

Privacy Notice

The International Alliance of ALS/MND Associations is committed to protecting the privacy of the users of its websites. The International Alliance of ALS/MND Associations collects no personal information about these users except where they specifically and knowingly provide it.

The International Alliance of ALS/MND Associations is committed to respecting and protecting your privacy. We have structured our website so that, in general, you can visit it without identifying yourself or revealing any personal information or health status. If you choose to provide us personally identifiable information (any information by which you can be identified) or health status, you can be assured that it will only be used to support your contact/relationship with The International Alliance of ALS/MND Associations.

This privacy notice will inform you as to how we look after your personal data when you visit our website (regardless of where you visit it from), or when you provide personal data to us through telephone and email communications or when you participate in other activities, such as surveys or events, or memberships; and this privacy notice tells you about your privacy rights and how the law protects you.

Purpose of this privacy notice

This privacy notice aims to give you information on how the International Alliance of ALS/MND Associations collects and processes your personal data through your use of this website, including any data you may provide through this website when you submit a query, sign up to our e-newsletters or donate; and how we collect and process any personal data you may provide by email and telephone communications.

Our websites and e-newsletters are not intended for children (anyone under the age of 18 years) and we do not knowingly collect data relating to children. If children access this website and look at the downloadable information provided, then that is under the responsibility of the child's parent/guardian – to make sure they are using the internet sensibly.

It is important that you read this privacy notice so that you are fully aware of how and why we are using your data. 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.

This privacy notice informs you of what to expect us to do with your personal information when you contact us or use our service.

We'll tell you:

- Why we are able to process your information
- What purpose we are processing it for
- Whether you have to provide it to us
- How long we store it for
- Whether there are other recipients of your personal information
- Whether we intend to transfer it to another country
- Whether we do automated decision-making or profiling
- The International Alliance of ALS/MND Associations is the controller for the personal information we process, unless otherwise stated.

There are many ways you can contact us, including phone, email, social media platforms and post. Our postal address:

The International Alliance of ALS/MND Associations
David Niven House
10-15 Notre Dame Mews
Northampton
NN1 2BG
England

For general contact please use <https://www.alsmndalliance.org>

You have the right to make a complaint at any time to the Information Commissioner's Office (ICO), the UK supervisory authority 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.

What data do we collect from you?

Personal data, or personal information, means any information about an individual from which that person can be identified. It does not include data where the identity has been removed (anonymous data). We may collect, use, store and transfer different kinds of personal data about you which we have grouped together as follows:

- **Identity Data** includes first name, last name, title, date of birth and gender.
- **Contact Data** includes, billing address, delivery address, email address, telephone numbers and website URL.
- **Financial Data** includes bank account and payment card details.
- **Transaction Data** includes details about payments from you and other details of donations or fundraising you have provided to us.
- **Technical Data** includes internet protocol (IP) address, your login data, browser type and version, time zone setting and location, browser plug-in types and versions, operating system and platform and other technology on the devices you use to access this website.
- **Profile Data** includes your interests, preferences, feedback and survey responses.
- **Usage Data** includes information about how you use our services and deal with us.

We may collect special category data about your health with respect to MND when organising conferences or other events, to ensure any special requirements are met. We may also collect special category data about your health with respect to MND when conducting surveys. We collect this data from you with your explicit consent and process it on the basis of us having a legitimate business interest to process the data to run such events properly; and on the basis that the surveys are necessary for reasons of public interest in the area of public health. This type of special category data is never disclosed or transferred to any other third parties without your explicit consent, and where possible it is deleted or anonymised as soon as possible.

We do not collect any **Special Categories of Personal Data** about you (this includes details about your race or ethnicity, religious or philosophical beliefs, sex life, sexual orientation, political opinions, trade union membership, genetic and biometric data). Nor do we collect any information about criminal convictions and offences.

How do we get information?

Most of the personal information we process is provided to us directly by you for one of the following reasons:

- You have made an information request to us
- You wish to attend, or have attended an event
- You subscribe to our newsletter
- You are representing an organisation
- You wish to, or have become a member
- You have submitted a presentation to us
- You have donated to us
- You have made an enquiry or complaint to us

We also receive personal information indirectly, in the following scenarios:

- An employee or member of ours, has given your contact details as an emergency contact or referee
- A complainant refers to you in their complaint correspondence

Your data protection rights

Under data protection law, you have rights we need to make you aware of. The rights available depend on our reason for processing your information.

Your right to access

You have the right to ask us for copies of your personal information. To find out how to do this follow this link <https://ico.org.uk/your-data-matters/your-right-of-access/>

Your right to rectification

You have the right to ask us to rectify information you think is inaccurate. You also have the right to ask us to complete information you think is incomplete. To find out how to do this follow this link <https://ico.org.uk/your-data-matters/your-right-to-get-your-data-corrected/>

Your right to erasure

You have the right to ask us to erase your personal information in certain circumstances. To understand more about this, please follow this link <https://ico.org.uk/your-data-matters/your-right-to-get-your-data-deleted/>

Your right to restriction of processing

You have the right to ask us to restrict the processing of your information in certain circumstances. To understand more about this please follow this link <https://ico.org.uk/your-data-matters/your-right-to-limit-how-organisations-use-your-data/>

Your right to object to processing

You have the right to object to processing if we are able to process your information because the process forms part of our public tasks or is in our legitimate interest. To find out more about this please follow this link <https://ico.org.uk/your-data-matters/the-right-to-object-to-the-use-of-your-data/>

Your right to data portability

This only applies to information you have given us. You have the right to ask that we transfer the information you gave us from one organisation to another or give it to you. This only applies if we are processing information based on your consent or under, or in talks about entering into a contract and the processing is automated. To understand more follow this link <https://ico.org.uk/your-data-matters/the-right-to-object-to-the-use-of-your-data/>

If you wish to exercise any of the rights set out above, please contact us.

