



Williams Syndrome Ireland

WSI General Data Protection Policy (GDPR)

WSI Governance

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1. Introduction

This document outlines the WSI Policy for the management of member's Personal Data.

2. WSI GDPR Policies

The following policies will be applied WSI's handling of member's Personal Data.

2.1. Data Subjects

Members of WSI, their families, volunteers and specialists with an interest in WS can register with the organization in order to participate in the activities of WSI.

2.2. Types of Personal Data

WSI will hold three different categories of Personal Data concerning the individuals referred to in Section 2.1. In all cases the minimum level of Personal Data will be retained as necessary for that specific category. These data categories are as follows:

2.2.1. Basic Personal Data

This basic data contains information such as; the individual's name, address, phone numbers and email address. Additional data on individuals is also recorded such as; age, sex, year diagnosed, fish test information

2.2.2. Medical Information

This information will be collected for individuals affected by Williams Syndrome who attend any of our overnight camps. Medical Information is held prior to and during overnight events organized by WSI to assist the event organizers to provide appropriate care for the duration of the camp. This information includes particulars of medical conditions affecting the individual and the medicines involved in the treatment of these conditions. This Personal Data is immediately erased at the end of each event.

2.2.3. Photographs and Videos

All individuals who register with WSI will be requested to allow the collection, retention and publication of photographs and videos of themselves and their families participating in WSI events. Members may refuse to allow WSI to collect and publish this information and this refusal will not affect that member's rights and participation in WSI activities and events.

2.3. Purpose of Data

Each category of personal data is stored and processed by WSI as follows:

Category	Purpose	Legal Basis
Basic Personal Data Retention Period = For the duration of their membership	To manage and administer WSI membership. To communicate regularly with members. For example the distribution of newsletters and other communications. To include members in decision making at the AGM and to invite members to organised events.	Processing is necessary because it is in the vital interest of the WSI members that WSI communicates with its members and for WSI members and their families to participate in WSI events, on an ongoing basis.



	To manage and investigate complaints	
Category	Purpose	Legal Basis
Medical Information Retention Period = During the preparation period and the duration of a WSI event.	To understand the specific medical condition of all WS individuals who attend any of WSI's overnight events To manage any of the specific needs those individuals may have while attending any of WSI's overnight events. To supervise all medicines that individuals may be using while attending any of WSI's overnight events	This data is held because it is the vital interest of the WS individuals who attend any of WSI's events to ensure their health and safety. In all cases parental or guardian consent will be obtained for personal data concerning children under 16 years and vulnerable WS adults
Category	Purpose	Legal Basis
Photographic and Video Recordings. Retention Period: For an indefinite period.	To promote WSI services to individuals affected by Williams Syndrome and to the general public in Ireland. To communicate news of WSI events to the WSI membership and the general public. To assist fundraising efforts using leaflets or online line promotions.	Processing is necessary for WSI's legitimate interest in promoting the organisation in the interest of people affected by WS in Ireland. In all cases parental or guardian consent will be obtained for the processing and possible publication of these images.

2.4. WSI Data Controller

The WSI Data Controller implements the appropriate technical and organizational measures to ensure that Personal Data is processed in accordance with GDPR regulations. The Data Controller must take all reasonable care to ensure that the procedures are adhered to at all times and must be able to demonstrate that processing is performed in accordance with these regulations and that the measures are reviewed and updated as appropriate. The WSI Committee will appoint the Secretary of the Committee to act as the Data Controller.

2.5. WSI Members Rights

All members of the Association will be able to request WSI to provide a copy of their specific personal information stored by WSI.

When personal data is being collected from members WSI will inform members about:

- personal data that is being collected and the categories of personal data
- the purpose to which this data is being collected
- how it is processed
- the right to request access to their personal data in the future
- the right to correct or delete this data and
- the right to register a complaint with the relevant authority.



In all cases explicit consent is sought from the members for the retention of Personal Data for each of the data types outlined in Section 2.2.

