

At Magee, cord blood donations translate into hope

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Joshua Marshall, 7, plays with his youngest sibling, 5-month-old Logan. Joshua received a cord blood transplant when he was 6 months old to combat a life threatening disorder known as Severe Combined Immunodeficiency.

Joshua Marshall has an immune system because of a child he never knew.

The curly headed 7-year-old from Portersville in Butler County was born with severe combined immunodeficiency, an extremely rare disease that makes children vulnerable to germs the rest of us fight off without even knowing it.

For children with SCID, an ear infection can be devastating, and chickenpox can be fatal.

Today, though, Joshua is relatively healthy because he received a cord blood transplant at Children's Hospital of Pittsburgh when he was 6 months old.

Cord blood comes from the umbilical cord and placenta of newborns. It contains stem cells that can grow into mature blood cells, and in Joshua's case, gave him a mostly functional immune system.

Cord blood transplants have been used for several years, primarily to treat childhood leukemia, but despite their effectiveness, most umbilical cords and placentas are disposed of after birth without the blood being saved.

That's what a new program at Magee-Womens Hospital of UPMC is trying to change.

Under the Dan Berger Cord Blood Program, which started last year, women who give birth at the hospital can either donate their cord blood for free to be available for others or save it for their own family's use by paying a fee to one of three private cord blood banks.

The hospital, which is holding an update on the program for donors and other hospital officials today, said that even in its short lifetime, the effort has had a major impact.

At Magee-Womens, 169 women preserved cord blood with private banks last year, but so far this year, 584 mothers have donated cord blood to the public bank and 191 to private banks, "so we've quadrupled what we did last year," said Mary Wiegel, cord blood program director.

Still, with Magee recording nearly 10,000 births a year, that means only about 10 percent of all women are donating or preserving their cord blood.

Ms. Wiegel said there may be several reasons why nine out of 10 women are not donating cord blood. Some may think there will be a fee, which is standard in other hospitals. Others may falsely believe that it violates the guidelines of the Roman Catholic Church or other religious denominations, even though it doesn't involve the destruction of an embryo.

And despite the hospital working to get the word out, many women don't hear about the program until they arrive to give birth, and "their main priority at that point is the baby and being focused on the delivery and assuring themselves that everything is going to be OK."

There is reason to believe the Magee numbers will go up as the program gains experience.

At the New York Blood Center, which has collected cord blood for more than 10 years, the "vast majority" of mothers agree to donate, and after some cord blood is winnowed out because it has too few stem cells to use or the mother has been ill, the center ends up with usable donations from 35 percent to 40 percent of all mothers, said Dr. Andromachi Scaradavou, a cord blood transplant specialist there.

"Mostly what I try to tell moms," said Ms. Wiegel, "is that they have a decision to make and that this is very important and could potentially help their child or help save another child's life."

Deborah and Mark Marshall say their family's story is a testament to that.

When Joshua was born in the summer of 2001, he was healthy -- partly because he had limited immunity that had been passed on to him by his mother during pregnancy and as she breast-fed him.

The night before Thanksgiving, though, his grandfather noticed he was intermittently turning blue and was breathing shallowly and rapidly, Mrs. Marshall said, and the family was advised to take him to Children's Hospital.

That began a two-month odyssey to find out what was wrong with Joshua and then what the best treatment for him would be.

An initial chest X-ray shocked the doctors, Mrs. Marshall said, because Joshua's lungs were completely opaque. It turned out he had pneumocystis carinii, she said, a fungal infection that had made his lungs stiff and unresponsive.

Because pneumocystis has been associated with AIDS, Mrs. Marshall also had to undergo an HIV test.

Eventually, after a spinal tap, lung biopsy, many blood tests and consultations with several specialists, Joshua's blood was sent to the Mayo Clinic so his immune cells could be tested in the laboratory.

It was only after the Mayo doctors found that his immune cells were extremely dysfunctional that Children's doctors gave the Marshalls their diagnosis -- severe combined immunodeficiency.

The Marshalls were given two treatment options to save Joshua's life: a bone marrow transplant from Mr. Marshall at Duke University, a leading center for treating the immune disorder, or a cord blood transplant for which they could stay at home.

They opted for the cord blood not only because it would allow them to stay together close to home, but because donated cord blood does not have to match the recipient's blood as closely as bone marrow does in order to succeed.

That's because cord blood has infantile stem cells, which have not developed as fully as the adult stem cells in bone marrow.

The other advantage of cord blood, Dr. Scaradavou said, is that if a match is found, it can easily be made available, since it is frozen and can be transported and thawed out. Bone marrow transplants have to be fresh, she said, which means the donor must be healthy and able to donate within 24 to 48 hours of the transplant.

Another emerging strength for cord blood, she and others said, is that it is somewhat easier to find matches for African Americans and other minority ethnic groups in the United States who have distinctly different patterns of blood markers than Caucasians do.

Only about a quarter of the potential bone marrow donors on the national registry are minorities, but nearly 40 percent of the cord blood units on the registry have been donated by minority mothers, according to the National Marrow Donor Program.

Cord blood transplants are also beginning to offer hope for other conditions, said Dr. Dennis English, vice president of medical affairs at Magee-Womens, including Type 1 diabetes and sickle cell anemia.

For Joshua Marshall, the transplant has given him a new lease on life, even though his family still has to be careful about exposing him to infections.

The caution stems from the fact that Joshua only got a partially functional immune system from the transplant. His T cells, which kill off invading germs, are fine, but his B cells, which identify and latch onto the invaders, are subpar, the Marshalls said.

As a consequence, he has to get infusions of immunoglobulin every six weeks through a permanent port in his chest, a process he dislikes, except that "the ending's fun 'cause I might get a toy sometimes when we go Toys 'R' Us and get stuff."

Because his B cell function must be constantly replenished, the Marshalls said, his immune system never "remembers" his previous diseases, so he is vulnerable to getting the same infections over and over again.

Despite all that, he is able to play outdoors with his younger brothers, dig in the dirt with his dad and generally live the life of a 7-year-old boy on a family farm.

The Marshalls are deeply grateful for the unknown mother who donated her child's cord blood.

"We couldn't have been any luckier," Mr. Marshall said, "if he'd been born normal."