



Wolfram Syndrome UK Privacy Policy

Registered Charity in England and Wales (1152445)

Your privacy is important to Wolfram Syndrome UK (WSUK). This privacy statement provides information about the personal information we collect, and the ways that WSUK uses that personal information. This privacy statement aims to cover all of our activities.

WSUK may change this policy at any time in line with legislative changes or changes to the policy of the organisation. Please check our website from time to time to ensure you are aware of any changes.

WSUK adheres to the Principles of the Data Protection Act (DPA) 1998 (UK) and relevant European Union Data Protection Directives, including General Data Protection Regulation (GDPR) from 25th May 2018.

In this policy document:

'we' or 'WSUK' means Wolfram Syndrome UK

'you' means any person(s) about whom we collect non-personal and/or personal information

What information do we collect?

We collect several different types of information. In general, we collect and store information about those that are affected by Wolfram Syndrome. We collect this data to ensure that we can communicate with all those affected and to keep you up to date with the work we as a charity and the researchers are doing. We collect the contact data of our fundraisers and supporters to track the success of any event, to measure our impact as a charity and to deliver our financial transparency to our supporters and the Charity Commission. We work to secure explicit consent to contact you about unrelated events, and to share your information with any additional party. Permission will always be asked to share a contact email when trying to connect WS affected families or individuals with each other to provide support, when they are in the same locality/area.

1. Your browsing

The YouTube videos on our website make use of cookies. A cookie is a series of characters that is generated by our website and stored on your computer. YouTube may collect personal data through cookies used on their website. To view their privacy policy [click here](#).

2. Your contact with us

If you contact us by telephone, email or by letter, we retain a copy of your contact to help us respond to enquiries. We only collect this information if you provide it to us and do not hold on to it for longer than necessary.

WSUK's email accounts are provided by JMV Solutions, their privacy policy can be seen [here](#), and use Outlook where all email messages and addresses are stored. All email messages are deleted, including from the server, when they no longer require any action.

3. WSUK mailing lists

We hold contact details for the WSUK quarterly newsletter, a supporter's mailing list and community mailing list. WSUK's mailing lists are administered through MailChimp, who store the name and email address of all individuals on the mailing list and track information on engagement with the messages sent. MailChimp's privacy policy can be viewed [here](#). WSUK also hold a copy of all mailing lists on our server.

Only individuals who specifically opt in to receive our newsletter or updates through our online sign up form or WSUK paper/email consent form, will receive messages and have their details stored. You may choose to stop receiving all or any particular communication from us at any time through a link at the end of all communications sent via MailChimp or by emailing the WSUK office, admin@wolframsyndrome.co.uk, by putting in the subject line NO and what you would like to stop receiving. Please ensure you keep us to date of your wishes.

4. Your attendance at WSUK conference

We collect information about delegates at the WSUK Conference. This information is collected directly by WSUK. Data collected may be name, contact details (address, email, telephone number), dietary and accessibility requirements.

5. Fundraising

We collect the personal information of people who take up charity places for WSUK fundraising charity events, or who are actively fundraising for WSUK. This is collected to allow effective registration, to support you in your fundraising efforts and to monitor success. We will not contact you about other things without your explicit permission.

WSUK uses multiple online giving platforms to administer all online donations. These platforms collect and hold all information on fundraisers and donors to fulfil this role. WSUK has access to this fundraising information which is used and stored for accounting purposes where it is supplied by the fundraiser or donor. We will not contact a fundraiser or donor without their explicit permission.

6. Photographs and Video recordings

With your consent we will store your contact details, any photos, audio and video recordings. No individuals will be identified without explicit consent. All photos and video recordings are the property of WSUK, which means unless a person has specified 'no' they can be used on the WSUK website, newsletter, social media pages, any WSUK publications and/or advertising

banners. A consent form must always be filled in and signed where photos, audio or filming will take place.

7. Social Media

WSUK is active on Facebook, X, Linked in and Instagram. WSUK does not collect data from these social media sources although we will endeavour to answer messages directed through these platforms. All messages sent to WSUK this way are governed by the privacy policies of the specific platform.

8. Our staff and volunteers

We hold personal information about our staff, Trustees and volunteers.

How long do we keep your information?

We keep your information for as long as it is necessary to deliver any associated projects effectively for you, and track our charity impact. In some cases, our funding agreements will require that we retain documentation relating to project finances, attendance, and delivery for a period of 6 years. Your data will be retained securely in such situations to meet the obligations of our funders and good financial practice.

You may ask us to destroy any personal information that we hold on you so that you receive no further information or contact from us. In this circumstance, if you are currently registered for an event then we will contact you to confirm your wish to continue involvement, and if so remove your data subsequent to completion.

You may ask to have a copy of the information we hold about you, and to amend, update, add to or delete it at any time. Should you wish to restrict the use of your personal data please contact us at admin@wolframsyndrome.co.uk or in writing at the address supplied on the WSUK website.

Who has access to your information?

Our members of staff have access to your personal information. If you provide information through a specific event, that information will be shared with any co-organisers. Finally, some information may be shared with event venues to ensure that any personal needs are met on the day.

As detailed above, we may use third parties to provide services on our behalf, including MailChimp, GofundMe, Give as you Live and PayPal. Those parties only collect and hold the information they need to provide the service, though data is held in accordance with their own privacy policies.

We may disclose personal information if we receive a complaint about any content that you have posted or transmitted to or from one of our sites, if required to do so by law or if we believe such action is necessary to protect and defend the rights, property or personal safety of WSUK, any child or vulnerable adult, our staff, any visitor or third party. Except as indicated above we will not use or transfer this data to any third parties without your explicit consent permission.

Publications

We publish information leaflets, reports and newsletters for our community, supporters and those that interact with WSUK. From time to time these may contain personal information about members of the WS community, our supporters or collaborators. We never publish any information or any explicitly identified image without clear consent from those concerned. If you have sent a photo, video or audio to us we will take that as your consent for us to use/publish this. We might use quotes from feedback forms but will always ask for your consent if anything in the quote is identifiable.

Can you access the information we hold about you?

Yes, you have the right to access information stored about you by WSUK. You need to write to us at the address below or email us at admin@wolframsyndrome.co.uk. We will then provide you with the following information:

- ❖ What personal data is stored
- ❖ The purposes for which the data is being processed
- ❖ Who has access to your data

What security measures do we have?

All data files are protected by an encrypted password in our cloud storage. Any records of passwords are kept securely locked away in a safe when not required. The WSUK laptop requires a password unlock to be able to access files on it. All this is only accessed by one person. While we cannot ensure or guarantee that loss, misuse or alteration of data will not occur, we shall endeavour to prevent this.

Links to other websites

WSUK's website (www.wolframsyndrome.co.uk) contains links to other 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 and conditions of use as we cannot be held responsible for the protection or privacy of any information you provide to a third party.

Any questions about privacy?

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

E-MAIL

admin@wolframsyndrome.co.uk

TELEPHONE

01903 211358

POST

9 Church Way
Worthing
West Sussex
BN13 1HD

Wolfram Syndrome UK are committed to protecting your personal information, keeping it safe and being clear about what we do with it.
We will never under any circumstances sell your information.