

## Registration/Donor Information

Full Name: \_\_\_\_\_

Birth date : \_\_\_\_/\_\_\_\_/\_\_\_\_ SNS N.º: \_\_\_\_\_ CEDACE N.º \_\_\_\_\_

### I – WHAT IS THE REGISTRY

The Portuguese Bone Marrow Donors Registry was created in 1995 by the Ministry of Health with the purpose of establishing in Portugal, a registry of voluntary donors available for cell donation to benefit those who have a disease that requires a bone marrow transplant and that don't have a compatible donor within their family. The cells can be obtained by two different processes, as explained below, allowing the patients to obtain a new bone marrow which will help to cure their disease. The Portuguese Registry, known as the National Center for Bone Marrow, Stem or Cord Blood Cell Donors - CEDACE, is part of a worldwide network of Registries called the World Marrow Donor Association (WMDA). After registering in CEDACE, the potential donor will be automatically registered in WMD allowing patients to access donors from their country or others throughout the world.

### II – REGISTRY PURPOSES

As people are genetically very different, finding a compatible donor out of the family may be complex. The registries are networked and contain information on thousands of donors from around the world based on each participant's HLA Study. The match between a donor and a patient is determined by genetic markers known as HLA antigens. The main goal of CEDACE is to search, through the HLA System, for a suitable donor for a patient, either in the Portuguese Registry or in the WMDA, thus providing each patient the possibility of accessing thousands of potential registered donors.

### III- REGISTRATION REQUIREMENTS

Only few donors registered in the Registry may one day be called up for a patient due to the characteristics of the HLA System genetic diversity and the time between registration and activation can be long. For that reason, the Registry accepts **healthy people aged between 18 and 45, although donations can occur up to 55 years of age. Registration takes place only once and is valid until the age of 55** after which, the donor is removed from the database. In order to proceed with the registration, the potential donor must complete the attached Medical Survey which is intended to protect health of both donor and patient. The evaluation is done by a qualified healthcare professional and if there are no contraindications, a blood sample will be collected for the HLA Typing.

The registration and HLA typing are the first steps towards being considered a donor. If there is a HLA type match between the patient and donor, new blood samples from the donor will be necessary to confirm this compatibility. If the tests indicate that there is a perfect similarity between donor and patient, the donor is asked to confirm, once again his/her availability for the donation. If so, a medical examination and clinical tests will be carried out, prior to preparation for cell collection. The cells needed for transplantation can be obtained by 2 processes:

- By placing a catheter in a vein, usually in the arm, through which the blood circulates to a machine that collects only the cells needed for the transplant, and returning the remaining cells and plasma to the donor. For the collection to be possible, the donor must make a subcutaneous injection of a hematopoietic growth factor 5 days before the cell collection leading the cells from the bone marrow into the bloodstream. The collection takes between 4 to 6 hours, after which the donor can return to his daily activity;
- Through direct collection in the bone marrow existing in the bones of the pelvis. In this case the donor has to go to the operating theatre and undergo general anaesthesia. The cells are collected through needles inserted into the pelvic bones not needing any growth factor and the process takes between 1 to 2 hours. This process requires the donor to stay in the hospital for 24h. In both processes, the amount of cells collected is in a very small percentage and the organism recovers very quickly. The procedure is always chosen by the donor, although, sometimes, the medical team that will transplant the patient may prefer one procedure over another.

For more detailed information please do not hesitate to contact us at: [dadorcedace@ipst.min-saude.pt](mailto:dadorcedace@ipst.min-saude.pt).

#### IV – WITHDRAWAL

Donors may cancel the registration in CEDACE at any time by notifying the Registry. However, giving up during an activation process can put the patient's life at risk.

#### V - SAFETY

The registration in CEDACE implies a blood collection and, later on, in case of donating cells by one of the 2 processes explained above, all the procedures will be explained in detail.

#### VI –PAYMENTS

The donor is not remunerated for the donation.

The CEDACE will reimburse duly documented expenses and loss of earnings incurred by the donation.

#### VII – COSTS

The tests carried out during a donation process will not be charged to the donor.

#### VIII – CONFIDENTIALITY

The identities of both donor and recipient will never be revealed throughout the entire process. All data registered in CEDACE is anonymous and the donor identification will be encrypted ensuring donor anonymity.

