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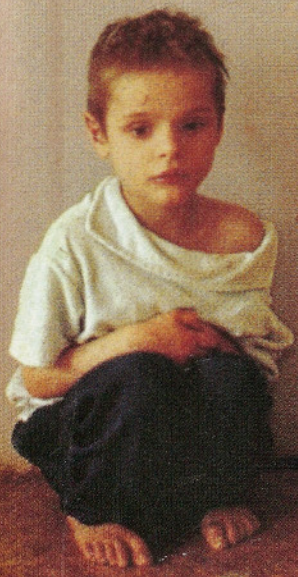

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Could They Save This Baby?

The unborn child had one chance to escape his brother's fate

BY JOHN PEKKANEN

ALL AFTERNOON Heather Dahley felt her anxiety growing. *When are they going to call?*

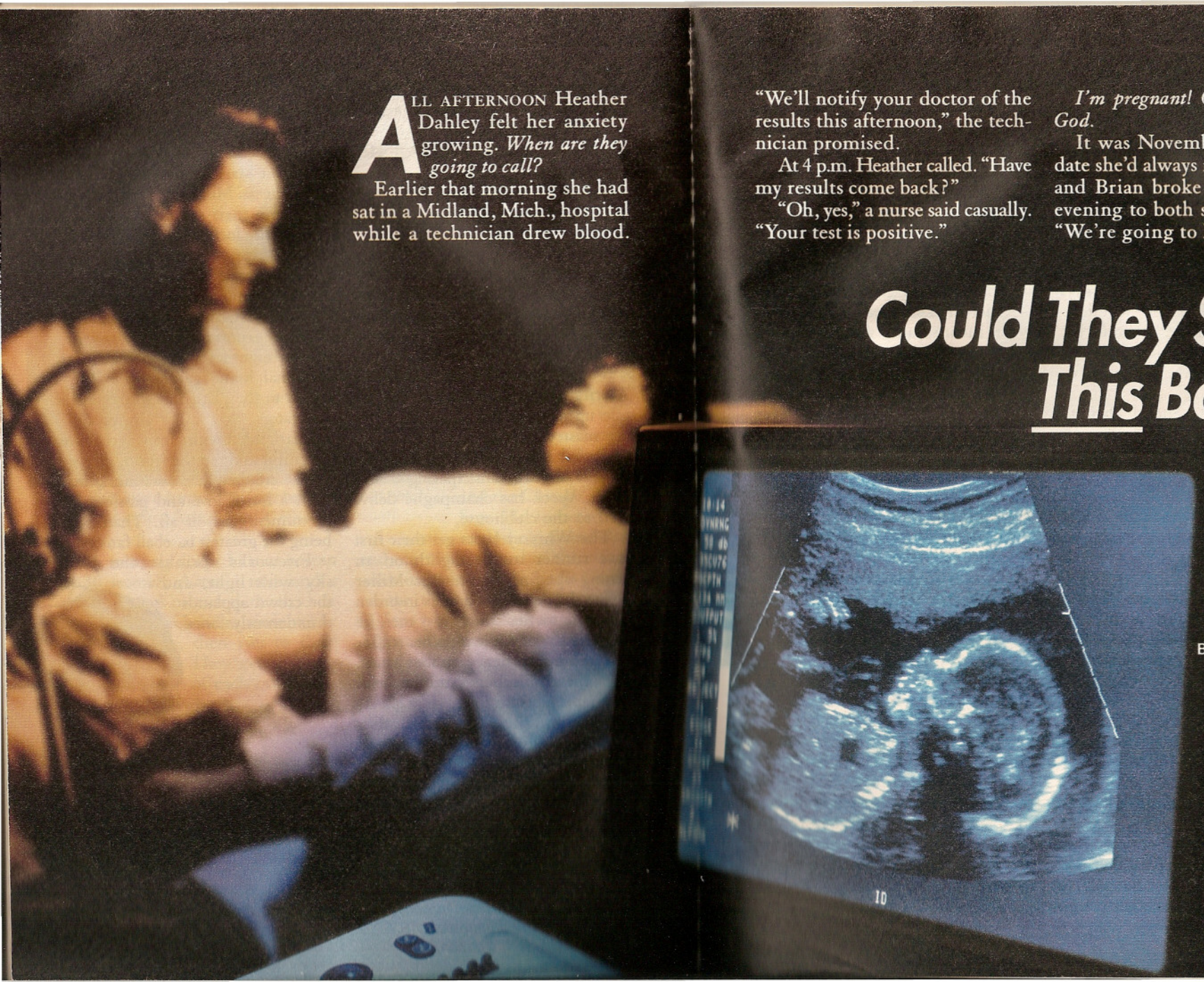
Earlier that morning she had sat in a Midland, Mich., hospital while a technician drew blood. "We'll notify your doctor of the results this afternoon," the technician promised.

