

Privacy Policy

The MS International Federation is committed to protecting the privacy and personal information of those that visit our websites, complete our surveys, fundraise for us, help us in project evaluation or otherwise interact with us to further the MS Movement. This privacy notice details your personal data and privacy rights and how the law protects you.

If you choose to provide us with 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 MS International Federation.

Important notice! These privacy terms relate to all of the websites, domains and sub-domains owned or operated by the MS International Federation. These include: <https://www.msif.org>, <https://www.worldmsday.org>, <https://www.progressivemsalliance.org>, <https://www.cykelnerveninternationalion.org>, <https://www.kissgoodbyetomsglobal.org> and <https://www.againstms.org>. Your continued use of any of these sites is confirmation of your consent to these terms.

1. SCOPE

Welcome to the MS International Federation privacy notice.

The MS International Federation is committed to protecting the privacy of the users of its websites. The MS International Federation collects no personal information about these users except where they specifically and knowingly provide it.

The MS International Federation is committed to respecting and protecting your privacy. We have structured our websites so that, in general, you can visit them 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 MS International Federation.

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; 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 MS International Federation 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.

This website and our 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 the 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.

Controller

MS International Federation is the controller and responsible for your personal data (collectively referred to as "MSIF", "we", "us" or "our" in this privacy notice).

We have appointed a data protection officer (DPO) who is responsible for overseeing questions in relation to this privacy notice. If you have any questions about this privacy notice, including any requests to exercise your legal rights, please contact the DPO using the details set out below.

Contact details

Our full details are:

Full name of legal entity: Multiple Sclerosis International Federation

Title of DPO: IT Manager

Email address: DPO@msif.org

Postal address: Skyline House, 3rd Floor, 200 Union Street, London, SE1 0LX

Telephone number: +44 (0)20 7620 1911

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.

Changes to the privacy notice and your duty to inform us of changes

This version was last updated in April 2018.

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.

Third-party links

This website 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 MS International Federation 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 MS International Federation.

The MS International Federation 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 MS International Federation will use the information you supply only to respond to your enquiry.

2. 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.

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- **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 multiple sclerosis when organising conferences or other events, to ensure any special requirements are met. 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. This type of special category data is never disclosed or transferred to any other third parties without your explicit consent.

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.

3. HOW DO WE COLLECT YOUR PERSONAL DATA?

We use different methods to collect data from and about you including through:

Direct interactions. You may give us your Identity, Contact and Financial Data by filling in forms or by corresponding with us by post, phone, email or otherwise. This includes personal data you provide when you:

- make donations to us;
- subscribe to our publications;
- enter a competition, promotion or survey; or
- give us some feedback.

Automated technologies or interactions. As you interact with our website, we may automatically collect Technical Data about your equipment, browsing actions and patterns. We collect this personal data by using cookies, and other similar technologies. We may also receive Technical Data about you if you visit other websites employing our cookies. Please see our cookie policy below for further details.

Third parties or publicly available sources. We may receive personal data about you from various third parties and public sources as set out below:

- Technical Data from the following parties:
 - (i) analytics and search information providers such as Facebook based outside the EU;
- Identity and Contact Data from publicly available sources such as Companies House and the Electoral Register based inside the EU.

4. HOW DO WE USE YOUR PERSONAL DATA?

We will only use your personal data when the law allows us to. Most commonly, we will use your personal data in the following circumstances:

- Where we need to perform the contract we are about to enter into or have entered into with you.
- Where it is necessary for our legitimate interests (or those of a third party) and your interests and fundamental rights do not override those interests.
- Where we need to comply with a legal or regulatory obligation.

Generally, we do not rely on consent as a legal basis for processing your personal data.

5. WHY DO WE USE YOUR PERSONAL DATA?

We use your personal data to process and manage your donations, fundraising activities and enquiries, necessary for the performance of the contract between us.

1. With your permission, we will email you our newsletter. We only email you if you have asked us to; or
2. We genuinely believe you have a legitimate need for our services and deem this to represent a legitimate interest in line with the ICO's guidance.

If at any point you decide you would prefer us not to contact you, let us know and we won't. We may also use your personal data for:

1. Administering any accounts;
2. Processing your bank/credit card details in order to process your donation; and
3. Market research.

We will only use your personal data where we are allowed to by law, e.g. carrying out an agreement we have with you, fulfilling a legal obligation, because we have a legitimate business interest or where you agree to it.

We do not use your data for automated decision making or profiling.

Change of purpose

We will only use your personal data for the purposes for which we collected it, unless we reasonably consider that we need to use it for another reason and that reason is compatible

with the original purpose. If you wish to get an explanation as to how the processing for the new purpose is compatible with the original purpose, please contact us.

If we need to use your personal data for an unrelated purpose, we will notify you and we will explain the legal basis which allows us to do so.

Please note that we may process your personal data without your knowledge or consent, in compliance with the above rules, where this is required or permitted by law.

6. COOKIES

When you access and use this website the pages you access, together with a cookie, will be downloaded to your computer.

Cookies are software applications which store information about your visit to our website on your hard drive. This information supplied by cookies can help the MSIF provide you with a better experience when using this website by analysing the way in which people use the site. Cookies do not identify you personally but they do identify your computer.

