

# National Marrow Donor Program<sup>®</sup> and Be The Match<sup>®</sup> Key Messages, Facts & Figures

# About Us

For people with life-threatening blood cancers - like leukemia and lymphoma - or other diseases, a cure exists. Be The Match<sup>®</sup> connects patients with their donor match for a life-saving marrow or umbilical cord blood transplant. People can be someone's cure as a member of the Be The Match Registry<sup>®</sup>, financial contributor or volunteer. Be The Match provides patients and their families one-on-one support, education, and guidance before, during and after transplant.

Be The Match is operated by the National Marrow Donor Program<sup>®</sup> (NMDP), a nonprofit organization that matches patients with donors, educates health care professionals and conducts research so more lives can be saved. To learn more about the cure, visit <u>BeTheMatch.org</u> or call 1 (800) MARROW-2.

## The Need for Marrow and Cord Blood Transplantation

- Every year, more than 12,000 patients in the U.S. are diagnosed with life-threatening diseases such as leukemia or lymphoma for which a marrow or umbilical cord blood transplant from an unrelated donor may be their best or only hope of a cure.
- About 70 percent of patients in need of a transplant do not have a matching donor in their family. They depend on the Be The Match Registry to find an unrelated donor or umbilical cord blood unit.
- Financial resources are needed to:
  - Add new members to the Be The Match Registry
  - Assist transplant patients with uninsured costs, including timely donor searches and posttransplant care
  - o Advance transplant research

### Helping Patients Receive the Treatment they Need

- The Be The Match Registry is the world's largest and most diverse registry of potential marrow donors and donated cord blood units. With more than 10.5 million potential donors and nearly 185,000 available cord blood units, our growing registry is helping more patients than ever before get the transplant they need.
- On average, more than 52,000 new potential donors join the Be The Match Registry each month. More than 626,000 new potential donors joined in 2012.
- In 2012, our network of public cord blood banks recruited more than 20,800 cord blood units.
- In 2012, more than 14,000 U.S and international searches of the Be The Match Registry were conducted on behalf of patients seeking a matching donor or cord blood unit. More than 5,800 patients went on to receive a transplant
- We facilitated more than 5,800 marrow, PBSC and umbilical cord blood transplants in 2012, an average of nearly 490 transplants each month.
- Since we began operations in 1987, we have facilitated more than 55,000 marrow, peripheral blood stem cell (PBSC) and umbilical cord blood transplants.
- In 2012, more than 1,600 patients received assistance, and more than \$2.5 million was paid to qualifying patients through the Be The Match Foundation<sup>®</sup> Patient Assistance Program.



# **Serving All Communities**

We work with civic, community, corporate and faith-based organizations to recruit potential donors and add cord blood units from diverse communities.

Composition of the Be The Match Registry by Race and Ethnicity	Number and % Potential Adult Donors	Number and % Cord Blood Units
African American or Black	Nearly 720,000 7%	More than 13,000 7%
American Indian/Alaska Native	Nearly 115,000 1%	300 0.2%
Asian	More than 720,000 7%	Nearly 18,000 10%
Hispanic (identified as either Hispanic or Latino ethnicity)	More than 1 million 10%	Nearly 34,000 18%
Multiple Race	Nearly 395,000 4%	Nearly 17,000 9%
Native Hawaiian or Other Pacific Islander	More than 16,000 0.2%	174 0.1%
White	More than 7.1 million 67%	Nearly 111,000 60%

Note: Percentages may not add up to 100% due to rounding.

# Likelihood of Finding a Matching Adult Donor by Race and Ethnicity (Based on 7 of 8 matching)

• A patient's likelihood of having a donor on the Be The Match Registry who is willing and able to help save a life is estimated to range from 66% to 93%, depending on race and ethnicity. Cord blood improves likelihood of finding an appropriate cell source. In 2012, 39 percent of minority patients who received a transplant used cord blood.

All patients, depending on race and ethnicity	66-93%
African American or Black patients	66%
American Indian and Alaska Native	82%
Asian or Pacific Islander	73%
Hispanic or Latino	72%
White	93%

Source: NMDP Bioinformatics, 2010

Note: Percentages are based on matching an adult donor only. Cord blood further increases the chance of finding a match for some patients.

We are committed to increasing access and improving outcomes for all patients in need. Barriers to transplant include lack of access to health care, no or limited insurance coverage, lack of timely referral for transplant, decline in health status, and inability to find a matched donor or cord blood unit. The NMDP and Be The Match are working to address these barriers.



# **Registry Members' Chance of Being Contacted and Going on to Donate**

Because of the vast variation in tissue types, we can't predict an individual's chance of donating. If you have a relatively common tissue type, you might be one of many who could match a searching patient. If you have an uncommon tissue type, you may never match a patient—or you might be the only one out of more than 10.5 million registry members who can save a person's life.

- About 1 of every 40 U.S. Be The Match Registry members will be called for additional testing to see if they are the best match for a specific patient.
- About 1 in 300 will be selected as the best possible donor. These potential donors will have an
  information session with their donor center representative to learn about the donation process. If
  they agree to continue, they will undergo a physical exam to make sure donation is safe for them
  and the patient.
- On average, 1 in every 540 members on the U.S. Be The Match Registry in the U.S. will go on to donate bone marrow or peripheral blood stem cells to a patient.
- Reasons someone may not move forward toward donation include:
- They are not the best match for the patient
- They have health issues that make them ineligible to donate
- They decide not to proceed, for a variety of reasons
- The patient's health or treatment plan changes

### Research

Research is essential to the NMDP's mission. In 2012, together with its research partner, CIBMTR (Center for International Blood and Marrow Transplant Research<sup>®</sup>), the NMDP shared the results of cutting-edge research through:

- A total of 55 peer-reviewed journal articles and
- 41 abstracts presented at professional conferences.
- 19 clinical studies open to accrual and 225 observational studies in progress.

### **Organizational Statistics**

The NMDP is the hub of a global transplant network including donor centers, transplant centers, cord blood banks and registries in 41 countries. Forty-five percent of all transplants facilitated by the NMDP in 2012 involved either an international donor or recipient.

The NMDP employs nearly 860 staff based at its Minneapolis Coordinating Center and 25 locations across the United States.

Our network partners include:

- 100 apheresis centers
- 92 collection centers
- 40 cooperative registries
- 49 donor centers
- 25 cord blood banks
- 44 recruitment groups
- 174 transplant centers
- 461 research center partners

#### Our media relations staff is available to answer questions 24-hours a day at (612) 817-6442.