

DKMS Donor-Patient Contacts

Information Sheet for Transplant Centers

Anonymous Correspondence		
Information after donation	Our coordinators may inform our donors about their recipients 'approximate age, sex and country where the transplant took place. Therefore, the recipients can accordingly be informed of the approximate age, sex and nationality of their donor. Please be careful not to pass on any further data regarding our donors to your recipients. Further details such as donor ID, date of birth, height, weight or collection center should be protected and kept anonymous.	
Why should the anonymity be protected?	<ul style="list-style-type: none"> - Both sides have the right to remain anonymous - The altruistic nature of the donation should be guaranteed. Thereby, recipients are protected from potential demands from the donor - Protection from emotional participation (Both donors and recipients are free to decide whether they want to establish anonymous or direct contact. Therefore, they can choose the level of emotional participation themselves) - Donors are able to decide as freely as possible about whether or not to give any subsequent donations and do not need to justify their choice to the recipient - Both parties have the option of getting to know each other while under the protection of anonymity. This allows them to find out whether they are on the same wavelength in advance. 	
Start & length	It is possible to establish anonymous contact between donors and recipients through DKMS or the transplant center right after the stem cell transplantation. The period of anonymity lasts for two years in Germany. In case of a second donation (PBSC/BM) this period is extended another year from the date of the subsequent donation. In case of a MNC there will be an extension of anonymity up to 3 months, or individual clarification with the clinic and the patient. If the patient passes away, anonymous correspondence is also possible between the relatives and the donor.	
Guide to anonymous correspondence	<p>What information cannot be shared in anonymous correspondence?</p> <ul style="list-style-type: none"> - Names (this includes family names, pet names, friends, clubs, fantasy names, names of transplant centers or donor registers, initials...) - Diagnoses - the recipient's exact age - Locations / holiday destinations/ Regional specifics (festivals, dialects,...) - Profession - Exotic hobbies (e.g. facade climbing) - Exact dates (the recipient's story with exact dates) - Pictures - To be able to examine each and every gift conscientiously, we allow only one gift per side - Letters and their contents should not be published on the internet (e.g. social media portals) <p>=> any information that endangers the protection of anonymity</p>	<p>And what is allowed?</p> <ul style="list-style-type: none"> - Country of origin - ethnic origin - family - general descriptions of relationship
Please forward to this address	DKMS Donor-Patient Contacts Kressbach 1 72072 Tübingen	<p>Please include the donor ID, patient ID and the patient's name.</p> <p>For any questions, please contact: donor2patient@dkms.de</p>

Release of Personal Information

Criteria and procedures

If your recipients should express the wish to get to know their donor, the following steps have to be considered:

- Has the period of anonymity already expired or will it expire in the next two months?
- Is the recipient aware of the consequences of ending the anonymity?
- Once the personal information has been exchanged, there is no way of undoing the exchange
- Anonymity and all its related protection for both parties will be void and cannot be restored
- The recipient and donor might not get along with each other
- We suggest that donors and recipients correspond anonymously before their personal information is released. Especially if uncertainties are involved, it can help to release only certain details, such as a first name and an email address
- The recipient should fill out the request form legibly and sign it. (If the necessary documents are not available, DKMS can provide them to you. It does not matter to DKMS which form is used by the patient)
- When informing DKMS about recipients who want to get to know their donors, please do not send requests before having the recipient's signed form of consent at hand.
- As soon as DKMS have received the donor's form of consent, DKMS will let you know immediately and request the patient's release form if it has not yet been sent.
- Should a recipient pass away, the exchange of personal information with the patient's relatives is possible as well. In this case, any existing restriction due to the period of anonymity restriction is void.

Patient Follow-up Requests

Information

In accordance with the ZKRD and WMDA standards, DKMS will ask for a first update on your recipient's state of health 3 months after transplantation and send you a follow up questionnaire, as fillable PDF, for this purpose. We kindly ask you to complete this questionnaire as quickly as possible and return it. Should no response have been received within six weeks, DKMS will send out a reminder. If the donor has expressed the wish to receive information regarding the recipient's state of health, we provide them with generalized updates based upon the information we receive. Only in certain circumstances or if the donor repeatedly asks for updates further follow-ups will be requested 12- and 24-months post-transplant or annually after 24 months have passed.

Due to the JACIE-accreditation scheme in certain collection centers, we ask for engraftment data (ANC >500/ μ l, WBC >1000 and Platelets >20/ μ l) in our first follow up form.