

Place NMDP Bar Code label here

## NATIONAL MARROW DONOR PROGRAM®

*Creating Connections. Saving Lives.®*



### Donor Registration and Consent for HLA Typing

**NOTE:** *This form contains information necessary for you to make an informed decision regarding marrow and blood stem cell donation. It is very important that you carefully read and complete all sections of this form. Thank you for your interest in joining the federally authorized Registry, the C.W. Bill Young Cell Transplantation Program, administered by the National Marrow Donor Program (NMDP).*

#### Factors to Consider Before Signing Up

Patients searching the Registry for an unrelated donor are counting on volunteers to be willing and accessible if ever identified as a match. If you decide to join, you should carefully consider the commitment to remain on the donor file until age 61. The NMDP is aware there are reasons for you to be unavailable when contacted. When patients are searching, however, time is essential. If you have a change in address, a major change in long-term health, or a change in your commitment to be a potential donor, please notify your donor center **immediately**.

You will be asked to answer questions related to your health as part of the process of becoming a volunteer potential donor. The purpose of this medical evaluation is to minimize the risks to both the patient and you, the donor. In addition to the medical evaluation, please carefully review the information below.

#### Are You Currently at Risk for HIV (the AIDS Virus) or Hepatitis?

**Please read this** before you decide whether you should be HLA tissue typed. You will be asked if you have read this information and if you have any questions. You also will be asked to acknowledge that you have answered all of the questions truthfully, and that you are not in any of the risk categories listed.

***If you are at risk for HIV (the AIDS virus) or hepatitis, you cannot be a donor. Based on FDA requirements for blood donors, if your answer to any of the following questions is "yes", you are considered at risk for either HIV or hepatitis and must disqualify yourself from the Program.***

1. Have you ever been diagnosed with HIV or have you tested positive for HIV, the AIDS virus?
2. Have you ever been diagnosed with hepatitis B or C?
3. Have you ever had a bleeding problem or other clotting factor deficiency or have you required human-derived clotting factor concentrates?
4. In the past 5 years have you used a needle, even once, to take any illegal or non-prescribed drugs?
5. In the past 5 years have you taken money or drugs in exchange for sex?
6. In the past 5 years have you had sex, even once, with another male? (Male Only)

If you do not qualify to be a potential donor based on your answers to the above questions, **please accept our thanks** for your interest.

# Confidential Donor Information Form



Last Name(s)

Please print the letters, numbers and "X's" as shown below.

A B C D E 1 2 3 4 5 X

First Name

Birth Date

Age

Social Security Number\*

Middle Name

Sex

Male  Female

Driver's License No.

State

(\*Not providing Social Security Number may limit the ability to locate updated address information. The NMDP does not share information with outside agencies.)

## Donor Telephone / E-mail Information

E-mail Address

(Area Code) Home Telephone

(Area Code) Work Telephone

Ext.

I would like to stay connected. Please send me the donor e-newsletter.

(Area Code) Cell / Pager

Language Preference (for future contacts)

Yes  No

## Current Mailing Address

Address 1

(Apartment number if applicable)

Address 2

(Apartment number if applicable)

City

State

Zip/Postal Code

## Home / Permanent Address (If different from mailing address)

Address 1

Address 2

City

State

Zip/Postal Code

## Race and Ethnicity Information

**Ethnicity:** Since certain HLA types may be more common in each racial and ethnic group, the information below will help in selecting donors for further HLA testing at later stages of the search process. (Please check one):  Hispanic or Latino  Not Hispanic or Latino

**Race:** Of which group(s) are you a member? (Check all that apply)

### American Indian or Alaska Native

- 33 Alaska Native or Aleut
- 34 North American Indian
- 46 American Indian South or Central American
- 47 Caribbean Indian

### Black or African American

- 12 African
- 13 African American
- 14 Black Caribbean
- 15 Black South or Central American

### Asian

- 01 Chinese
- 02 Filipino (Pilipino)
- 04 Japanese
- 05 Korean
- 06 South Asian
- 07 Other Southeast Asian
- 45 Vietnamese

### Native Hawaiian or Other Pacific Islander

- 48 Guamanian
- 60 Hawaiian
- 49 Samoan
- 50 Other Pacific Islander

### White

- 51 Eastern European
- 52 Mediterranean
- 59 Middle Eastern
- 53 North Coast of Africa
- 54 North American
- 55 Northern European
- 56 Western European
- 57 White Caribbean
- 58 White South or Central American
- 61 Other White

Place NMDP Bar Code label here

# Confidential Donor Information Form (cont.)

## Employer Information

Company Name

Address 1

Address 2

City

State

Zip/Postal Code

E-mail Address

## Spouse's Information

Not Applicable

Last Name(s)

First Name

Middle Name

(Area Code) Home Telephone

(Area Code) Work Telephone

Ext.

