



WSF PRIVACY NOTICE : MEMBERS

Adopted May 2018. Reviewed January 2020 & April 2021. Next Review April 2023.

This privacy notice explains how and why we use your personal information. This means you stay informed and allows us to use your data fairly and lawfully.

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?

The Williams Syndrome Foundation is a charity registered with the Charity Commission in England and Wales with Charity No. 281014, registered with the OSCR with charity No. SC049897 and a Company Limited by Guarantee (Company No. 01523794).

In this policy, ‘we’, ‘us’, ‘our’ or ‘the WSF’ refers to the Williams Syndrome Foundation (also known as the WSF); ‘you’ or ‘your’ means any person(s) from or about whom we collect personal information/data. Personal information/data is information that can be used to identify a living individual, for example name, address, telephone number or email address.

“PAP” refers to the members of our Professional Advisory Panel. An up-to-date list of our PAP members and their specialisms can be found on our website www.williams-syndrome.org.uk.

“WS” refers to Williams Syndrome.

We take your privacy seriously and adhere to the Principles of the General Data Protection Regulation (GDPR) and relevant European Union Data Protection Directives such as the Privacy and Electronic Communication Regulations (PECR). For help and guidance about any aspect of the law relating to privacy and data protection, visit the Information Commissioner’s website at www.ico.gov.uk

What information do we collect?

We collect various different types of personal information:

1. When you join us as members of the WSF:

Families

- (All) Names, titles, and aliases.
- (All) Contact details such as telephone numbers, addresses, and email addresses.

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- (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 members with WS) 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).
- Photographs provided express consent has been given for all photographs stored / used by the WSF.

This data is collected in order that we can register you as a member family and provide services including sending a welcome pack, providing practical information, sending of magazines (paper and electronic) and contact in case of a query.

This information is only collected and stored with your consent, gained when you first provide the data or completed the 2018 consent form. Your choices relating to your consent for us to store and use your data are stored on our electronic database.

The information we collect about your family member with WS includes their full name, gender and date of birth. It also includes **Health Information** such as additional diagnoses and medical treatment, other personal information about their family, medical, educational and social care, health, development and behaviour.

This information increases the understanding of WS and helps us to direct research and provide resources around the needs of our members with WS. We only collect this information from you if you choose to provide it to us – (consent is our lawful basis for processing these data). You can choose to terminate your membership or ask us to delete any data at any time by emailing enquiries@williams-syndrome.org or calling 0208 567 1374.

Under the Data Protection Act 2018, (Schedule 1, Part 2, Paragraph 16) concerning ‘Support for individuals with a particular disability or medical condition’, patient support groups such as the WSF can continue processing data in special categories such as health information and genetic/biometric data, outside of the usual consent requirements, when in the public interest. This means that once we have your consent to process the data you provided us with for the member with WS, we will continue to process the data until you tell us otherwise. For further information on the Data Protection Bill, please see www.legislation.gov.uk or www.ico.org.uk

Professionals

We collect information from clinicians and other professionals such as social workers and researchers in order to register you as professional members, because you have contacted us, or we have contacted you for the purpose of providing you with information, networking or other professional collaboration (e.g., with professionals who are not the WSF members). Information/data collected includes name, address, telephone, email address, job title and place of work. You can choose to terminate your membership and/or have your data deleted at any time by emailing enquiries@williams-syndrome.org or calling 0208 567 1374.

2. When you make a financial transaction, such as a donation, paying in funds raised or buying merchandise:

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We collect information about our sources of income in order to produce accurate financial statements and to comply with the law relating to the retention of financial data (for example the Companies Act 2006 and Gift Aid).

When you make a donation via the WSF website or Facebook page we collect certain information to enable us to process the transaction. This information includes your name, address, email address, telephone number, bank and bank account details, reason for donation, items ordered and/or donations made. Some of this information is shared with our secure payment partners PayPal to affect the transaction. Your credit/debit card details are recorded on PayPal's secure site and we recommend that you consult PayPal's data protection policy on their website.

If using one of our other online fundraising and donations partners such as JustGiving or Virgin Money Giving, you will be asked to provide personal information and will be asked whether you consent to us making contact with you (in which case we will use that data in accordance with this policy). Please also refer to the privacy policies of the fundraising platforms which are on their websites.

If you make a payment or a donation by any other method, e.g., post, charity cheque, direct debit/standing order, we retain a paper and electronic record of your financial transaction. This is shared with our chosen auditors and if we are legally required to disclose it, to the relevant authorities. By voluntarily submitting your personal information to us, you are consenting to the use of your personal information for effecting a payment or donation. If you submit a signed Gift Aid Declaration to us, we retain it for HM Revenue & Customs (HMRC) purposes and will share with HMRC to comply with our legal requirements.

