



**PRIVACY POLICY**

**PRADER-WILLI RESEARCH FOUNDATION**

**AUSTRALIA LIMITED**

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**Date** June 2020

## **1 INTRODUCTION**

- 1.1 Prader-Willi Research Foundation Australia Limited (ABN 21 605 291 816) ('Prader-Willi Research Foundation Australia', 'us' or 'we') recognises and values the importance of protecting the privacy of our stakeholders, collaborators, partners, customers, research participants, clients, prospective clients, patients, prospective patients, relevant health service providers, donors, fundraisers, suppliers and any other third parties ('Individuals').
- 1.2 Prader-Willi Research Foundation of Australia works to improve clinical outcomes and treatments for Prader-Willi syndrome. By focusing on both short and long term outcomes, our research program will change the lives of people living with this condition and their families. To enable us to fulfil our responsibilities relating to research, education and training, clinical services, fundraising, marketing and development, or to otherwise carry out our functions ('Operational Purposes'), we may need to collect a broad range of personal information from individuals.
- 1.3 Prader-Willi Research Foundation Australia is committed to handling personal information (including health and other sensitive information) in accordance with applicable laws, including the Australian Privacy Principles set out in the Privacy Act 1988 (Cth).
- 1.4 In the course of providing services or in connection with the Operational Purposes, we may collect personal information about you, either directly or indirectly from you. This Privacy Policy informs you of why and how we collect, hold, use and disclose your personal information. By using our website located at <https://http://praderwilli.org.au/> or by otherwise engaging with us, you are indicating your acceptance of this Privacy Policy. If you do not agree to this Privacy Policy, you must not use our website or engage with us.

## **2 WHAT IS PERSONAL INFORMATION?**

- 2.1 Personal information is any information or an opinion about an identified individual or an individual who can be reasonably identified from the information or opinion. Information or an opinion may be personal information regardless of whether it is true.

## **3 WHY DO WE COLLECT, HOLD OR USE YOUR PERSONAL INFORMATION?**

- 3.1 We collect personal information reasonably necessary for one or more of our functions or activities in connection with the Operational Purposes. This personal

information may include sensitive information, and in some instances may include health information. You may decide to provide your personal information to The Prader-Willi Research Foundation Australia for a range of different reasons. By way of example you may wish to:

- 3.1.1 participate in a research project;
- 3.1.2 donate money to The Prader-Willi Research Foundation Australia;
- 3.1.3 fundraise for The Prader-Willi Research Foundation Australia;
- 3.1.4 collaborate with The Prader-Willi Research Foundation Australia;
- 3.1.5 attend an event or course run by The Prader-Willi Research Foundation Australia;
- 3.1.6 receive communications from The Prader-Willi Research Foundation Australia;
- 3.1.7 apply for employment at, or volunteer for, The Prader-Willi Research Foundation Australia;
- 3.1.8 provide services to The Prader-Willi Research Foundation Australia; or
- 3.1.9 connect with us via social media.

#### **4 HOW DO WE COLLECT YOUR PERSONAL INFORMATION?**

- 4.1 We may collect personal information from you in person, in writing, by telephone, through our website and by other electronic communication channels. We may also collect this personal information through our staff and through our contracted agents and other service providers. Wherever practicable, we will collect personal information from you directly.
- 4.2 We may from time to time need to obtain personal information from others, for instance where individuals are receiving clinical services, to ensure that we are fully informed in relation to the issues that we need to address.
- 4.3 We also collect personal information through events and activities that we hold or are involved in, such as seminars, workshops, promotional events, fundraising and other activities.
- 4.4 The types of personal information we collect will depend on the purposes for which you interact with The Prader-Willi Research Foundation. The personal information we may collect from you may include:
  - 4.4.1 your full name and prefix (e.g. Mr or Mrs)
  - 4.4.2 your address

- 4.4.3 your phone number
- 4.4.4 your email address, so that we can authenticate you electronically and administer your account
- 4.4.5 your date of birth
- 4.4.6 your gender
- 4.4.7 your social network contact and publicly available details
- 4.4.8 your employer
- 4.4.9 your country or state of residence
- 4.4.10 your medical history including, where relevant, a family medical history
- 4.4.11 your credit card details and other information which will allow us to process your transaction
- 4.4.12 other demographic information
- 4.5 You may not be able to deal with or interact with Prader-Willi Research Foundation or receive information from us if you do not provide us with your personal information.
- 4.6 We may from time to time collect 'sensitive' information and health information from you. Where we do so, we will separately seek your consent.

