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 Be The Match Registry®. The National Marrow Donor Program® (NMDP) is entrusted to operate the federally authorized C.W. Bill Young Cell Transplantation Program, including the Be The Match Registry.

Factors to Consider Before Signing Up

Patients searching the Be The Match 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 join. 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 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) 

First Name 

Middle Name 

Sex  Male  Female 

Birth Date  M M / D D / Y Y Y Y 

Age 

Driver’s License No. 

Social Security Number* 

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. 

(Area Code) Cell / Pager 

Language Preference (for future contacts) 

Current Mailing Address

Address 1 

Address 2 

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  Non 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 

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 

Please print the letters, numbers and “X’s” as shown below.

A B C D E 1 2 3 4 5  X 

Donor Registration and Consent for HLA Typing 
National Marrow Donor Program® 
For internal use only: Document F00746 Revision 1 
12378; JUN 2010 

Continue on to Page 3
### Confidential Donor Information Form (cont.)

#### Employer Information
- **Company Name**: [Name]
- **Address 1**: [Address]
- **Address 2**: [Address]
- **City**: [City]
- **State**: [State]
- **Zip/Postal Code**: [Zip/Postal Code]
- **E-mail Address**: [Email]

#### Spouse’s Information
- **Last Name(s)**: [Name]
- **First Name**: [Name]
- **Middle Name**: [Name]
- **(Area Code) Home Telephone**: [Phone]
- **(Area Code) Work Telephone**: [Phone]
- **Ext.**: [Extension]
- **E-mail Address**: [Email]

#### First Contact Person
- **Last Name(s)**: [Name]
- **First Name**: [Name]
- **Middle Name**: [Name]
- **(Area Code) Home Telephone**: [Phone]
- **(Area Code) Work Telephone**: [Phone]
- **Ext.**: [Extension]
- **E-mail Address**: [Email]
- **Relationship Code**: [Code]
- **Language Preference**: [Language]
- **Address**: [Address]
- **City**: [City]
- **State**: [State]
- **Zip/Postal Code**: [Zip/Postal Code]

#### Second Contact Person
- **Last Name(s)**: [Name]
- **First Name**: [Name]
- **Middle Name**: [Name]
- **(Area Code) Home Telephone**: [Phone]
- **(Area Code) Work Telephone**: [Phone]
- **Ext.**: [Extension]
- **E-mail Address**: [Email]
- **Relationship Code**: [Code]
- **Language Preference**: [Language]
- **Address**: [Address]
- **City**: [City]
- **State**: [State]
- **Zip/Postal Code**: [Zip/Postal Code]
Medical Evaluation

Your answers to all questions are confidential. This medical evaluation below is designed to protect you, as well as safeguard the patient who might receive your blood stem cells. Although you may be medically suitable at this time, you may become medically unable to donate in the future.

1. Are you between the ages of 18 and 60 years? ................................................................................................................... ☐ Yes ☐ No

2. Are you in good general health? .......................................................................................................................................... ☐ Yes ☐ No

3. Are you at risk for HIV or hepatitis? (Answer this question “yes” if you would respond “yes” to any of the six HIV and hepatitis risk questions listed on page one.) .................................................................................................... ☐ Yes ☐ No

Please explain “yes” answers to questions 4 through 9 in detail below so your responses can be properly evaluated.

4. Have you ever had a serious illness such as: cancer • diabetes • breathing problems including asthma • sleep apnea or shortness of breath • heart disease including heart surgery • heart attack • heart-related chest pains • stroke • bleeding problems or blood clots • liver disease • autoimmune disorder such as lupus, multiple sclerosis, or rheumatoid arthritis? ........................................................................................................................................................ ☐ Yes ☐ No

5. Have you ever had neck, back, hip or spine problems?...................................................................................................... ☐ Yes ☐ No

6. Have you ever received a solid organ, marrow or stem cell transplant? ............................................................................. ☐ Yes ☐ No

7. Are you currently taking any medications prescribed by a physician? ................................................................................ ☐ Yes ☐ No

8. In the past 12 months have you needed treatment in an emergency room, been hospitalized, or had surgery? ............... ☐ Yes ☐ No

9. Is there anything else about your health that we should be aware of? ................................................................................ ☐ Yes ☐ No

Explanation of "yes" responses (for questions 3 through 9)


Donation History

Have you been a blood donor in the past? ............................................................................................................................ ☐ Yes ☐ No

Would you like to be contacted for blood donation? .................................................................................................................. ☐ Yes ☐ No

Have you been a platelet or apheresis donor in the past? ........................................................................................................ ☐ Yes ☐ No

Would you like to be contacted for platelet or apheresis donation? .......................................................................................... ☐ Yes ☐ No

Would you like to be contacted for other volunteer opportunities? .......................................................................................... ☐ Yes ☐ No

OFFICE USE ONLY - Optional

Evaluator’s Signature __________________________ Date MM/DD/YYYY

Phlebotomist’s Signature __________________________ Date MM/DD/YYYY

Donor Registration and Consent for HLA Typing

National Marrow Donor Program®

For internal use only: Document F00746 Revision 1

12378; JUN 2010

Continue on to Page 5
I. INVITATION AND PURPOSE

You are invited to participate in the Be The Match Registry®. The National Marrow Donor Program® (NMDP) is entrusted to operate the federally authorized C.W. Bill Young Cell Transplantation Program, including Be The Match Registry. The registry is administered by the 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 you are identified as a possible donor for a patient, additional testing would be required to determine if your tissue type matches the patient’s closely enough for a transplant. If you are determined to be the best available match for a patient, you may be asked to donate blood stem cells.

By signing this form, you are registering as a potential donor. You are also giving the NMDP permission to collect, retain and use your personal identifying information and your contact information, and to share this information with NMDP donor centers. Likewise, you are giving the NMDP and Be The Match FoundationSM permission to exchange between them your contact information and any updates to your contact information. You are further giving the NMDP permission to collect a blood sample or swab of your cheek cells. 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 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 bloodstream. (See Steps of Donation on page 4 of your Donor Copy 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 over a four to six week period.

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 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 contribute 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

If a blood sample is requested to join the registry, you should know there is minimal risk associated with the blood draw. 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.

V. VOLUNTARY PARTICIPATION AND WITHDRAWAL

If you decide to join the Be The Match 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 providing 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 contribute toward the cost of your initial tissue typing and, if so, will be told of this in advance of the swab of cheek cells or blood draw procedure.) 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 be disclosed only for purposes identified in this consent form or for purposes related to the operation of the federally authorized C.W. Bill Young Cell Transplantation Program in compliance with the requirements of the federal Privacy Act. Your personal identifying information will not be disclosed to transplant centers. 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.

You may be periodically contacted by the NMDP and Be The Match Foundation in an effort to keep your address information current, to provide you with program updates, and to share opportunities for involvement through, among other things, volunteering, donating money and advocating for our cause.

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 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 Be The Match Registry and with the NMDP.
- I consent to have my sample stored by the NMDP to be available for the Be The Match Registry purposes and for possible future testing to determine if I match a searching patient.

Donor’s Signature

Today’s Date

Print Donor’s Name