FOWLER'S SYNDROME UK

Privacy Policy

Definitions

- References to "**FSUK**", "**us**", "**we**" or "**our**" refers to Fowler's Syndrome UK (registered charity number 1196903);
- References to "**you**", "**your**", or "**user**" refers to the person providing personal data to us which may be through using our Website or providing personal data to us via phone, email, letter or other correspondence, or similar means used by us to collect your personal data;
- References to **"Policy"** means this Privacy Policy; and
- References to "**Website**" refers to www.fowlerssyndrome.co.uk.

Who we are

Fowler's Syndrome UK is a registered charity (charity number 1196903), and our registered address is 42 York Street, Twickenham, TW1 3BW.

This Policy sets out how we, as a data controller, collect, use, store, transfer and protect any personal data you give us through our Website, or through any other means for example, phone, email, letter or other correspondence, or similar means used by us to collect your personal data.

About this Policy

- Please read this Policy carefully. This Policy is intended to be read alongside, and in addition to, our Website terms and conditions.
- This Policy explains:
    - what personal data we may collect about you;
    - how we use personal data we collect about you;
    - when we may use your personal data to contact you;
    - whether we will disclose your personal data to anyone else;
    - how long we will retain your personal data;
    - where we will store your personal data; and
    - your choices regarding the personal data you provide to us.
- We are committed to safeguarding your personal data. Whenever you provide personal data to us, we are obliged to use your personal data in accordance with applicable data protection laws.
- Our Website contains links to websites owned and operated by third parties. These third-party websites have their own privacy policies, including relating to their use of cookies. We recommend that you read these, as these will govern the use of personal data you submit, or which is collected by cookies whilst visiting these third-party websites. We cannot accept any responsibility or liability for the privacy

practices of such third-party websites and your use of such websites is at your own risk.

Changes to this Policy

- We keep this Policy under regular review to ensure that it continues to meet all applicable legislative requirements, and the needs of FSUK and our community.
- We may update this Policy at any time. If we make any changes to this Policy, we will post the updated version on our Website.
- This Policy was last updated on 09.09.24

How we collect your personal data

We collect your personal data using different methods, including both direct and indirect collection of personal data.

Direct collection of your personal data may include through:

- **Your interactions with us**: You may give us your personal data by filling in online forms or by corresponding with us by post, phone, email or otherwise. This includes personal data you provide when:
    - applying to participate in any of our services (including responding to any research or surveys, taking part in any forums or groups we may offer, and any other services we may offer);
    - purchasing one of our products;
    - joining as a member of our community;
    - signing up to attend one of our events;
    - creating an account on our Website;
    - making a donation or fundraise for us;
    - submitting any applications for funding or projects which we may process;
    - subscribing to our service or publications (for example, newsletters that we may send);
    - sharing your stories with us regarding Fowler's Syndrome;
    - consenting to marketing or request marketing materials to be sent to you;
    - volunteering for us; and/or
    - providing us with feedback or contact us.
- **Automated technologies or interactions**: We will collect certain information, which may include personal data, through cookies and other similar technologies. Please see our Cookie Policy for further detail relating to this.

We may also collect your personal data indirectly, including through:

- **Third parties**: We may receive personal data about you from various third parties including but not limited to:
    - independent organisers, such as the London Marathon;
    - third-party payment platforms where you may give donations, for example Just Giving and/or professional fundraising agencies;
    - friends, family or others that may sign you up for events; and/or
    - surveys or research studies.

- **Social media platforms**: Any engagement or communication that you make with us through social media platforms. Dependent on your settings, we may be able to access personal data if publicly available, for example any photos that you may tag us in or when you repost. Please ensure you are comfortable with your privacy settings and the privacy policies of the respective social media platforms.
- **[Publicly available sources**: In certain circumstances, we may need to conduct additional checks (for example, in relation to larger donations) which may include us receiving your personal data (including Identity and Contact Data) through publicly available sources such as corporate websites, Companies House, or anti-money laundering providers, allowing us to fully understand someone's interests and support for us.]

What types of personal data do we collect about you

Personal data means any information about an individual from which that person can be identified.

We may collect, use, store, transfer and protect different kinds of personal data about you which we have grouped together as follows:

- **Identity Data**: Your first name, last name, username or similar identifier, marital status, title, date of birth and gender;
- **Contact Data**: Your billing address, delivery address, email address and telephone number;
- **Financial Data**: Your bank account and payment card details;
- **Transaction Data**: Detail about payments or donations from you and other details of products you may have purchased from us;
- **Special categories of personal data**: please refer to 'Special categories of personal data' below;
- **Technical Data**: Internet protocol ("**IP**") address, your login data and other technology on the devices you use to access our Website. Please refer to our Cookies Policy for further information;
- **Profile Data**: Your username and password, purchases or orders made by you, your interests, preferences, feedback and survey responses;
- **Usage Data**: Information about how you interact with and use our Website and services; and
- **Marketing and Communications Data**: Your marketing preferences relating to receiving marketing from us or third parties and your communication preferences.

