

PRIVACY POLICY

The All-Party Parliamentary Group on Motor Neurone Disease (APPG on MND) is committed to protecting your personal information and being transparent about what information we hold.

Who is the data controller?

The Motor Neurone Disease (MND) Association provides the secretariat to the Group and is the data controller. For further information, please contact Susie Rabin on mndappg@mndassociation.org or call 0203 875 8909.

What personal data is collected and how is it used?

The data which we obtain from you and process is:

- Name, title, political party* and role
- Email address
- Phone number (if given)
- Topics of interest

Your data will be collected if you attend an event organised by the Group or take part in any research or inquiries. We may record personal information about you, including your opinions, in minutes of meetings. Your data will also be collected via an online form when signing up to our mailing list whereby you give your consent to be updated on the work and activities of the Group.

Our lawful bases for using this data are consent and legitimate purposes. You can withdraw your consent at any time using the contact details provided above.

*Please note that this information is only captured for MPs and Peers.

Who will your data be shared with?

Your data will be shared with the data processor acting on behalf of the MND Association.

Please note that under the rules which Parliament has set for APPGs, the names of APPG officers (but not their contact details) are published on the Group's web page. The names, political parties, constituencies and photos of the Group's officers are published on the APPG on MND web page.

We may make the membership of the APPG public.

How long will your data be kept?

We will keep your personal information only for as long as is necessary to fulfil the purposes for which we collected it, and in accordance with applicable laws. This may be until you

withdraw your consent or object to further contact. However, we may retain your details on a suppression list to help ensure we do not continue to contact you.

How are cookies used on our web page?

The APPG web page is hosted on the MND Association's website. Like most other websites, the MND Association uses cookies which are small text files that sites transfer to your computer, phone or tablet. They make interacting with a website faster and easier. Wherever possible the MND Association uses aggregated or anonymous information which does not identify individual users to the website.

What are your rights?

- The right to be informed about the collection and use of your personal data
- The right to receive a copy of the data we hold about you
- The right to rectification if the data we hold about you is incorrect or incomplete
- The right to have the data we hold about you to be erased in certain circumstances
- The right to restrict the way we use your personal data in certain circumstances
- The right to have the data we hold about you transmitted to another organisation
- The right to object to the processing of your data in certain circumstances

You also have the right to make a complaint to the Information Commissioner's Office (ICO), which is the supervisory authority. The ICO can be contacted via www.ico.org.uk/global/contact-us.

Last reviewed: 13 December 2021