E-mail Address

## First Contact Person

Please provide the names and complete addresses for two of your nearest relatives or friends. Choose only individuals **who do not live with you and who do not live with each other**, and who will know how to reach you in future years if your address changes or we are unable to contact you.

Last Name(s)

First Name

Middle Name

(Area Code) Home Telephone

(Area Code) Work Telephone

Ext.

E-mail Address

Relationship

Relationship Code:

01 - Parent 02 - Sibling 04 - Child  
05 - Other Relative 06 - Friend

Language Preference

Address

(Apartment number if applicable)

City

State

Zip/Postal Code

## Second Contact Person

Last Name(s)

First Name

Middle Name

(Area Code) Home Telephone

(Area Code) Work Telephone

Ext.

E-mail Address

Relationship

Relationship Code:

01 - Parent 02 - Sibling 04 - Child  
05 - Other Relative 06 - Friend

Language Preference

Address

(Apartment number if applicable)

City

State

Zip/Postal Code



# DONOR REGISTRATION AND CONSENT FOR HLA TYPING

National Marrow Donor Program®

1 (800) MARROW-2

marrow.org

## I. INVITATION AND PURPOSE

You are invited to participate in the federally authorized Registry, the C.W. Bill Young Cell Transplantation Program (Registry). The Registry is administered by the National Marrow Donor Program (NMDP) under a federal contract. The NMDP was established in 1986. Its primary goal is to identify unrelated donors for patients in need of a blood stem cell transplant but who have no family member who is a suitable tissue match. We ask you to read this form and ask any questions you may have before agreeing to enroll as a potential blood stem cell donor (potential donor).

The NMDP works with hospitals that treat patients with life-threatening blood diseases that can be treated with a blood stem cell transplant. When a volunteer registers as a potential donor, his/her tissue type is listed on the donor file and is compared with the tissue type of patients in need of a transplant. If a volunteer donor is identified as a potential donor for a patient, additional testing is required to determine if the volunteer donor's and patient's tissue types are closely enough matched for a transplant. If a volunteer donor is determined to be the best available match for a patient, he/she may be asked to donate blood stem cells.

By signing this form, you are registering as a potential donor. You are also giving the donor center permission to collect, retain and use your personal identifying information and your contact information, and to share this information with the NMDP or other donor centers. You are further giving the donor center permission to collect a blood sample or swab of your cheek cells and to transfer this sample to the NMDP. You are also giving the NMDP permission to determine your tissue type, to store your sample for as long as you remain registered, and to conduct further testing of your stored blood sample to determine if you match a searching patient.

Blood stem cells grow into mature blood cells and can be collected from either the bone marrow or the blood stream. (See Blood Stem Cell Donation Insert.) The chance that you will be selected to donate blood stem cells depends on your tissue type. Since the beginning of the NMDP, about one potential donor in 200 listed on the donor file has donated. It is important for you to know that if you are selected as a donor, blood stem cell donation may require 30 to 40 hours of your time.

## II. PROCEDURES FOR PARTICIPATING IN THE REGISTRY THROUGH THE NMDP

If you want to be a potential donor, you will be asked to answer a series of questions regarding your health. These questions are similar to the questions asked of blood donors. They are designed to protect you, as well as to ensure that it would be safe to use your blood stem cells for transplant.

After answering the health questions, signing the consent form, and providing your personal contact information, your eligibility will be determined. If you are still suitable, you will be asked to either give 10 mL (2 teaspoons) of blood drawn from a vein in your arm, a few drops of blood from a finger stick, or a collection of cheek cells from inside your mouth using a cotton-tipped swab. Some of your sample will be sent to a laboratory for tissue typing (HLA typing). You may be asked to pay all or a portion of the cost for your initial tissue typing. Your tissue type will be included on the list of potential donors.

