



WSF PRIVACY NOTICE : MEMBERS

Your personal data – what is it?

“Personal data” is any information about a living individual which allows them to be identified from that data (for example a name, photographs, videos, email address, or address). Identification can be directly using the data itself or by combining it with other information which helps to identify a living individual (e.g. WSF membership number). The processing of personal data is governed by legislation relating to personal data which applies in the United Kingdom including the General Data Protection Regulation (the “GDPR”) and other legislation relating to personal data and rights such as the Human Rights Act.

Who are we?

This Privacy Notice is provided to you by the Williams Syndrome Foundation which is the data controller for your personal data (whether provided to attain membership or any subsequent written communication with the WSF).

The WSF will process some or all of the following personal data where necessary to perform its tasks:

- (All) Names, titles, and aliases;
- (All) Contact details such as telephone numbers, addresses, and email addresses;
- (For WS members) We may process information such as gender, age, education, family composition, and dependants;
- (All) Subscription payment history and methods i.e. bank account details;
- (For WS members) the personal data we process may include sensitive or other special categories of personal data such as mental and physical health, genetic data (FISH test results);
- (All) Relationship data (where there are other family members of the WSF);
- Express consent has been provided for all photographs stored / used by the WSF.

How we use sensitive personal data

We may process sensitive personal data including, as appropriate:

- information about you / your child’s condition in order to confirm the WS diagnosis once confirmation is processed the genetic report documentation is securely deleted.
- personal health information is often provided by members requesting support / advice / guidance from the WSF or our PAP, or third-party professionals who have made themselves available to the WSF for advice. Where the WSF facilitates support / advice / guidance it will not share any personal data and all records of the personal health information will be deleted upon completion of the request.

Do we need your consent to process your sensitive personal data?

In limited circumstances, we may approach you for your written consent to allow us to process certain sensitive personal data. If we do so, we will provide you with full details of the personal data that we would like and the reason we need it, so that you can carefully consider whether you wish to consent.



The WSF will comply with data protection law. This says that the personal data we hold about you must be:

- Used lawfully, fairly and in a transparent way.
- Collected only for valid purposes that we have clearly explained to you and not used in any way that is incompatible with those purposes.
- Relevant to the purposes we have told you about and limited only to those purposes.
- Accurate and kept up to date.
- Kept only as long as necessary for the purposes we have told you about.
- Kept and destroyed securely including ensuring that appropriate technical and security measures are in place to protect personal data from loss, misuse, unauthorised access and disclosure.

We use your personal data for some or all of the following purposes:

- To manage your membership;
- To contact you by post, email, telephone or using social media (e.g., Facebook, Twitter, [WhatsApp](#));
- To maintain our own accounts and records;
- To seek your views, opinions or comments;
- To notify you of changes to our services, events and staff;
- To send you communications which you have requested and that may be of interest to you. These may include information about events, WS resources, research information;
- To process relevant financial transactions including grants, fundraising, gift-aid and legacies.

What is the legal basis for processing your personal data?

The WSF is a small registered charity initiated to help families affected by Williams Syndrome. By applying for membership, you have given us consent to administer your membership. Consent is the legal basis for the WSF to process your personal data. You have received a consent form detailing additional specific consents which you may opt-in for in order for you to receive the full benefits of membership with the WSF and relating to different aspects of the charity's operations. We will always take into account your interests and rights. This Privacy Notice sets out your rights and the WSFs obligations to you.

Sometimes the use of your personal data requires your additional consent and we will contact you accordingly.

Sharing your personal data

This section provides information about the third parties with whom the WSF may share your personal data. These third parties have an obligation to put in place appropriate security measures and will be responsible to you directly for the manner in which they process and protect your personal data. It is likely that we will need to share your data with some, or all, of the following (but only where necessary):

- The data controllers listed above under the heading "Other data controllers the WSF works with";
- Our agents, suppliers and contractors. For example, we may ask a commercial provider to publish or distribute magazines on our behalf, or to maintain our database software;
- On occasion, researchers, if we have received consent from you.



- Upon your request, when you have asked for support in a medical / educational / social care issue and we need to share your personal details to obtain the help you need. This will only occur with your express consent.

How long do we keep your personal data?

We may keep some other records for an extended period of time. For example, it is currently best practice to keep financial records for a minimum period of 8 years to support HMRC audits or provide tax information. We will keep all other personal data for as long as you are a member of the WSF. If you tell us you would like to leave, your data will be removed within 30 days. If your membership lapses, we will keep your personal data for 4 months to allow your membership to be renewed without the requirement of completing a full membership pack.

Your rights and your personal data

You have the following rights with respect to your personal data:

When exercising any of the rights listed below, in order to process your request, we may need to verify your identity for your security. In such cases we will need you to respond with proof of your identity before you can exercise these rights.

- ***The right to access personal data we hold on you***
At any point you can contact us to request the personal data we hold on you as well as why we have that personal data, who has access to the personal data and where we obtained the personal data from. Once we have received your request we will respond within one month.
- ***The right to correct and update the personal data we hold on you***
If the data we hold on you is out of date, incomplete or incorrect, you can inform us and your data will be updated.
- ***The right to have your personal data erased***
If you feel that we should no longer be using your personal data or that we are unlawfully using your personal data, you can request that we erase the personal data we hold.
When we receive your request, we will confirm whether the personal data has been deleted within 30 days or the reason why it cannot be deleted (for example because we need it for to comply with a legal obligation).
- ***The right to object to processing of your personal data or to restrict it to certain purposes only***
You have the right to request that we stop processing your personal data or ask us to restrict processing. Upon receiving the request, we will contact you and let you know if we are able to comply or if we have a legal obligation to continue to process your data.
- ***The right to data portability***
You have the right to request that we transfer some of your data to another controller. We will comply with your request, where it is feasible to do so, within one month of receiving your request.
- ***The right to withdraw your consent to the processing at any time for any processing of data to which consent was obtained***
You can withdraw your consent easily by email or by post (see Contact Details below).
- ***The right to lodge a complaint with the Information Commissioner's Office.***
You can contact the Information Commissioners Office on 0303 123 1113 or via email <https://ico.org.uk/global/contact-us/email/> or at the Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire SK9 5AF.



Transfer of Data Abroad

Any personal data transferred to countries or territories outside the European Economic Area (“EEA”) will only be placed on systems complying with measures giving equivalent protection of personal rights either through international agreements or contracts approved by the European Union. [Our website is also accessible from overseas so on occasion some personal data (for example consented photographs) may be accessed from overseas].

Further processing

If we wish to use your personal data for a new purpose, not covered by this Privacy Notice, then we will provide you with a new notice explaining this new use prior to commencing the processing and setting out the relevant purposes and processing conditions. Where and whenever necessary, we will seek your prior consent to the new processing.

Changes to this notice

We keep this Privacy Notice under regular review and we will place any updates on this web page [\[add URL\]](#). This Notice was last updated in May 2018.

Contact Details

Please contact us if you have any questions about this Privacy Notice or the personal data we hold about you or to exercise all relevant rights, queries or complaints at:

Email: ceo@williams-syndrome.org.uk