No fee usually required

You will not have to pay a fee to access your personal data (or to exercise any of the other rights). However, we may charge a reasonable fee if your request is clearly unfounded, repetitive or excessive. Alternatively, we may refuse to comply with your request in these circumstances.

What we may need from you

We may need to request specific information from you to help us confirm your identity and ensure your right to access your personal data (or to exercise any of your other rights). This is a security measure to ensure that personal data is not disclosed to any person who has no right to receive it. We may also contact you to ask you for further information in relation to your request to speed up our response.

Time limit to respond

We try to respond to all legitimate requests within one month. Occasionally it may take us longer than a month if your request is particularly complex or you have made a number of requests. In this case, we will notify you and keep you updated.

Please contact us at alliance@als-mnd.org if you wish to make a request.

Sharing your information

We will not share your information with any third parties for the purposes of direct marketing. We use data processors who are third parties who provide elements of services to us. We have contracts in place with our data processors. This means they cannot do anything with your personal data unless we have instructed them to do so. They will not share your information with any organisation apart from us. They will hold it securely and retain it for a period we instruct.

Links to other websites

Third-party links

Our websites may include links to third-party websites, plug-ins and applications. Clicking on those links or enabling those connections may allow third parties to collect or share data about you. We do not control these third-party websites and are not responsible for their privacy statements. When you leave our website, we encourage you to read the privacy notice of every website you visit.

If you subscribe to any of our e-newsletters, fundraising or other communications resources, the International Alliance of ALS/MND Associations will retain your details so that we can email you as requested. You may unsubscribe or manage your subscriptions at any time by following the link at the bottom of all emails or contacting the International Alliance of ALS/MND Associations.

The International Alliance of ALS/MND Associations will not share your email address with any other individuals or organisations without your permission, unless stated explicitly below.

If you submit a query or contact us via the website, the International Alliance of ALS/MND Associations will use the information you supply only to respond to your enquiry.

Data Security

We have put in place appropriate security measures to prevent your personal data from being accidentally lost, used or accessed in an unauthorised way, altered or disclosed. In addition, we limit access to your personal data to those employees, agents, contractors and other third parties who have a business need to know. They will only process your personal data on our instructions and they are subject to a duty of confidentiality.

We have put in place procedures to deal with any suspected personal data breach and will notify you and any applicable regulator of a breach where we are legally required to do so.

How long will data be kept?

We will only retain your personal data for as long as necessary to fulfil the purposes we collected it for, including for the purposes of satisfying any legal, accounting, or reporting requirements.

To determine the appropriate retention period for personal data, we consider the amount, nature, and sensitivity of the personal data, the potential risk of harm from unauthorised use or disclosure of your personal data, the purposes for which we process your personal data and whether we can achieve those purposes through other means, and the applicable legal requirements.

By law we, and our payment gateway are legally obligated to retain essential information about your donation (including Contact, Identity, Financial and Transaction Data) for seven years for tax purposes. We do not retain payment card details.

Any private messages sent to us via social media (e.g. Facebook Messenger) will be deleted once the enquiry has been dealt with.

In some circumstances we may anonymise your personal data and special category data (so that 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.

Your right to complain

We work to high standards when it comes to processing your personal information. If you have queries or concerns, please contact us at alliance@als-mnd.org

Changes to this privacy notice

We keep our privacy notice under regular review to make sure it is up to date and accurate
JULY 2018

Visitors to our website

Analytics

When you visit www.alsmndalliance.org, we use a third-party service, Google Analytics, to collect standard internet log information and details visitor behaviour patterns. We do this to find out such things as the number of visitors to various parts of the site. This data is only processed in a way that does not identify anyone. We do not make, and do not allow Google to make, any attempt to find out the identities of those visiting our website.

Cookies

Our website currently sets a single cookie which is used by our content management system to identify a specific user session. You can disable cookies in your browser and still use all areas of the website with no ill effects.

Cookies are small text files which are stored on your computer. No personal information is stored in the cookies set by our website.

Search Engine

Our website search and decision notice search is powered by Graphics Coop. Search queries and results are logged anonymously to help us improve our website and search functionality. No identifiable personal information is collected by us or Graphic Coop.

Security and performance

We use a third-party web application firewall to help maintain the security and performance of our website. The service checks that traffic to the site is non-threatening. The service will block traffic that is not using the site as expected. To provide this service the firewall processes visitors' IP addresses. We rely on the privacy shield framework to transfer this information to the firewalls server. This information is then held for 7 days. Graphics Coop hosts our website in the UK and holds traffic information for 12 months.

Purpose and legal basis for processing

The purpose for implementing all the above is to maintain and monitor the performance of our website and to constantly look to improve the site and the services it offers to our users. The legal basis we rely on to process your personal data is article 6(1)(f) of the GDPR, which allows us to process personal data when it is necessary for the purposes of our legitimate interests.