

## DKMS Donor-Patient Contacts

### Information Sheet for Transplant Clinics

Anonymous Correspondence			
Information after donation	<p>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.</p>		
Why should the anonymity be protected?	<ul style="list-style-type: none"> <li>- Both sides have the right to remain anonymous</li> <li>- The altruistic nature of the donation should be guaranteed. Thereby, recipients are protected from potential demands from the donor</li> <li>- 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)</li> <li>- 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</li> <li>- 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.</li> </ul>		
Start & length	<p>It is possible to establish anonymous contact between donors and recipients through DKMS or the transplant center right after the stem cell donation. The period of anonymity lasts for two years in Germany. In case of a second donation (either PBSC/BM or a DLI), this period is extended another year from the date of the subsequent donation. If the patient passes away, anonymous correspondence is also possible between the relatives and the donor.</p>		
Guide to anonymous correspondence	<p><b>What information cannot be shared in anonymous correspondence?</b></p> <ul style="list-style-type: none"> <li>- Names (this includes family names, pet names, friends, clubs, fantasy names, names of transplant centers or donor registers, initials...)</li> <li>- Diagnoses</li> <li>- Future vacation spots</li> <li>- Locations</li> <li>- Regional specifics (Christkindelsmarkt, Karneval, dialects,...)</li> <li>- Exotic jobs (e.g. national champion of cake baking 2012)</li> <li>- Exotic hobbies (e.g. facade climbing)</li> <li>- Exact dates (the recipient's story with exact dates)</li> <li>- Pictures cannot be forwarded</li> <li>- Gifts with a value greater than 20€ can not be forwarded</li> <li>- To be able to examine each and every gift conscientiously, we decided to introduce this new <b>one-gift policy</b>.</li> <li>- Letters and their contents should not be published on the internet (e.g. social media portals)</li> <li>- the recipients' exact age</li> </ul> <p>=&gt; <b>any information that endangers the protection of anonymity</b></p>	<p><b>And what is allowed?</b></p> <ul style="list-style-type: none"> <li>- Country of origin</li> <li>- ethnic origin</li> <li>- profession</li> <li>- family</li> <li>- general descriptions of relationships</li> </ul>	
Please forward to this address	<p>DKMS gemeinnützige GmbH Donor-Patient Contacts Kressbach 1 72072 Tübingen Germany</p>	<p><b>Please include the donor ID, patient ID and the patient's name.</b></p>	<p>For any questions, please contact:  Tel.: +49 7071/943-2303 E-Mail: 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
  - The protection guaranteed by anonymity will vanish
  - The recipient and donor might not like 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, the 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 our 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.

**A DKMS template for a form of consent for recipients can be found on pages 3 and 4 and a blank consent form is also attached to this message.**

## Patient Follow-up Requests

### Information

In accordance with the German 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 for this purpose. We kindly ask you to fill out this questionnaire as quickly as possible and return it to us. Should no response have been received within six weeks, we will send out a reminder. If our 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/ $\mu$ l, WBC >1000 & Platelets >20/ $\mu$ l) in our first follow up form.

You will find templates for our 3 and 12 month follow-up requests on pages 5 and 6.



### **Information regarding the release of personal information**

Before you agree to share your contact information with your blood stem cell donor, we would like to provide you with a few thoughts for your consideration.

Of course the positive aspects of direct contact are in the forefront such as being able to meet your 'genetic twin' and that you might, as has happened many times before, develop a meaningful, long term friendship.

However, the exchange of personal information can also bring with it risks.

After the exchange of personal information, you are no longer protected by the anonymity provided to you by the donor's registry and the clinic. Should any friction or demands develop between you and the donor, DKMS and the transplant centre would no longer have any influence.

Important genetic characteristics match between you and your blood stem cell donor. This does not necessarily mean that you are also similar or identical in any other aspects of your lives. Along with the fascinating questions about similarities between you and the donor also comes the possibility of differences. This means that the contact between you and the patient might also be difficult or break off.

Thank you!

