dallas child™

THE MAGAZINE PARENTS LIVE BY IN DALLAS AND COLLIN COUNTIES

april 09

5 EXPERTS ANSWER PARENTS' TOUGH QUESTIONS

DJ Lucy Wrubel shares her spin on parenting

+ cord blood TO BANK, DONATE OR DISCARD

COMMUTER MARRIAGES. Are They Worth It?

110 things to do in April

lifeline

HOW AN UMBILICAL CORD COULD SAVE YOUR CHILD'S LIFE

WORDS **GRETCHEN SPARLING**

When Joseph Davis Jr. of Cedar Hill was 2 years old, his parents were prepared for him to die.

The healthy couple's DNA carries recessive sickle-cell genes, which the Davises did not know about prior to the birth of their first child. Joseph Jr. represents the one-in-four chance of the Davises' children inheriting two recessive sickle-cell alleles, meaning he was born with sickle-cell anemia.

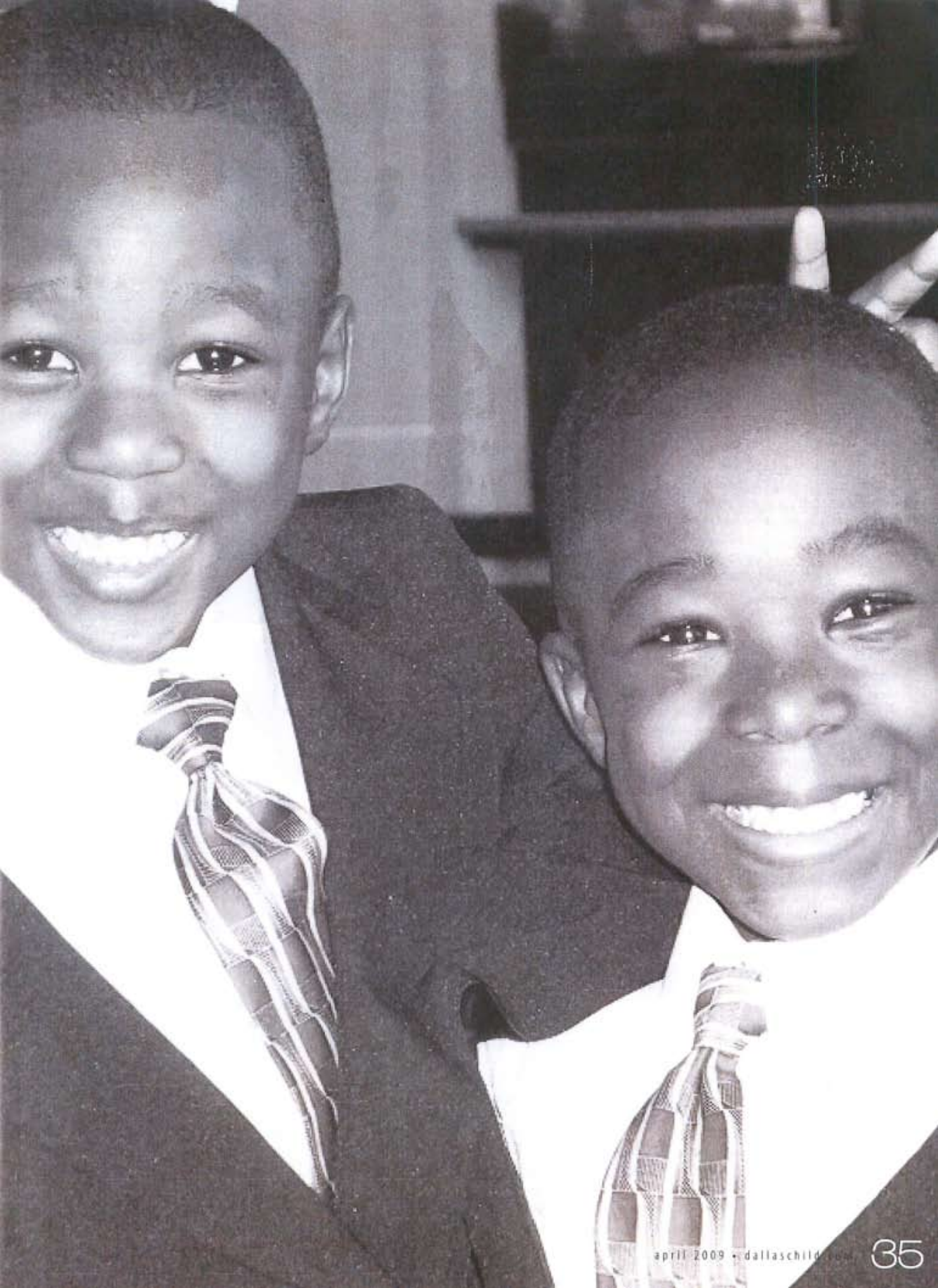
Doctors quickly identified that Joseph Jr.'s blood disease was among the more serious cases of sickle-cell anemia. The newborn ran exceedingly high fevers and wailed in constant pain. His cries were only temporarily quelled with blood transfusions, antibiotics and painkillers. "Our doctors told us that unless he had a stem-cell transplant, he may not make it to his teens — at that time he was barely 2 years old," recalls Joseph Davis, the little boy's father. The family, along with Joseph Jr.'s physicians, began a worldwide search to find a tissue match that would give him the life-saving stem-cell transplant.