Special categories of personal data

Certain types of personal data are more sensitive than others. This "special category personal data" about you includes personal data about health, disability, race, ethnicity, criminal offences (or alleged offences), political opinions, biometrics or religion.

We may collect and receive special category personal data about you as part of some of our services. This will only be collected with your explicit consent and may include personal data regarding your general health (including both physical and mental health), any disabilities or

health conditions you may have, and your race or ethnicity. For example, this may be collected as part of the following activities:

- When you provide personal data to us in relation to any services or groups that you may be a part of, or give someone else permission to provide this personal data on your behalf; or
- When you respond to surveys that we may send and you complete.

Please note, we do not encourage members of our community to share personal data such as detail in relation to their medication or prescriptions by any means (including on social media platforms or in any forums or groups) [and we do not actively collect or retain personal data in relation to the same]. [If at any time personal data relating to medications or prescriptions sharing is discussed amongst FSUK community members and received by us for any reason, we will delete this personal data as soon as possible.]

How we use your personal data

We use your personal data in our capacity as a registered charity. You agree that your personal data may be used by us [and carefully selected third parties chosen by us] for any of the following purposes:

- registering and managing online accounts you may have with us;
- registering you as a participant for and managing any events that we may host, including but not limited to support or focus groups, webinars or roundtables, or any other targeted sessions;
- for research purposes including use of aggregated and/or anonymised data in any research findings or surveys conducted by us [and/or third parties];
- fulfilling any contractual agreements between you and us, including but not limited to providing any products, services or relevant information to you;
- providing you with a personalised browsing experience when you are using our Website and/or understanding how we can improve our Website;
- for fundraising or charitable purposes, including relating to you volunteering for us or any monitoring and reporting in relation to our use of charitable funds;
- processing any applications for funding and/or administering or overseeing any projects that we may fund, or any donations you may give (for example through third-party providers such as Just Giving or other professional fundraising agencies);
- interacting with you on social media platforms;
- for fraud prevention purposes including completing money laundering checks (which may be required occasionally);
- to send you details (including by post, phone, e-mail, SMS or social media) of other products and services which we think may interest you, provided you have consented to direct marketing. Please refer to the Marketing section of this Policy below for further detail;
- to raise funds for our charitable causes, or contacting you regarding donations you have made, applications you have submitted, or online content you have signed up for;
- to research, analyse and improve our charity and our work;
- to analyse and improve services and content offered by us (including services, products and our Website) and provide a positive experience for you;

- for our administration and operation purposes, for internal record keeping and/or security purposes;
- contacting you about any content you provide;
- personalising the way we present our content to you;
- operating and administering our Website and understand how individuals use our Website;
- maintaining a public profile on both traditional and social media;
- developing and maintaining relationships with vendors, partners and other companies;
- responding to any complaints or queries that you may have; and/or
- to comply with our legal and regulatory requirements (for example, requirements set out by the Charity Commission or Fundraising Regulator).

Our legal basis for processing

The law requires us to have a legal basis for collecting and processing your personal data, meaning that we only collect and process your personal data in accordance with applicable data protection laws in the UK including the Data Protection Act 2018, UK GDPR, the Privacy and Electronic Communications (EC Directive) Regulations 2003 and any other applicable data protection laws from time to time.

We rely on one or more of the following legal bases for processing:

- **Performance of a contract with you**: Where we need your personal data to perform the contract we are about to enter into or have entered into with you, for example if you purchase an item from us or have agreed to participate in any research or survey.
- **Legitimate interests**: We may use your personal data where it is necessary to further our charitable purposes, conduct our charity and pursue our legitimate interests, for example to prevent fraud and enable us to give you the most secure customer experience. We ensure we consider and balance any potential impact on you and your rights (both positive and negative) before we process your personal data for our legitimate interests. We do not use your personal data for activities where our interests are overridden by the impact on you (unless we have your consent or are otherwise required or permitted to by law). Legitimate interests may include:
    - Raising funds for our charitable causes, or contacting you regarding donations you have made, applications you have submitted, or online content you have signed up for;
    - Researching, analysing and improving our charity and charitable work;
    - Analysing and improving services and content offered by us (including services, products and our Website) and providing a positive experience for you;
    - For our administration and operation purposes (including relating to our Website and understanding how individuals use our Website), for internal record keeping and for security purposes;
    - Contacting you about any content you provide;
    - Personalising the way we present our content to you;

