

Privacy policy donors Caribbean

Introduction:

The protection of your privacy is very important to Matchis. As a center 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 protection of your data. Your data is being stored and protected at Matchis in the Netherlands (later described as Matchis) and therefore in line with Dutch legislation for data protection.

You have voluntarily provided 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 of matching and donation 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.

For whom is this statement written?

This statement applies to the processing of personal and medical data of stem cell donors registered with Matchis Dutch center for stem cell donors in need of matching a donor to a patient. The transplant centers are responsible for the processing of patient data and are therefore obliged to comply with the Dutch AVG, the GDPR in the case of a foreign European transplant center, or any equivalent regulation in other parts of the world. In this privacy policy we focus on the use of the data of Matchis stem cell donors. By processing 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)
- Full address
- Contact details (email/telephone)
- Date of birth, gender at birth, weight and height
- Details about your health

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.
- 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. For what purposes do we use your personal data?

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 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 optimize the use of the website.
- to help improve Matchis policies and procedures.
- to log information to support the promotion of stem cell transplants.
- to analyze 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.

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 newsletter, you can let us know via an opt-out at the bottom of the 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 Matchis, and with all the appropriate safeguards and measures.

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 obtaining your specific 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 authorized to do so as part of their job. You can check and amend some, but not all, of your own personal details by contacting Matchis via the contact form.

6. Responsibility for the protection of your information

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 authorized 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 who assess the donor on eligibility to donate are registered* physicians, and are therefore automatically bound by a professional confidentiality agreement.

*The AruBIG register is a register, similar to the BIG register in the Netherlands, which records the jobs of people who work in a number of professions in the healthcare sector.

8. With whom are your data shared?

Your data will only be shared as pseudonymized data with people or organizations for the purpose of the stem cell donation and transplantation processes. We never sell personal data to third parties under any circumstances. When we 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. To deliver our services securely and reliably, in cooperation between Matchis and Matchis Caribbean, the latter has outsourced the digital infrastructure of applications and systems to Matchis. This includes hosting, application operation and data storage, and Matchis processes all personal data submitted and generated as long as data is processed.
- 8.2. The following details are uploaded to the “Search & Match Service”, the global stem cell donor database of the World Marrow Donor Association (see <https://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 at birth
 - 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.
- 8.2.1. The Search & Match Service of the WMDA is used by members to search for the right donor. Due to its international character, a processing agreement has been concluded with the members in which standard contractual provisions are included. These contractual provisions guarantee the protection of donor data in accordance with the GDPR regulation.
- 8.3. When a match is found for a donation, the following details are shared with the hospital or collection center where your stem cells will be collected, and the transplant center where the stem cells will be administered to the patient, with the purpose referred to in chapter 3.

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

- Donor’s identification number
- Date of birth
- Gender at birth
- 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 center (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)

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 anonymized. The necessary anonymized DNA from your buccal mucosa (test material) will be destroyed at your request.
- 9.2. A donation has been made for a patient: The data will be saved for 30 years, in accordance with the (inter)national laws and regulations.

10. Security measures

Matchis actively works to secure your information on a technical basis in line with ISO27001 certification. All of our permanent and temporary employees are bound by a confidentiality agreement. You can be fully confident that we do that can be reasonably expected of us to protect your data from unauthorized use.

11. Anonymity rule

By (inter)national law and regulation, the personal data of the donor and the patient are treated as strictly confidential. This includes the fact that we 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 policy.

12. Data control

- 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 9.2 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. Anonymizing 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 anonymized (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. We recommend that you consult this Privacy Policy regularly, so that you remain aware of any changes.

15. Data protection officer

Matchis employs a data privacy- and a data protection officer. If you have any questions about any of the data processing activities we perform, you can contact us by email at DP@matchis.nl.

16. Contact details and where you can send your questions or complaints

If you have any questions about the protection of your personal data, or how we use your personal information, you can also contact us via <https://www.matchiscaribbean.com/contact>.

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