



Society for Mucopolysaccharide Diseases
MPS House, Repton Place
White Lion Road, Amersham
Bucks, HP7 9LP

0345 389 9901
mps@mpsociety.org.uk
www.mpsociety.org.uk

Society for Mucopolysaccharide Diseases

Policy No.

Privacy and Cookies Policy

We want everyone who supports us, or who comes to us for support, to feel confident and comfortable with how any personal information you share with us will be looked after or used. This Privacy Policy sets out how we collect, use and store your personal information (this means any information that identifies or could identify you).

The Society for Mucopolysaccharide Diseases Privacy Policy may change so please remember to check back from time to time. Where we have made any changes to this Privacy Policy, we will make this clear on our website or contact you about any changes.

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1. Who we are

Here at the Society for Mucopolysaccharide Diseases, we are committed to protecting your personal information and making every effort to ensure that your personal information is processed in a fair, open and transparent manner.

We are a "data controller" and a "data processor" for the purposes of the Data Protection Act 1998 and (from 25 May 2018) the EU General Data Protection Regulation 2016/679 ("Data Protection Law"). This means that we are responsible for, and control the processing of, your personal information.

For further information about our privacy practices, please contact our Data Protection Officer by:

- Writing to us: Bob Stevens Group CEO
Society for Mucopolysaccharide Diseases
MPS House
Repton Place
White Lion Road
Amersham

Bucks
HP7 9LP

- Calling us on 03453899901
- Emailing us at mps@mpssociety.org.uk

2. How we collect information about you

Everything we do, we do to ensure that we can help people affected by an MPS, Fabry or related disease get both support and respect. We want to make sure you receive the communications that are most relevant to you, be it through visiting our website or receiving emails, post or phone calls. We want to make sure you receive the best attention when you book on an event, become a member or make a donation.

We collect information from you in the following ways:

When you interact with us directly: This could be if you ask us about our activities, register with us for training or an event, make a donation to us, ask a question about something in relation to MPS, Fabry or related disease, purchase something, apply for a job or volunteering opportunity or otherwise provide us with your personal information. This includes when you phone us, visit our website, make a purchase, or get in touch through the post, or in person.

When you interact with us through third parties: This could be if you provide a donation through a third party such as Just Giving or one of the other third parties that we work with and provide your consent for your personal information to be shared with us.

When you visit our website: We gather general information which might include which pages you visit most often and which services, events or information is of most interest to you. We may also track which pages you visit when you click on links in emails from us. We also use "cookies" to help our site run effectively. There are more details below – see 'Cookies'.

We use this information to personalise the way our website is presented when you visit to make improvements and to ensure we provide the best service and experience for you. Wherever possible we use anonymous information which does not identify individual visitors to our website.

From other information that is available to the public: In order to tailor our communications with you to your background and interests we may collect information about you from publicly available sources or through third party subscription services or service providers.

3. Information we collect and why we use it

Personal Information

Personal information we collect includes details such as your name, date of birth, disease type (if applicable) email address, postal address, telephone number and credit/debit card details (if you are making a purchase or donation), as well as information you provide in any communications between us. You will have given us this information whilst, registering your interest in having contact with the Society, making a donation, registering for an event, placing an order on our website or any of the other ways to interact with us.

We will mainly use this information:

- To process your donations or other payments, to claim Gift Aid on your donations and verify any financial transactions.
- To provide the services or goods that you have requested.
- To provide affected individuals, parents and carers, support and advice through our advocacy service.
- To update you with important administrative messages about your donation, an event or services or goods you have requested.
- To comply with the Charities (Protection and Social Investment) Act 2016 and follow the recommendations of the official regulator of charities, the Charity Commission, which require us to identify and verify the identity of supporters who make major gifts so we can assess any risks associated with accepting their donations.
- To keep a record of your relationship with us.
- Where you volunteer with us, to administer the volunteering arrangement.

If you do not provide this information, we will not be able to process your donation, sign you up to access support and advice (if required) sign you up for a particular event or provide goods and services you have requested.

We may also use your personal information:

- To contact you about our work and how you can support us.
- To invite you to participate in surveys or research or other similar activities.

Sensitive Personal Information

If you share your personal experience or the experiences of a friend or relative, we may also collect this health information. If you provide us with any Sensitive Personal Information by telephone, email or by other means, we will treat that information with extra care and confidentiality and always in accordance with this Privacy Policy. You can of course decide if you want to remain anonymous, if you are happy to share your personal details with staff members or if you would like us to share your story with the media or other parties as part of our work telling people's personal stories about MPS, Fabry or related diseases.

A special note about the Sensitive Personal Information we hold

Data Protection Law recognises that some categories of personal information are more sensitive. Sensitive Personal Information can include information about a person's health, race, ethnic origin, political opinions, sex life, sexual orientation or religious beliefs.

If you contact the Advocacy Service you may choose to provide details of a sensitive nature.