At 4 p.m. Heather called. "Have my results come back?"

"Oh, yes," a nurse said casually. "Your test is positive."

I'm pregnant! Oh, thank you, God.

It was November 21, 1994, a date she'd always remember. She and Brian broke the news that evening to both sets of parents. "We're going to have a healthy



baby this time," Heather insisted to her worried mother.

Inevitably, their memories drifted back to Brandon and to the heartbreak they had experienced a year earlier.

BRANDON DAHLEY had come into the world on May 14, 1993, two years after Heather and Brian were married. Basking in his parents' love, Brandon beamed whenever they played "Twinkle, Twinkle, Little Star" on his music box. They called their son "the world's happiest baby."

The happiness ended abruptly when Brandon was just six months old. The day before Thanksgiving his fingertips and lips turned blue. A chest X ray revealed that his lungs had filled with fluid.

For over ten days, Brandon's fragile grip on life was sustained by a tangle of breathing tubes and intravenous lines. On the morning of December 13, one of the doctors met with Brian and Heather.

"We believe Brandon has something called severe combined immunodeficiency—SCID," the doctor said. This genetic defect prevents the development of a normal immune system. SCID babies, susceptible to infections that normal babies fight off, seldom live beyond their first year.

A biopsy of a mysterious rash Brandon had developed revealed graft-versus-host disease (GVHD), a condition caused when the foreign cells from his blood transfusions attacked his organs. "GVHD happens when the immune system is compromised," the doctor explained.

Finally he told Heather and Brian the worst news: "There's nothing else we can do medically."

The next morning Heather held Brandon one last time. "I'll always love you," she whispered. Brian held his son and said good-bye.

Grief-stricken, Heather and Brian wept inconsolably for weeks. "I know we can never replace Brandon," Heather finally told Brian, "but we have to have another baby. It's the only thing that will ever heal us."

Bleak Chances. Since there was no family history of SCID, doctors had sent samples of Brandon's and his parents' blood to Dr. Jennifer Puck at the National Institutes of Health in Bethesda, Md., for DNA testing. Puck headed one of the research teams that in 1993 identified a genetic mutation that causes SCID.

Six months after Brandon's death, Heather received the news. "Brandon definitely died of X-linked SCID," a doctor said. Heather was less prepared for what followed: tests also showed that she was the carrier.

Phoning Puck for more information, Heather learned that her son had suffered from a form of SCID caused by a mutation on the X chromosome. "I'd estimate it occurs in only about one of every 100,000 people," Puck said.

"What are our chances of having another baby with SCID?" Heather asked.

A girl would be born with a normal immune system or, at worst, be a SCID carrier, Puck replied. That's because female babies have two X chromosomes—one from each parent—thus ending up with at least one normal copy of the gene.

"What about a boy?"

"He'd stand a 50-50 chance of being healthy," Puck said, since males have only one X chromosome. "Overall, your chance of having a SCID-afflicted baby is one in four."

Despite the risk, Heather wanted to have a child more than anything. That evening she said to Brian, "At least we know the odds of having a healthy baby are in our favor."

"But what if we have another baby with SCID?" Brian asked.

"We can't be that unlucky twice," she answered.

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Dr. Alan Flake could offer hope—but no promises.

Risky Option. At 11 weeks pregnant, Heather underwent testing to determine the sex of her fetus. "It's a boy," she told Brian in a choked voice. Then a genetic counselor called three weeks later with DNA results: "I'm so sorry, but your baby tested positive for SCID."

As Heather lay in bed that night, devastated, snippets of her conversation with the counselor drifted back to her. The woman had recommended that Heather speak to Dr. Alan Flake, director of fetal surgery at the Children's Hospital of Michigan in Detroit.

From his earliest training in fetal surgery, Flake, 39, was determined to make an impact on medicine. He'd seen many children suffering from immunological disorders such as SCID. Bone-marrow transplants sometimes offered a cure, but they

carried risks. *Was it possible to perform such a transplant before a baby was born?* Flake wondered.

He believed that in the first months after conception, the fetal immune system wouldn't attack foreign cells because it doesn't yet recognize transplanted cells. The more the fetus develops, however, the more aggressive its immune system becomes.