Any sample not used for initial tissue typing may be stored for future testing to determine if you match a searching patient. If you are identified as a potential tissue match for a patient, additional testing may be needed. If possible, stored samples will be used for this testing, however, you may be asked to provide a fresh blood sample.

## III. POSSIBLE RISKS AND BENEFITS OF REGISTERING AS A POTENTIAL DONOR

There is minimal risk associated with donating blood. You may experience bruising around the site of the blood draw, infection at the puncture site, or more rarely, fainting.

Registering as a potential donor is not expected to benefit you directly in any way. If you donate blood stem cells for a patient, the patient may benefit from the transplant. At each step in the process, you will be given more information and the opportunity to continue or to stop.

## IV. REQUIREMENTS FOR YOUR CONTINUED PARTICIPATION

Your participation continues until you pass the maximum age limitation (which currently is 61 years old), until you withdraw, or until it is determined that you cannot be located, whichever comes first. The NMDP expects that you will keep the NMDP or the donor center informed of changes in your contact information (for example, changes in name, address, phone, etc.). If your health changes after you join, it's possible you may no longer be able to donate blood stem cells. If you experience any changes in your long-term health, you should notify your donor center or the NMDP. You may be periodically contacted in an effort to keep your address information current and to provide you with program updates.

# DONOR REGISTRATION AND CONSENT FOR HLA TYPING

National Marrow Donor Program®

1 (800) MARROW-2

marrow.org

## V. VOLUNTARY PARTICIPATION AND WITHDRAWAL

If you decide to join the Registry as a potential donor, you are free to withdraw at any time. If you withdraw, your tissue type will no longer be available for searching patients, and if you have a sample stored, it will be destroyed. No matter what you decide, now or in the future, your decision will not affect your ability to use the services of the Registry or the NMDP, if needed.

## VI. SAFETY

The only physical risk associated with registering as a potential donor is donating the blood sample for tissue typing. The risks associated with the blood draw are slight. If an injury does occur, treatment will be available, including first aid, emergency treatment and further care as needed.

## VII. REIMBURSEMENT AND COSTS TO YOU

You will not be paid for participating as a potential donor and, if you donate blood stem cells, you will not be paid for the donation. (You may be asked to pay for the cost of your initial tissue typing and, if so, will be told of this in advance of the blood draw.) You will not be charged for any expenses resulting from further testing to identify you as the best available donor or for the collection of your blood stem cells.

## VIII. CONFIDENTIALITY

The NMDP and the donor center have procedures in place to keep each potential donor's personal information and donor status private and confidential. Your tissue type and sample stored by the NMDP will be identified by a code and will be stored separately from the personal identifying information that you provide when registering to be a potential donor. Your personal identifying information will not be disclosed to transplant centers. Your personal identifying information also will not be disclosed for any purposes other than those identified in this consent form without your further consent. If you are selected as a potential matching donor for a searching patient, your personal identifying information and contact information will be used in attempting to locate you.

## IX. POTENTIAL ADDITIONAL REQUESTS

As a volunteer donor, you may be contacted about donating other types of blood products, such as whole blood or white blood cells for a patient, or asked if you would like to participate in a research project. If you are contacted for one of these types of requests, you would be given more information and asked to sign another consent form. You are free to say no to any of these requests.

## X. QUESTIONS OR CONCERNS

If you have questions or concerns about participating as a potential donor, please contact the local donor center coordinator. If you have any questions or concerns about the NMDP, please contact the NMDP Donor Resources Department at 1-800-526-7809. You will be given a copy of this consent form for your records.

## XI. DONOR STATEMENT OF CONSENT

My signature below indicates that:

- I have read this form and consent to its terms.
- I have read the information provided in this form on risk for HIV and hepatitis.
- I have provided accurate health information.
- I have read the educational materials provided.
- I have been given the chance to ask questions.
- I have given correct and complete contact information.
- I consent to have a sample collected.
- I consent to have my sample tissue typed and listed on the Registry and with the NMDP.
- I consent to have my sample stored by the NMDP to be available for Registry purposes and for possible future testing to determine if I match a searching patient.

\_\_\_\_\_  
Donor's Signature

MM / DD / YYYY

Today's Date

\_\_\_\_\_  
Print Donor's Name

F00350V3.0A



If any, how much did you contribute to the cost of your tissue typing? ..... \$   
(This information will be used for statistical purposes only.)