

Confidentiality policy

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1 Purpose

Unrelated stem cell donors donate their blood stem cells anonymously to an anonymous patient worldwide. Matchis and the affiliated transplant centers are not allowed to reveal the identity of the recipient to the donor or to their family, and visa versa.

With reference to and to comply with the Decree Eisenbesluit Lichaamsmateriaal 2006, article 9.1, it is Matchis' policy to protect the donor and patient against unauthorized release of their personal data or other confidential information that could lead to disclosure or exposure of their identity.

This policy supports the protection of confidential donor and patient personal data shared with third parties with whom Matchis collaborates, such as the collection centers and transplant centers.

2 Definitions and abbreviations

Definitions or abbreviations	Clarification
GRID	Global registration identifier donors
SEC	Single European code

3 Scope

The department professional services under the responsibility of the medical director, is mainly responsible for the implementation of this policy.

In general this policy is applicable for all departments and staff within Matchis and made available to other stem cell donor registries and receiving transplant centers of blood stem cells originated from Matchis donors.

4 Responsibilities

4.1 Medical director

- Responsible for complying with above mentioned decree Eisenbesluit Lichaamsmateriaal 2006.

4.2 Team leader Donor services

- Responsible for the implementation of this policy and related procedures.

4.3 Team leader Transplant center services

- Responsible for the implementation of this policy and related procedures.

4.4 Employees

- Are assigned with the duty to safeguard (identifiable) information within the boundaries of their respective functions.

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4.5 Receiving transplant centers / registries

- Are bound to this policy by agreeing to comply with the “Minimal criteria” which is implied when requesting a Matchis donor.

4.6 Affiliated national collection- and transplant centers

- Are legally bound to national law and regulation regarding the anonymous donation.
Are contractually bound to agreements on donor and patient confidentiality as described, but not limited to the provisions in this document.

5 Labelling of products

In the event that the transplant center receives a product from which the identity of the donor could be traced in any way, it is the responsibility of the transplant center to treat this information confidential and to keep it out of sight of the recipient and his family and friends.

6 Information to the donor

After the donation, Matchis is allowed to inform its donor, if desired, about the patient's sexe assigned at birth and age indication.

Matchis is permitted to provide to the donor an indication about the health (and survival) status of the patient to whom the donor has donated.

7 Information to the patient

The receiving transplant center is only allowed to share information about the donor to the patient that cannot reveal the identity to the donor. This means that it is not allowed to share information about the exact age and country of origin.

The donor registry or donor centre may have additional confidentiality policies of which the receiving transplant center must take note if provided to them.

8 Correspondence

Our policy allows communication through anonymous letters and/or cards. Small gifts are allowed but may not have specific characteristics which may reveal its origine or the identity of the patient or donor or have high monetary value.

Any communication, letter or card must be in English. It is not permitted to mention and/or use names, addresses, countries or indications in any form that could lead to the identification of the sender.

The sender must be aware that both the Donor Center and the Transplant Center are entitled to refrain from forwarding the letter or card if it does not comply to Matchis established detailed instructions or in their opinion, it is not appropriate. The sender should also be aware that the other party or recipient may not want to - or be unable to - return a reply or response.

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9 Risks and control

Matchis has established conditions that will maintain the anonymity of the donor and patient in different kind of communication forms between patient and donor.

Requesting registries and transplant centers have agreed to our confidentiality policy, summarized in Matchis general conditions (Minimal criteria to access a donor from Matchis Foundation stem cell donor database).

Should an identity breach unexpectedly occur, Matchis will handle the incident according to the 'data security incident and data breaches' procedure.

10 Review

This policy will be reviewed every 3 years, earlier if changes occur in law or regulation.

11 Miscellaneous

N.A.

12 Related standards

Institution, organisation	Article
Eisenbesluit Lichaamsmateriaal 2006	9.1
Wet Veiligheid Kwaliteit Lichaamsmateriaal	21
EU directive 2004/23	14
WMDA	3.10.1; 6.07

13 Related documents

Document ID	Document name
DS-100	Minimal criteria to access a donor from Matchis Foundation stem cell donor database
MAT-10	Registry manual Matchis
MAT-23	Assessment of communication between donor and patient
QA-46	Data security incidents and data breaches