

MS IRELAND PRIVACY STATEMENT

Introduction

The Multiple Sclerosis Society of Ireland ("MS Ireland") is a charity, registered in Ireland as CHY05365, with its head office at **80 Northumberland Road, Dublin, Ireland**, email: info@ms-society.ie.

You should know what information we collect and how we use it.

The objectives for which MS Ireland exists are:

- to facilitate people with MS to control their lives and environment, to live with dignity and participate in the community,
- to provide support for the families and carers of people with MS,
- to co-operate with the medical, scientific, social and caring professions to promote scientific research into the cause of, cure for and management of MS, and the alleviation of medical and social symptoms,
- to exchange and disseminate information relating to MS, and
- to provide an identifiable focal point by developing an efficient, effective and caring organisation to serve the needs of people with MS.

MS IRELAND is committed to protecting the privacy of people who use our services, employment candidates and current employees, contacts, fundraisers, business partners, and other third parties we deal with, such as family members.

This Privacy Statement details how MS IRELAND collects, uses, discloses, transfers and stores your personal information. It applies to personal data about you that we collect, use and otherwise process in connection with your relationship with MS IRELAND.

MS IRELAND as Controller of your Personal Data

MS IRELAND is a nationwide charity that operates from its headquarters in Northumberland Road in Dublin, the MS Care Centre at 65 Bushy Park Road, Rathgar, Dublin 6, and through employed regional workers and offices. MS IRELAND also has a network of Voluntary Branches, each of which processes personal data submitted to it directly and/or through a client's consent when he or she has ticked the "*I would like my details sent to the nearest Voluntary Branch*" on MS IRELAND's Lifetime Membership Form or the MS Care Centre Contract of Care. Any personal information processed by MS IRELAND in connection with this Privacy Statement is ultimately controlled by a MS IRELAND as the "data controller" as provided for under the General Data Protection Regulation ("GDPR"), the Irish Data Protection Acts, 1988 to 2018, and the Data Protection Commission (DPC) Guideline for the Charity and Voluntary Sector.

The elected Secretary of each Voluntary Branch is the controller of the personal data processed in that branch.

You may request information about the personal data that MS IRELAND holds about you by emailing us at dataprotection@ms-society.ie or writing to us at 80 Northumberland Road, Dublin, Ireland.

Please note that throughout this Privacy Notice the word "website" refers to <https://www.ms-society.ie>.

Collection and Processing of your Personal Data

1. INFORMATION COLLECTED BY USING MS IRELAND WEBSITE

- 1.1 You are not required to provide any personal information to access public areas of MS IRELAND's website.
- 1.2 However, when you visit the MS IRELAND website we record your IP address and details of your visit, including the date and time. An IP address is an assigned number, similar to a telephone number, which allows your computer to communicate over the internet. In addition to your IP address the following technical information will also be collected: your login information, browser type and version, time zone setting, browser plug-in types and versions, operating system and platform, information about your visit including the full Uniform Resource Locators (URL), clickstream to, through and from the website (including date and time), pages viewed, download errors, page interaction information (such as scrolling clicks) and methods used to browse away from the website.
- 1.3 MS IRELAND uses this IP information for its legitimate interests to compile statistical data on the use of our website and to track how users navigate through our website in order to enable us to evaluate and improve.
- 1.4 Personal information such as names, addresses, email addresses, telephone numbers, and other personal data relating to services that we are providing to you will only be collected from users of the website who voluntarily input such information.
- 1.5 Focus Limited website designer in Bristol, England, acts as a data processor for MS Ireland in relation to the MS IRELAND website. In this capacity, Focus has sight of data regarding: donations, staff, the personal information of clients (including names, addresses, email addresses), enquiries and memberships.

2. CONTACT SALESFORCE DATABASE

- 2.1 We may retain information you have provided us with in MS IRELAND's contact database. Information that we typically hold in our database includes:
 - 2.1.1 your contact information, including your name; job title; organisation's name; address; phone number(s), email address(es) and other identification information;
 - 2.1.2 the area(s) that you have an interest in,
 - 2.1.3 historical fundraising activity for MS IRELAND.
- 2.2 Once your details are included in MS IRELAND's contact database we may also record details of any:
 - 2.2.1 MS IRELAND's mailing lists you have subscribed to or unsubscribed from;

- 2.2.2 mailings (including services updates and event invitations) we have sent you;
 - 2.2.3 hyperlinks you have clicked in any mailing that we have sent you;
 - 2.2.4 meetings we have held with you;
 - 2.2.5 event invitations you have replied to; and
 - 2.2.6 events you have attended.
 - 2.2.7 your care records.
- 2.3 From time to time we may ask you by email to review your contact details and preferences, and update them as necessary. This not only helps us to keep the contact information we hold about you up-to-date, it also ensures that we only send you information that you have requested and/or is relevant to you.

3. INTERACTIONS WITH MS IRELAND

We retain personal information relating to interactions between MS IRELAND and people who use our services, clients, job applicants and current employees, contacts and business partners, including information relating to the services that we provide. We only retain information that is necessary for the purposes set out in this Privacy Statement.

