation to TSA.	To process financial transactions including one-off and recurring donations, membership fees, event registration fees and expense reimbursements.
Sensitive health information for members of TSA and people who contact our information and support services.	To provide our information and support services and to tailor information and our services to the needs of our members and others who contact us. We also collect sensitive information to support our systemic advocacy work.

- 2.3.2.** Collect personal information by a method which is fair, lawful and not unreasonably intrusive.
- 2.3.3.** Where reasonable, collect information about an individual from that individual. When this is not possible, ask the individual providing the information (usually a parent or a carer) to seek the consent of the individual.

2.4. Dealing with unsolicited personal information

Under APP 4, TSA will:

- 2.4.1.** Identify that unsolicited information is received when information is provided outside of that requested by TSA activities
- 2.4.2.** Determine whether the unsolicited information could have been received as a part of TSA activities, as documented in this policy under APP 3.
- 2.4.3.** If it could not have been, determine whether destruction or de-identification of the unsolicited information is legal and practical.
- 2.4.4.** If it is, to destroy or de-identify this information.

Examples of unsolicited personal information applicable to TSA:

- If a member writes a letter of a personal nature to TSA containing health information and other details. Whether the person is requesting information or support would be key to determining whether it falls within TSA activities under APP 3.
- Other examples provided by the OAIC are:
 - misdirected mail received by an entity
 - correspondence to Ministers and Government departments from members of the community, or other unsolicited correspondence to an entity
 - a petition sent to an entity that contains names and addresses
 - an employment application sent to an entity on an individual's own initiative and not in response to an advertised vacancy
 - a promotional flyer containing personal information, sent to an entity by an individual promoting the individual's business or services.

2.5. Notification of the collection of personal information

Under APP 5, TSA will:

- 2.5.1. Include all APP 5 matters in the summary privacy policy. See Appendix 1 for this summary.
- 2.5.2. Include a link to the summary privacy policy in all communication with individuals. This includes:
 - email newsletters;
 - membership application forms;
 - membership renewal forms;
 - donation forms;
 - forms for the TSC professionals network;
 - surveys;
 - website forms, including for donations, memberships, event registrations;
- 2.5.3. during phone calls that provide TSC information and support;
- 2.5.4. emails sent as a part of providing TSC information and support.

2.6. Use or disclosure of personal information

Under APP 6:

- 2.6.1. TSA will only use personal information for the primary purpose for which it was collected unless the individual would reasonably expect us to do so.
- 2.6.2. TSA will never sell or exchange or release personal information about an individual for commercial gain.
- 2.6.3. TSA will use personal information to keep individuals better informed about TSA activities and services, for example through a newsletter. Individuals have the right to opt out of receiving these additional communications at any time.
- 2.6.4. TSA will use de-identified or aggregate information for research and public health information.
- 2.6.5. TSA may request consent from the individual to use their personal information for a secondary purpose.
- 2.6.6. TSA will disclose personal information if TSA has a legal obligation to disclose that overrides the provisions of the primary legislation.

Example 1:

If personal information was provided so that TSA could provide TSC information and support to a personal affected by TSC, this information would not be used for direct fundraising and donation requests. It may be used for sending of TSC-related health information at or information about TSA services at a later date. Personal information may be used to conduct TSC related research.

Example 2:

If personal information is provided from a health professional upon joining the TSC Professionals Network, that information would not be used for direct fundraising and donation requests. It may be used to communicate with the health professional about research, guidelines for managing TSC and TSA activities of interest to health professionals at a later date.

2.7. Direct Marketing

Under APP 7, TSA will:

- 2.7.1. Use personal information collected from an individual for direct marketing only where the individual would reasonably expect this marketing. For example, direct mail for fundraising campaigns may be sent to individuals who have previously donated to TSA or participated in fundraising.
- 2.7.2. Always provide a clear and simple way for individuals to request not to receive direct marketing.
- 2.7.3. Seek to comply with other related legislation and best practice related to direct marketing such as the anti-SPAM and do not call registers.

2.8. Cross Border Disclosure

Under APP 8:

- 2.8.1. When personal information is disclosed to an overseas recipient, TSA will take reasonable steps to ensure that the overseas recipient does not breach the Australian Privacy Principles. This may be through confirmation that the overseas entity is subject to a law or scheme that offers substantially similar protections to the Australian Privacy Principles.

2.9. Adoption, use or disclosure of government related identifiers

Under APP 9:

- 2.9.1. TSA will not use a government identifier as its own identifier
- 2.9.2. TSA will not collect government identifiers unless there is a specific purpose for collection.
- 2.9.3. TSA will not disclose government identifiers unless required to do so by the law.

2.10. Quality of personal information

Under APP 10, TSA will take reasonable steps to ensure the information it collects, holds and discloses is accurate, up to date and complete. This includes:

- 2.10.1. Keeping records of dates that data was collected.
- 2.10.2. Keeping records of dates that data has been verified.
- 2.10.3. Confirm personal information and update (if required) when TSA interacts with an individual, such as through a donation, event attendance, phone call or email.

