Privacy Policy

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Drafted by:	Meagan Henry, Operations & Administrations Coordinator	Approved by Board on	August 2026
Responsible person:	Amy Coote, CEO	Scheduled review date:	August 2028 (subject to any changes to legislation or the Privacy Act)

1. Introduction

M Riewoldt Holdings Limited (t/a Maddie Riewoldt's Vision) (**MRV**) is an Australian registered company and not for profit, registered charity. MRV funds vital research to accelerate next generation prevention, diagnosis and treatments for Bone Marrow Failure Syndromes, while providing support, guidance and resources to patients and their families.

When handling your personal information, MRV complies with the relevant privacy laws despite MRV not being subject to some of these laws. These privacy laws include the *Privacy Act 1988* (**Privacy Act**) and relevant state and territory health privacy laws.

2. Purpose

The purpose of this policy is to provide information to you, those we assist and our donors about how we collect and handle (use, disclose and store) your personal information and, where applicable, your sensitive information (including health information).

This policy is also a framework for how Maddie Riewoldt's Vision will handle personal and sensitive information internally.

We may update this policy from time to time when our information handling practices change.

3. Definitions

Personal information means information or an opinion about an identified individual, or an individual who is reasonably identifiable, whether the information or opinion is true or not, and whether the information or opinion is recorded in a material form or not.

Sensitive information is a type of personal information and includes health information, genetics, race, political opinion or membership, religion, philosophical beliefs, union membership, sexual preference, criminal record and biometrics and biometric templates.

Health information includes information about physical or mental health or a disability an individual has had at any time, an individual's express wishes about future provision of health services to him or her, any health service that has been or is to be provided to an individual, any personal information collected to provide or in providing a health service, information collected in connection with a donation or intended donation of body parts, organs or body substances, genetic information that is or could be predictive of health at any time of the individual or a relative of the individual and healthcare identifiers.

4. Types of personal information we collect

The kinds of personal information we may collect will vary depending on the purpose of our interaction with you and may include the following:

- **identifying information** about you such as your name, gender and date of birth;
- **contact details** such as your postal address, email address and phone number;
- **information about your background** (e.g.: ethnicity, languages spoken)
- **financial information** such as your bank account and credit card details and donation amounts (if you are a donor);
- **business details** such as your position and business contact details; and
- **photographs** and other images of you if you have consented to this and where you are identifiable.

If we provide you with our Tele-Support Service, we may also collect the following personal and sensitive information about you:

- **health information** such as the information you provide to us and the notes we make during the course of providing health services to you, your medical history and disability information, and results or diagnoses from consultations undertaken by other healthcare professionals/specialists.

We may also collect information about how you use our website, such as:

- pages you visit;
- online forms you fill in;
- your interactions with our website;
- your language preferences; and
- searches you make.

5. How we collect your information

We collect your personal information through a variety of means. This includes directly from you when you engage with us and, on occasions, indirectly.

We may also collect personal information from you via mail, email, or via our website or other internet applications including social media (e.g. Facebook, Twitter), or by phone.

We may also collect personal information about you from third parties in the following circumstances:

- from your guardian, parent, family member or carer.

Where your personal information is collected from a third party, we will take steps to inform you of this (if you are over 18). This may occur through this Privacy Policy, verbal notices from staff, or other forms relevant to the collection of your personal information.

6. How we will use and disclosure your information

Use of personal information

We use your personal information where it is reasonably necessary for one or more of our functions or activities.

To deliver our services

We may use your personal information to provide services to you. This may involve:

- confirming your identity;
- communicating with you; and
- providing our services to you such as:
    - Tele-Support Service
    - Peer Support Program; and
    - Research.

To provide updates on our services and events.

We may use your personal information for the purposes of providing you with updates on the services we provide and where we will be providing them.

Where you have subscribed to such services, we may use your personal information to send you our news and updates and to alert you to upcoming events. Further information on how you may opt out of this service is available below under the heading 'Requests to Stop Direct Marketing From Us'.

To process donations

Where you have donated to MRV, we may collect personal information about you in order to process that donation and communicate with you about other opportunities to donate.

Disclosure of personal information

We may disclose your personal and health information to certain third parties. This will only be done in accordance with the applicable privacy legislation and with your consent.

We may disclose personal information, with your permission, to the following third parties:

- your doctor and allied health professionals when required to provide holistic support.

7. Storage and Security of your personal information

MRV takes reasonable steps to protect your personal information against misuse, interference and loss, and from unauthorised access, modification and disclosure. These steps include:

- utilising trusted practice software to record and store your personal and health information;
- limiting access to your personal information on a need-to-know basis;
- implementing privacy protection measures with our staff and volunteers; and
- regularly updating and auditing our storage and data security systems.

All personal information we collect is stored in secure cloud storage which is protected by industry standard cyber security.

When no longer required, we destroy personal information in a secure manner in accordance with the requirements of the Privacy Act and relevant health privacy legislation.

8. Requests to Stop Direct Marketing From us

We may communicate with you by phone, electronically or mail, about our current and new services, campaigns and events , including participation in any programs we develop. This may take the form of newsletters or marketing emails.

You may ask us at any time to stop sending you direct marketing information or being contacted by or on our behalf, in a particular way or at all by unsubscribing directly from email communications or contacting admin@mrv.org.au.

9. Access or correct your personal Information

We take reasonable steps to ensure that the information we hold about you is accurate, up-to-date, complete, and relevant when we use it or disclose it.

You have the right to seek access to, or correction of, the personal information we hold about you. If you dispute the accuracy of information we hold about you, you may request to have it reviewed and/or corrected. We will notify you in writing and explain our reasons if we refuse to give you access to, or correct, the personal information we have recorded about you.

You can seek a copy of what personal information we hold about your or seek to correct it by contacting us at admin@mrv.org.au.

10. How to make a complaint about privacy

We take complaints regarding your privacy very seriously. If you wish to lodge a complaint about how we've handled your personal information, please contact us in writing at admin@mrv.org.au.

If you are not satisfied with our response, you may contact the Office of the Australian information Commissioner to make a complaint. Further information may be found at https://www.oaic.gov.au/privacy/privacy-complaints/lodge-a-privacy-complaint-with-us

11. Further information on your privacy rights

You can find out more about your right to privacy from the Office of the Australian information Commissioner. This can be found on their website at www.oaic.gov.au.