4. PROCESSING OF YOUR PERSONAL INFORMATION

- 4.1 MS IRELAND, in the MS Care Centre, the regional offices, and throughout its network of Volunteer Branches, will only collect and process personal information where it has a legal basis for doing so. This includes where MS IRELAND is providing a service to you or fulfilling a Care Centre or Regional Office contract with you, where MS IRELAND has to comply with a legal duty, where you consent to the collection and use, where MS IRELAND has a legitimate interest in collecting and processing the personal information, or where the processing is necessary in the public interest. When personal information is processed, the basis of processing will be in accordance with relevant Irish and EU data privacy laws, our legal obligations and to meet our information security requirements.
- 4.2 MS IRELAND uses personal information which we have collected from you in order to:
- 4.2.1 provide you with a more tailored and effective service and/or care;
 - 4.2.2 perform analysis aimed at improving our products, services and technologies for people with MS;
 - 4.2.3 communicate with you through certain mandatory service communications such as welcome letters, appointment reminders and our terms and conditions;
 - 4.2.4 communicate with you in connection with any services that we are providing to you and otherwise perform the services for you that you have engaged us to provide;
 - 4.2.5 ensure compliance with regulatory requirements and applicable law;

- 4.2.6 provide updates and newsletters, including our MS News magazine by mail and our electronic newsletter, and invitations to events and meetings;
 - 4.2.7 carry out administrative purposes (including within the MS IRELAND regional offices and the network of Voluntary Branches), which may include, for example, accounting and billing, auditing and identification checking;
 - 4.2.8 undertake systems testing, maintenance and development in order to ensure network and information security;
 - 4.2.9 to let you know ways you can get involved in our fundraising and campaigns;
 - 4.2.10 when you are making a donation, registering for a campaign or event, as appropriate, you may be asked to provide personal details such as name, email address, postal address, phone number or payment information as needed;
 - 4.2.11 prevent fraud; and
 - 4.2.12 market our services and products to you where MS IRELAND has a legitimate interest or you have consented to us doing so and in accordance with your preferences.
- 4.3 MS IRELAND will only collect, use and otherwise process information revealing racial or ethnic origin, political opinions, religious beliefs or relating to your health or sexual orientation or otherwise which is treated by applicable data protection laws as a "sensitive" or "special" category of personal information, where and only to the extent that you have given your explicit consent unless we are otherwise permitted or required to collect, use and process such information under applicable data protection laws, including but not limited to where this is necessary in connection with providing our agreed services to you.
- 4.4 Any data collection that is optional will be made clear to you. However MS IRELAND may need to collect and process personal information for certain legal compliance purposes or in order to perform certain services for you, including compliance with legal requirements relating to our anti-fraud, anti-money laundering or 'know your customer' obligations. If you choose not to give us this personal information then it may delay or prevent MS IRELAND from meeting MS IRELAND's obligations or it may mean that MS IRELAND cannot perform certain services for you. MS IRELAND will advise you if this is the case.

5. MARKETING and INFORMATION COMMUNICATIONS by MS IRELAND

- 5.1 We may wish to use the personal information that we collect about you to provide you with relevant marketing communications. This may include sending tailored direct marketing and information e-mails and other communications relating to our services or those of our MS IRELAND regional offices or Voluntary Branches, and sending you invitations to seminars and other events related to the care of yourself or your family member.
- 5.2 We shall only send such marketing communications to you to the extent that doing so is in the legitimate business interests of MS IRELAND or where you have consented to us doing so. As set out in the Data Subjects Rights table below, you may withdraw that consent at any

time by contacting us at dataprotection@ms-society.ie. In addition, each electronic communication that you receive shall have a very clear "unsubscribe" option, which will allow you to stop receiving similar communications in the future.

6. EXCHANGE OF INFORMATION

6.1 MS IRELAND shares data between our regional offices and our Voluntary Branches, where necessary, for the purposes outlined in this Privacy Statement. MS IRELAND ensures that your personal information is shared in accordance with applicable data protection laws, at all times providing protection to your personal information and your rights.

7.1 MS IRELAND has relationships with third parties in order to provide services for people with MS, such as medical professionals. In some instances we may disclose your personal information to third parties where this is necessary to perform the services for which you have engaged MS IRELAND or otherwise in furtherance of an outsourcing or other data processing arrangement. In those circumstances MS IRELAND will ensure that the third party is contractually bound to only process personal information in accordance with applicable data protection laws and with MS IRELAND's specific instructions and requirements, and at all times in a manner that protects your rights under applicable data protection laws. Our suppliers and service providers will be required to meet our standards on processing information and security. The information we provide them, including your information, will only be provided in connection with the performance of their function. They will not be permitted to use your information for any purposes other than those outlined in this Privacy Statement.

7.2 In relation to any other third parties, MS IRELAND will only disclose or transfer your information where you have given your consent or where we are required to do so by law or other regulatory code or practice.

