

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

Before you agree to share your contact information with the patient, we would like to provide you with a few thoughts for your consideration.

Of course the positive aspects of direct contact are in the foreground 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. Many patients would like to be able to thank their donors personally and feel that this is first properly possible by having direct contact.

The exchange of personal information can also bring with it risks. Should the patient later have a recurrence of their original illness or other health problems in the future, this might weigh more greatly upon the donor than it would have had the anonymity been kept. Furthermore, an unhindered decision about a further stem cell donation or a lymphocyte donation at a later date, though unlikely after two years have passed since a transplant, might be more difficult.

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

Furthermore it is important for you to know that contact between us and the patient is only possible via the patient's transplant centre. This means that it might be necessary to provide your details to a registry or transplant clinic in order to provide your details to the patient. In many cases this is the only means of completing a release of personal information.

Should you have any questions or concerns, please do not hesitate to call us.

Thank you

Your Donor Request Coordination Team

Please return to:

Medical Department  
DKMS  
Ashburnham House  
Castle Row, Horticultural Place  
London  
W4 4JQ

Fax: +44 (0)208 747 5667  
Email: [followup@dkms.org.uk](mailto:followup@dkms.org.uk)

**Consent form for the release of personal information**  
**Donor ID / GRID:** \_\_\_\_\_

**YES, I agree to provide the patient with the following information:**

Please only enter the information that you want to provide to my blood stem cell recipient.

Name:

Address:

City/Postcode:

Telephone:

Email Address:

Birthdate:

I declare that the information entered here may be provided to the blood stem cell recipient and, should it be necessary for the exchange of personal information between me and the patient, also to the transplant centre and/or the coordinating registry.

Permission to release this information cannot be withdrawn once submitted.

\_\_\_\_\_  
Date

\_\_\_\_\_  
Donor's signature

**NO, I do not agree to the release of any personal information to my blood stem cell recipient.**

\_\_\_\_\_  
Date

\_\_\_\_\_  
Donor's signature

I need more time for consideration. Please contact me again on \_\_\_\_\_.