

RULES OF OPERATION FOR INTERNATIONAL PATIENTS

1. Starting and Terminating a Search

1.1 Registration of international patients in MDPB-R.

Preliminary searches can routinely be initiated from outside Belgium:

The MDPB-R can accept requests on behalf of international patients if coming from:

- From a National Registry (HUB) who is a WMDA member.
- Directly from an EBMT accredited Transplant Center in absence of a National HUB. These Transplant Centers should have an accreditation for allogeneic transplants from EBMT, JACIE or a comparable organization.

Preliminary search requests have to be sent to MDPB-R through EMDIS (European Marrow Donor Information System) or by fax/email using the WMDA search forms or any other similar form.

1.2 Cancellation

A formal cancellation of the donor search must be sent in case of a search termination.

(through EMDIS for or by fax/email for non EMDIS countries)

1.3 HLA typing

Donor centers shall perform HLA testing by molecular methods in an EFI or ASHI accredited lab.

HLA class I typing	
HLA class I low resolution DNA typing:	- Loci A - Loci B - Loci C
HLA class I high resolution DNA typing:	- Loci A - Loci B - Loci C
HLA class II typing	
HLA class II low resolution DNA typing:	- DR1 - DQ1
HLA class II high resolution DNA typing:	- DRB1 - DQB1 - DPB1
HLA class II high resolution DNA typing:	- DRB3 - DRB4 - DRB5

Prices can be found in the MDPB LST006 Fee schedule donor and MDPB LST007 Fee schedule cord blood.

1.4 CT Sample Procurement

The total quantity of blood samples for Confirmatory Typing must not exceed 50 ml per donor.

The Donor center, when requested for blood for Verification typing (Confirmatory Typing) shall perform the following tests:

infectious disease markers (IDM)	
Syphilis	
HBs Ag	
HBcore antibody	
Anti-HIV1-2 antibodies	
Anti-CMV antibodies	
Anti-hepatitis C virus (anti-HCV) antibodies	
Other tests	
ABO and Rh typing	if not already performed

1.5 Work-Up

Work-ups should be submitted using the WMDA search forms or any other similar forms.

1.6 **Reservation of a donor**

The maximum reservation period is 3 months. Requests for extensions of this period should be accompanied with a reasonable argument.

A donor selected for a specific patient shall be placed on a “reserved” status from the time of the Verification Typing until the donation is reached if a precise date or period of time (not exceeding 3 months from the initial request) has been determined by the transplant physician. If this is not the case, the donor can be recruited for any other. Requests for extensions of the period of 3 months shall be accompanied with a reasonable argument

In the search process, after transmission of the test results, the donor shall be reserved for a patient for 60 days, after dispatching a blood sample the donor shall be reserved for 60 days.

1.7 **Cryopreservation**

The cells of a voluntary donor shall always be transfused as soon as possible to the patient. Cryopreservation of HPC, M or HPC, A is not recommended and should not be done, except for very specific cases and MAC approval is mandatory for Belgian donors (not applicable for MNC, A). (MAC = Medical Advisory Committee).

In case of cryopreservation the Patient Registry shall be contacted (as informed consent from the donor is necessary for disposal in case of no infusion).

Planned cryopreservation

A formal agreement between Transplant Center and the Registry shall be obtained by MAC approval. The Registry will contact the Donor Center with the motivated decision of the MAC.

Unexpected cryopreservation

This situation shall remain exceptional, and necessitates immediate information of MAC/Registry and Donor Registry and expected date of transplantation.

In both cases: final decision lies with the Donor Center.

2. Patient-Donor Contact

It is the policy of the Marrow Donor Program Belgian Registry (MDPB-R) that the donation shall remain completely **ANONYMOUS**. Indirect, anonymous communication in the form of letters, cards, or gifts between donor and recipient is allowed post-donation and may not contain any reference to the sender's identity or location. Donor and recipient shall not be allowed to exchange direct correspondence. All correspondence, if any, will go through the MDPB-R and shall be censured by the Donor Center or the transplant physician. Items received must be sent to the other party within 1 month from date of receipt.

When receiving anonymous communication from a donor or recipient it is the responsibility of the Donor Center or Transplant Center to screen the content to ensure donor and patient anonymity is maintained. Unacceptable content within the correspondence or gift must be removed prior to forwarding to the MDPB-R. A Donor Center or Transplant Center can decide not forwarding the message or present (in its whole or partially) if they judge it more appropriate considering the circumstances.

Screening Cards, Letters and Gifts for Anonymity

Type	Accepted	Not accepted
Donor, patient names		Not accepted
Country of donor or patient	Accepted.	
Transplant and donor center information		Not accepted.
Contact details (telephone numbers,...)		Not accepted
Gender	Accepted.	
Age	Accepted.	
Disease	Mostly accepted.	No genetic diseases
Professions	General professions acceptable.	No specific professions.
Food		Not accepted.
Gift cards, DVD's, CD's		Not accepted.
Photos		No personal photos with people in the picture.

3. Pricing

Prices are listed in the Fee Schedule donor – cord blood posted on the website www.infodonor.be.