3. When you fundraise or volunteer for the WSF:

We collect and store your contact details, including your name, address, telephone number and email address, plus any other information you provide voluntarily, such as your reason for fundraising/volunteering. We also store details of your online fundraising page/s and the event/s you are taking part in or the fundraising/volunteering/awareness-raising you are undertaking. Our bases for collecting and storing these data are that this meets our legitimate interests, to raise the funds we need to ensure the sustainability of our key services and to meet our legal requirements, for example to maintain accurate financial records, to enable us to make accurate Gift Aid claims and to report where necessary to the Charity Commission.

When contacting us about fundraising, we will store emails you send us and will record in written/note form details of telephone conversations, in order that we can help your fundraising. We will also direct you to our chosen online fundraising partners such as Virgin Money Giving or JustGiving, who will collect your personal information when you set up an online fundraising page to collect sponsorship.

We collect this information to enable us to send administrative messages, to thank and support you, send you fundraising materials and contact you in case of query. This information also enables us to meet our legal requirements to accurately produce accounts/financial statements/gift aid.

4. When you browse the WSF website:

We collect anonymous, non-personal information about the users of our website. Whenever you access our website or download information, the web server automatically records the following non-personal information: the date and time you accessed our website, how long you were on the site, your Internet

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domain name and the internet browser you use. This information helps us to improve our website service.

We make use of cookies. A cookie is a series of characters that is generated by our website and stored on your computer when you visit our site. The cookie does not collect or contain personal information about you but allows us to track how often you return to our site and records our Member's Forum login names. The cookie does not track your movements on other websites. You do not have to accept our cookie in order to be able to use our website.

Currently we are using Google Analytics to analyse the audience of the website and improve our content. No personal information is collected from Google Analytics. For further information on the privacy policy concerning Google Analytics, please visit:

<https://policies.google.com/privacy/update?hl=en>

5. When you are employed by the WSF or become a trustee:

We hold personal information about our current and past employees and trustees, including name, address, telephone number, email address, date of birth, employment history, bank account information, tax and national insurance and pensions, details of other trusteeships, directorships and declarations of interest.

This information enables us to meet our legal requirements in relation to employment and also charity governance and take decisions on employee and trustee recruitment and employment, future strategy and to enable us to further our charitable aims.

Legal Basis for Processing Your Data

Each time we process your data, we must have a 'Legal Basis' for doing so.

GDPR (EU Regulation 2016/679) states that in order to collect, store or process different categories of data, organisations who are 'data controllers' need to meet one or more of a number of 'legal bases for processing' data. This includes Specific, Informed Consent (i.e., where you have given your consent, such as when you join us as a member), Meeting our Legitimate Interests as a charity (except where this would override your individual rights or interests), Meeting our Legal Requirements (e.g., to maintain accurate financial statements under the Companies Act, 2006) and Carrying out the requirements of a Contract.

Depending upon the level of consent provided, your data will be stored and processed allowing us to:

- Effectively administrate your membership(s).
- Respond to requests for assistance, registration for events and requests for resources and merchandise from members.
- Administrate donations, fundraising, legacies etc.
- Direct research, provide statistical analysis and direct future resource provision.
- Communicate with you about your membership, events, research, fundraising and other WSF activities that we think may be of interest to you.
- Send you WSF publications including the WSF Magazine.

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- Use your photographic images in our publications and/or website/social media.

We have contacted all members who joined prior to the 2018 GDPR to gain express / explicit consent for the use of their data as per the above. Some members have not completed a consent form but have continued to opt in as members by providing their annual subscription fee. These members will only receive information from us directly to do with the financial administration of their membership until a consent form has been completed and returned.

Data Security and Access

Keeping your data safe

We have implemented technology and policies to protect your privacy from unauthorised access and improper use. These are constantly kept under review and will be updated as necessary to comply with legal requirements. Health information we collect, and store is classified as sensitive under the GDPR and therefore has a higher level of security.

Data provided as part of your WSF membership is stored securely on a server in the United Kingdom. Regular back-ups of data are taken at secure facilities, arranged by our IT Officer and also located in the United Kingdom. Any paper records are stored securely in the United Kingdom.

We use providers of bulk email, survey and event registration services and store limited data (email addresses, not health or other sensitive data) on their secure servers located in the USA to enable us to communicate with you cost effectively. These companies incorporate the Standard Contractual Clauses into their Data Processing Addendum and continue to protect EU personal data in accordance with Privacy Shield Principles.

