Donations Please

Bone marrow transplants can cure many diseases, but more donors are needed.

November 28, 2014 By Kate Ferguson

According to Be the Match, the world's largest, most diverse marrow registry, the group's mission is to deliver cures for blood cancers. Last year, Be the Match facilitated 6,300 transplants. What's more, the registry accesses 22.5 million donors and 601,000 cord blood units worldwide. Despite these impressive numbers, however, African-American donors aren't joining the database in large enough numbers. This means black people have less access to potential matches.

Caucasians make up the largest population group in Be the Match's registry at about 67 percent, says Barbara Nolan, a manager of community engagement with the group. African Americans represent about 7 or 8 percent of donors and other population groups make up about 20 percent of registered donors.

Here, Real Health chats with Nolan about bone marrow donations.

Why don't more African Americans donate bone marrow?

I don't think it's due to apathy. First of all, we typically have not had a strong donation history, whether it's blood, organ, tissue, let alone marrow, and I think that might be part of it. Historically, we've had some concerns about the medical community that need to be addressed before we feel comfortable involving ourselves in making donations of this type. But I also think one of the bigger issues is lack of awareness and education about who Be the Match is and what we do, and how we can involve not only African Americans but the general community in regard to the mission. But I also think the more opportunities we have to share who we are and what we do with the community, the more aware people can then become. It's up to Be the Match to make opportunities to join the registry predominant in our community. We have more work to do for sure, and we rely on media and other sponsors to help us get the word out.

Why is marrow donation so important, especially for African Americans?

It's very important specifically for African Americans because bone marrow is matched genetically. Having enough African-American bone marrow donors ensures that when African-American patients search, they'll have access to potential donors who are like them. When we think about diseases marrow can cure, sickle cell is one of those illnesses. African Americans are

disproportionately affected by sickle cell in the community and so we want to make sure we get enough people in the database who can help those patients who are suffering from sickle cell to get the transplant that they need.

Are there any requirements in terms of who can donate bone marrow?

Because we want to make sure that we are keeping our donors as safe as possible and we're not putting them in any kind of medical jeopardy, we do have some basic medical guidelines. We want to make sure the person who is donating doesn't have a chronic lung disease, doesn't have heart disease or a cancer that they're dealing with, or [is] a diabetic requiring insulin. In addition, back conditions can be a big deferral because we have to medically clear people for the more invasive of the two bone marrow donation procedures, which is the marrow harvest. But we more often than not do the stem cell collection procedure. So if you have back alignment problems, a slipped or herniated disc or anything like that, when we're taking the marrow out from your hipbone, it can cause pressure to radiate up your spine. We don't want to aggravate a condition that you already have, so we watch for back problems that can make someone ineligible to donate marrow. And we also rule out donors who are at risk of autoimmune illnesses, such as HIV, hepatitis or lupus.

Are there any age requirements?

We focus on recruiting people from ages 18 to 44. The reason we do that is because transplant doctors are requesting younger donors. Typically, younger donors yield better outcomes for the patient. But people who are beyond the age of 44 can still support the mission of Be the Match, [though] we prefer that they connect us with maybe the younger people in their family. We do a lot of focus recruitment on college campuses. Additionally, people who don't meet the age requirements may also make a contribution to help support the mission of Be the Match. And they can also still join the database, but the likelihood of them being called is really small, and they would need to go online and pay a tissue typing fee to join the registry at that point.

What's being done to address the issue of African Americans' distrust of the medical community so that this group might feel more comfortable with the system and want to participate in something like this?

We tie a lot of our events to our transplant centers. Our transplant centers and collection centers are where donors go be collected, and the transplant centers are where patients go to be treated. We like to bring in the medical community in our information opportunities as much as we can and we do a lot of proactive education with the Student National Medical Association, which is an organization of African-American medical students. A lot of us get our information from people who are closest to us, so as we educate our emerging medical leaders and they're sharing that message with their core network on campuses and at home in their communities, we're finding that that helps a lot. We also visit the churches and make ourselves available to answer questions. I think a lot of times the distrust comes from not having people available to answer questions, as well as a lack of transparency in the information that we're getting, or from the organization that

we’re getting it from. That’s when we don’t really put our trust or faith in an organization. Be the Match tries to be as transparent as possible as well as be available to accommodate questions and concerns and address those issues head-on as they come up. It takes a lot of work. That’s why any time we have the opportunity to raise awareness and share information, doing so helps us and patients in the long run.

What else about bone marrow donation is important for people to know?

I think one thing is how important it is to stay committed once you’ve chosen to donate marrow. The reason why I say that is because we want to avoid as often as possible the situation that might come up when someone [is matched] as a potential donor but they haven’t really thought about the process and what that commitment really means. When someone chooses to opt out at the next stage, that’s kind of a very scary place for families to be. It’s hard enough to find that match, and then when they find that match, if they learn that person wasn’t interested to begin with then that’s like wasted resources, and it’s very heartbreaking for the families and for us. It’s a hard conversation for us to have, so remain committed, honor the commitment, stay available, and let us know if your commitment changes. It’s better to do that before you’re called as a potential donor than after.

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