

POLICY 40 – PRIVACY

Developed by

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40.1 Introduction

- 40.1.1 This Privacy Policy outlines how the MJD Foundation Limited (**MJD Foundation**) aims to protect the privacy of your personal information, your rights in relation to your personal information managed by the MJD Foundation and the way the MJD Foundation collects, holds, uses and discloses your personal information.
- 40.1.2 It also outlines how you can seek access to and correct your personal information and make a privacy complaint.
- 40.1.3 In handling your personal information, the MJD Foundation complies with the *Privacy Act 1988* (Cth) (**Privacy Act**), the 13 Australian Privacy Principles in the Privacy Act and all relevant Australian privacy laws.
- 40.1.4 This Privacy Policy was last updated on 23 January 2023.

40.2 Personal Information we collect and how we use and disclose it

40.2.1 Clients (individuals who we assist)

40.2.1.1. What kinds of personal information do we collect about you and how do we collect your personal information?

Generally, the kinds of personal information we collect about you include your contact and identification information such as your name, address, telephone number, date of birth, email address or any other verification details. We may also collect your sensitive information (which includes health information), such as medical records from your health clinic and information about your age and/or disability. We may also collect research data that may include your personal information. We may also collect images of your face in a photograph and/or recording of your voice and/or face in a film or video (with your consent). We may also collect other information required for the MJD Foundation's functions and activities and in some circumstances, we may also hold other personal information provided by you.

If we are collecting research data, we will ask for your consent for each separate research project.

We collect most of your personal information directly from you, including when we interact with you in person, in writing by way of email or post, by telephone/video conference or through our website or any other website of a related entity or partner. We may also collect your personal information from other sources such as your family members or carers, clinics, the NDIA, hospitals and government agencies. Generally, the MJD Foundation will only collect your personal information from sources other than you if it is unreasonable or impracticable to collect your personal information from you.

40.2.1.2. Why do we need your personal information?

We collect, hold, use and disclose your personal information where it is reasonably necessary for the purposes of:

- a) providing our goods (including equipment) and services and advice to you and enabling you to participate in our programs;
- b) enabling us to communicate with you about the goods or services we are providing you or the program you are participating in;
- c) informing you about our goods, services and/or programs which we think you may be interested in;
- d) improving our goods, services and programs;
- e) processing donations or sponsorships;
- f) applying for subsidies and grants;
- g) medical research and testing;
- h) providing medical care;
- i) raising awareness and/or funding for the MJD Foundation and research to help find a treatment or cure for Machado-Joseph Disease;
- j) accounting, billing and other internal administrative purposes;
- k) complying with our legal obligations; and
- l) otherwise managing the MJD Foundation's internal business operations and processes.

The MJD Foundation may also use your personal information for purposes related to the above purposes and for which you would reasonably expect the MJD Foundation to do so in the circumstances, or where you have consented, or where the use is otherwise in accordance with law.

Where your personal information is used or disclosed, the MJD Foundation takes steps reasonable in the circumstances to ensure it is relevant to the purpose for which it is to be used or disclosed. You are under no obligation to provide your personal information to the MJD Foundation. However, without certain information from you, the MJD Foundation may not be able to provide its products and/or services and/or programs to you.

40.2.1.3. To whom do we disclose your personal information?

The MJD Foundation discloses your personal information for the purpose for which the MJD Foundation collects it. That is, generally, the MJD Foundation will only disclose your personal information for a purpose set out at paragraph 40.2.1.2.

Further, we will talk to you and ask you to sign Client Authorisation forms, requesting your consent before we share your personal information (including any medical records, research records and other personal information such as images and voice recordings of you).

Generally, this may include disclosing your personal information to:

- a) third parties who assist us in supplying our goods, services and programs or who perform functions on our behalf, to other third parties where required by law and to anyone else to whom you authorise us to disclose it;
- b) relevant government agencies to apply for subsidies and grants or audit processes, including Centrelink, NDIA, etc;
- c) Northern Territory Government, Queensland Government and Northern Territory/Victorian Clinical Genetics Services;

- d) Councils such as the Aboriginal Land Council, Local/Regional Councils;
- e) service providers who help us with our functions and activities including [e.g. marketing services];
- f) the MJD Foundation's professional advisors, agents, contractors, consultants and related bodies;
- g) support providers such as disability support providers, residential support providers, etc; and
- h) insurance providers.

From time to time, we may compile statistical data from the personal information we have collected. In these instances, the data will be aggregated and de-identified before it is disclosed to third parties.

The disclosures of your personal information from the MJD Foundation to third parties are on a confidential basis and/or otherwise in accordance with law. The MJD Foundation may also disclose your personal information with your consent or if disclosure is required or authorised by law.

40.2.2 Donors

40.2.2.1. What kinds of personal information do we collect about you and how do we collect your personal information?

Generally, the kinds of personal information we collect about you include your contact and identification information such as your name, address, telephone number, date of birth, email address or other verification details. We may also collect details regarding your credit card, banking details, financial details or other payment details or any other information as required to carry out the MJD Foundation's functions and activities.