2.11. Security of personal information

Under APP 11, TSA will take reasonable steps to protect personal information from misuse, loss, unauthorised use, modification or disclosure. Specifically:

- 2.11.1. Secure internet technologies will be used for the exchange of personal information.
- 2.11.2. TSA will comply with the PCI Security Standards for handling payment card information.
- 2.11.3. Personal information will be centralised on a secure server, and offline copies will only be used for back up or temporary use. Offline backup copies to be stored in a secure location, which may be the residence of a volunteer.
- 2.11.4. Staff and volunteers will be discouraged from emailing personal information.
- 2.11.5. Staff and volunteers will be discouraged from printing personal information. If personal information is printed it will be destroyed securely when it is no longer needed e.g. by shredding.
- 2.11.6. Personal information will be destroyed or permanently de-identified when it is no longer needed for the purpose for which it was collected

2.12. Access to personal information

Under APP 12, TSA will make information held on an individual is accessible to them on request (except where frivolous and vexatious). This will be available free of charge.

2.13. Correction of personal information

Under APP 13, if an individual informs TSA that information TSA holds is not accurate, complete or up to date, TSA will take reasonable steps to ensure the information provided is accurate and up-to-date.

3. Public summary privacy policy

This policy will be published on the TSA website. The link to the PDF of the more detailed policy will be included.

This policy was last updated on 24th October 2015.

This policy is reviewed annually. We invite your comments by email to info@tsa.org.au.

The personal information we hold

We hold contact information for the members of Tuberous Sclerosis Australia (TSA), members of the TSC Professionals Network, people who contact our information and support services, people who attend TSA events and people who make a donation to TSA.

We hold financial information for people who make a donation to TSA.

We hold sensitive health information for members of TSA and people who contact our information and support services.

Why we collect personal information

We collect personal information to allow us to provide our services. This includes sending information by post and email, connecting people with TSC to health professionals and holding educational events.

We also collect personal information to support our fundraising. We contact previous donors and fundraisers to give them information about our organisation and the people we help and to ask for their ongoing support.

We collect financial information to allow us to process financial transactions including one-off and recurring donations, membership fees and event registration fees.

We collect sensitive health information to allow us to provide our information and support services and to tailor information and our services to the needs of our members and others who contact us.

What happens if you do not provide us with personal information

You may be able deal with us anonymously or using a pseudonym. We will advise you of whether this is an option when you contact us. We will provide information and support about TSC to you as best we can with as little personal information as you are willing to provide.

We require personal information for all TSA members. You will not be able to become a member of TSA without providing personal information.

We are able to receive anonymous donations. You will be able to make a donation to TSA without providing personal information.

Due to regulations, we require personal information about all individuals and organisations who fundraise for TSA. We will not be able to authorise a fundraiser without collecting personal information.

How we collect and hold this information

We may collect information by paper form, on our website, by telephone or email.

All personal and sensitive information is held in our online database, secured by passwords and encryption.

From time to time it may be held in printed or electronic files for us by our staff, volunteers and suppliers. These are destroyed when they are no longer required to carry out our work.

Financial information is destroyed when the related financial transactions have been processed.

When we share this information

The information is used by TSA staff and volunteers. Our volunteers include the TSA committee, regional contacts and others that help us with our work.

We share personal information about members of the TSC Professionals Network with people with TSC seeking a health professional in their area.

We share contact information with our suppliers. For example, our mailing list is provided to our printer when they send printed information (such as our magazine) in the post. If we share personal information with individuals or organisations outside Australia we will ensure these organisations offer very similar protections as the Australian privacy regulations.

We share financial information only for the purposes of processing financial transactions.

We never share individual sensitive health information. We may use this information to provide aggregated, de-identified information for research and advocacy purposes. For example, we may share the number of people living with TSC in a particular area or in a particular age range.

How we use photographs

TSA may hold and use photographs of you if:

- You have attended a TSA organized event
- You have submitted photos to use to tell part of your TSC story

We will always seek permission to take photographs of you. You can revoke this permission at any time. If you revoke permission we will take reasonable steps to remove this content from any online publications and exclude this content from all future printed and online publications.

How you can access your information and seek correction

You can request a copy of your information at any time. Please contact:

Clare Stuart
General Manager
Tuberous Sclerosis Australia
17 Linksvie Rd
Springwood NSW 2777
clare@tsa.org.au

How we handle your feedback and complaints

A complaint about the way we collect, store, use and disclose personal information should first be made in writing to the address above. We will respond within 30 days.

If the complaint cannot be resolved in this timeframe, the complaint may be taken to the Office of the Australian Information Commissioner. See www.oaic.gov.au.

4. Related documents

Available on the TSA Handbook site

- Payment Card information handling procedures (being drafted)
- TSC Information and support procedures (being drafted)

Further reading

- Summary of the privacy principles:
<http://www.oaic.gov.au/privacy/privacy-resources/privacy-guides/app-quick-reference-tool>
- Detailed guide to the privacy principles:
<http://www.oaic.gov.au/privacy/applying-privacy-law/app-guidelines>