The DKMS Donor-Patient Contacts Department



Please send back to:

DKMS gemeinnützige GmbH  
Donor-Patient Contacts  
Kressbach 1  
72072 Tübingen  
Germany

donor2patient@dkms.de

**Consent for the Release of Personal Information to the Stem Cell Donor of**

[Redacted]

**Yes, I agree to release the following information to my stem cell donor:**  
Please enter only the information you wish to share with your donor.

**Name**

**Address**

**City / Postcode**

**Country**

**Date of Birth**

**Phone**

**Email**

I agree that the information written above can be released to my stem cell donor.

\* I hereby agree that the details entered here can be processed by DKMS for the purpose of providing direct contact between the patient and the donor.

.....

Date Signature Patient [Redacted]

Should the patient be underage, we ask the patient's guardian to sign this form.

**No, I do not agree to share personal information with my stem cell donor.**

.....

Date Patient Signature [Redacted]

**I need more time for consideration before making a decision.**

\* This consent may be revoked at any time without providing any reason by notifying DKMS either via post (DKMS gemeinnützige Gesellschaft mbH, Donor-Patient Contacts, Kressbach 1, 72072 Tübingen, Germany) or via email (donor2patient@dkms.de).

**Patient Follow-up Request – 3 months post transplantation**



DKMS gemeinnützige GmbH  
Kressbach 1  
72072 Tübingen, Germany

**Contact:** Donor-Patient Contacts  
T +49 7071 943 2303  
F +49 7071 943 1399  
Donor2patient@dkms.de

**Recipient Follow-up (Post Allogeneic Stem Cell Transplantation)**

Patient Name: [REDACTED]  
 Patient DOB: [REDACTED]  
 Patient ID: [REDACTED] / EMDIS [REDACTED]  
 Donor ID: DEDKM [REDACTED]  
 Transplant Center: [REDACTED]  
 Date of Donation: [REDACTED]

Patient alive?	<input type="checkbox"/> Yes	<input type="checkbox"/> No, date of death _____ <small>(yyyy/mm/dd)</small>
If yes, patient last seen on:	_____ <small>(yyyy/mm/dd)</small>	
If no, reason of death?	<input type="checkbox"/> GvHD <input type="checkbox"/> Relapse <input type="checkbox"/> Sepsis <input type="checkbox"/> MOF <input type="checkbox"/> Infection <input type="checkbox"/> Other: _____	
Product infused?	<input type="checkbox"/> Yes <input type="checkbox"/> No	
Discharged from hospital?	<input type="checkbox"/> Yes, day + _____ <input type="checkbox"/> No	
If no, reason:	<input type="checkbox"/> GvHD <input type="checkbox"/> Relapse <input type="checkbox"/> Sepsis <input type="checkbox"/> MOF <input type="checkbox"/> Infection <input type="checkbox"/> Other: _____	
Patient lost to follow-up?	<input type="checkbox"/>	
Engraftment:: ANC >500/µl	day + _____	not achieved <input type="checkbox"/>
		not performed <input type="checkbox"/>
WBC>1000/µl <small>(only if ANC not performed)</small>	day + _____	not achieved <input type="checkbox"/>
		never below <input type="checkbox"/>
Platelets>20/µl <small>(w/o platelet transfusions)</small>	day + _____	not achieved <input type="checkbox"/>
		never below <input type="checkbox"/>
Adverse events during transplant infusion?	<input type="checkbox"/> Yes <input type="checkbox"/> No	
If yes, please specify:	_____	
Recurrence of original disease?	<input type="checkbox"/> Yes, day + _____ <input type="checkbox"/> No	
If yes, meanwhile successfully treated?	<input type="checkbox"/> Yes <input type="checkbox"/> No	
Acute GvHD?	<input type="checkbox"/> None <input type="checkbox"/> Grade I <input type="checkbox"/> Grade II <input type="checkbox"/> Grade III <input type="checkbox"/> Grade IV	
If yes, please specify (organ/s):	_____	
Infections?	<input type="checkbox"/> Yes <input type="checkbox"/> No	
If yes, please specify:	_____	
If yes, meanwhile successfully treated?	<input type="checkbox"/> Yes <input type="checkbox"/> No	
Has the patient been re-transplanted, or given T-cells?	<input type="checkbox"/> Yes <input type="checkbox"/> No	
If yes, please specify:	<input type="checkbox"/> PBSC <input type="checkbox"/> BM <input type="checkbox"/> DLI	
Source of cells:	<input type="checkbox"/> the same unrelated donor <input type="checkbox"/> other unrelated donor <input type="checkbox"/> related	
If related, please specify :	<input type="checkbox"/> identical <input type="checkbox"/> mismatched <input type="checkbox"/> haploidentical	
Karnofsky <input type="checkbox"/> / Lansky <input type="checkbox"/> / ECOG <input type="checkbox"/> score:	Calculated on _____ <small>(yyyy/mm/dd)</small>	
Form completed by:	Signature: _____	Date: _____ <small>(yyyy/mm/dd)</small>

