

| Ezer Mizion Bone Marrow Donor Registry SOPs |                |                    |
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## Privacy Policy of Ezer Mizion Bone Marrow Donor Registry

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## 1. Overview

This Privacy Policy reflects the commitment of the Ezer Mizion Bone Marrow Donor Registry to respect your privacy rights and to protect your personal information, including sensitive and medical information, and describes how we collect, store, and use information, as well as your rights in this regard.

The Ezer Mizion Registry complies with the Israeli Protection of Privacy Law (1981) and the Privacy Protection Regulations (2018). In addition, we are required to comply with standards set by the World Marrow Donor Association (WMDA), which apply to many aspects of our activities, including donor recruitment, informed consent and eligibility assessment, and protection of personal data.

By disclosing your personal information to us, you confirm that you consent to the collection, use, and disclosure of your personal details in accordance with this Policy. Please note that this Policy also applies to cases in which your personal information is provided to us by a third party. In such cases, we take reasonable steps to ensure that you have consented to that organization providing us with the information and that it applies appropriate policies to protect your personal data.

This Policy refers to all individuals registered in the Registry as hematopoietic stem cell donors as "Donors," whether they have actually donated. In addition, this Policy also refers to "Patients," where relevant to the transplantation process and its outcomes.

## 2. Why We Collect Your Personal Information

Our primary purpose in collecting personal information is to enable matching between patients in need of bone marrow transplantation and donors who have joined the Registry, to provide patients in Israel and worldwide with the opportunity to find suitable donors. We may also collect personal information for secondary purposes that are closely related to our primary purpose, such as research and similar activities, in accordance with the rules governing research in Israel.

In general, we are required to collect personal information to perform one or more of the following activities:

- Registering and enrolling new donors in the Ezer Mizion Registry.
- Managing the information contained in the Registry (including locating donors, verifying donor identity, and updating contact details).
- Enabling searches of the Registry by hospitals to identify matches between patients requiring bone marrow transplantation and potential donors.
- Fundraising, awareness raising, research, or educational activities.
- Ongoing communication with donors, as required.
- Research and data analysis to improve the way we communicate with our supporters.

## 3. Donor's Information

### 3.1 Information collected upon registration

We hold essential donor information that enables us to identify potential donors and help save the lives of patients in need of bone marrow transplantation. If you are eligible and agree to join the Registry as a potential donor, you will be required at the time of registration to provide the following details:

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- Name
- Date of birth
- National identification number
- Sex
- Weight
- Contact details, including email address, mailing address, street, and telephone numbers
- Medical information regarding medical eligibility
- Ethnic origin
- Blood type
- Tissue typing (HLA) – data used for matching donors and patients

A new donor joining the Registry will be assigned a unique identification number, which is the sole means by which their tissue typing details and relevant test results can be accessed for matching with a patient.

### 3.2 Additional information

If you are identified as a potential match for a patient, we will request additional personal and sensitive medical information to enable the patient's medical team to further assess compatibility and the likelihood of a successful donation. This information may be collected directly from you or transferred to the Ezer Mizion Registry by healthcare providers authorized by the Registry to provide bone marrow collection services. Additional information collected at this stage may include:

- Presence of infectious diseases
- Medical history
- Repeat tissue typing and blood type test results
- Travel history
- Summaries of physical examinations

We collect or receive this additional information only after you provide your consent. This information is shared with transplant centers in Israel and other registries worldwide in an anonymized form. Additional information collected after donation includes:

- Details of the donation process
- Reports on the donor's recovery progress following donation

In addition, the Ezer Mizion Registry will collect and retain communications or correspondence with donors. From time to time, Ezer Mizion may also collect personal information from donors through satisfaction surveys and marketing activities.

### 3.3 Retention period of your personal information

We will retain your personal data for as long as necessary to carry out our activities described above in Section 2, and in accordance with applicable law.

A donor may withdraw from the Registry for several reasons: reaching the maximum donation age (60), requesting removal from the Registry, medical ineligibility, or refusal to proceed with a donation request. Donor data, which are registered anonymously in the WMDA global donor

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database, will no longer appear in searches for new patients after the donor withdraws from the Registry, regardless of the reason for withdrawal.

However, our handling of data on donors who have withdrawn depends on whether they donated bone marrow. If a donor has donated bone marrow, their personal information is linked to the relevant patient, and we will retain it in accordance with the law. A donor who was never identified as a match for any patient during their time in the Registry and who withdrew for the reasons noted above will no longer be presented as an available donor in Registry searches.s.

