

Marrow match: a mother's race against time

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[Sunday, Dec. 16, 2007](#)

Last weekend, Oprah Winfrey proved she can bring out the crowds for a presidential candidate. Now those who love Nicole Nelson hope the TV star can help save the young mother's life.

In September, Nelson was diagnosed with aplastic anemia. She needs a bone marrow transplant to save her life, but the search for a matching donor is complicated by her ethnic heritage. And time is running out.

So her relatives and friends, including her co-workers at Concord Hospital, have launched an e-mail campaign to try to get Winfrey's attention. Their hope is that Winfrey's TV show can bring a national focus to the desperate need for bone marrow donors, particularly among minorities.

One friend managed to get a packet about Nelson's plight into Winfrey's hands during her visit to New Hampshire last Sunday to stump for Democratic Sen. Barack Obama.



Nicole and Rick Nelson pose with their daughter, Katie, in their Concord home. Nicole Nelson is receiving blood transfusions to battle her aplastic anemia. Her long-term prognosis depends on a bone marrow transplant.

"There's a concerted effort by many people in Concord to try to get the word out to as many people as possible about the need for donors to be screened for possible bone marrow transplants," said Dr. Robert Johnson, a Concord internist.

When they found out Winfrey was coming to campaign for Barack Obama, he said, "It seemed like that was just fate that she was here."

Lately, fate has been cruel to Nicole Nelson.

After she was diagnosed with the rare blood disorder, she learned she has an even rarer tissue type that so far has made finding a match elusive.

A physician's assistant, Nelson talks about her medical condition with the detachment of a clinician: her body's lack of vital stem cells to produce blood cells, the transfusions that are keeping her alive for now, the bone marrow transplant that could save her life.

But the tears come whenever she talks about what it may mean for her little girl, 15-month-old Katie, if a matching donor is not found soon.

"It's very difficult to think about what her life would be like without a mom," Nicole said. "You have a perfect life, and such a supportive and loving family, and all of a sudden you could lose all of that."

At first, Nelson, 35, had dismissed her constant fatigue as a natural result of having a baby, and a work schedule that at times meant being on call overnight. But after her nurse practitioner expressed concern about her unexplained bruising, she underwent blood tests that showed some abnormal results.

As Nelson's blood counts kept dropping through the summer, her physician ordered a biopsy. On Sept. 18, she got the news: It was aplastic anemia, a blood disorder that only two people in a million get.

"It was this out-of-body, surreal experience," she said. "I was sitting there thinking, how could I have something that is so rare?"

Her best chance for a bone marrow donor was a close relative, but none matched. So Nelson's tissue type was enrolled in a worldwide registry that includes 11 million people. Again, the news from that preliminary screening was not good: "I matched five people."

The only American match was no longer eligible to donate; the other four live in Japan.

That curious fact led Nelson to ask her parents about her ancestry -- and she discovered that her French-Canadian great-grandfather had been half Abenaki Indian. It was something her family never mentioned when she was growing up in the North Country.

"If the circumstances were different, I think I'd be excited, but it's turned out to be a big problem, because minorities are so underrepresented in the national donor registry," she said. "My tissue type is very rare, so we just can't find anyone to match me."

And while the registry is seeking additional blood testing from the potential Japanese donors, her doctor has warned her a true match is highly unlikely since she has no Asian ancestry.

Rick Nelson, her husband of five years, has contacted the Abenaki nation, which has posted information on-line about their desperate search. A veteran police sergeant in Peterborough, he's also working through the law enforcement community to spread the word.

"I wish I had the luxury of being private about this illness, but I can't," Nicole said. "Because I need someone else's help, and it's probably going to be a stranger."

And she's not convinced her match will be of French-Canadian or Abenaki heritage. "I think genetically we're all so close to one another that at this point we've all mixed ourselves up. It could be anyone."

Nelson knows the efforts on her behalf will also benefit others. "There's 6,000 of us waiting for matches," she said.

"Every one has a family out there that loves them. There's a story like mine for every one of those people."

Nelson said she's been buoyed by the support of her family and friends -- and touched by the kindness of others. "It's been truly heartwarming to see the kind of support we've had, the people -- strangers -- who send Katie teddy bears in the mail, and cards."

One young woman who showed up at a recent bone marrow screening -- a simple swab of cheek cells -- at Concord Hospital had just turned 18 and so was newly eligible to be a donor.

"She told her family that's what she wanted to do on her birthday," Nelson said, near tears again. "People who don't even know me want to help."

Like others enduring a life-threatening illness, Nelson said, her family has gained a new sense of perspective through this ordeal.

"If we get through this," she told her husband the other night, "Nothing else in life would ever matter again as long as we're all healthy."

But for now, there's a grim timetable at work: Every blood transfusion that Nicole gets also increases the risk of a bone marrow transplant. And with her immune system dangerously compromised, she doesn't dare go Christmas shopping or to holiday gatherings this year.

Her mother and sisters take turns helping Nicole at home while Rick is at work. Little Katie seems unaware of her mother's illness, surrounded as she is by such loving care.

Nelson admits she worries her daughter won't recognize her after a bone marrow transplant. She'll have to be away for a month, and she'll lose her hair from the chemotherapy and radiation designed to suppress her immune system.

And here's where Nelson's professional knowledge makes coping with her diagnosis more difficult. She knows that even if all goes well, there are post-transplant implications -- and not just the danger that her body will reject the foreign stem cells.

"I will be unable to have any more children," she said softly. "I'll be in menopause. And there's this chronic graft-versus-host disease ..."

She's trying hard not to dwell on all that.

"I have to keep telling myself it's better than death," she said. "My goal is to watch my daughter grow up."