7. TRANSFER OF INFORMATION ABROAD

8.1 In very rare circumstances, personal data may be transferred to or accessed from countries whose laws provide a level of protection for personal data, not always equivalent to the level of protection that may be provided in your own country. In particular if you are located inside the European Economic Area ("**EEA**") your personal information may be transferred to a country outside of the EEA.

8.2 MS IRELAND ensures that cross border transfers comply with all relevant laws and regulations and in addition, we enforce the highest privacy and data management standards across all our offices through MS IRELAND Data Protection Policy. A copy of that policy may be obtained by contacting MS IRELAND at dataprotection@ms-society.ie.

8.3 Unless:

8.3.1 you have expressly consented to the transfer of personal information;

8.3.2 the transfer is necessary for the performance of the services for which MS IRELAND has been engaged or the conclusion or performance of a contract concluded in your interests; or

8.3.3 the transfer is otherwise permitted by applicable data protection laws,

MS IRELAND will only transfer your personal information to a country that is deemed to have an adequate level of protection under the applicable data protection law or otherwise where MS IRELAND has put in place adequate safeguards to protect the personal information. In particular where MS IRELAND sends your personal information outside of the EEA, MS IRELAND shall only do so where the recipient of the information is subject to:

8.3.4 binding corporate rules;

8.3.5 standard data protection clauses approved under applicable law;

8.3.6 an approved code of conduct; or

8.3.7 an approved certification mechanism.

8.4 Further details on the safeguards adopted by MS IRELAND may be obtained by contacting MS IRELAND at dataprotection@ms-society.ie.

8. DATA RETENTION

MS IRELAND shall only retain your personal information for so long as there is a reasonable need to retain the information for the purposes set out in this Privacy Statement. Further details on MS IRELAND's policy in relation to retention periods can be found in our Record Retention Policy. A copy of that policy may be obtained by contacting MS IRELAND at dataprotection@ms-society.ie.

The MS Care Centre is registered as a provider by the Health Information and Quality Authority (HIQA) and complies with HIQA's *Information Management Standards for National Health and Social Care Data Collections*.

9. PROTECTION OF YOUR PERSONAL DATA

MS IRELAND is committed to protecting the security of your personal information. We use a variety of security technologies and procedures to help protect your personal information from unauthorized access, use, or disclosure, across all of our computer systems, networks, website, mobile phones, regional offices and Voluntary Branches.

Data Subject Rights

You have rights in respect of the personal data that we collect and process concerning you.

Access	<p>You are entitled to details concerning the processing of your personal data. This includes details of the data being processed, the purposes of the processing, any recipients of your data, the period for which the information is processed, the source of the information, any international transfers of the information and how we protect it. You may also request details of any automated decision making, including profiling, of your personal data.</p> <p>You are entitled to a copy of the personal data we process about you.</p>
Corrections	<p>You are entitled to have any incomplete and inaccurate personal information held by us corrected on request.</p>
Right to be Forgotten	<p>In some cases, you may request to have your personal data erased where the data is no longer necessary for the purposes for which it was collected and/or processed or you withdraw consent to our use of it.</p> <p>We may advise that we must continue processing your data if there are grounds other than your consent for processing your data, where processing is in compliance with a legal obligation, for reasons of public interest or for the exercise or defense of legal claims.</p>
Restrict Processing	<p>You can ask us to restrict the processing of data MS IRELAND holds about you if you dispute the accuracy of the data we process about you or if you have objected to the grounds upon which we process the information.</p> <p>Where you have asked us to restrict processing the information we shall only hold, process and erase the information as permitted by you or as permitted by the Data Protection Acts, 1988 to 2018 or the GDPR. We will advise you if we do not agree with your request.</p>
Data Portability	<p>Where processing of your data is carried out by automatic means, you are entitled to receive a copy of that information in a machine-readable format and for that to be provided to another data controller, where technically possible.</p>

<p>Object</p>	<p>You may object to MS IRELAND collecting, using and otherwise processing your personal data where the basis for the processing is MS IRELAND's legitimate interests or the processing is in the public interest. In such circumstances we shall cease processing your personal information unless we are legitimately processing the information on a different basis, there are compelling legitimate grounds for continuing to process the personal information, or we are otherwise permitted to under applicable data protection laws, which MS IRELAND will so advise.</p>
<p>Withdraw Consent</p>	<p>Where you have given us consent to process your personal data for any of the purposes outlined in this Privacy Statement and we have no other legal basis for processing, you shall be entitled to withdraw that consent.</p>
<p>Right to Complain</p>	<p>If you have concerns or complaints regarding this Privacy Statement or the manner in which MS IRELAND collects, uses and otherwise processes your personal data we would like to hear from you.</p> <p>If you consider that we have not processed your data according to these rights and we have not addressed your complaint in this regard, you are entitled to lodge a complaint in Ireland to the Data Protection Commission at www.dataprotection.ie.</p>

This Privacy Statement may be updated from time to time.

The current version of this Privacy Statement can be found on the MS IRELAND website or may otherwise be requested at dataprotection@ms-society.ie.

Contact Information

If you have any questions in relation to this Privacy Statement please contact us at dataprotection@ms-society.ie.