Donor Community

Key Messages

The Donor Community is a closed group on Facebook that connects registry members who have been called as a potential match for a patient with people who have gone on to donate either bone marrow or PBSC (peripheral blood stem cells). The overall goal is to further educate members to decrease/eliminate fears and concerns and to increase member availability.

Why the donor community is important (messages for use with POTENTIAL & PAST DONORS):

- We want potential donors to have all of their questions answered so that they can make an informed donation decision.
- Potential donors often want to hear directly from someone who has been through the donation process.
- Currently, about 50 percent of all registry members are not able or willing to donate when called as a potential match.
- There are many reasons a registry member may no longer be willing or able to donate, such as a change in health or life circumstances. Some members don’t remember signing up, or misunderstand their commitment to help any patient.
- This can be devastating for patients and their families. Delays in the search for a donor can be life-threatening.
- Members have the right to change their mind about being a donor at any time because donating is always voluntary. However, by interacting with others who have been through the process, more members may more fully understand what donating means and say yes.

Donor involvement (messages for use with PAST DONORS only)

- To be added to the Facebook group, I can send you a text with a link and you can request to join.
- Members are looking to hear from real donors – not just what Be The Match representatives have to say about the process.
- How to interact with members:
  - Share your donation story – Most likely, members won’t know anyone who has actually donated. Tell them what it was like.
  - Ask questions – Find out what people are curious about and then help answer.
  - Answer member questions – This is an outlet for people who were recently called as a match to ask honest questions and get insight from people’s firsthand experiences.

To join the Donor Community (messages for use with POTENTIAL & PAST DONORS):

- Click the following link to get to the closed group on Facebook: <insert link>
- Click the “Join Group” button.
- To ensure only past donors or potential donors join the community, you’ll need to answer three screening questions before our Community Manager grants you access. When asked for the group password, enter “MarrowSavesLives”.
  - We’ll also ask you to verify your first and last name, and confirm that you’ve donated previously or are currently in a patient search for a matching donor.
- A Community Manager will grant you access to the group.
Once in the group, be sure to read the pinned post about the group guidelines. It includes appropriate group conduct, donor/patient confidentiality and that content should not be considered medical advice.

- If you have any questions about the Donor Community, contact the Community Managers at DonorCommunity@nmdp.org