



'Be a Committed Donor'

Many Minority Bone Marrow Donor Registrants Don't Follow Through When Asked to Give

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July 2, 2007



Vinay Chakravarthy, a 28-year-old Indian man with acute myeloid leukemia, lies in his hospital room at Boston Medical Center. Chakravarthy is desperately searching for a bone marrow donor. Like many minorities, Chakravarthy has struggled to find a donor who is a genetic match and willing to go through with the donation.

Imagine being told that you have a chance at a winning ticket, not for a multimillion dollar jackpot but for a chance to save your own life.

In an seeming eternity of illness, Vinay Chakravarthy had a few brief moments when he almost grasped the fleeting edge of that hope -- before it was snatched away.

The 28-year-old medical resident from California, who is suffering from acute myeloid leukemia, a cancer of the blood and bone marrow, was told just three weeks ago that the National Marrow Donor Program registry had identified a potential donor for the life-saving procedure.

The match was described as a 10-in-10, or as close to genetically identical as possible. And the news gave Chakravarthy and his wife, Rashmi, a 26-year-old medical student, the first bit of hope since he had been readmitted to the hospital, his leukemia back after only two months in remission.

But the chance for a cure ebbed as quickly as it had swept into their lives. The donor, their transplant coordinator told them, was "unavailable."

Needle in a Haystack

There are 6 million people registered on the National Bone Marrow registry, but most minorities struggle to find a donor.

In 2006, only 480,000 donors were identified as African-American or black, while 415,000 Asians were registered and 580,000 on the list are Hispanic.

As a South Asian, Chakravarthy's odds of finding a match were estimated to be about 1 in 20,000 compared to 1 in 15 for a Caucasian.

In the past, recruitment to the bone marrow registry had focused on attracting the percentage of each ethnic group within the general population, according to Dr. Dennis Confer, chief medical officer of the National Marrow Donor Program.

"If you look at the population as a whole," Confer said, "Asians are only a small percentage of the population" in the United States.

In addition to the small number of donors that minorities have to pull from, they are often hamstrung by the genetic specificity required of donors.

Dr. David Cronin, a transplant physician, and Greenwall Faculty Scholar at Yale University, describes how donors are identified: "You try to get as close to being identical as you can. First it's identical twins, then siblings, then a parent because you have at least half their genetic material, and as you keep looking you keep extending your family. An Italian is more genetically identical to an Italian-American than an Irish-American."

Since that family is often racial or ethnic in origin, the need for genetic specificity significantly narrows the donation pool for minorities.

For example, a Japanese-American woman with leukemia may have more than 400,000 Asian donors to search through for a match, but her best chance is from a donor with Japanese ancestry, significantly reducing the pool that she can search.

African-Americans struggle the most to find donors because they are the most heterogeneous genetically. Their ancestry of slavery has commingled the genes of a wide variety of African ethnic groups with Caucasians and Native Americans, making the idea of searching for an "African-American" donor almost a contradiction in terms.

Who Is Available?

But as Chakravarthy's learned, beating the odds of finding a match is only half the battle. "Unavailable" is a word that has dashed the dreams of many ill minorities eagerly hoping for a bone marrow donor.

The "availability" of a donor after a match is identified averages between 40 to 70 percent, according to the NMDP.

Caucasians have the highest amount of donor availability; almost 85 percent of identified donors are available, according to Konfer.

African-Americans experience the lowest rates of availability, between 30 to 40 percent.

The NMDP estimates that for people of Asian origin, only 50 percent of identified donors become available for a match.

There are often three reasons why donors are unavailable. The NMDP either can't track them down; the donor has health issues that prevent them from donating; or they simply refuse.

"If I could answer why a donor says no, I'd be a very famous man," said Dr. Galen Switzer of the University of Pittsburgh Medical Center.

Switzer has been running a five-year study on donor unavailability, trying to understand why the commitment to register doesn't turn into a commitment to give.

For many donors, it's simply fear from a lack of understanding of the donation process and the almost nonexistent risks involved in donating bone marrow. Bone marrow donation is one of the least invasive transplant procedures, lasting two to three hours and allowing donors to go home the same day.

Two procedures exist to extract bone marrow. Donors can have bone marrow taken from their hip bone, a procedure that requires local anesthesia and will result in soreness in the lower back for up to a week or two following the procedure.

Donors can have a peripheral blood stem cell donation, in which they take a drug for five days to help their blood generate the stem cells found in bone marrow, which is then drawn from the patient. In the latter procedure, donors experience bone aches while taking the medicine. Neither procedure results in any risk to the donor's health.

For others, a change in life circumstances may prevent them from giving. Still others donate in the name of a specific individual -- like in the drives being held for Chakravarthy - - and don't understand that they may be called upon to donate to someone else who is sick. Younger donors, who frequently switch jobs and relocate, can be difficult to find.

Preliminary research has also found that reasons not to donate vary from one ethnic group to another.

"Among African-Americans, there is a deep distrust of the medical establishment due to government-run experiments conducted on them in the '40s, '50s and '60s," Switzer explained.

"We find with Asian-Americans," said Switzer, "that the decision to donate is not made by the individual. Instead, it's a decision the family will make together. Many donors express concern that their families will not support the idea of donating."

It's that fact that Rashmi finds difficult to fathom.

"The South Asian community raises us to promote community. I was just so shocked that someone could say no when they could save someone's life. And it shocked me even more that it was my own community."

The Committed Donor

Chakravarthy and his wife's experience has led them to refocus their registration campaign and adopt a new slogan: Be a Committed Donor.

"Initially we were just saying register, register. It's easy to do a swab, now I want to ask people to be a committed donor," said Rashmi.

Both say that the experience of having a match and then losing it can be turned into something positive.

"It's not just our race and our ethnicity. It's every minority out there. And I want to do something to make a difference. And you can make a difference, we're not just increasing his odds, we're increasing everyone's odds," Rashmi added.

Donation drives for Chakravarthy have registered more than 8,000 South Asian bone marrow donors in a little less than four weeks. South Asian celebrities like Kal Penn and the Bollywood actress Radhika have made public service announcements, and Chakravarthy's Web site even has a letter of support from Sen. Barack Obama, D-III.

Chakravarthy isn't alone in his search. Other minorities are also desperately searching, including the parents of Else Yu, a 4-month-old baby, the oldest of triplets from California.

Time is running out for Chakravarthy. His doctors told him Sunday that his body isn't responding to his current course of chemotherapy. On his Web site, www.helpvinay.org, he makes this plea:

"The fear that Rashmi and I feel. . . IT IS UNBEARABLE. It exists in every second, every minute, every hour. I just want to say one thing to those out there scared to donate . . . I understand what fear is. For those of you who fear, I want you to know: I wish I could take that fear instead of mine, I would snatch it in a second if it meant not going through this."

To learn more about Vinay Chakravarthy or find a bone marrow drive in your area visit www.helpvinay.org.