#### 4. Patient's Information

Transplant centers in Israel and worldwide registries affiliated with the Ezer Mizion Registry provide us with personal information about patients to identify the most suitable donors. Patient details provided to us by transplant teams include:

- Name and identifying number (not necessarily a national ID number)
- Date of birth
- Sex
- Details of the treating healthcare providers
- HLA tissue typing
- Blood type
- CMV status
- Relevant diagnoses and other clinical information assisting in donor–patient matching
- Progress reports on patient recovery following transplantation and transplant outcomes

We require strict maintenance of donors' and patients' anonymity both before and after transplantation. However, we recognize that donors and patients (after transplantation) may wish to communicate directly. We will allow the sharing of identifying details of donors and patients where consent is provided by both parties. International privacy laws may limit our ability to facilitate direct contact between donors or patients worldwide.

#### 5. Additional Information We Hold and Use

When you use or visit our website, you may provide your name, contact details, and other personal information. This may occur through:

- “Contact Us” features for the general public and supporters
- Checking whether you are registered as a donor in our Registry
- Updating donor details (for registered donors)

When you contact us through these channels, we will use your personal information for the purpose for which you contacted us, which typically includes:

- Responding to your inquiry or request
- Enabling you, as a registered donor, to update your contact details in our Registry

Our website uses cookies and other technologies (such as Google Analytics) to collect data about your use of our website. During your visit, we may collect login information through cookies and other technologies, including your IP address. This information is not stored in a manner that personally

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identifies you, but it may be used to improve website usability and to tailor the browsing experience to user preferences.

## 6. Disclosure to Authorized Third Parties

Sections 3–5 above describe the various ways in which we disclose donor and patient information to third parties. In addition, we may disclose personal information that we collect to:

- Third-party service providers contractually bound to us, where required, to enable them to provide their services, including medical laboratories, IT service providers, data storage providers, website and server hosting providers, and marketing service providers.
- Our insurers, only as necessary and as permitted by law.
- Regulatory authorities and law enforcement bodies as required by law, in connection with existing or future legal proceedings, or to establish, exercise, or defend our legal rights
- Third parties that collect and process data related to our website on our behalf
- Third-party research organizations, subject to individual consent and where the research is approved (as applicable) by a human research ethics committee and by us. Information transferred for research purposes is anonymized.

Third parties are subject to our security, access, confidentiality, and privacy protection arrangements and may use your personal information only for the purpose for which it was provided. Overseas registries are subject to privacy standards equivalent to those we are required to meet and to which we are committed under the WMDA Data Use Agreement.

Where possible, your information will be provided to these organizations on an anonymized basis. Your name and contact details will not be transferred to a third-party organization unless it provides you with medical services. We disclose your sensitive information only for the purpose for which you provided it, for related purposes you would reasonably expect, or with your consent.

We do not provide sensitive information, such as medical details, for any marketing purpose, and we will never sell your personal information.

## 7. How We Store Your Information

We are committed to ensuring the security of the personal information we collect.

To prevent unauthorized access or disclosure, we have implemented appropriate physical, electronic, and managerial procedures to safeguard your personal information and protect it from misuse, interference, loss, unauthorized access, modification, or disclosure.

We retain donor and patient records as reasonably required to safeguard donors and patients and to comply with health records and privacy laws.

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## 8. What Are Your Rights

### 8.1 Access and Updates

You are entitled to request access to your personal information and to have it updated if you believe it is inaccurate.

To protect your personal information from unauthorized disclosure, we use procedures to verify your identity and the information you are requesting.

To request access to or update your personal information, please send the following details to: [Ezermizioninfo@bmdr.org.il](mailto:Ezermizioninfo@bmdr.org.il).

- Name, date of birth, address, and contact details
- A description of the information you are requesting access to
- Your signature authorizing the request

### 8.2 Withdrawal from the Registry

You are entitled to request removal from the Registry and deletion of your personal details from our records.

To withdraw from the Registry, please send your personal details (full name, date of birth, ID number, and phone number) to: **Ezermizioninfo@bmdr.org.il**

### 8.3 Complaints

If you believe that we have breached privacy principles and wish to lodge a complaint, please contact us at the address below, providing details of the alleged breach:

**Data Protection Officer:** [dpo@ami.org.il](mailto:dpo@ami.org.il)

Your complaint will be reviewed, and we will respond in writing, outlining the outcome of the review and the steps we have taken or will take to address it.

## 9. Review and Updates

We may amend this Privacy Policy at any time by publishing an updated version on our websites. We recommend that you review our websites regularly to ensure that you are familiar with our current Privacy Policy.