

## Leiden branch

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## Privacy policy donors

### Introduction:

The protection of your privacy is very important to Matchis. As a centre for stem cell donors, we process your personal information, including details about your health, so therefore it is of major importance for you, and for us, to ensure a safe and reliable processing of your data. This careful use of your data is enforced by the Dutch Algemene Verordening Gegevensbescherming (AVG) (General Data Protection Regulation (GDPR) in English). You can also refer to: [www.autoriteitpersoonsgegevens.nl](http://www.autoriteitpersoonsgegevens.nl)

You have voluntarily provided Stichting Matchis with your personal information for the purpose of registering as a stem cell donor. As well as the basic information, we also ask you for additional details. You are under no obligation to include these details but they are very important for keeping our register up to date. During the whole process we collect and use your personal and medical data. A unique registration number is linked to your data so that we can share your details using a pseudonym. This document is to help you understand which data we will collect about you, how we collect it, what we use it for and what rights you have with regard to your data.

### Who is this statement written for?

This statement applies to the processing of personal and medical data of stem cell donors registered with Matchis. The transplant centres are responsible for the processing of patient data and are therefore obliged to comply with the AVG, or the GDPR in the case of a foreign transplant, or any equivalent regulation. The same applies to processing donor data received from other registries that are used for the benefit of a Dutch patient. In this privacy policy we focus on processing the data of Matchis stem cell donors. By processing or use we mean the retrieval, storage, disclosure and destruction of personal and medical information, data or details.

### 1. Personal data – which personal data do we collect?

#### 1.1. Registration details

When you decide to register as a potential donor, we ask you for the following details, which we use to find the right match for the patient and then, to be able to call you:

- First name and surname (in accordance with your passport)
- Date of birth
- Full address
- Contact details (email/telephone)
- Date of birth, gender, weight and height
- Ethnicity (for any genetic traits, e.g. non-Western origin)
- Blood or plasma donor number, if you are also a blood or plasma donor
- Details about your health and use of medication

Once the registration is complete, the following additional details can be processed:

- HLA typing: this is the tissue typing of a small part of your DNA, which can be matched with a patient's tissue type.
- CMV status: this is a check for the presence of any antibodies to the cytomegalovirus (CMV), which is a potentially dangerous infection for a patient.
- Blood group.
- KIR typing: these are so-called 'killer immunoglobulin-like receptors', that play a role in the patient's acceptance of your stem cells.
- CCR5 check: to see if you are possibly less susceptible to HIV (the virus that causes AIDS).

When you are called up to actually donate your stem cells, we will ask you for, and process, the following extra information:

- Occupation
- Bank details, in connection with any expense claims
- Additional information about your health and use of medication
- Additional contact details

## 2. What do we use your personal data for?

We will use the information that you give us:

- to assess if you are eligible to be registered as a stem cell donor. This is done using the information you provide during the online registration, or that you give us at a later stage.
- to be able to select the most appropriate donor for a patient. We do this by using the global database for stem cell donors: the "Search & Match Service" of the World Marrow Donor Association (WMDA).
- to ask you for a blood sample when there is a match between you and a patient.
- to be able to call you up for a medical examination when there is a match between you and a patient.
- to coordinate the request for a Dutch stem cell donor for patients (nationally and worldwide).
- to facilitate scientific research, such as statistical information. Your personal details cannot be traced back from this kind of research.
- to optimise the use of the website.
- to help improve Matchis' policies and procedures.
- to log information to support the promotion of stem cell transplants.
- to analyse patterns in the database.
- to send out selective emails (newsletters) to particular groups of people.

- for recruitment purposes, such as asking you to promote stem cell donation in your area, or if you are no longer eligible to be a stem cell donor yourself, that you may perhaps consider being a volunteer or supporting us in a similar way.
- It could be that we give you information via our newsletter about the Sanquin foundation, the blood donor bank, and on their behalf, ask you to (also) become a blood donor\*.

There is some overlap in some of these reasons for using your personal data, so there could be different reasons for using your personal information.

\*If you do not wish to receive our newsletters, you can always let us know via an opt-out at the bottom of the first newsletter.

### **3. On what legal grounds do we process your personal data?**

We process your personal data and your extra personal details, such as your medical information, only with your legal consent, for the purposes of the legitimate activities of Stichting Matchis, and with all the appropriate safeguards and measures, as defined in the Algemene Verordening Gegevensbescherming (AVG).

### **4. Your consent**

We request your consent to allow us to process your personal data in an abridged version of this privacy policy, using a 'declaration of consent' that you sign when you register. At a later stage, when you are called up for a possible donation, you will again be asked for your consent to process and transfer additional personal and medical data. Data that will be used for specific scientific research will only be provided after we have received your consent.

### **5. Access to your personal information**

Other people using the website, and other institutions involved in the process, will not be able to see your personal details. Your personal details can be accessed by Matchis employees who are authorised to do so as part of their job. You can check and amend some, but not all, of your own personal details via the personal donor portal.

### **6. Responsibility for the protection of your information**

Stichting Matchis is at all times responsible for the protection of the data that you have provided us with, even when this is processed for us by third parties. To ensure this, we have entered into agreements with the said third parties, aimed at guaranteeing your privacy. You are responsible for the content of the information that you voluntarily disclose to us.

