

Data protection and privacy statement

This Data Protection and Privacy Policy sets out the standards you can expect when we ask for or record your personal information, and explains how we'll use it.

Our Commitment

When we handle and store the personal information including photographs and video relating to those affected by Mucopolysaccharide and related lysosomal diseases, siblings, members as well as prospective clients and individuals we will follow the law, including the Data Protection Act 1998.

When we ask you for personal information we promise to:

- Explain why we need it
- Only ask for what we need
- Treat it as confidential

When we record and use your personal information we promise to:

- Only access it when we have a valid reason to do so
- Only share what is necessary and relevant
- Protect it and make sure nobody has access to it who shouldn't
- Not sell it to commercial organisations

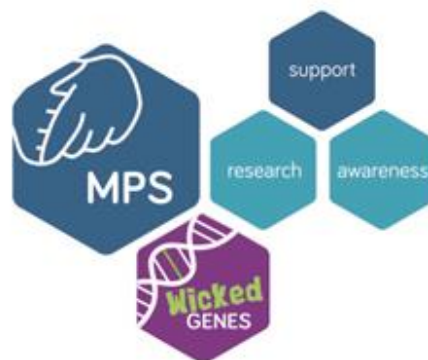
When we share your personal information with another organisation we promise to:

- Ensure that this is only done with your consent, or if we are required to do so by law
- Follow the [ICO Data Sharing Code of Practice](http://www.ico.org.uk/media/for-organisations/documents/1068/data_sharing_code_of_practice.pdf) to ensure the other organisation treats your information with the same level of care we do

(www.ico.org.uk/media/for-organisations/documents/1068/data_sharing_code_of_practice.pdf)

If you are unhappy with how we record and use your information you should follow our complaints procedure.

Please let us know as soon as possible if anything relating to your contact details or issues changes, which may affect the information we hold.



Giving Your Consent

We must ask your consent to record, use or share personal information

What you are agreeing to

If you give your consent you are saying:

Data such as contact details, date of birth; advocacy support, medical and treatment history; membership history and details (including payment information and queries and complaints will be held by the MPS Society and used for the following reasons:

- to administer and manage your membership;
- to provide an individual advocacy and support service
- to provide access and participation in MPS Society events;
- to provide support in awareness and income generation;
- to enhance and improve the MPS Society's support services:
- to maintain the MPS Society disease data registry
- to provide information on research and clinical trial opportunities
- to recruit to clinical surveys;
- to fulfil the MPS Society's regulatory functions;
- and to communicate with you.

Some of this information is provided by you when you make enquiries with us or with your application for membership. Other information will be obtained during the course of your membership from you or third parties, such as other members to enable us to carry out the purposes set out above.

We may also use your information for fundraising and marketing purposes if you have consented separately for this. This fundraising and marketing may be by mail, telephone, fax, social media or email.

Sometimes we'll refer you to another organisation / MPS expert clinical centre for specialist advice. We can help you to get an appointment and we'll pass on the information you've already provided so you don't need to do it again.

How you give your consent

On contacting the MPS Society by telephone or electronically you will be sent a Data Protection Act: Client Consent Form

How to withdraw your consent

If you have changed your mind about consent you have already given, contact the MPS Society

Sensitive Information

Some of the information we ask you for or which you provide may be sensitive personal data, such as information about medical conditions. We will not use such sensitive personal data except for the purposes of processing your membership, providing an advocacy and support service, maintaining the MPS Society disease data registry, safeguarding and for the purpose of making any reasonable adjustments where possible to enhance your membership.

Disclosure of information to third parties

We will never sell your personal data to third parties and we do not disclose your information to any third parties or bodies with which we are not associated unless we have your permission to do so or are required to do so by law.

How we will store your information

We will store your information on a secure server which is only accessed by the MPS Society. Paper copies of your information is also stored securely and is accessed by staff of the MPS Society

The Role of the Data Controller

A data controller is responsible for your data and must make sure that your data is processed in accordance with the law. They are responsible for making sure that the information held about you is accurate and is stored securely.

Obtaining the information we hold about you

You have a right to ask for a copy of your information and to correct any inaccuracies. Under the Data Protection Act 1998, the MPS Society is required to respond to your request within 40 days. If you would like a copy of the information we hold about you, please write to Head of Operations and Governance, Society for Mucopolysaccharide Diseases, MPS House, Repton Place, White Lion Road, Amersham, Bucks HP79LP. A fee of £10 is payable. Cheques should be made payable to "The MPS Society".