Our websites may collect some or all of the following cookies:

- ✓ **Strictly necessary cookies.** These are cookies that are required for the operation of a website. They include, for example, cookies that enable users to log into secure areas of a website, use donation systems or make use of e-billing services.
- ✓ **Analytical/performance cookies.** These types of cookies allow providers to recognise and count the number of visitors and to see how visitors move around their website when they are using it. This assists providers in improving the way their website works, for example, by ensuring that users are finding what they are looking for easily.
- ✓ **Functionality cookies.** These are used to recognise users when they return to a website. They enable the personalisation of content, the recognition of users and remember user preferences (for example, their choice of language or region).
- ✓ **Targeting cookies.** These cookies record a user's visit to a website, the individual pages visited and the links followed. If the cookie is set by a third party (for example, an advertising network) which also monitors traffic on other websites, this type of cookie may also be used to track a user's movements across different websites and to create profiles of their general online behaviour. Information collected by tracking cookies is commonly used to serve users with targeted online advertising.

You can disable cookies using your browser software (for information on how to do this check your browser information/help facilities). You will still be able to browse the website if you do this with no loss of functionality.

We may use the information collected by cookies to monitor the performance of the website.

Please note that third parties (including, for example, advertising networks and providers of external services like web traffic analysis services) may also use cookies, over which we have no control. These cookies are likely to be analytical/performance cookies or targeting cookies.

To find out more about UK law on cookies and other aspects of online privacy, visit the website of the UK Information Commissioner's Office.

7. DISCLOSURES OF YOUR PERSONAL DATA

We may have to share your personal data with the parties set out below for the purposes set out in paragraph 5 above.

- ✓ Other members of the MS International Federation acting as joint controllers or processors and who are based both inside and outside of the EEA.
- ✓ Service providers acting as processors based within the EEA who provide the following services:
 - Salesforce.com EMEA Ltd – contact relationship management system (UK) ([privacy](#))
 - Stripe UK – payment processing (UK) ([privacy](#))
 - Paypal UK – payment processing (UK) ([privacy](#))
 - RaiseNow AG – donation processing (Switzerland) ([privacy](#))
 - GetResponse Sp. z o.o. – mass email provider (Poland) ([privacy](#))
 - Justgiving – donation processing (UK) ([privacy](#))
 - Worldpay Limited (UK) ([privacy](#))
- ✓ Service providers acting as processors based outside of the EEA who provide the following services:
 - WP Engine – website hosting (Australia, USA, UK) ([privacy](#))
 - Zapier, Inc – system integration platform (USA) ([privacy](#))
- Professional advisers acting as processors or joint controllers including lawyers, bankers, auditors and insurers based in the United Kingdom who provide consultancy, banking, legal, insurance and accounting services.
- ✓ HM Revenue & Customs, regulators and other authorities acting as processors or joint controllers based in the United Kingdom who require reporting of processing activities in certain circumstances.

We require all third parties to respect the security of your personal data and to treat it in accordance with the law. We do not allow our third-party service providers to use your personal data for their own purposes and only permit them to process your personal data for specified purposes and in accordance with our instructions.

8. INTERNATIONAL TRANSFER

We may share your personal data within the MSIF Group. This may involve transferring your data outside the European Economic Area (**EEA**).

We ensure your personal data is protected by requiring all our group entities to follow the same rules when processing your personal data.

Whenever we transfer your personal data out of the EEA, we ensure a similar degree of protection is afforded to it by ensuring at least one of the following safeguards is implemented:

- We will only transfer your personal data to countries that have been deemed to provide an adequate level of protection for personal data by the European Commission.
- Where we use certain service providers, we may use specific contracts approved by the European Commission which give personal data the same protection it has in Europe.
- Where we use providers based in the US, we may transfer data to them if they are part of the Privacy Shield which requires them to provide similar protection to personal data shared between the Europe and the US.

Please contact us if you want further information on the specific mechanism used by us when transferring your personal data out of the EEA.

9. 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.

10. DATA RETENTION

How long will you use my personal data for?

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 you can ask us to delete your data: see Request erasure below for further information.

In some circumstances we may anonymise your personal 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.

11. YOUR LEGAL RIGHTS

Under certain circumstances, you have rights under data protection laws in relation to your personal data.

You have the right to:

Request access to your personal data (commonly known as a "data subject access request"). This enables you to receive a copy of the personal data we hold about you and to check that we are lawfully processing it.

Request correction of the personal data that we hold about you. This enables you to have any incomplete or inaccurate data we hold about you corrected, though we may need to verify the accuracy of the new data you provide to us.

Request erasure of your personal data. This enables you to ask us to delete or remove personal data where there is no good reason for us continuing to process it. You also have the right to ask us to delete or remove your personal data where you have successfully exercised your right to object to processing (see below), where we may have processed your information unlawfully or where we are required to erase your personal data to comply with local law. Note, however, that we may not always be able to comply with your request of erasure for specific legal reasons which will be notified to you, if applicable, at the time of your request.

Object to processing of your personal data 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 as you feel it impacts on your fundamental rights and freedoms. You also have the right to object where we are processing your personal data for direct marketing purposes. In some cases, we may demonstrate that we have compelling legitimate grounds to process your information which override your rights and freedoms.

Request restriction of processing of your personal data. This enables you to ask us to suspend the processing of your personal data in the following scenarios: (a) if you want us to establish the data's accuracy; (b) where our use of the data is unlawful but you do not want us to erase it; (c) where you need us to hold the data even if we no longer require it as you need it to establish, exercise or defend legal claims; or (d) you have objected to our use of your data but we need to verify whether we have overriding legitimate grounds to use it.

Request the transfer of your personal data to you or to a third party. We will provide to you, or a third party you have chosen, your personal data in a structured, commonly used, machine-readable format. Note that this right only applies to automated information which you initially provided consent for us to use or where we used the information to perform a contract with you.

Withdraw consent at any time where we are relying on consent to process your personal data. However, this will not affect the lawfulness of any processing carried out before you withdraw your consent. If you withdraw your consent, we may not be able to provide certain products or services to you. We will advise you if this is the case at the time you withdraw your consent.

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.