



When you apply to become a member of, or have a connection¹ with, the Hereditary Spastic Paraplegia Support Group (HSPSG), HSPSG obtains data about you. This statement explains how we look after that data and what we do with it. This statement is derived from the HSPSG Data Protection and Confidentiality Policy which is available as a separate document.

HSPSG has a legal duty under the General Data Protection Regulation to prevent your information falling into the wrong hands. We must also ensure that the data we hold is accurate, adequate, relevant and not excessive.

Normally the only data we hold comes directly from you. We would like to contact you to;

- tell you about our meetings,
- send you our newsletter
- provide you with information and support
- be able to put you in touch with other members
- alert you to opportunities to find out about or take part in relevant activities,
- alert you to opportunities to find out about or take part in research trials.
- tell you about ways in which you might like to support HSPSG.

You have the right to ask us not to contact you about any of these things by writing to the HSPSG Chair by post or email at one of the addresses below. Whenever we collect data from you, we will make it clear how we intend to use the data. You do not have to provide us with any additional information unless you choose to.

HSPSG will not publicise or share your information with any other organisation or individuals without your consent. You may change or withdraw your permissions to use your information, but not retrospectively. To change or withdraw your permissions write by post or email to the HSPSG Chair at one of the addresses below.

Personal data is stored securely in our membership database. We restrict access to those who have a need to know, and we train these people in handling the information securely.

¹ A connection with HSPSG includes raising funds, working professionally with members, supplying relevant services to members and giving presentations at HSPSG events.

The database may be used to create anonymised summary information about the membership – for example the proportion of the membership with each type of HSP. Such data would not allow individuals to be identified. The anonymised summary data may be shared with relevant researchers in line with HSPSG charitable objectives.

You have the right to a copy of all the information we hold about you (apart from a very few things which we may be obliged to withhold because they concern other people as well as you). To obtain a copy, write to the HSPSG Secretary by post or e-mail at the addresses given on the HSPSG website <http://hspgroup.org>.

You may be required to provide proof of identity. We aim to reply as promptly as we can and, in any case, within the legal maximum of 30 days.

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