



prader-willi syndrome association

PRIVACY POLICY

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1.0

Introduction

The Board of Prader-Willi Syndrome Association (Vic) Inc is committed to protecting the privacy of personal information which the organisation collects, holds and administers in compliance with the Victorian and Australian privacy legislation and principles.

Personal information is information or opinion which directly or indirectly identifies a person or from which your identity can reasonably be determined.

Sensitive information is personal information that includes information about racial or ethnic origin, political or religious beliefs, sexual preferences or practices, criminal record; or health. This information will only be collected if it is necessary to do so and you have consented to its collection. We do not use or disclose your sensitive information other than as allowed by the law or with your consent.

2.0

Purpose

The purpose of this document is to provide a framework for Prader-Willi Syndrome Association (Vic) Inc of Victoria when dealing with privacy considerations

Our Privacy Policy is based on the need to meet the requirements of the changes to the Privacy Act 1988 and our requirement to meet the Australian Privacy principles (APP) 2014.

The Privacy Act sets standards for the way we must deal with personal information by regulating:

- How we collect and hold your personal information;
- The purposes for which we collect ,use and disclose that personal information;
- The kind of personal information we collect and security for storage of your personal information;
- Our openness and transparency about our Privacy Policy;
- Your right of access to personal information and to correct inaccuracies of your personal information;
- How an individual can complain about a suspected breach of privacy laws
- Disclosure of any international transfer of information

2.0

The kinds of personal information that PWS collects and holds.

2.1

The Prader-Willi Syndrome Association of Victoria Inc will primarily collect information from families, donors and job applicants and other persons who are involved with Prader-Willi Syndrome association of Victoria.

2.2

The Prader-Willi Syndrome Association of Victoria Inc only collects information that is necessary in order to carry out its primary functions and activities or where it is required by law.

2.3

The Prader-Willi Syndrome Association of Victoria Inc collects and administers a range of personal information for the purposes of:

- Membership contact details,
- Collecting extra information for special events where duty of care requires medical information
- Submitting resumes and job application
- Registering for an event , conference or newsletter
- Collecting feedback about training sessions and special events from services and education.
- Collecting evaluation forms ,opinion surveys and questionnaires
- Collecting information to facilitate donations including name and contact details and when required credit card details.

2.4

We will give you the option of not identifying yourself when completing evaluation forms or opinion surveys.

3.0

How we collect personal information

3.1

We collect information lawfully and discretely from the person concerned via face to face meetings, emails, letters questionnaires or forms.

3.2

On occasions personal information may be collected from other sources such as doctors and other carer agencies. When information is collected from a third party we take reasonable steps to notify the person as soon as possible.

3.3

When we receive unsolicited information we determine if it is necessary to our primary functions if not it is destroyed in the appropriate manner.

3.4

Also the Prader-Willi Syndrome Association of Victoria website has the facility to submit other personal information which may include submitting your contact details, requesting additional information on topics of interest, registering for an event, conference or newsletter submitting your contact details when making donations to the Association, providing feedback, providing information to support fundraising or awareness promotions or submitting your resume and job application.

3.5

The organization is committed to protecting the privacy of personal information it collects, holds and administers but it recognizes that internet security is not foolproof. The Prader-Willi Syndrome Association of Victoria Inc in accordance with the requirements of the privacy Act takes reasonable measures to protect its website and make it as secure as possible. The Prader-Willi Syndrome Association of Victoria Inc considers that any information posted on its website is done so with the consent of the person who posted the information and that they have consented to the collection of that information.

4.0

The purpose for which PWSA collects, holds, uses and discloses personal information

4.1

The Prader-Willi Syndrome Association of Victoria Inc will ensure that stakeholders are informed as to why we collect the information and how we administer the information gathered.

The Prader-Willi Syndrome Association of Victoria Inc will only collect information which the organisation requires for its primary functions which are:

- To promote awareness of Prader-Willi Syndrome(PWS) in the community
- To support initiatives for and provide resources for parents, carers and people with PWS
- To provide access to PWS education and training programs for the community
- Responding to enquiries and to support PWS families via Conferences, Family Days, expert speakers and the PWS Newsletter and camps
- Fundraising and other marketing activities
- Managing the organisation, and day to day communication

4.2

We may also collect personal information for the purpose of recruitment of staff.

4.3

On occasions it is necessary to collect sensitive personal information in order to fulfill the association's duty of care .For example it is necessary to collect medical/health /behaviour management information for the purposes of staffing and organizing camp and Family Day arrangements and training delivery.

4.4

We only use the personal information for which it was given or for the purposes of the fulfilling the primary functions of the organisation. in ways that the person would reasonably expect us to use the information.

In certain circumstances it will be necessary to disclose your personal information to others for the purposes for which we collected it. For example, we may disclose your personal information to carers who are assisting with PWSA activities.

You are entitled to know the identities of any third party to which we disclose your personal information, and you may access these details at any time.

4.5

We do not send personal information outside Australia without your consent.

5.0

How Prader-Willi Association of Victoria holds personal information

5.1

We recognise the essential right of individuals to have their information administered in ways which you would reasonably expect – protected on one hand, and made accessible to them on the other.

5.2

We protect the personal information we hold against loss, unauthorized access, use, modification, interference or disclosure by:

- Computers having security passwords and virus protection
- Personal information is stored in a locked filing cabinet
- Personal information that is no longer of current use is securely stored for the required seven years
- Personal information that is no longer required after that period is shredded in a secure fashion prior to disposal

6.0

Individuals may access their personal information and seek correction of it.

6.1

The Prader-Willi Syndrome Association of Victoria will ensure that stakeholders have the right to:

- Request access to any personal information we hold about them. unless there are legal reasons we cannot. Any denial of a request for access to personal information will be accompanied by an explanation setting out our reasons for doing so.
- Request personal information to be corrected. At any time you may request access to personal information or that that we correct or update your personal information to ensure it is accurate and complete.
- The request must include your name, and the nature of your request address
- The request is to be dealt with in a reasonable timeframe
- Requests by individuals to access and seek to correct their personal information can be made to

The Secretary
Prader-Willi Syndrome Association of Victoria.
PO Box 92 Kew Victoria 3101
Phone 0451797284

7.0

Complaints

7.1

You may complain to Prader-Willi Syndrome Association of Victoria if you suspected breach of privacy laws, refused access to your personal information or to make corrections to your personal information.

Complaints about a suspected breach of privacy laws should be made to

The Secretary

Prader-Willi Syndrome Association of Victoria.

PO Box 92 Kew Victoria 3101

Phone 0451797284

The request must include your name, address and the nature of your complaint

- The complaint is to be dealt with in a reasonable timeframe
- The Boards response to the complaint will be accompanied by an explanation within 30 days as required by the Privacy legislation.
- If you are not satisfied with our response to your complaint after this meeting, you can refer your complaint to the Office of the Australian Information Commissioner by:

Office of the Australian Information Commissioner
enquiries@oaic.gov.au or

Phone 1300 363 992

Or the Victorian Privacy Commissioner