2.6. Sharing of Personal Data

WSI will not disclose personal data to third party processors in any case whatsoever. In certain cases third parties may wish to contact our members for a variety of reasons. In cases where the WSI Committee deems that this contact may be of benefit to our members the Secretary of WSI will notify our members of the third party request. In these cases it will be a matter for individual members to decide if they wish to make contact with the third party. For example a Research Institution may wish to make contact with WS families in Ireland to carry out research into a specific aspect of Williams Syndrome.

2.7. Processing of Personal Data

2.7.1.1. General

The WSI Secretary will provide access to personal data to specific members of the WSI Committee for the execution of specific activities such as;

1. Organizing Events
2. Distribution of Newsletters
3. Distribution of Other Communications to members
4. Statistical Analysis of Williams Syndrome
5. Access to Photographs and Videos for publication in the WSI Newsletter, Website and other social media sites controlled by WSAI.

Those members of the WSI Committee who are granted access to personal data as part of their work on behalf of the organization will not store this information on personal computers, smartphones or other devices.

2.7.2. Data Storage

The Secretary will maintain all personal data in secure location which is password controlled. This password will be changed annually or as deemed necessary during the year. The data will be stored in password controlled files which will also be subject regular changes as stipulated above. In addition the Data Controller will exercise all reasonable care to ensure that personal data is secured at all times

2.7.3. Data Maintenance

The Secretary will be responsible to ensure that personal data accuracy is maintained over time such as, for example, when changes of address or email address occur.

The Secretary will be responsible for the deletion of personal data in cases such as:

- Deletion of personal data that is out of date
- Death of a member or termination of membership
- Member requests that all personal data should be removed.

3. GDPR Procedures

WSI will implement the following internal procedures:

3.1. New Membership Procedure

All new members of WSI will complete a membership registration form. This form will record basic personal data that is required for WSI for the vital and legitimate purposes as outlined in Section 2.3. New members will be provided with one page leaflet explaining what personal data is recorded and the reasons



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for the processing of this data. The leaflet will also explain their rights over the personal data that WSI uses and who to contact in WSI if they have any queries or complaints.

New members will be asked to provide explicit consent to WSI storing and processing of photographs and videos which contain images of themselves or their families. New members have the right to refuse to grant permission to WSI to store and processes photographic and videos images if they wish and this position will not affect their membership of WSI in any respect.

See Membership Form

3.2. Medical Data Request Procedure

All members who apply to attend our regular camp events are required to complete a Medical Information Form which outlines any medical conditions that affect the individuals attending the event. This information is collected for the vital and legitimate reasons outlined in Section 2.3. This form also requires information concerning the details of any medication that is prescribed for the individual as well as any allergies that apply in each individual case. Members completing this form are informed why this sensitive information is being sought and must sign the form to certify that the information provided is correct.

3.3. Request to Correct, Amend Personal Data

All members of WSI have the right to request disclosure of the personal data that is currently held by WSI. Members may request this information by writing to WSI and requesting disclosure. WSI's public policy statement on GDPR provides details of this process. These requests will be handled in a reasonable period.

3.4. Request to Delete Personal Data

All members of WSI have the right to request the deletion of any personal data that is held by WSI.

3.5. Personal Data Breach Procedure

The Secretary will log any breaches which are detected. This log will include such details as the parties involved, the purpose of the processing, the categories of personal data and the recipients involved. Members will be notified of data breaches without undue delay' where the Secretary is aware of an incident which exposes the data of the Members to risk.

4. WSI GDPR Data Protection Notice

The WSI GDPR Data Protection Notice will be published on the WSI website and members will informed of the notice. This document covers the following aspects:

- Member's rights over their Personal Data stored by WSI.
- What Personal Data WSI stores and uses
- How WSI collects this information
- How long WSI keeps the Personal Data

See Overleaf:



Williams Syndrome Ireland

WSI Data Protection Notice

Introduction

This document outlines how WSI uses information that you provide to us and informs you about your data protection rights as defined in EU regulations GDPR.

What Personal Data is Processed by WSI?