### **Website Interaction**

- 4.7 We may also collect information about how you access, use and interact with the website. This information may include:
  - 4.7.1 the location from which you have come to the site and the pages you visited; and
  - 4.7.2 technical data, which may include your IP address, the types of devices you are using to access the website, device attributes, browser type, language and operating system.
- 4.8 We use cookies on the website. A cookie is a small text file that the website may place on your device to store information. We may use persistent cookies (which remain on your computer even after you close your browser) to store information that may speed up your use of our website for any of your future visits to the website. We may also use session cookies (which no longer remain after you end your browsing session) to help manage the display and presentation of information on the website. You may refuse to use cookies by selecting the appropriate settings on your browser. However, please note that if you do this, you may not be able to use the full functionality of the website

- 4.9 If you do not provide us with your personal information we may not be able to provide you with our services, communicate with you or respond to your enquiries.

## **5 HOW DO WE USE OR HOLD YOUR PERSONAL INFORMATION?**

- 5.1 We use and hold your personal information to facilitate the Operational Purposes, as well as our general operational, technical and administrative purposes. We may from time to time share the personal information we collect with any of our relevant third parties, including our partners, suppliers, collaborators, advisers and business associates. We would only share your personal information with third parties where it is necessary in undertaking those activities that you have agreed to be involved.
- 5.2 Where you participate in research or a clinical study, we may use your personal information (including sensitive information or health information) to create articles, reports, papers, presentations or other outputs. We will not, without your consent, publish your personal information in any form, unless it has been presented in aggregated form, is anonymised or de-identified.
- 5.3 To keep you up to date with our services, publications and other resources, we may place you on a communications list, including mail, telephone and/or email. At any time, if you no longer wish to receive this information just let us know and we will remove your details from the contact list.
- 5.4 We may also disclose your personal information to others where:
- 5.4.1 we are required or authorised by law to do so;
  - 5.4.2 you may have expressly consented to the disclosure or the consent may be reasonably inferred from the circumstances; or
  - 5.4.3 we are otherwise permitted to disclose the information under the Privacy Act.

## **6 COMMUNICATIONS**

- 6.1 Where you register to receive a service or to otherwise engage with Prader-Willi Research Foundation, you may opt-in to Prader-Willi Research Foundation sending advertising, fundraising and other direct marketing material to you.
- 6.2 You may opt-out of the provision of direct marketing materials by using the functional unsubscribe option or by contacting us.

## **7 SECURITY**

- 7.1 We take reasonable steps to prevent the personal information we hold about you from misuse, interference or loss, and from unauthorised access, modification or disclosure. Our security measures meet industry standards and you can feel

confident in our processes. These may include access control procedures, network firewalls, encryption and physical security. Although we will endeavour to protect your personal information, we are unable to guarantee that any information you transmit to us over the internet is 100% secure.

## **8 UPDATING YOUR PERSONAL INFORMATION**

- 8.1 We will take reasonable steps to ensure that the personal information we hold, use and disclose is accurate, up to date and complete. However, we will not necessarily take any administrative steps to verify the accuracy or completeness of the information you provide to us (or a third party) at the time of collection.
- 8.2 If you suspect or believe that the personal information we have is not accurate, complete or up to date, please contact us at the details below and we will respond to your request within a reasonable period. When responding, we will take reasonable steps to correct that information and to ensure that it remains accurate, complete and up to date in the future. If for some reason we are unable to correct your personal information, we will provide you with our reasons and your further options for complaint. We will not ordinarily charge you for requesting the correction of your personal information.

## **9 ACCESS TO YOUR PERSONAL INFORMATION**

- 9.1 You are entitled to access the personal information we hold about you, on request, subject to a limited number of exceptions. If for some reason we are unable to provide you with access to your personal information, we will provide you with our reasons as well as your further options for complaint. If we did not collect your personal information directly from you, it may be more practical for us to pass your access request on to the relevant third party who did collect that information from you.
- 9.2 You may make an access request via the contact details below and we will respond to your request within a reasonable period. We will not ordinarily charge you for gaining access to your personal information.

## **10 HOW LONG WILL WE KEEP YOUR PERSONAL INFORMATION?**

- 10.1 We do not retain personal information after we have used the personal information for the purposes for which we collected or received it. The duration that we keep your personal information for will be influenced by the nature of that information, and any applicable regulatory requirements. For all types of personal information, when no longer required, Prader-Willi Research Foundation will use its best endeavours to ensure that all such information will be deleted or destroyed in a secure manner and in a reasonable timeframe.

## **11 HOW TO CONTACT US OR MAKE A COMPLAINT**

- 11.1 If you would like to contact us, including to ask a question, update your personal information, request removal from our communications or make a complaint, we may be reached at the details below:

E: [info@praderwilli.org.au](mailto:info@praderwilli.org.au)

- 11.2 If you are unhappy with our response to your complaint, you have the right to make a complaint to the Office of the Australian Information Commissioner (OAIC). Details of how to contact the OAIC are provided on its website at [www.oaic.gov.au](http://www.oaic.gov.au).

## **12 CHANGES TO THIS POLICY**

- 12.1 We may modify or amend the provisions of this Privacy Policy from time to time. We will take reasonable steps to bring any such modifications or amendments to your attention.
- 12.2 You may obtain a copy of our current policy from our website or by contacting us at the contact details above.