We will only use this information:

- For the purposes of dealing with your enquiry, support need, training, and quality monitoring or evaluating the services we provide.
- We will only ever share your information with your permission and explicit consent, for the purposes stated and agreed (for example if you requested us to speak to a particular health professional)
- We will only use anonymised data for the purposes of research and statistical monitoring.
- The MPS Society may contact you to invite you to participate in surveys or research projects about particular issues.
- We will not pass on your details to anyone else without your express permission except in exceptional circumstances (Examples of exceptionality includes anyone reporting serious self-harm or posing a threat to others or children contacting us and sharing serious issues such as physical abuse or exploitation).
- Where you have given us your explicit written consent or otherwise clearly indicated to us that you are happy for us to share your story, then we may publish it on our blog or in other media.

4. Profiling: making our work more unique to you

We want to improve how we talk to you and the information we provide through our website, services, products and information. To do this we may sometimes use profiling and screening methods so that we can better understand our supporters, your preferences and needs to provide a better experience for you.

We may carry out targeted fundraising activities using profiling techniques based on the information that we hold about you. We may also work with third party organisations who provide additional insight, this may include providing wealth screening information or general information about you that is publicly available.

This information can be appended to the information that you have provided which allows us to use our resources more effectively by better understanding the background of our supporters and making appropriate requests based on what may interest them and their capacity to give.

You can of course opt out of this activity at any time. To do this, email: info@mpssociety.org.uk with the subject line 'Please stop analysis of my data' or by contacting us directly on 0345 3899901

5. Legal basis for using your information

In some cases, we will only use your personal information where we have your consent or because we need to use it in order to fulfil a contract with you (for example, because you have placed an order on our website).

However, there are other lawful reasons that allow us to process your personal information and one of those is called 'legitimate interests'. This means that the reason that we are processing information is because there is a legitimate interest for the Society for Mucopolysaccharide Diseases to process your information to help us to achieve our vision of ensuring that everyone living with problem associated with MPS, Fabry and related diseases gets both support and respect.

We may also use and retain your information under legitimate interest as set out within the exemptions within the GDPR Data Protection Policy

Whenever we process your Personal Information under the 'legitimate interest' lawful basis we make sure that we take into account your rights and interests and will not process your personal information if we feel that there is an imbalance.

Some examples of where we have a legitimate interest to process your Personal information are where we contact you about our work via post, use your personal information for data analytics, conducting research to better understand who our supporters are, improving our services, for our legal purposes (for example, dealing with complaints and claims), or for complying with guidance from the Charity Commission.

6. Marketing

We will only contact you about our work and how you can support us by phone, email or text message, if you have agreed for us to contact you in this manner.

However, if you have provided us with your postal address we may send you information about our work and how you can support The MPS Society by mail unless you have told us that you would prefer not to hear from us in that way.

You can update your choices or stop us sending you these communications at any time by contacting info@mpssociety.org.uk.

7. Sharing your Information

The personal information we collect about you will mainly be used by our staff (and volunteers) at the Society for Mucopolysaccharide Diseases so that they can support you.

We will never sell or share your personal information with organisations so that they can contact you for any marketing activities. Nor do we sell any information about your web browsing activity.

We may however share your information with our trusted partners and suppliers who work with us on or on our behalf to deliver our services, but processing of this information is always carried out under our instruction. We make sure that they store the data securely, delete it when they no longer need it and never use it for any other purposes. Some examples of where we may share your information are with our fulfilment partners who help to create and send information to you to reduce our costs, with our partners who help us to process donations and claim Gift Aid and our partners who help us to manage our social media accounts.

We enter into contracts with these service providers that require them to comply with Data Protection Laws and ensure that they have appropriate controls in place to secure your information.

Legal disclosure

We may disclose your information if required to do so by law (for example, to comply with applicable laws, regulations and codes of practice or in response to a valid request from a competent authority); or, in order to enforce our conditions of sale and other agreements.

8. Keeping your information safe

We take looking after your information very seriously. We've implemented appropriate physical, technical and organisational measures to protect the personal information we have under our control, both on and off-line, from improper access, use, alteration, destruction and loss.

Unfortunately the transmission of information using the internet is not completely secure. Although we do our best to protect your personal information sent to us this way, we cannot guarantee the security of data transmitted to our site.

Our websites may contain links to other sites. While we try to link only to sites that share our high standards and respect for privacy, we are not responsible for the content or the privacy practices employed by other sites. Please be aware that advertisers or Web sites that have links on our site may collect personally identifiable information about you. This privacy statement does not cover the information practices of those websites or advertisers.

Any debit or credit card details which we receive on our website are passed securely to Sage Pay our payment processing partner, according to the Payment Card Industry Security Standards.

9. How long we hold your information for

We only keep it as long as is reasonable and necessary for the relevant activity, which may be to fulfil statutory obligations (for example, the collection of Gift Aid) or where retention of the data helps towards the furthestmost of clinical trials, treatment options or other such relevant outcomes.

