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## **ON A MISSION: THIS HERO NEEDS A HERO**

*By Melissa Nicefaro*

Seven months ago, Seun Adebisi had it all. At 26-years-old, he'd just graduated from Yale Law School and accepted a job at the prestigious Goldman Sachs financial firm. He'd just gotten word that one of the top coaches in the skeleton sport was indeed going to train him for the 2014 Winter Olympics in Sochi, Russia. Seun would represent Nigeria as the first competitor the country ever sends to the Olympics.

His dreams were unfolding right before his eyes. He blinked and everything changed. On June 5, 2009, he heard those four dreaded words: You may have cancer.

A week earlier, he went to Yale University's student health center to have a swollen lymph node checked out.



“The petite, fiery-haired doctor who examined me lifted her eyebrows and practically whistled. I was immediately scheduled for a battery of tests,” Adebisi wrote in his blog (<http://nigeria2014.wordpress.com>).

A week later, his fears were upgraded. Preliminary results were in and Seun was told he likely had cancer. Lymphoma and leukemia gave him two options: hide, or face it head-on.

He spent six weeks at Memorial Sloane-Kettering Cancer Center and left in early November with a mission: to find a match with a donor who can save his life. He needs new, healthy stem cells and he needs them now.

“A cord blood match may bring the best possible outcome,” says Seun. “We’re doing our best to give myself the best possible chance for finding a matching donor.”

He still blogs often.

“All right, cancer, you picked a fight with me and now it’s on! I’m fighting a twinge of anger at the nurse who examined my swollen lymph nodes several months ago and dismissed them. What’s done is past, and now I have to focus on getting well. I’ve notified my friends and my mother,” he wrote in his blog on June 12.

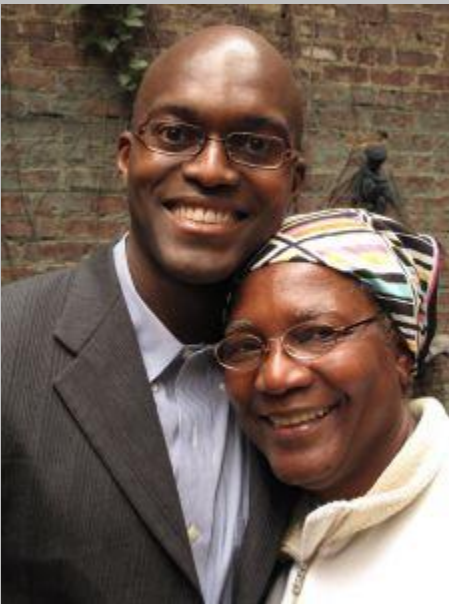
He called it a possible blessing in disguise, an experience that had already deepened his empathy for others. He immediately knew that he could link his Olympic quest to the struggles and victories of cancer survivors.

“And, cancer or not, this experience will infuse each day with added meaning. I am grateful for the blunt reminders to not take anything in life for granted. We should pursue our dreams sooner than later!” he wrote.

That’s just the type of guy Seun is.

“He’s always been very sympathetic and goes out of his way to help other kids, even when he was little,” says Seun’s mom, Adebimpe (Bimpe) Adebisi.

He worries about his mom and how she is dealing with her pain and frustration.



“I normally manifest fear as restlessness and it only comes through when I sit in meditation, when I look inside and try to find out what’s going on. It’s hard to surrender to my emotions. That’s been an issue I’ve struggled with—to be more authentic with myself,” he says. He has recently joined a support group called Friends in Need, made up of a group of people who are facing life-threatening illnesses or who have lost a loved one.

“To hear people talk about their fear so honestly helped me get in touch with my own vulnerabilities. Sometimes I find myself putting on a braver face than I actually feel. I understand that my energy can impact someone else’s energy. By keeping my optimism as high as I can, it allows others to be courageous. It’s not always in sync with what I’m feeling, though,” he says.

He is planning a donor recruitment drive at the Yale Club in New York City on January 10 and just got word that his Nigeria donor drive—the country’s first ever registry—is a go.

“I’m scared when I consider the possibility of dying young and not having the chance to fulfill many of my dreams—competing in the Olympics and having children and grandchildren,” he says candidly.

He reroutes the fear. He stays strong and centered.

“Life goes on,” says Seun. “The best way to capture the essence of life is to lose one’s self in service of others. My passion has been centered more and more on the way my story can affect the lives of others. I hope that the awareness I’m building, if not me, someone will find a life-saving transplant.”

“A sad fact of the matter is that minorities needing transplants find a match only 17 percent of the time. There’s a significant underrepresentation. African Americans comprise eight percent of the national bone marrow registry. Most of them—including me—have no idea such an urgent need exists. I think it’s tragic that this lack of awareness prevents so many complications in finding a match in a life-saving transplant,” he says.

In his Nov. 16 blog post, he explains: “The transplant team favors a cord blood transplant over a mismatched bone marrow donor. In a cord blood transplant, umbilical cord blood – which is rich in marrow-generating stem cells – is engrafted into the patient. As in my search for a bone marrow donor, I don’t have a matching cord blood unit. However, because the T-cells in umbilical blood are relatively naive, they are less likely to attack my organs in Graft Vs. Host Disease, or GVHD, than the T-cells from a mismatched adult donor.”

Seun says it’s a bit like having a sword hanging over his head by a thread.

