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RESCUE MISSION

*Sickle cell sufferers
need black donors
for bone marrow*

By **Ashley Hopkinson**
Staff writer

For the first time in a year, Philomenia Johnson has some good news to report.

A bone marrow donor has been found for her 15-year-old daughter, who has been battling

sickle cell disease and the debilitating pain that comes with it for most of her life.

"It's like breathing a sigh of relief," Johnson said. "I'm not saying there won't be hard times. But she can play."

Sickle cell disease, which predominately affects African-Americans, is a genetic blood disorder that causes sickle-shaped red blood cells to exist where normally shaped red blood cells should. The misshapen cells stick together and block oxygen flow to areas of the body, triggering episodes of excruciating pain that cause fevers, chest pains, seizure,

organ damage and strokes.

For Johnson's daughter, Hidea Smith, the disorder has caused severe respiratory infections in her lungs and most recently, kidney failure, said Dr. Julie Kanter, who performs pediatric bone marrow transplants at Tulane Medical Center.

The chance of finding a permanent cure for Hidea by locating a bone marrow match was a long shot.

Kanter said delivering the news this month that not one, but two matching donors had been

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ELIOT KAMENITZ / THE TIMES-PICAYUNE

Sickle cell patient Hidea Smith, 15, seen with her mother, Philomenia Johnson, recently learned a bone marrow donor has been found for her. 'It's like breathing a sigh of relief,' Johnson said.

METRO

At Tulane, just 15% of black patients find match

MARROW, from B-1

found was “amazing,” especially after friends and relatives held four separate drives to attempt to locate a match.

On average, donors are found for just 15 percent of Tulane’s African-American patients who need transplants, she said.

“For Caucasian kids, they may have five matches, and for an African-American child, one. And then you have to call that one donor and hope they are still able to donate or willing to donate at that time,” she said.

That’s because only 7 percent of the 9 million people registered to be donors in the United States are black, said Natalie Rowe, community development and recruitment executive for the National Marrow Donor Program in Louisiana.

In fact, a white patient has a 92 percent chance of finding a donor on the registry compared with a 66 percent chance for a black patient. The numbers are similarly low for Asian, Indian and other minority groups, Rowe said.

Raising awareness at Essence

This year, the registry has held several drives to raise awareness, the most successful taking place at the Essence Festival, where a record 262 people signed up.

Rowe said the average drive yields just 15 to 20 black donors.

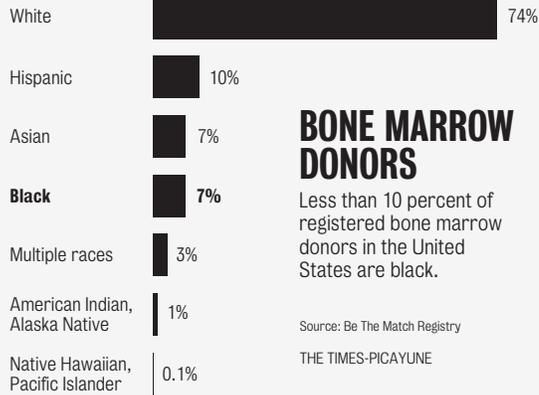
Johnson’s first encounter with sickle cell disease was more than two decades ago, when her son, Lainey, was diagnosed in a routine newborn screening.

At times, “it’s like they took turns,” she said about her children’s hospitalizations. Lainey, 22, has a genetic blood disorder called beta thalassemia, and Hidea, 15, has hemoglobin SS, a more severe form of the disorder, Kanter said.

Lainey was sick less often, but Hidea has not been so lucky. Since January, she’s been to the hospital 16 times. Johnson calls 2011 their “worst year.”

A typical sickle cell patient must go to a hospital for routine blood transfusions and pain management. Bone marrow transplants are generally reserved

PERCENT OF REGISTERED BONE MARROW DONORS IN THE UNITED STATES:



BONE MARROW DONORS

Less than 10 percent of registered bone marrow donors in the United States are black.