    - Maintaining a public profile on both traditional media and social media and interacting with you on social media platforms;
    - Providing you with a personalised browsing experience when you are using our Website and/or understanding how we can improve our Website;
    - Any fundraising or charitable activities, including relating to you volunteering for us or any monitoring and reporting in relation to our use of charitable funds;
    - Registering and managing any online accounts you may have with us;
    - Registering you as a participant for and managing any events that we may host, including but not limited to support or focus groups, webinars or roundtables, or any other targeted sessions;
    - For research purposes including use of aggregated and/or anonymised data in any research findings or surveys conducted by us [and/or third parties];
    - Developing and maintaining relationships with vendors, partners and other companies; and/or
    - Responding to any complaints or queries that you may have.
- **Legal or regulatory obligation**: We may use your personal data where it is necessary for compliance with a legal or regulatory obligation that we are subject to. For example, we may be required to share your personal data with various regulators, such as the Charity Commission or Fundraising Regulator. We will identify the relevant legal or regulatory obligation when we rely on this legal basis.
- **Consent**: We rely on consent only where we have obtained your active consent to use your personal data (including special category personal data in relation to which you are required to provide explicit consent) for a specified purpose, for example if you subscribe to receive marketing from us (please refer to the Marketing section of this Policy below for further detail) or consent to your data being collected as part of any research or survey we may conduct. You have the right to withdraw your consent to any usage of your personal data for any purposes reliant on your consent at any time.

We may undertake marketing to you using your personal data

If you have consented, we may contact you for marketing purposes (including but not limited to publicity about us and/or the work we are doing) by email and/or .direct mail / post (where you have provided your postal address), unless you have told us that you do not wish to receive such information.

If you wish to contact us either to obtain information about the work that we are doing, or to request that we stop sending you such information, please email us at hello@fowlerssyndrome.co.uk or write to us at 42 York Street, Twickenham, TW1 3BW with the details of your request.

You may also opt out of marketing emails at any time by clicking the unsubscribe link in any marketing email from us.

How we keep your personal data safe

We have put in place appropriate technical and organisational measures (including physical, electronic and security measures) to prevent your personal data from being accidentally lost, used or accessed in an unauthorised way, altered or disclosed.

Whilst we use our best efforts to ensure the security of your personal data, please be aware that we cannot guarantee the security of information transmitted over the Internet.

How long we keep your personal data for

We retain your personal data only for as long as reasonably necessary to fulfil the purposes we collected it for, including for the purposes of satisfying any legal, regulatory, tax, accounting or reporting requirements. We may retain your personal data for a longer period in the event of a complaint or if we reasonably believe there is a prospect of litigation involving you.

[By law we are required to keep your basic personal data for [6] years after your interactions with us.]

In some circumstances you can ask us to delete your personal data: see 'Your legal rights' below for further information.

We may also anonymise your personal data (meaning it can no longer be associated with you) for research or statistical purposes, in which case we may use this information indefinitely without further notice to you.

Sharing your personal data with third parties

Sometimes, we may be required to share your personal data with third parties which are not part of FSUK. These may include:

- third parties that we may be collaborating with in providing services to you and/or that may be assisting us with joint research, projects or surveys;
- where we are under a legal or regulatory duty to do so, we may disclose your personal data to the police, regulatory bodies, legal advisors or the Charity Commission, and/or, where we consider this necessary, to protect our rights, or the rights of our personnel, visitors or users;
- other service providers may process your personal data on our instructions. These may include IT suppliers (including website, software and app providers), email management service providers, cloud hosting providers, professional advisors, database providers, backup and disaster recovery specialists and email providers. Our suppliers and service providers will be required to meet appropriate security standards when processing your personal data, and the information we provide them (including your personal data) will only be processed in connection with the performance of their function. They will not be permitted to use your personal data for any purposes other than those outlined in this Policy;
- in connection with the sale, transfer or disposal of our charity, provided such use of your personal data is substantially in accordance with the terms of this Policy; and/or
- if we buy or sell any other business or assets, we may disclose information which may include your personal data to the prospective seller or buyer, and/or if

substantially all of our assets are acquired by a third party, personal data held by us may be one of the transferred assets.

We do not sell or trade your personal data with other third-party organisations, for example for marketing purposes.

