

Muscular Dystrophy Ireland Privacy Statement/Notice

Muscular Dystrophy Ireland (MDI) commits to:

1. Obtain and process information fairly.
2. Keep it only for one or more specified, explicit and lawful purposes.
3. Use and disclose it only in ways compatible with these purposes.
4. Keep it safe and secure.
5. Keep it accurate, complete and up-to-date.
6. Ensure that it is adequate, relevant and not excessive.
7. Retain it for no longer than is necessary for the purpose or purposes needed.
8. Give a copy of their personal data to that individual, on request.

About Muscular Dystrophy Ireland

Muscular Dystrophy Ireland (MDI) is a national membership organisation that provides support to people who are living with neuromuscular conditions and to their families. We are both a registered charity and a company limited by guarantee.

Our commitment to your privacy

Muscular Dystrophy Ireland is committed to protecting the privacy and personal data of our members, supporters and other stakeholders in compliance with the Data Protection Acts 1988 and 2003, as amended in 2018, and will comply with all applicable legislation including the General Data Protection Regulation (GDPR 2016/679), and the Irish Privacy and Electronic Communications Regulations 2011.

This policy outlines how MDI collects, processes, stores and manages the personal data you provide to us. Please read the policy carefully to understand our views and practices regarding your personal data and how we will treat it. By visiting www.mdi.ie and all sub-domains you are accepting and consenting to the practices described in this policy. Please note the terms of this policy are subject to change, so please review before supplying any information.

Queries

If you have any queries in relation to this policy or to request a copy of Muscular Dystrophy Ireland's data protection privacy policy, please contact the Data Protection Lead at mdiinfo@mdi.ie or phone 01 623 6414.

For the purposes of the GDPR, the data controller is Muscular Dystrophy Ireland.

Our site and subdomains may, from time to time, contain links to and from the websites of strategic partners. If you follow a link to any of these websites, please note that these websites have their own privacy policies and that we do not accept any responsibility or liability for these policies, or for their subsequent processing of your personal data. Please check these policies before you submit any personal data to these websites.

Personal data we may collect about you

Muscular Dystrophy Ireland collects details provided by you for the purpose of becoming a member, using MDI services, subscribing to our newsletter and Ezine, making donations, sponsoring someone taking part in an event or activity, making a direct debit, recruiting and managing staff and volunteers. All information that we hold concerning you as an individual will be held and processed by MDI strictly in accordance with the provisions of the Data Protection Acts 1988 and 2003, as amended in 2018. Such data will be used by the organisation to administer our relationship with you as a valued member or stakeholder and to provide you with information about MDI activities, services, events and news.

The types of personal data you give us

You may give us personal data about you, when you enquire about our services and activities, become a member, request information, fill in forms on our website, www.mdi.ie, or correspond with us by phone, text, e-mail or social media. This includes, but is not limited to, information you provide when you share information via websites which we manage. The types of information are:

- **Personal Data** – this includes any information that identifies you, either directly or indirectly. For example, it may include your first name, last name, postal address, e-mail address, phone number, date of birth, gender, financial and credit card and debit card information, your personal preferences about being contacted, your comments about our services and your photograph. This information will be collected if you submit it to us yourself, or where you have consented to a third-party contacting us on your behalf. This information can be captured through direct contact initiated by you or by your filling out the following forms, either online or on paper, for example:
 - Membership form
 - Conference registration
 - Online event registration
 - Testimonial form
 - Donation form
 - Subscription to e-zine
 - Subscription to newsletter
 - Contact request
 - Fundraising activity or event registration
 - Job application
 - Volunteer application.
- **Special Categories of Personal Data** – These categories include, health/medical information, genetic data, racial/ethnic origin, political opinions, religious or philosophical beliefs, trade union membership, and data related to sexual orientation. We only process this data in line with the Lawful Processing Conditions: Special Categories (Article 9) of the GDPR.
- **Non-identifiable Data** – this information is collected from visitors to our website, through cookies (small files that transfer to your computer's hard drive when you browse a website), and may include your IP address, the pages you visited, the browser you use, for example. This information is not stored by us in relation to the service we provide to you but can be used in the short term. We will make no attempt to identify individual visitors, or to associate technical details listed above with any individual. The information is

used to allow us to improve the information we are supplying to our users, find out how many people are visiting our sites and for statistical purposes. Some of the above information is used to create summary statistics which allow us to assess the number of visitors to the different sections of our site, discover what information is most and least used, inform us on future design and layout specifications, and help us make our site more user friendly.

Our use of your personal data

All information that we hold concerning you as an individual will be held and processed by MDI strictly in accordance with the provisions of the Data Protection Acts 1988 and 2003, as amended in 2018. The information you provide will be used solely for the purpose for which you provided it.

Operational purposes

We may use your personal data for a number of operational purposes, including, but not limited to:

- Carrying out our obligations arising from any contracts entered into between you and us and to provide you with the information and services that you request from us
- Providing you with information about other opportunities to support Muscular Dystrophy Ireland where you agree to receive such information
- Furthering our charitable aims, including for fundraising activities, where you agree to receive such information
- Providing you, or permitting selected third parties to provide you, with information about services, research, treatments and clinical trials we feel may interest you, where you agree to receive such information.

