



## **Prader Willi Syndrome Association Ireland Privacy Statement**

This privacy statement sets out how Prader Willi Syndrome Association Ireland applies data protection principles in accordance with its legal obligations, under Irish and European law, regarding the storage and transmission of personal data collected on this website under The Data Protection Acts 1988 & 2003 (“The Acts”) and Statutory Instrument Number 336 of 2011 European Communities (Electronic Communications Networks and Services) (Privacy and Electronic Communications) Regulations 2011 (“SI 336/2011”).

Prader Willi Syndrome Association Ireland is a registered company limited by guarantee without a share capital. Its company number (Companies Registration Office Ireland) is 364058 and its charity number (Office of the Revenue Commissioners—Charities Section, Ireland) is CHY15171.

By using the Prader Willi Syndrome Association Ireland website, you consent to the terms of this Privacy Statement. This website contains external links to other websites and Prader Willi Syndrome Association Ireland is not responsible for the privacy policies of these websites.

### **1. Types of information collected**

Prader Willi Syndrome Association Ireland may collect and process information and personal data about you when you become a member, subscribe to our mailing list, fill out a form, make a donation, register for an event, email us or report a problem with our site. The information we collect may include your name, e-mail address, mailing address, phone number, credit card information and information relating to your experience with Prader-Willi Syndrome. Prader Willi Syndrome Association Ireland will use the data you provide in line with the purpose for which you provided it and may also use this data in anonymised form for research purposes.

### **2. Reasons for collecting your information**

Prader Willi Syndrome Association Ireland may use information held about you in any of the following ways:

- To improve our website;
- To provide you with information, products or services that you request from us or which we feel may interest you if you have consented to be contacted for such purposes;
- To carry out our obligations arising from any contracts entered into between you and us - e.g. event registrations or membership;

- To allow you to participate in interactive features of our service (e.g., surveys), when you choose to do so;
- To notify you about changes to our service;
- To process donations.

### **3. Disclosure of information to third parties**

We do not disclose information about identifiable individuals, but we may use aggregate anonymised information about our users to advance our objectives. We do not sell, trade, or otherwise transfer your personally identifiable information to third parties. This does not include trusted third parties who assist us in operating our website, processing transactions, conducting our activities in furtherance of our charitable purposes, or servicing you, so long as those parties agree to keep this information confidential. We may also disclose your personal information to third parties if we are under a duty to disclose or share your personal data in order to comply with any legal obligation. Non-personally identifiable visitor information may be provided to other parties for marketing, advocacy, research or other uses. Our site may, from time to time, contain links to and from the websites of our partner networks and affiliates. If you follow a link to any of these websites, please note that Prader Willi Syndrome Association Ireland does not accept responsibility for the privacy policies of these websites.

### **4. Security procedures**

Prader Willi Syndrome Association Ireland takes its data protection responsibilities very seriously and will take all reasonable precautions to prevent the loss, misuse, alteration or unauthorised access to information you give us. Agents of Prader Willi Syndrome Association Ireland who have access to information you give us in the course of providing services to us will be required to keep that information confidential and only to use it for the specific purposes agreed with the Prader Willi Syndrome Association Ireland. Prader Willi Syndrome may transfer, store or process your data at a destination outside the European Economic Area (EEA). By submitting your data you consent to this transfer, storage and/or processing.

### **5. Accessing copies of information that Prader Willi Syndrome Association Ireland holds about you**

If you have given us information about yourself and would like copies of that information, to update that information, or to delete the information that we hold about you please contact us at Prader Willi Syndrome Association Ireland, Carmichael Centre, North Brunswick Street, Dublin 7, Ireland, or by email to [webmaster@pwsai.ie](mailto:webmaster@pwsai.ie). Please supply sufficient information to enable us to identify you and outline what information you are seeking us to supply to you, update or delete.

### **6. Cookies**

Like many other sites, <http://pwsai.ie> employs 'cookies', which are small text files that can help websites improve the service they offer to users. [Click here to learn more about cookies](#). Our use of cookies is managed by our hosting service, Wordpress.com, under their parent company, Automattic. [You can read the Automattic statement on Privacy and Cookie use here](#).

Information collected by cookies is used to provide necessary services to users, such as allowing them to make donations. Cookies are also used to help us understand more about how our website is used by our supporters – for example, how many people visit our website, how often they visit, what search terms are used to find our website, what other websites link to us, and what parts of the world traffic to our website comes from – and so how we can improve what we do to better suit our community's needs.

You are always free to decline our cookies. To do this, you can modify your web browser to refuse cookies, or to let you know when you receive new cookies. [Click here to learn how to manage the cookies stored on your computer.](#)

Please remember that if you decline cookies, or ask for notification each time a cookie is being sent, it may affect your experience of the pwsai.ie website (and of other websites). It may also prevent you from being able to make donations via websites. (You can always restore your browser's use of cookies by using the same settings as used for declining cookies.)

#### **7. Updates to procedures**

Prader Willi Syndrome Association Ireland will regularly review its data protection procedures and any updates to this statement will be posted on this page.

#### **8. Further Information**

Queries about this privacy statement may be directed to [webmaster@pwsai.ie](mailto:webmaster@pwsai.ie) or Prader Willi Syndrome Association Ireland, Carmichael Centre, North Brunswick Street, Dublin 7, Ireland.