**Please send back to:**

**donor2patient@dkms.de**

**3M**

## Patient Follow-up Request – 12 months post transplantation



DKMS gemeinnützige GmbH  
Kressbach 1  
72072 Tübingen, Germany

**Contact:** Donor-Patient Contacts  
T +49 7071 943 2303  
F +49 7071 943 1399  
Donor2patient@dkms.de

### Recipient Follow-up (Post Allogeneic Stem Cell Transplantation)

Patient Name: [REDACTED]  
 Patient DOB: [REDACTED]  
 Patient ID: [REDACTED] / EMDIS [REDACTED]  
 Donor ID: DEDKM [REDACTED]  
 Transplant Center: [REDACTED]  
 Date of Donation: [REDACTED]

Patient alive?	<input type="checkbox"/> Yes	<input type="checkbox"/> No, date of death _____ <small>(yyyy/mm/dd)</small>
If yes, patient last seen on:	_____ <small>(yyyy/mm/dd)</small>	
If no, reason of death?	<input type="checkbox"/> GvHD <input type="checkbox"/> Relapse <input type="checkbox"/> Sepsis <input type="checkbox"/> MOF <input type="checkbox"/> Infection <input type="checkbox"/> Other: _____	
Patient lost to follow-up?	<input type="checkbox"/>	
Patient readmitted to hospital?	<input type="checkbox"/> Yes, on _____ <small>(yyyy/mm/dd)</small>	<input type="checkbox"/> No
If yes, reason:	<input type="checkbox"/> GvHD <input type="checkbox"/> Relapse <input type="checkbox"/> Sepsis <input type="checkbox"/> MOF <input type="checkbox"/> Infection <input type="checkbox"/> Other: _____	
If yes, patient discharged afterwards?	<input type="checkbox"/> Yes, on _____ <small>(yyyy/mm/dd)</small>	<input type="checkbox"/> No
Recurrence of original disease?	<input type="checkbox"/> Yes, on _____ <small>(yyyy/mm/dd)</small>	<input type="checkbox"/> No
If yes, meanwhile successfully treated?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Chronic GvHD?	<input type="checkbox"/> None <input type="checkbox"/> Mild <input type="checkbox"/> Moderate <input type="checkbox"/> Severe If yes, please specify (organ/s): _____	
Infections?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
If yes, please specify:	_____	
If yes, meanwhile successfully treated?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Secondary graft failure?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Has the patient been re-transplanted, or given T-cells?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
If yes, please specify:	<input type="checkbox"/> PBSC <input type="checkbox"/> BM <input type="checkbox"/> DLI Source of cells: <input type="checkbox"/> the same unrelated donor <input type="checkbox"/> other unrelated donor <input type="checkbox"/> related If related, please specify : <input type="checkbox"/> identical <input type="checkbox"/> mismatched <input type="checkbox"/> haploidentical	
Karnofsky <input type="checkbox"/> / Lansky <input type="checkbox"/> / ECOG <input type="checkbox"/> score:	Calculated on _____ <small>(yyyy/mm/dd)</small>	
Form completed by:	Signature: _____	Date: _____ <small>(yyyy/mm/dd)</small>

**Please send back to:**

**donor2patient@dkms.de**

**12M**