## 7. Who are the people processing your data?

Employees who have access to your personal data because of their job are authorised for this and have signed a confidentiality agreement. This declaration is signed by everyone who has access to the data due to the work they do for Matchis. The donor physicians are also BIG\* registered and are therefore automatically bound by a professional confidentiality agreement.

*\*The BIG register is a Dutch register, which records the jobs of people who work in a number of professions in the healthcare sector*

## 8. Who are the data shared with?

Your data will only be shared as pseudonymised data with people or organisations for the purpose of the stem cell donation process. We never sell personal data to third parties under any circumstances. We can choose to outsource tasks, for processing your registration, for example. We have entered into data processing agreements with these so-called sub-processors that include provisions and measures to protect your data.

8.1. The following details are uploaded to the “Search & Match Service”, the global stem cell donor database of the World Marrow Donor Association (see [www.WMDA.info](http://www.WMDA.info)). The WMDA is established in the Netherlands and is therefore regulated by European law:

- Identification and registration number of the donor
- HLA type
- Gender
- Date of birth
- If provided:
  - Blood group
  - CMV status
  - Height
  - Weight
  - And other details that research has shown could significantly contribute to a successful stem cell transplant

8.2. When a match is found for a donation, the following details are shared with the hospital or collection centre where your stem cells will be collected, and the transplant centre where the stem cells will be administered to the patient, with the purpose referred to in Part 3.

The following details will be shared with the (patient’s) transplant centre:

- Donor’s identification number
- Date of birth
- Gender

- Additional, relevant medical information, such as HLA type, assessment results, blood test results and other diagnostics
- Height, weight, use of medication (if relevant)

The following details will be shared with the stem cell collection centre (where the donor will donate the stem cells):

- Donor's name
- Date of birth
- Gender
- Medical information, such as assessment results, blood test results and other diagnostics
- Height, weight, use of medication (if relevant)

8.3. The following details will be shared with Stichting Sanquin if you have indicated that you are a blood donor:

- Donor's name
- Address
- Contact details
- Gender
- Date of birth
- Sanquin identification number
- Blood group
- CMV results
- HLA typing details

## 9. How long will the data be saved?

9.1. The information has been provided to us as a potential donor, but a request for a donation has not yet been made: The data will be saved until the donor reaches the age when a donation can no longer take place (currently up to age 56), and then the registration will be removed. The data will then be made anonymous.

9.2. A donation has been made for a patient: The data will be saved for a minimum of 30 years, in accordance with the national laws and regulations (EU Directive 2006/86 and WMDA standards), to ensure the traceability of the information concerning the donation.

## 10. Security measures

Stichting Matchis actively works to secure information and has an NEN7510/ISO27001 certified information management system whereby organisational, technical and administrative measures are taken to protect your personal data within our organisation.

We regularly check our system using risk analyses, internal checks and independent audits.

If we contract sub-processors to process data, we check whether this third party has taken all appropriate security measures to protect your data. All of our permanent and temporary employees are bound by a confidentiality agreement. You can be fully confident that we do all that can be reasonably expected of us to protect your data from unauthorised use.

## 11. Anonymity rule

By law, the personal data of the donor and the patient are treated as strictly confidential. This includes the fact that Matchis may never disclose the identity of the donor to the patient, or vice versa. Both the donor and the patient are made aware of this anonymity rule through Matchis' "confidentiality policy".

## 12. What are your rights?

- You have the right to access, correct, exchange and restrict the use of your personal data, you have the right over the transferability of your personal data and you can object to it or withdraw your consent.
- You can ask us to improve, add to, remove or block the data you have provided us with, if the data is factually incorrect or has been processed in a way that is in violation of a legal requirement. For this you can also send us a detailed written request.
  - Within four weeks of receiving a detailed request for a change or deletion, we will inform you that it has been done or give a reason for any refusal.
- A request can be refused if it is against the law. If you have donated stem cells, we are obliged to save your data for 30 years after the donation. See point 10.2 for full details.
- You do have the right to withdraw your consent. Withdrawing your consent will have no consequences for all the historical used data. When requesting a withdrawal, make it clear which consent you wish to withdraw.

## 13. Anonymising data

If you have deregistered as a donor or if you have reached the age when you may no longer donate, your personal data will be anonymised (made anonymous). Your personal data will be deleted in a way that your identity can no longer be traced. Any remaining data will be used for statistical and scientific purposes.

## 14. Amending or adding to data we have already collected

The data that we collect from you is needed to ensure the proper care of both you and the patient in accordance with current scientific practice. This data may be restricted or expanded should it appear that the quality of the care is not negatively affected but that, indeed, there is added value through it.

By completing the declaration of consent, you explicitly give Matchis your consent to do so. Matchis will publish all changes to collected data, in advance, via this explanatory statement on our website.

## 15. Our data protection officer

We employ a data protection officer. If you have any questions about any of the data processing activities we perform, you can contact our officer by email at [DP@matchis.nl](mailto:DP@matchis.nl).

## 16. Contact details and where you can send your questions

If you have any questions about our Privacy policy, or how we use your personal information, you can always contact us at: [DP@matchis.nl](mailto:DP@matchis.nl)

You can also write to us by post.

Having contacted us about your complaint, if you feel that the problem has still not been solved, or you are still unhappy with the situation, there are further options. For example, you can always file a complaint with the data protection authority: ([www.autoriteitpersoonsgegevens.nl](http://www.autoriteitpersoonsgegevens.nl))

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