Source: Be The Match Registry
THE TIMES-PICAYUNE

COMMON QUESTIONS:

► What is a bone marrow transplant?

A procedure to replace damaged or unhealthy bone marrow, destroyed by radiation or chemotherapy, with healthy bone marrow.

► What happens when I donate?

There are two ways to donate. The most common procedure is similar to donating plasma or platelets. Your blood is removed through a needle in one arm and passed through a machine that separates out the blood-forming cells. The remaining blood is returned to you through the other arm. Your blood-forming cells are back to their normal levels within four to six weeks. The procedure takes about three hours. Bone marrow can also be extracted through a needle in the back of the donor’s pelvis. The procedure is done under anesthesia at a hospital in about 24 percent of the cases.

► Who can become a donor?

Anyone between the ages of 18 and 60 who is in good general health.

► How do I sign up?

Visit bethematch.org/stepup or call 800.627.7692.

Source: National Marrow Donor Program and local health professionals

for the most severe cases and for people battling leukemia, lymphoma and other diseases of the blood, Kanter said.

In Hidea’s case, her body is rejecting blood transfusions, and a bone marrow transplant is her only chance to escape a laundry list of complications, including a significantly higher risk of death, she said. If it is successful, she’ll be cured.

“She has had one of the more severe reactions to blood transfusions,” Kanter said. “She was very, very sick and in the ICU for days. It is very risky for us to give her blood again.”

Seeing the need

When a patient needs a bone marrow transplant, the first step is to turn to family members, who are most likely to have the specific tissue type needed. Tissue type is inherited, like skin and eye color, so patients are most likely to find a match within their own race or family. But only 30 percent of patients will find a family match.

In Hidea’s case, her brother has the disease, so he can’t be donor. And because the disease is inherited, her parents were also disqualified. So she looked to the registry and got lucky.

Rowe attributes the spike in registrations at the Essence Festival to one fact: People respond

when they see an immediate need. However, Rowe said people need to understand that the need is constant, especially in the black community.

“One of the main reasons I believe people in the African-American community are not on the registry is because they are not educated about the need in their community, and once they are educated, we sign them up right there,” Rowe said.

Adding to the deficit is the number of myths circulating about bone marrow transplants, she said.

“Usually when people are hesitant, it’s because they are confused.”

Rowe said once she explains the process, she asks potential participants whether they would save a life if they knew they could. About 4,000 people in Louisiana are living with the disease.

“I ask ... if you were the only person that can save someone’s life, would you do it?” Rowe said. “Most of the time people say, ‘When you put it that way, I guess so.’”



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RESCUE MISSION: SICKLE CELL SUFFERERS NEED BLACK DONORS FOR BONE MARROW –By Ashley Hopkinson

This is my favorite article for several reasons. It's one of the last stories I reported on for *The Times-Picayune* and it's the story I was given the most time to report. This story has also received the largest community reaction of any story I've ever written. The day after the story was printed I had at least a dozen e-mails and phone calls from people in the community who wanted to thank me for writing the article and wanted to know how they could help. As a reporter and an African American, it was a touching and humbling experience that taught me the depth of what health reporting can do for a community. It can highlight someone's battle with an illness, while explaining a larger issue and the role individual people can play in making a difference.

I initially pitched the story to my editors as one about how young black children in New Orleans were battling sickle cell disease. I wanted to cover the health topic because I knew it was underreported. However, in the midst of my reporting I spoke to a source who said this: "Only 7 percent of the 9 million people registered to be donors in the United States are black." Once I heard that staggering statistic, the focus of my story changed and I began to write it from the perspective of Sickle Cell patients waiting on bone marrow transplants. It became a story about how one battle can be compounded by another battle—the search to find a compatible donor when most donors do not match your ethnicity. In reporting the story, I spoke to several doctors who specialize in Sickle Cell Disease and its treatment. I also spoke to longtime donor coordinators about the complications minorities face in securing compatible donors. In the end, I chose to use Hidea's story because it was compelling and she was able to find a donor, despite the odds against her.

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