We collect your personal information directly from you when you provide your information to us in person, in writing by way of email or post, by telephone/video conference, through our website or the website of a related entity or partner or via third party fundraising platforms when donating funds to us.

40.2.2.2. Why do we need your personal information?

We collect, hold, use and disclose your personal information where it is reasonably necessary to enable us to process your donation, communicate with you about your donation, inform you about our goods, services and/or programs which we think you may be interested in, accounting, billing and other administrative purposes, complying with our legal obligations and otherwise managing the MJD Foundation's internal business operations and processes.

The MJD Foundation may also use your personal information for purposes related to the above purposes and for which you would reasonably expect the MJD Foundation to do so in the circumstances, or where you have consented, or where the use is otherwise in accordance with law.

Where your personal information is used or disclosed, the MJD Foundation takes steps reasonable in the circumstances to ensure it is relevant to the purpose for

which it is to be used or disclosed. You are under no obligation to provide your personal information to MJD Foundation. However, without certain information from you, the MJD Foundation may not be able to process your donation and/or involve you in the products, services and programs it provides.

40.2.2.3. To whom do we disclose your personal information?

The MJD Foundation discloses your personal information for the purpose for which the MJD Foundation collects it. That is, generally, the MJD Foundation will only disclose your personal information for a purpose set out at paragraph 40.2.2.2.

This means that, if you provide consent, we may publicly acknowledge you as a donor.

We do not disclose your personal information to other charities (including to enable them to send you information about their goods, services and programs) or other third parties unless required or authorised by law or with your consent. If this is the case, disclosures of your personal information from the MJD Foundation to third parties are on a confidential basis and/or otherwise in accordance with law.

40.2.3 Employees and prospective Employees/ Volunteers/ Contractors

40.2.3.1. What kinds of personal information do we collect about you and how do we collect your personal information?

Generally, the kinds of personal information we collect about you include your contact and identification information such as your name, date of birth, address, telephone number, email address or any other verification details. We may also collect other personal information including your gender, work history, qualifications, tax file number, bank account details, referee information and any other information you include in your application and, in respect of contractors, payment details.

We may also collect sensitive information about you, including your health information, such as when you are applying for a position at the MJD Foundation and the personal information is relevant to the recruitment process through which you must progress (including working with children or criminal record checks) or where you are an employee and the health information is relevant to your employment with the MJD Foundation.

In some circumstances, the MJD Foundation may also hold other personal information about you.

We collect this personal information directly from you when you provide your information to us in person or in writing by way of email or post, or by telephone/video conference or through our website when applying for, enquiring about, or registering for opportunities with us. We also collect your personal information from your nominated referees, and through criminal history and working with children checks.



Generally, the MJD Foundation will only collect your personal information from sources other than you if it is unreasonable or impracticable to collect your personal information from you.

40.2.3.2. Why do we need your personal information?

We may collect, hold, use and disclose your personal information where it is reasonably necessary for the purposes of processing and assessing your application for current and future positions with MJD Foundation (including volunteer positions), allowing you to provide services to us (including communicating with you about those services), providing training to you, communicating with you about opportunities with us, improving our services, informing you about our good, services and/or programs which we think you may be interested in, accounting, billing and other internal administrative operations, complying with our legal obligations and otherwise managing the MJD Foundation's internal business operations and processes.

The MJD Foundation may also use your personal information for purposes related to the above purposes and for which you would reasonably expect the MJD Foundation to do so in the circumstances, or where you have consented, or where the use is otherwise in accordance with law.

Where your personal information is used or disclosed, the MJD Foundation takes steps reasonable in the circumstances to ensure it is relevant to the purpose for which it is to be used or disclosed. You are under no obligation to provide your personal information to the MJD Foundation. However, without certain information from you, the MJD Foundation may not be able to process your application and/or involve you in the products, services and programs it provides.

40.2.3.3. To whom do we disclose your personal information?

The MJD Foundation discloses your personal information for the purpose for which the MJD Foundation collects it. That is, generally, the MJD Foundation will only disclose your personal information for a purpose set out at paragraph 40.2.3.2.

Generally, this may include disclosing your personal information to individuals (such as our clients) participating in our programs, third parties who assist us in supplying our goods, services and programs or who perform functions on our behalf and other third parties where required by law (including Government agencies to conduct criminal history and working with children checks).

The disclosures of your personal information from the MJD Foundation to third parties are on a confidential basis and/or otherwise in accordance with law. MJD Foundation may also disclose your personal information with your consent or if disclosure is required or authorised by law.

40.2.4 iTunes App Users – MJDF Digital Keyboard

40.2.4.1. What kinds of personal information do we collect about you and how do we collect, use or disclose your personal information?

We do not collect, hold, use or disclose any personal information about you when you use the MJDF Digital Keyboard application.

We do not collect, hold, use or disclose any data or messages when you use the MJDF Digital Keyboard application.