Such Data will be used by the organisation to administer our relationship with you as a member or stakeholder and to provide you with information about MDI activities, services, events and news. We will contact you using the contact information you provided upon signing up to MDI for that purpose.

Security – How do we store and protect your information?

MDI takes, and will continue to take, all reasonable steps (which includes relevant technical and organisational measures) to guarantee the safety of the data you provide to us and we will only use the data for the intended purpose.

Once we have received your information, we will take all reasonable technical, organisational procedures and security features to try to prevent unauthorised access to, unlawful processing or disclosure of your personal data.

Muscular Dystrophy Ireland will take all reasonable steps necessary to ensure that your personal data is processed securely and in accordance with this Privacy Policy.

Disclosure of your information

We may disclose your personal information to third parties in the following circumstances:

- If we are under a duty to disclose or share your personal data in order to comply with any legal obligation, or to protect the rights, property, or safety of any Muscular Dystrophy Ireland entities, our service recipients or others. This includes exchanging information with other companies and organisations for the purposes of national security, fraud protection and credit risk reduction.
- Where we engage the services of third parties, such services are covered by an appropriate contract, and any data acquired in the course of such services is processed in compliance with the GDPR.

Access to information

Muscular Dystrophy Ireland will endeavour to ensure that the information we hold will be accurate and up to date. The accuracy of your information is important to us.

Please inform us of any changes to your personal information.

Your rights with regard to your information

As an individual, you have a right under the Irish Data Protection legislation, to obtain information from us with regard to our processing of your data.

You have the right to access personal data we hold which relates to you, including a description of the data we hold on you, how we acquired such data, and the

purposes for which it is being used. This right requires that you will be given a copy of your personal data which you may have supplied to us via the Site or in other correspondence and interactions.

To exercise this right, you must make your request in writing, posting it to our address as specified and including with the request an item such as a utility bill which will verify your address and identity. No fee is required for this service.

Data Protection Lead
Muscular Dystrophy Ireland
75 Lucan Road
Chapelizod
Dublin 20 DR77

A request will be dealt with as soon as possible and we will endeavour to respond to your request within one month from the date on which your request was received. You have the right to have inaccurate personal data corrected. If you discover that we hold inaccurate personal data about you, you have a right to instruct us to correct that information. Such an instruction must be in writing and must contain evidence of the correct information. We will respond as soon as possible, and in any event within one month from the date on which your instructions are received. Furthermore, we will share your corrective instructions with any organisation with whom the incorrect information has been shared in the 12 months prior to the date of your instructions. In certain circumstances, you have the 'Right to be Forgotten'. This means that you can request that Muscular Dystrophy Ireland removes any and all references to you from our records and systems. We will comply with all such requests in a timely manner, as required by the Data Protection Regulation, unless other operational or legal obligations require us to retain such data for a particular purpose or period of time.

You have the right, at all times, to restrict or object to processing of your personal data which you find intrusive, excessive or unwarranted. Muscular Dystrophy Ireland will respect your right to do so but may need to continue such processing where required do to so by law, or within the terms of an existing contractual arrangement.

You have the right to data portability (to obtain data that a data controller holds on you and to reuse it for your own purposes) where technically feasible and appropriate.

If you feel your personal data has been processed inappropriately, please let us know and we will do everything we can to rectify the situation. You have the right to lodge a complaint with the Irish Office of the Data Protection Commission if you feel your rights or freedoms have been infringed upon. This can be done by clicking the link <https://forms.dataprotection.ie/contact>.

Your Consent

When you access our website, www.mdi.ie, you will have an opportunity to review our Privacy Policy. By continuing to use our website, you indicate that you agree with the provisions of that Policy (this page).

- By providing us with your personal data and indicating your preferences with regard to the processing of such data, you have the opportunity to consent to the collection and use of this information in accordance with the purposes described. Where you provide us with your consent, you agree to allow us to share your details with third parties whom we engage to carry out services on our behalf; such services are covered by an appropriate Data Processor contract, and we undertake that any data acquired in the course of such services is processed in compliance with the GDPR.

Changes to our privacy policy

We reserve the right to make changes to our privacy policy at any time.

Any changes we may make to our privacy policy in the future will be posted on this page.

Please check this page occasionally to see any updates or changes to our privacy policy.

Regularly reviewing this page ensures you are always aware of what information we collect, how we use it and under what circumstances.

What if I do not agree with this privacy policy?

If you do not agree to our processing of your data in the manner outlined in the policy, please do not submit any personal data to us.

Contact Us

Questions, comments and requests regarding this privacy policy are welcomed and should be addressed to:

Data Protection

Muscular Dystrophy Ireland,

75 Lucan Road

Chapelizod

Dublin

D20 6414

Email: mdiinfo@mdi.ie

Tel: 01 623 6414