WSI uses member's data for the provision of services to members and related matters as defined below:

Category	Purpose	Legal Basis
<p><i>Basic Personal Data</i></p> <p><i>Retention Period = For a period of 5 calendar years</i></p>	<p>To manage and administer WSI membership.</p> <p>To communicate regularly with members. For example the distribution of newsletters and other communications.</p> <p>To include members in decision making at the AGM and to invite members to organised events.</p> <p>To manage and investigate complaints</p>	<p><i>Processing is necessary because it is in the vital interest of the WSI members that WSI actively involves its members and communicates with its members on an ongoing basis.</i></p> <p><i>Members and their families often drop out of active membership due to the ongoing pressures that come with being a family with additional needs. It is very important not to penalise them for this and to keep them aware of activity that may be of interest to them, even on a one off basis. Older guardians may not be familiar with using Social Media or WhatsApp Messaging to access event information.</i></p>
Category	Purpose	Legal Basis
<p><i>Medical Information</i></p> <p><i>Retention Period = During the preparation period and the duration of a WSI event.</i></p>	<p><i>To understand the specific medical condition of all WS individuals who attend any of WSI's overnight events</i></p> <p><i>To manage any of the specific needs those individuals may have while attending any of WSI's overnight events.</i></p> <p><i>To supervise all medicines that</i></p>	<p><i>This data is held because it is the vital interest of the WS individuals who attend any of WSI's events to ensure their health and safety.</i></p> <p><i>In all cases parental or guardian consent will be obtained for personal data concerning children under 16 years and vulnerable WS</i></p>



	<i>individuals may be using while attending any of WSI's overnight events</i>	<i>adults</i>
Category	Purpose	Legal Basis
<i>Photographic and Video Recordings.</i> <i>Retention Period: For an indefinite period.</i>	<i>To promote WSI services to individuals affected by Williams Syndrome and to the general public in Ireland</i> <i>To communicate news of WSI events to the WSI membership and the general public</i> <i>To assist fundraising efforts using leaflets or online line promotions</i>	<i>Processing is necessary for WSI's legitimate interest in promoting the organisation in the interest of people affected by WS in Ireland.</i> <i>In all cases parental or guardian consent will be obtained for the processing and possible publication of these images.</i>

Will WSI Share Members Personal Information?

The WSI Data Controller will provide access to personal data to specific members of the WSI Committee for the execution of specific activities such as;

1. Organizing Events
2. Distribution of Newsletters
3. Distribution of Other Communications to members
4. Statistical Analysis of Williams Syndrome in Ireland
5. Access to Photographs and Videos for publication in the WSI Newsletter, Website and other social media sites controlled by WSI.

Those members of the WSI Committee who are granted access to personal data as part of their work on behalf of the organization will not store this information on personal computers, smartphones or other devices.

WSI will not disclose personal data to third party processors in any case whatsoever. In certain cases third parties may wish to contact our members for a variety of reasons. In cases where the WSI Committee deems that this contact may be of benefit to our members the Data Controller will notify our members of the third party request. In these cases it will be a matter for individual members to decide if they wish to make contact with the third party. For example a Research Institution may wish to make contact with WS families to carry out research into a specific aspect of Williams Syndrome.

What is WSI's Personal Data Security and Retention Policy?

WSI maintains appropriate and organisational measures to protect members data against unlawful or accidental destruction, loss, alternation, unauthorised disclosure of or access to Personal Data. We ensure the level of security appropriate to the risks that are presented. These measures are evaluated regularly by the WSI Committee to ensure the ongoing integrity and confidentiality of Personal Data.

WSI retains your information for as long as necessary to administer your membership of WSI and participation in WSI events.

What are WSI Members Rights over their Data?

All WSI members have a right to:

- Request WSI to provide a copy their specific personal information stored by WSI.



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- *Have inaccurate information about them corrected*
- *Have their personal data erased.*
- *Withdraw their consent for the processing of personal data*
- *Restrict processing of their personal data*

Members may request any of the above actions by emailing the WSI Secretary at info@williamssyndromeireland.ie

How Can WSI Members Raise a Complaint?

All Data Protection queries/complaints should be sent to the WSI Secretary at our mail address as provided on our website or at info@williamssyndrome.ie.

References

[1] General Data Protection Regulation (GDPR) <https://gdpr-info.eu/art-4-gdpr/>

[2] AA Ireland Data Protection Notice*

[3] Eir Superannuation Scheme Privacy Notice

* Examples of other GDPR Privacy Notices