#### IX - FREE AND INFORMED CONSENT FOR DIGITALLY PROCESSEMENT OF PERSONAL DATA, LABORATORY RESULTS AND HLA TYPING

(Donor Name) \_\_\_\_\_, with the identification document number \_\_\_\_\_, confirm having been informed that personal data, name, address and telephone contacts will be included in the CEDACE National Database, as well as, the immunogenetic analysis data (HLA Typing) is intended to be compared with those of patients in need of bone marrow transplantation.

Furthermore, I confirm to have been informed that my personal data will only be analysed in comparison with the patient's immunogenetic data in case of activation as a potential donor and that this analysis will only be carried out by a Qualified Professional (MD or technician accredited for this purpose). The responsibility of handling this data is entirely of CEDACE Technical Department.

I also confirm, after reading the information, that I have been clarified of all doubts and **declare to consent that personal data, such as gender, age, HLA typing and other clinical information decisive for the selection of a Panel Donor** (but that do not allow my nominative identification), can be digitally processed and submitted to WMDA – World Marrow Donors Association.

**For confidentiality reasons, all documents concerning registrations of potential donors that do not proceed due to clinical criteria, will be destroyed, after informing the candidate, within six months of receiving the information/document.**

**Donor**

**Healthcare Professional**

Doctor  Nurse  Other

\_\_\_\_\_  
(Legible Signature)

\_\_\_\_\_  
(Legible Signature)

**Donor identify verify by:** CC  Passport  Other

**Date:** \_\_\_\_/\_\_\_\_/\_\_\_\_

## INQUIRE

All responses are confidential and are intended to protect you and the patient who will receive your bone marrow

### To be filled in by the Potential Donor

Gender: M <input type="checkbox"/> F <input type="checkbox"/>	Weight: _____	Height: _____	Age: _____ years
Origin (ethnicity): _____	Date of birth: ____/____/____		
Naturality: _____	Nationality: _____		

	Yes	No
1. Have you ever donated blood If so state where: _____ Have you ever been refused as a blood donor after donating blood? State the reason? _____	<input type="checkbox"/>	<input type="checkbox"/>
2. Do you have any heart disease? If yes, please state which one: _____	<input type="checkbox"/>	<input type="checkbox"/>
3. Do you have any lung disease? If yes, please state which one: _____	<input type="checkbox"/>	<input type="checkbox"/>
4. Do you have any kidney disease? If yes, please state which one: _____	<input type="checkbox"/>	<input type="checkbox"/>
5. Do you have or have had any thyroid disease, diabetes or other autoimmune disease? _____	<input type="checkbox"/>	<input type="checkbox"/>
6. Do you have any neurological disease (eg. Epilepsy)? _____	<input type="checkbox"/>	<input type="checkbox"/>
7. Do you have any disease of the digestive system? If yes, please state which one: _____	<input type="checkbox"/>	<input type="checkbox"/>
8. Do you have or have had any malignant disease? _____	<input type="checkbox"/>	<input type="checkbox"/>
9. Have you ever had hepatitis? If so and, in case you know, how long ago was it? _____ and what was the Type: A, B or C _____	<input type="checkbox"/>	<input type="checkbox"/>
10. Do you have any chronic disease? Please state which? _____	<input type="checkbox"/>	<input type="checkbox"/>
11. Have you ever had a surgery? If yes, please indicate the reason: _____	<input type="checkbox"/>	<input type="checkbox"/>
12. Have you had any blood transfusions since 1980? If yes, please indicate the reason: _____	<input type="checkbox"/>	<input type="checkbox"/>
13. Have you been undergoing any medical treatment for more than 6 months? If yes, please indicate the treatment and the reason: _____	<input type="checkbox"/>	<input type="checkbox"/>
14. Was there any case of Creutzfeldt-Jakob Disease in your family (Human variant of mad cow disease)?	<input type="checkbox"/>	<input type="checkbox"/>
15. Have you ever been submitted to a tissue/organ transplant or treatments with growth hormones?	<input type="checkbox"/>	<input type="checkbox"/>
16. Have you ever used injectable drugs not prescribed by a Medical Doctor?	<input type="checkbox"/>	<input type="checkbox"/>
17. Do you consider having any behaviour or life habits that make you susceptible to be a carrier of infectious-contagious diseases?	<input type="checkbox"/>	<input type="checkbox"/>

Observations:

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