The search, which spanned more than a year, left the Davises empty-handed. It was during this time that mom Darlene Davis learned about the uses of cord blood in stem-cell transplants. "No one ever spoke to me about cord blood before I had Joseph in 1999," she says. However, since Joseph Jr. was born with sickle-cell anemia, his cord blood would have been unusable anyway.

That's when an unexpected pregnancy changed the Davises' lives forever. Darlene, who struggled to conceive Joseph Jr., discovered she was pregnant, and amniocentesis revealed that the baby's tissue was a sickle-cell-free match to Joseph Jr. The family had a second chance to save cord blood for their family, and they knew exactly how they'd put it to use.

The stem cells retrieved from baby Isaac's umbilical cord proved to be Joseph Jr.'s lifeline. After chemotherapy eradicated Joseph Jr.'s immune system, his transplant physician, Dr. Joel Weinthal, pediatric hematology/oncology specialist at Medical City Hospital of Dallas, transplanted Isaac's

RIGHT: BROTHERS ISAAC AND JOSEPH JR. SHARE A LAUGH.



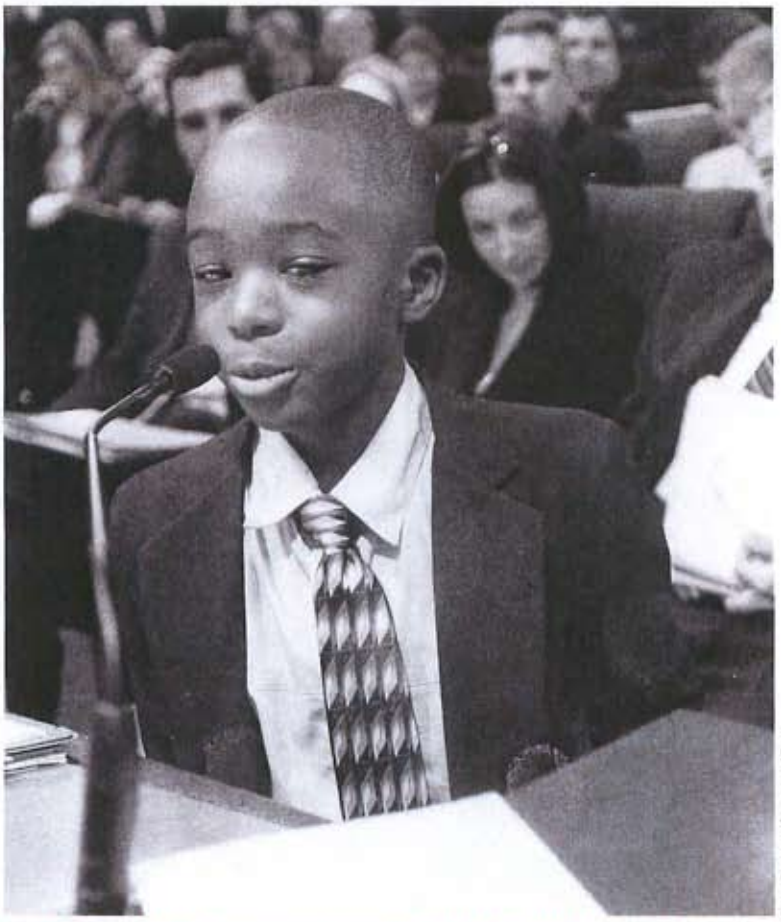


Photo Courtesy of Associated Press

ABOVE: JOSEPH JR. SHARES HIS STORY OF SURVIVAL WITH TEXAS LEGISLATORS PRIOR TO THE PASSING OF HOUSE BILL 709.