International transfers of your personal data

In addition, we (or third parties acting on our behalf) may also store or process personal data that we collect about you in countries outside the United Kingdom, which may have lower standards of data protection.

Whenever we transfer your personal data outside of the UK, we ensure a similar degree of protection is afforded to it by ensuring that the following safeguards are in place:

- We will only transfer your personal data to countries that have been deemed by the UK to provide an adequate level of protection for personal data, such as countries in the European Economic Area; and/or
- We may use specific standard contractual terms approved for use in the UK which give the transferred personal data the same protection as it has in the UK, namely The International Data Transfer Addendum to the European Commission's standard contractual clauses for international data transfers. To obtain a copy of these contractual safeguards, please contact us at hello@fowlerssyndrome.co.uk.

Your legal rights

Every individual has rights in relation to their personal data, which we would like to make sure you are fully aware of, and have detailed further below:

- **The right to access your personal data (commonly known as a 'subject access request')**: You may request access to, or copies of, your personal data which is held by us. We will provide you with this unless there is a legal exception that applies.
- **The right to rectification**: You may request that we correct any personal data we hold about you which you believe to be inaccurate or incomplete. We reserve the right to verify the accuracy of the new personal data you provide to us.
- **The right to erasure**: You may request that we erase your personal data in certain circumstances. You may also ask us to delete or remove your personal data where you have withdrawn your consent, successfully exercised your right to object to processing (see below), where we may have processed your personal data unlawfully or where we are required to erase your personal data to comply with local law. Some personal data that is being used under certain conditions may not be able to be deleted, such as research data, however in these instances we will ensure all personal data being used is anonymised so that this cannot be linked with you.
- **The right to restrict processing**: You may request that we suspend the processing of your personal data in one of the following scenarios: (i) if you want us to establish accuracy of the personal data; (ii) where our use of the personal data is unlawful but you do not want us to erase it; (iii) where you need us to hold the personal data even if we no longer require it as you need to establish, exercise or defend legal claims; or (iv) you have objected to our use of your personal data but we need to verify whether we have overriding legitimate grounds to use it.

- **The right to object to processing**: You may object to our processing of your personal data where we are relying on a legitimate interest (or those of a third party) as the legal basis for that particular use of your personal data (including carrying out profiling based on our legitimate interests). In some cases, we may demonstrate that we have compelling legitimate grounds to process your personal data which override your right to object.
- **The right to data portability**: You may request that we transfer the personal data that we have collected directly to you or a third party you have selected. We will provide to you, or a third party you have chosen, your personal data in a structured, commonly used, machine-readable format. Please note that this right only applies to automated processing which you initially provided consent for us to use or where we used the personal data to perform a contract with you.
- **The right to opt out of direct marketing**: You may object at any time to the processing of your personal data by us for direct marketing purposes. Please contact us in writing at hello@fowlerssyndrome.co.uk to inform us if you do not wish to receive any marketing from us.
- **The right to withdraw consent**: If we are relying on consent to process your personal data, you may withdraw your consent to this. However, this will not affect the lawfulness of any processing carried out before you withdraw such consent. If you withdraw your consent, we may not be able to provide certain products or services to you. We will advise you if this is the case at the time you withdraw your consent.

Third-party links

Our Website contains links to third-party websites and other applications. By clicking on those links, you may allow third parties to collect or share data about you. We do not control any third-party websites and are not responsible for their privacy policies or practices. When you leave our Website via a third-party link, we encourage you to read the privacy policy of each third-party website you visit.

Your duty to inform us of any changes

It is important that the personal data we hold about you is accurate and current. Please keep us informed if your personal data changes during your relationship with us (such as address or email address changes) by contacting us at hello@fowlerssyndrome.co.uk.

Complaints

You have the right to make a complaint at any time to the Information Commissioner's Office ("**ICO**"), the UK regulator for data protection issues (www.ico.org.uk). We would, however, appreciate the chance to deal with your concerns before you approach the ICO so please contact us in the first instance.

How to contact us

If you have any questions relating to how we collect, use, store, transfer and protect your personal data, or relating to the personal data we hold on you, if you wish to exercise one of

your data protection rights, or for any other reason related to this Policy, please contact us at hello@fowlerssyndrome.co.uk.

Policy Review and Amendments: This policy will be reviewed annually, by the end of the first quarter (Q1), to ensure that it continues to meet the needs of FSUK and its community.

FSUK
Registered Charity Number 1196903
Hello@Fowlerssyndrome.co.uk
42 York Street, Twickenham, TW1 3BW

Last reviewed on [02/03/26]
Reviewed and agreed by [IH, HE]