40.3 Overseas disclosures

- 40.3.1 The MJD Foundation does not disclose any personal information to overseas recipients.
- 40.3.2 However, if the MJD Foundation becomes likely to disclose personal information to any recipients located overseas, the MJD Foundation will update this privacy policy regarding the likely disclosures (including, if it is practicable to do so, the countries in which such overseas recipients are likely to be located).

40.4 Direct marketing

- 40.4.1 The MJD Foundation may collect, hold, use and disclose personal information in order to inform interested persons or entities of goods, services and/or programs offered by the MJD Foundation or to facilitate business relationships.
- 40.4.2 Individuals can opt-out of receiving such communications by contacting the MJD Foundation on the contact details set out in paragraph 40.9 below or through any opt-out mechanism contained in a marketing communication.

40.5 Storage and Security

- 40.5.1 We hold personal information in both electronic and hard-copy forms in secure databases on secure premises, accessible only by authorised staff. We may store your personal information with a third-party storage provider. Wherever possible we will store data inside Australia, however we may also store personal information in the 'cloud' which may mean that it resides on encrypted servers which are situated outside Australia.
- 40.5.2 The MJD Foundation takes steps reasonable in the circumstances to ensure that the personal information it holds is protected from misuse, interference and loss and from unauthorised access, modification and disclosure.
- 40.5.3 The MJD Foundation will destroy or de-identify personal information in circumstances where it is no longer required, unless the MJD Foundation is otherwise required or authorised by law to retain the information.

40.6 How to access or correct your personal information

- 40.6.1 The MJD Foundation takes steps reasonable in the circumstances to ensure personal information it holds is accurate, up-to-date, complete, relevant and not misleading. Under the Privacy Act, you have a right to access or seek correction of your personal information that is collected and held by the MJD Foundation. If at any time you would like to access or correct the personal information the MJD Foundation holds about you, or you would like more information on the MJD Foundation's approach to privacy, please contact the Privacy Officer using the contact details below.

- 40.6.2 The MJD Foundation will grant access to your personal information to the extent required or authorised by the Privacy Act and take steps reasonable in the circumstances to correct your personal information where necessary and appropriate.
- 40.6.3 To obtain access to your personal information:
- (a) you will have to provide proof of identity to ensure that personal information is provided only to the correct individuals and that the privacy of others is protected;
 - (b) the MJD Foundation requests that you be reasonably specific about the information you require; and
 - (c) the MJD Foundation may charge you a reasonable administration fee (clients are exempt from this fee), which reflects the cost to the MJD Foundation for providing access in accordance with your request.
- 40.6.4 The MJD Foundation will endeavour to respond to your request to access or correct your personal information within 30 days from your request.
- 40.6.5 If the MJD Foundation refuses to provide you with access to the personal information, the MJD Foundation will provide you with the reasons for the refusal and inform you of any exceptions relied upon under the Australian Privacy Principles, unless it would be unreasonable to do so.

40.7 Cookies

- 40.7.1 When you are accessing the MJD Foundation's website, the MJD Foundation uses 'cookies' which are small pieces of information sent from the website and stored by your browser on your computer's hard drive. Cookies that the MJD Foundation uses enable its systems to provide features of its services and allow you to visit its website without re-entering your username and/or password, personalize and improve your experience, and improve the functionality and user-friendliness of its services and monitor how its website is used through your computer.
- 40.7.2 This information is used by the MJD Foundation to improve and tailor its website functionality and better understand how you interact with the MJD Foundation's goods, services and/or programs and to monitor aggregate usage and web traffic routing on its website. You can modify your browser setting by editing your browser options to reject the MJD Foundation's cookies or to prompt you before accepting a cookie. However, if a browser does not accept cookies or if you reject a cookie, some portions of the MJD Foundation's online services may not function properly.
- 40.7.3 Our website contains links to other websites. When you access a website other than ours, we are not responsible for the privacy practices of that site. We recommend that you review the privacy policies of each website you visit.

40.8 Complaints

- 40.8.1 If you wish to make a complaint about a breach of any privacy laws by the MJD Foundation, please contact our Privacy Officer using the details below. We may request that you make your complaint in writing. We will investigate any complaint and will notify you of the outcome following the completion of the investigation.
- 40.8.2 At all times, privacy complaints:

- (a) will be dealt with seriously;
- (b) will be dealt with promptly;
- (c) will be dealt with in a confidential manner; and
- (d) will not affect your existing obligations or affect any commercial or other arrangements between you and the MJD Foundation.

40.8.2 In the event you are dissatisfied with the outcome of your complaint, you have the right to contact the Office of the Australian Information Commissioner by phoning 1300 363 992 or by visiting www.oaic.gov.au for further information.

40.9 Contact us

40.9.1 If you have any questions relating to this Privacy Policy please contact our Privacy Officer: Jacquie Hatt (Acting CEO) jacquie.hatt@mjd.org.au 1300-584-122

40.10 Updates to this Privacy Policy

40.10.1 This Privacy Policy may be updated from time to time. We will display a notice on our website www.mjd.org.au for a reasonable period after any material revisions have been made. We will keep the current version of this Privacy Policy on that website.