stem cells into his older brother's bloodstream. The cells multiplied and established a new, healthy immune system in Joseph Jr.'s body, free of sickle-cell anemia.

The umbilical connection of mothers to babies holds precious stem cells on which doctors and patients are increasingly counting to save lives. Some physicians are even looking beyond the immediate known uses of stem cells (in cases of leukemia or blood diseases) with optimism that these cells will make waves in regenerative medicine, potentially curing diseases like diabetes or restoring injured tissue in the brain and spinal cord.

Unlike the painful collection of bone-marrow stem cells, cord blood is painlessly collected at birth from a newborn's umbilical cord. However, many expectant parents find themselves struggling to weigh their options before baby's arrival. Should parents commit thousands of dollars to banking their baby's cord blood as a biological insurance policy? Should they opt to donate their baby's blood (free of charge) to patients in need? Or, should the entire discussion be tabled, awaiting more research and legislation?

IS IT HOPE OR HYPE?

The Davises' experience is one that most parents will never know. In most scenarios, it's impossible to know a child's future health, but the Texas state Legislature determined in 2007 that all parents-to-be should be aware of the uses of cord blood, which is otherwise discarded as medical waste. The Davises, along with other families impacted by cord-blood stem cells, testified at state legislative hearings that led to the passing of House Bill 709. This bill requires that all expectant moms receive a brochure explaining cord-blood donation and banking prior to the third trimester.

Dr. Jeffrey Thurston, OB/GYN at Texas Health Presbyterian Hospital Dallas and author of *1000 Questions About Your Pregnancy* (2007), says that he and his associates undergo formal training, perform research on the issues and even visit collection and storage facilities around the country so that they can better educate patients. "I emphasize that this really is a once-in-a-lifetime opportunity," says Thurston.

"The issue is that in the event of an illness like leukemia or other cancers where stem cells are applicable, people have relatively small families," explains Weinthal. "The chances are one in four that a couple will have another child that will match a sibling. So this leaves families accessing the bone-marrow and cord-blood registries to try and find stem-cell matches."

Here's where it gets tricky for parents: Doctors agree that it's easier for Caucasian patients to find matches than minority patients. "There are just more Caucasian donors in the giant pool that's out there," says Weinthal.

According to the National Cord Blood Program, between 1993 and 2003 (the latest available study) about 45 percent of cord-blood donors were Caucasian; 25 percent were African-American; 23 percent were Hispanic; and 7 percent were of Asian descent.

Why does race matter? "People from the same countries, or people who have the same ethnic descent, tend to have more similar genes, making transplants more successful," says Dr. Jennifer A. Cox, associate director of the stem-cell transplant team at Children's Medical Center of Dallas and assistant professor of pediatrics at UT Southwestern Medical Hospital.

More frequently, doctors are turning to cord blood, versus bone marrow, to treat patients in need. "Bone marrow must be matched to the recipient by inherited traits that determine tissue type," explains Cox. According to both Cox and Weinthal, cord blood allows for less stringent matching. "Technology that uses cord blood for the source of stem cells lets us cross genetic barriers in ways that we couldn't do with bone marrow," says Weinthal.

This flexibility has dramatically increased the demand for cord-blood stem cells. In cases like the Davises', says Weinthal, finding a match can be like "winning the lottery."

Parents are increasingly using private banking companies to store their child's cord blood — companies like Cord Blood Registry (CBR), established in 1992 and regarded by physicians as the largest and oldest cord-blood storage facility in the U.S. CBR spokeswoman Christine McMurry says that the company stored 7,014 cord-blood units in 2000, compared to 51,763 units in 2008. McMurry also reports that 52 successful cord-blood transplants occurred last year.

