

## **Post-Transplant Consent Form to Release Personal Information after Recipient Death**

### **I. PURPOSE OF THIS CONSENT**

All personal information about you and your relationship with the National Marrow Donor Program (NMDP) is strictly confidential. Release of any personal information without your written approval is a violation of Federal law punishable by fine or imprisonment.

This consent will allow you, if you wish, to give written permission to the NMDP to release personal information about yourself to the associated donor or the associated recipient's 1<sup>st</sup> degree relative when the recipient has passed away. First degree relatives include the recipient's spouse, parent/guardian, children, and siblings.

It is NMDP policy that no personal information about a donor or a recipient be shared with one another until at least twelve months have passed since the peripheral blood stem cell (PBSC) or bone marrow donation and transplant. However, should the recipient die within the first year after the transplant this policy may be waived.

**EXCEPTION:** If the recipient or donor is associated with a transplant center or donor registry located outside of the United States, it may not be possible to exchange personal information between the donor and a first degree relative of the recipient. In these circumstances the NMDP will assist in understanding the international center's rules, and also in facilitating these requests when it is possible.

### **II. POTENTIAL RISKS OF RELEASING YOUR PERSONAL INFORMATION**

You should be aware that there may be risks associated with exchanging your personal information with your donor or recipient's relative. These risks include, but are not limited to:

1. You will no longer be anonymous. The NMDP cannot prevent calls, letters, visits, or requests which you receive directly from the other party, their family, or others with whom your information has been shared.
2. There is no guarantee that the information you release will be acted upon by the other party as they may choose to not respond.
3. Exchanging personal information could create personal stress or have other impacts on you. It is important to consider how you will feel if you have little in common with the other party or their family, or if the recipient's family is actively grieving the loss of their loved one.
4. You could be subjected to unwanted attention from the media.
5. If contact is not maintained after your personal information is released, the NMDP will not make additional attempts to re-establish contact in the future.

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### **III. POTENTIAL BENEFITS OF RELEASING YOUR PERSONAL INFORMATION**

Just as there are potential risks to exchanging personal information, there may also be benefits. These could include:

1. You may develop lasting and important friendships as a result of exchanging your personal information.
2. You may receive attention or publicity that you find pleasing.

### **IV. LIMITATIONS OF THIS CONSENT**

You are free to accept or decline this Consent to Release Personal Information. Your decision will not affect your relationship with the National Marrow Donor Program or your donor center in any way. If you decline, you can change your mind at any time. However, if at this time you decide to release personal information, the NMDP cannot take back the information should you change your mind.

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### V. NATURE OF THE INFORMATION TO BE RELEASED

REQUIRED: ☐ I am a donor. ☐ I am the spouse or 1<sup>st</sup> degree relative of the recipient  
(relationship to recipient \_\_\_\_\_)

Please indicate what contact information you would like to provide to your associated donor or recipient's relative. Each item below is OPTIONAL, but at least one form of contact information is necessary. Any information supplied on this form will be provided to your consenting stem cell transplant partner/family member.

First Name: \_\_\_\_\_

Last Name: \_\_\_\_\_

Street Address: \_\_\_\_\_  
\_\_\_\_\_

City: \_\_\_\_\_

State/Zip Code/Country: \_\_\_\_\_

Telephone: \_\_\_\_\_

E-mail address: \_\_\_\_\_

Other: \_\_\_\_\_

### VI. Signatures

Your signature below indicates that you have read this consent and filled it out to reflect your wishes. A copy of this consent will be given to you for your records. If you have questions about this consent, please contact the Coordinator listed below at your Center or Registry:

\_\_\_\_\_  
Contact / Center Coordinator Name Phone#

\_\_\_\_\_  
Donor or Recipient-Relative Signature Date

\_\_\_\_\_  
Witness Signature Date

**TC/DC Coordinator completes this section:**

**Recipient ID:** \_\_\_\_\_ **Donor ID:** \_\_\_\_\_  
(Both the RID and DID must be present on this form when submitted to the NMDP)