“Every day I go, it’s a risk. Right now I’m in an outpatient phase of chemotherapy. I’m taking medication including steroids to clean up the remnants of the chemotherapy and to keep me as healthy as possible for the transplant. This might last anywhere from a month to six weeks. In that period, I want to do as much as I can, raising awareness and being an advocate,” he says.

He travels to Nigeria in mid-December for a trip that his mom calls a double blessing for new life: his brother’s wedding and the search for a stem cell match in his native land.

He has always reached out to others and now Seun relies on someone to reach out to him. He needs a bone marrow or cord blood transplant or he will die. His cancer is in remission, but will most likely relapse if he does not receive the help he needs. Typically this help would come from a sibling, since genetics plays a large role in acceptable matches, but his two half-brothers are no match.

His long-time friend Lauren Shapiro recently completed her residency in radiation oncology. She works at Memorial Sloane-Kettering where she was able to keep a close eye on her friend.

“He is someone who gives everything of himself and still has so much potential to give. Without a successful transplant, he will not survive. It will give him a second chance at life. He’s got so much promise and his aspirations are grandiose, but his future hinges on finding a donor,” says Shapiro.

“I found out along the way that lymphoma was not the only cancer I had, I had stem cell leukemia too,” Seun says. “Both are extremely rare forms of cancer. In the beginning, they told me the lymphoma was very curable, but then they realized the lymphoma was masking a deeper and more aggressive cancer in the stem cells, they realized my best chance for survival is a transplant.”

Seun believes his athletic background plays a role in how he faces challenges.

“My physical fitness and my youth helped in fighting the lymphoma. I started meditating ten years ago and then I started yoga about three years ago. It has made me more aware of how the mind and the body interconnect and how important it is to keep your mind healthy in order to maintain our body in the best possible condition. It’s so liberating,” he says.

Seun has hundreds of people pulling for him and pooling their resources to find him the help he desperately needs.

Tedd Collins, a cancer researcher, lost his 23-year-old daughter, also a Yale student to complications after a bone marrow transplant in August. He explains: “Registries recruit as many donors as possible in hopes that one will match a patient in need. After dealing with this with my daughter Natasha, I realized that this method doesn’t work best for everyone. Most often, especially when it comes to mixed race individuals, there are few, if any matches found in the registry.”

Collins' approach is different.

“We look at the person, go forward and try to find specific people. We form a relationship with people who have the ethnic background and genetics to be a match,” he explains.

“You're not doing it for the greater good, you're doing it for a specific person. Since most of the people we're dealing with are in imminent danger of dying, if they don't find a donor, they're dead, plain and simple. We are the last hope for these people, including Seun.”

Collins' daughter did find a donor, but the match was not close enough. She died in August from the complications of graft versus host (GVH) disease caused by a partially matched, unrelated donor not of her same race.

“The donors we're looking for are cord blood donors, not bone marrow donors,” says Collins.

There are two different ways to donate bone marrow: a bone marrow transplant can be performed or a donor could be put on medication that increases the number of stem cells in the blood stream and they're removed via a typical blood draw.

“They both come with some risk, but a little soreness on your side is a small price to pay for saving someone's life,” Collins says.

“Bone marrow transplants require perfectly matched donors from the same race. Cord blood donations allow you to take an unmatched, non-race-matched person and not run the risk of GVH disease. That is what causes a lot of deaths,” he explains.

He launched a non-profit organization called Natasha's Place, the National Mixed Heritage Cord Blood Bank and Donor Registry when his daughter was diagnosed with leukemia as a way to give people an alternative to either never finding a donor or receiving a bone marrow transplant that may kill them.

Collins is one of many people Seun has on his side.

“He has so many people helping him right now. It's beyond even my wildest expectations,” says Seun's mom.

“At first, it was hard to absorb. He had just graduated from Yale and a week later, he was facing a life-threatening illness,” she says. She went to Nigeria to be with her family and church group.



The wedding is viewed as two beginnings to the Adebisi family. A new life is starting when his brother is wed and Seun hopes to find a match for his stem cells.

In the meantime, Seun is in Salt Lake City, Utah, with another goal in mind. Seun has not lost his Olympic dream. This is not his first brush with competitive sports.

A top-notch swimmer for 16 years, he had a difficult time in the water because his muscle density is too high.

“I was deathly afraid of drowning and it took me a couple of years to even put my face under water. My mother would have to bribe me,” he says.

At 10 years old, he'd practice swimming for four or five hours a day, before and after school. He says it kept him out of trouble. By the time he was 14, he had already broken a Nigerian record and fourth in his age group in the U.S. He was on track to compete in the Olympics for Nigeria in 2000, but he fractured his spine before the games. Seun made a second attempt in 2004 and missed the Olympic qualifying time by one-tenth of a second.

“That sent me into a funk for a few years, but I still had the conviction that I should be in the Olympics. I started looking for a less competitive avenue and knew that a winter Olympic sport would probably be my best bet. Nigeria has never sent an athlete to the Olympics in any sport. I sat down with a few friends from law school and we settled on skeleton,” he says.

“I won't be as competitive as I could have been if I'd continued training without interruption, but I am going to give it my best,” says Seun.

“I consider myself a cancer survivor, but that's a title I have to earn every day. The word has taken on a whole new meaning and it seems I have a new way to look at life and responsibilities,” he says.

“I've gotten so much more out of this than I've lost and it may turn out to be one of the greatest blessings of my life to go through an experience like this and realize how precious life is and how important it is to stay connected to the present,” he says.