Yet, authorities like the American Academy of Pediatrics (AAP) maintain

that privately banking cord blood simply isn't necessary "except in cases where a family member already has a current need or a very high potential risk of needing a [stem-cell] transplant." The group deems the use of cord blood as biological insurance "unwise" in January 2007's *Pediatrics*.

More recently, however, in the March 2009 edition of *Pediatrics*, the AAP slightly eased its stance against private banking in response to a survey of stem-cell transplantation physicians that reports "no [physician surveyed] would recommend private cord-blood banking for a newborn with healthy siblings when both parents were of northern European descent; 11 percent would recommend banking when parents were of different minority ethnicities."

With all of the conflicting opinions, how is a parent to decide?

TO DONATE OR BANK

According to Weinthal, the true lifeline of cord blood connects present-day technologies to potential therapies developed in the future. "There's a whole new field in medicine called regenerative medicine — that's the potential to use your own stem cells for treating other diseases, not necessarily diseases of the blood or the immune system (rather, illnesses like strokes, heart attacks, traumatic brain injuries or diabetes). There are clinical trials going on in most of these fields (with animals, not people), and there's a lot of potential," says Weinthal.

He continues, "For the regular person who doesn't [have disease] in their family — which is an overwhelming majority of the population — [privately banking cord blood] is a personal and financial decision."

The cost of banking cord blood in a private facility varies with the company. CBR charges an initial collection fee of $2,000 (the blood is collected at a local hospital and shipped to the Arizona site to be cryogenically frozen), in addition to an annual storage fee of $125, explains McMurry. "If someone's going to choose a cord-blood bank, I don't think the answer is to choose the cheapest. Choose a bank that has a reputation and a track record of actually having had cords used successfully in transplants," advises Weinthal.

Thurston adds, "I tell my patients that I would give *anything* to have my kids' stem cells. For the price of less than half of the big-screen TV that dad bought last year, you might be able to grow your kid a new heart or liver down the road — or even provide the stem-cell transplant to save mom's life from a metastatic breast cancer 20 years from now."

On the other side of the argument, some parents criticize the act of privately banking cord blood and saving the cells only for an individual family when many patients wait in need of a transplant. Expectant parents have the option of donating cord blood to the Texas Cord Blood Bank (TCBB), which collects units free of charge exclusively at Medical City Hospital of Dallas. TCBB representative Mary Beth Frisk says that the organization is working to receive regulatory approval on a program that would provide donation kits to moms delivering at any Texas hospital.

While Weinthal likens donation to "doing good for mankind," Thurston warns that many public banks discard a large percentage of donations due to packaging and labeling error, in addition to stringent screening standards.

Currently, 4,000 units of cord blood sit cryogenically frozen in the San Antonio-based TCBB (established in 2001), says Frisk. "Only about 30 percent of donated cord blood meets our criteria for storage," she says. The Federal Drug Administration and the American Association of Cord Blood Banks enforce the standards for acceptance into the bank's registry, which heavily check a donor's medical background.

LEARN MORE

- Texas Cord Blood Bank
  210/731-5555
  www.bloodntissue.org
- Cord Blood Registry
  888/932-6568
  www.cordblood.com
- National Marrow Donor Program
  800/627-7692
  www.marrow-donor.org

'USE IT OR LOSE IT'

David Zitlow, vice president of public affairs for CBR, says that insurers' hands are tied when it comes to covering the cost of private banking — at least for now. Until the regenerative benefits of cord-blood stem cells are backed by research and proven success, Zitlow says it's not likely that insurance companies will offer coverage. However, he adds, it is likely that companies will recognize the value in this coverage as opposed to paying out for more expensive treatments.

Currently, he says he's watching the efforts of lobbyists to push for insurers to allow family banking expenses to be absorbed by flexible spending accounts.

Whatever your choice, Weinthal says that perhaps the most difficult aspect of deciding whether or not to bank or donate cord blood is time. "You have to make a decision right away, before the birth. It's use it or lose it. If you don't save it, it's gone forever." CC

Photo Courtesy of Cord Blood Registry

ABOVE: CORD BLOOD IS CRYOGENICALLY FROZEN AT THE TUCSON, ARIZ., CORD BLOOD REGISTRY (CBR) LABORATORY.