While we cannot absolutely guarantee that loss, misuse or alteration of data will not occur, we use all reasonable efforts to prevent this.

Who can access your data?

Only our members of staff can access your information and can share basic contact information with research partners who have received University Ethics Approval, PAP approval and Trustee Board approval for their research project. Basic data will only be shared for those members who meet the project criteria and who have provided explicit consent to participate in research projects.

We may use third party companies to provide services on our behalf. This could include services such as bulk email services, in order that we can communicate with members and supporters in the most cost-effective way. In these cases, email addresses will be stored on the third parties' servers and we will ensure that we have undertaken appropriate due diligence to ensure data security, confidentiality and that the companies are compliant with GDPR.

We may disclose personal information if required to do so by law or if we have reasonable grounds to believe that such action is necessary to protect and defend the rights, property or personal safety of the WSF, our members, any child or vulnerable adult or our staff.

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Except as indicated above we will not use or transfer this data to any third parties without your express permission.

How long do we keep your information?

We keep your information for only as long as is necessary or until you ask us to erase it. As WS is a lifelong condition, we will store and process the data (including the health information) you provided when joining the WSF, throughout the duration of your membership. We will contact WSF members periodically to ask you to update us about the data we hold in our database about your family member with WS. We will erase any data on request.

Where you have provided it, we will seek to refresh your consent to contact you about topics outside of your WSF membership from time to time. If you do not give consent, we will assume you do not wish to be contacted and will record this electronically and cease communication with you about these topics outside your membership. This will not affect your WSF membership and providing you with support and information services if you are also members.

If you apply for a position with the WSF and do not join the WSF, we will retain the data you provide, solely for recruitment and will not use it for marketing purposes. It is retained in order that we can answer any queries relating to the recruitment process.

Case Studies, Magazine articles, Social Media Content

Some people share social media posts with us to be published on our social media channels, articles for magazines and case studies to be used online or to support funding applications. Whilst we only use these with consent, once they are published, it is impossible for us to recall them given the impossibility of tracking anonymous users downloading online material and the logistics of recalling printed materials once disseminated.

Your Rights

Under the GDPR, individuals have a number of rights concerning their personal information and we will adhere to these:

You have the right to be **informed** about how and why we collect, store and use your information. We will do this when we collect your information, e.g., when you join us as members or when you sign up to receive emails through our website. This Privacy Policy is available on the WSF website or as a hard copy by request.

You have the right to **access** the personal information we hold about you. You can request this verbally or in writing and when we receive such a request, we will endeavour to respond quickly but within a maximum of one month. This is called a Subject Access Request (SAR) and there is no charge. Following this you have a right to request that any data held about you that you feel is inaccurate is **rectified** or completed if incomplete. You also have the '**right to be forgotten**', i.e., for all data we hold about you to be erased and also to require us to restrict or 'suppress' how we use your data (you might for example be happy for us to store it but not process it for certain purposes). Again, we will respond as quickly as we can to such requests but within a maximum of one month.

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To make a request, for example to access the information we hold about you, email enquiries@williams-syndrome.org.uk , call 0208 567 1374 or you can write to us at the address at the end of this policy document.

For full information about your rights under GDPR, please visit the Information Commissioner's website at <https://ico.org.uk/for-organisations/guide-to-the-general-data-protection-regulation-gdpr/individual-rights/>

Should you feel unhappy about the way/s in which we have collected, stored or processed your data and wish to make a complaint to a supervisory authority, please contact the office of the Information Commissioner (www.ico.org.uk)

Do we collect information about children and vulnerable adults?

Yes, we collect personal and medical information provided to us by members about children or vulnerable adults in their care. We place great importance on the security and accuracy of this information and only store this information in our secure database. We always obtain the consent of the guardian or responsible adult before collecting information about children and/or vulnerable adults.

Links to other websites

The WSF's website (www.williams-syndrome.org.uk) may contain links to selected websites which we feel may be of interest. Please note that once you use one of these links to leave our website, we do not have any control over that other website. Please exercise caution and refer to their privacy policy and/or terms & conditions of use before providing any personal information as we cannot be held responsible for the protection or privacy of any information you provide to a third party.

Changes to this Policy

We keep this Privacy Notice under regular review. All updates will be made available on our website www.williams-syndrome.org.uk/privacy-policy

Any questions?

If you have any questions or concerns about how we protect your personal information, please contact us.

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