10. Your rights

You have various rights in respect of the personal information we hold about you – these are set out in more detail below. If you wish to exercise any of these rights or make a complaint, you can do so by contacting us in writing at :

Bob Stevens Group CEO Society for Mucopolysaccharide Diseases, MPS House, Repton Place, White Lion Road, Amersham, Bucks, HP7 9LP , by email : mps@mpssociety.org.uk and by phone on 0345 3899901.

You can also make a complaint to to the data protection supervisory authority, the Information Commissioner's Office, <https://ico.org.uk/>: [

- Access to your personal information: You have the right to request access to a copy of the personal information that we hold about you, along with information on what personal information we use, why we use it, who we share it with, how long we keep it for and whether it has been used for any automated decision making. You can make a request for access free of charge. Please make all requests for access in writing, and provide us with evidence of your identity.
- Right to object: You can object to our processing of your personal information where we are relying on a legitimate interest (or those of a third party) and there is something about your particular situation which makes you want to object to processing on this ground. You also have the right to object where we are processing your personal information for direct marketing purposes. Please contact us as noted above, providing details of your objection.
- Consent: If you have given us your consent to use personal information (for example, for marketing), you can withdraw your consent at any time.
- Rectification: You can ask us to change or complete any inaccurate or incomplete personal information held about you.
- Erasure: You can ask us to delete your personal information where it is no longer necessary for us to use it, you have withdrawn consent, or where we have no lawful basis for keeping it.
- Portability: You can ask us to provide you or a third party with some of the personal information that we hold about you in a structured, commonly used, electronic form, so it can be easily transferred.
- Restriction: You can ask us to restrict the personal information we use about you where you have asked for it to be erased or where you have objected to our use of it.
- No automated-decision making: Automated decision-making takes place when an electronic system uses personal information to make a decision without human intervention. You have the right not to be subject to automated decisions that will create legal effects or have a similar significant impact on you, unless you have given us your consent, it is necessary for a contract between you and us or is otherwise permitted by law. You also have certain rights to challenge decisions made about you. We do not currently carry out any automated decision-making.

Please note, some of these rights only apply in certain circumstances and we may not be able to fulfil every request.

11. Cookies

'Cookie' is a name for a small file, usually of letters and numbers, which is downloaded onto your device, like your computer, mobile phone or tablet when you visit a website.

They let websites recognise your device, so that the sites can work more effectively, and also gather information about how you use the site. A cookie, by itself, can't be used to identify you.

How do we use cookies?

We use cookies to distinguish you from other users of our website. This helps us to provide you with a good experience when you come to our website and also allows us to improve the user experience.

The cookies we use

We use the categorisation set out by the International Chamber of Commerce in their UK Cookie Guide.

We use all four categories of cookies:

- Strictly necessary cookies are essential for you to move around our website and to use its features.

- Performance cookies collect anonymous information about how you use our site, like which pages are visited most.
- Functionality cookies collect anonymous information that remember choices you make to improve your experience, like your text size or location. They may also be used to provide services you have asked for such as watching a video or commenting on a blog.
- Targeting or advertising cookies collect information about your browsing habits in order to make advertising relevant to you and your interests.

No cookies, please

You can opt out of all our cookies (except the strictly necessary ones). Find out how to control and delete cookies in your browser.

But, if you choose to refuse all cookies, our website may not function for you as we would like it to.

If you have any questions about how we use cookies, please contact us.

12. Monitoring

Your communications with our teams (including by telephone or email) may be monitored and/or recorded for training, quality control and compliance purposes to ensure that we continuously improve our customer service standards.

To find out more about this policy and how we look after your personal information, contact us at:

Society for Mucopolysaccharide Diseases

MPS House

Repton Place

White Lion Road

Amersham

Bucks

HP7 9LP

Or call us directly on: 0345 3899901

Employment

Income tax and NI returns, income tax records and correspondence with the Inland Revenue: not less than 3 years after the end of the financial year to which they relate.

Records relating to events notifiable under the Retirement Benefits Schemes (Information Powers) Regulations 1995, and records concerning decisions to allow retirement due to incapacity, pension accounts and associated documents: 6 years from the end of the scheme year in which the event took place, or the date upon which the accounts/reports were signed/completed.

Statutory Maternity Pay records, calculations, certificates (Mat B1s) or other medical evidence: 3 years after the end of the tax year in which the maternity period ends.

Statutory Sick Pay records, calculations, certificates, self-certificates: 3 years after the end of the tax year to which they relate.

Wage/salary records (also overtime, bonuses, expenses): 6 years.

Name of CEO: Bob Stevens

Date: 15.06.2018

Change history record

Issue	Description of Change	Approval	Date of Issue
1	Original Document	15.06.18	17.06.18
2	N/A	N/A	N/A
3	N/A	N/A	N/A