Marrow Donor Program Belgium
Registry

Marrow Donor Program Belgium – Registry
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INFORMATION LETTER FOR PEDIATRIC PATIENTS SEARCHING FOR A STEM CELL DONOR IN RELATION TO THE PROCESSING OF PERSONAL DATA

The global search for a suitable stem cell donor

In consultation with the doctor of your child, it has become apparent that your child requires a stem cell transplant.

To this end, a suitable stem cell donor must be found. In order to find this stem cell donor, your hospital works with the Marrow Donor Program Belgium – Registry, the Belgian bone marrow registry.

Working with the Belgian bone marrow registry, we will search for the most suitable stem cell donor for you in our Belgian database of stem cell donors, and the databases of stem cell donors around the world through the World Marrow Donor Association.

In order to carry out this search, the personal data of your child will be passed on to various national and international organisations. More information regarding the actual processing of the personal data of your child in this regard can be found below.

What do we do with the personal data of your child and how do we protect it?

- Who is responsible for processing the personal data of your child?

The Marrow Donor Program Belgium – Registry, Motstraat 42, 2800 Mechelen, a subsidiary of the Belgian Red Cross, a public utility institution with legal status under the Act of March 30th 1891, is the controller of the personal data of your child, together with the hospital that has initiated the search for a suitable stem cell donor for your child.

The bone marrow registry and the hospital have entered into an agreement to this effect. If you would like more information on the essential content of this agreement, please contact the DPO of your hospital or the DPO of the bone marrow registry (see below).

- Which of the personal data of your child do we process?

As a patient, we process the following of the data:

- Standard personal data such as name, address, national registration number, telephone number etc.
- Sensitive personal data such as genetic data (DNA), ethnicity, health data (incl. blood group, infectious diseases, HLA results etc.).

- What are the purposes of and legal grounds for the processing of the personal data of your child?

We process the personal data of your child for various purposes:

- To assist persons in finding suitable human tissue in order to be able to perform the transplant that

is vital to these persons, to provide healthcare and/or for reasons of public interest in terms of public health.
- To provide sufficient safe stem cells, including informing and contacting people about donating stem cells. This is required in order to provide healthcare and/or for reasons of public interest in terms of public health;
- We also process this data for the purposes of scientific research in relation to transfusion, for epidemiological purposes or with the aim of gaining greater insight into medical conditions and their treatment, for internal validation and to optimise reporting on operational processes related to our task as a bone marrow registry or hospital in the service of public interest and public health; and
- Finally, we process the personal data of your child for the purposes of the management of complaints and disputes. This takes place on the grounds of our legitimate interest in being able to deal with a complaint or dispute and to indemnify our rights and interests.

- Who receives the personal data of your child?

We share the personal data of your child with:

- Processors who provide support services such as the World Marrow Donor Association, an external data platform and portal, call centres, text and email services, software suppliers etc.
- Domestic and foreign bone marrow registries and cooperative centres in order to be able to connect patients with suitable stem cell donors;
- Hospitals/doctors that may be able to facilitate stem cell donation;
- Insurance companies in order to provide cover in the case of complications that are not among the expected side effects of donation or for any physical harm arising from the donation;
- Recognised laboratories we work with;
- The Federal Agency for Medicines and Health Products in the scope of their blood monitoring authorisation;
- The Stichting Kankerregister in the scope of their legal duty; and
- The EBMT (European Group for Blood and Marrow Transplantation) and the CIBMTR (Center for International Blood and Marrow Transplant Research) in the United States in the scope of their research activities.

- Do we share the data of your child with countries or organisations outside the European Economic Area?

We provide the data of your child to stem cell registries and cooperative centres outside the European Economic Area in order to be able to search for a suitable stem cell donor outside the European Economic Area as well. This also allows those stem cells registries and cooperative centres to carry out scientific research in the context of transfusion, for epidemiological purposes or for the purpose of better understanding medical conditions and their treatment.
We also use processors (external data platform and portal, software suppliers etc.) outside the European Economic Area. We provide suitable safeguards through standard clauses regarding data protection or other suitable safeguards. These are available from us for review.

- For how long do we keep the data of your child?

The data will be stored in accordance with the legal requirements, namely for a period of at least 30 years and no longer than 50 years.

- What are your rights as a data subject?

You have several rights:

- You have the right to **access** the personal data of your child. In this way you can check which of the personal data of your child we process.
- You have the right to the **rectification** of the personal data of your child. In this way you can have incorrect personal data about your child corrected.
- You have the right to the **erasure** of the personal data of your child. This right allows you to have us 'forget' your child and delete any details we have about your child. We are not always obliged to erase the personal data of your child at your request. This is only required in the cases determined by law.
- You have the right to **restrict** processing concerning your child. In this way, you can ask us to limit the processing we carry out. We will then continue to store the data of your child but its use will be made stricter. We are not always obliged to grant such requests. This is only required in the cases determined by law.
- You have the right to **object** to the processing. In this way you can refuse the further processing of the data of your child by Belgian Red Cross-Flanders. We are not always obliged to grant such requests. This right can only be exercised when we are processing your data on the grounds of legitimate interest or to fulfil a duty in the public interest.
- You have the right to withdraw your **permission** if the processing takes place on the basis of your permission.
- You have the right to **object** to the processing of the personal data of your child for recruitment and communication purposes.
- You have the right to **data portability**. In this way you can quickly move, copy or pass on the data of your child from one controller to another. This right complements the right to access. It offers you a way to easily control the data of your child and use it again. This right can only be exercised when the processing relies on your permission or on an agreement you have entered into with us.

- Who can you contact for more information regarding the processing of your personal data?

The bone marrow registry and all cooperative centres have a Data Protection Officer (DPO). It is the specific duty of this person to monitor how the data may be used and how it must be protected when we process it.

In the case of any requests or queries concerning the processing of your personal data, you can contact the DPO of your cooperative centre *(To be completed by each center)*:

- By post:
- By email:
- By telephone:

The DPO of the bone marrow registry can be contacted as follows:

- By post: Rode Kruis-Vlaanderen, t.a.v. DPO, Motstraat 40, 2800 Mechelen;
- By email: DPO@rodekruis.be
- By telephone: 015-44 33 86

- Do you wish to submit a complaint to the Data Protection Authority?

If you have a complaint, this must be submitted to the supervising authority. In Belgium, this is:

Gegevensbeschermingsautoriteit
Drukpersstraat 35
1000 Brussel
contact@apd-gba.be
tel. 0032 2 247 48 00

I hereby declare that I have read this document and received sufficient information:

Name and first name of the ***patient****:*	
Name and first name of the ***parents/guardians****:*	
.... *Signature:* .... *Place:* .... *Date:*	.... *Signature:* .... *Place:* .... *Date:* ....

Surname and first name of the ***doctor*** *or qualified person:*	
Signature:	*Place:* .... *Date:* ....