In the 1980s, in collaboration with Esmail Zanjani, then professor of medicine at the University of Minnesota, Flake succeeded in transplanting bone-marrow cells from one fetal sheep to another in utero. Flake gained approval to experiment on humans in 1994.

Meeting with Heather and Brian, Flake offered an overview of his research. The transplant, he said, involved inserting a hollow needle through the abdominal wall into the uterus. Donor bone marrow was then transmitted into the fetal abdomen. If the experiment worked, he said, Heather's baby would be born with a normal immune system.

"But I can't promise you anything," Flake added. "It would be medical history."

"Where would the bone marrow come from?" Brian asked.

"It could come from almost anyone," Flake said, "because the fetus is so tolerant of foreign cells."

"If we do this," Brian said, "I'd like to donate marrow for our child."

Though Flake's explanation didn't erase the couple's deep uncertainty, the experimental transplant offered hope. Heather and Brian knew their decision had been made.

Precious Cargo. On February 19, 1995, doctors punctured Brian's lower back repeatedly and extracted 600 cubic centimeters of bone marrow. Flake immediately packed it into a cooler and flew to Reno, Nev., to Zanjani's lab.

Working through the night, the two doctors culled the lymphocytes, white blood cells that form the backbone of the immune defense. They got the lymphocyte count down to one one-thousandth of what it had been, a critical step for preventing the most lethal transplant threat, GVHD. Flake flew back to Detroit the next day, guarding his precious cargo as though it were a rare gem.

Later that morning Heather lay on a gurney in Detroit's Hutzel Hospital, Brian at her side. She clutched a picture of the son she'd lost. *Brandon, your life may save your brother's,* she thought, tears trickling down her cheeks.

Flake, noticeably tense, was studying ultrasound images. With him were Dr. Mark I. Evans, vice chairman of obstetrics and gynecology, and Linda Littmann, the diagnostic sonographer. The 16-week-old fetus in Heather's womb weighed about four ounces and measured only 4½ inches. His abdomen—the target of the procedure—was no bigger than a quarter.

Heather winced as Dr. Evans carefully slid a needle through her uterus and into the amniotic sac, then pushed it toward the baby's abdomen. Flake, Evans and Littmann peered intently at the monitor. The ultrasound images revealed the fetal vessels, allowing Evans to avoid them.

"You're there!" Littmann announced.

Evans squirted a drop of saline solution into the baby. As a swirling gray cloud rose in the abdomen, Evans said, "Right on target. We're ready for the marrow."

Flake handed Evans a syringe with less than a thimbleful of bone marrow. Evans squeezed, and the bone-marrow cells flooded into the baby's lower abdomen. The transplant had gone flawlessly.

If things continued according to plan, the marrow cells would first migrate to the liver, where they would form colonies that would go to the spleen, lymph nodes, thymus gland and into the spaces of the developing bones. Then they'd manufacture all the necessary blood components, along with a functioning immune system. But doctors wouldn't know for sure if the procedure had worked until after the baby was born.

Chilling News. By early summer Heather's pregnancy had become blissfully ordinary. Now, late in the afternoon of June 29, she rested on her side while Littmann ran the ultrasound probe over her abdomen. With them was Flake, who'd been watching like an anxious parent.

"He looks a little small," Littmann said.

Flake agreed, frowning. "We need to get Mark in here."

A chill swept over Heather. Something had gone wrong.

Arriving quickly, Evans studied the screen. "He doesn't look like he's grown much at all since his last ultrasound," he said.

An overriding fear gnawed at Flake: GVHD was one cause of slow fetal growth. If the disease had developed, the baby would probably die.

Flake and Evans moved off to confer alone. Minutes later Evans broke the news to Heather: "He'll do better if we perform the Caesarean section tomorrow morning."

Just after 6 a.m. the next day, Evans made a transverse cut along Heather's lower abdomen. He reached in and gently tugged on the baby, then stopped suddenly. "The cord's wrapped around his neck," he said. As Evans carefully freed the cord, Flake breathed a sigh of relief. Another cause of slow fetal growth is a wrapped cord. *Maybe GVHD wasn't the culprit after all,* he thought.

Suddenly the baby let out a long, loud squawk. *Thank you, God,* Heather said to herself as muffled cheers filled the delivery room.

Nurses cleaned four-pound, three-ounce Taylor Thomas Michael Dahley and placed him in a tiny incubator. Flake had the baby kept in isolation while he ordered tests to determine if the transplant had been successful.

On July 21, three weeks to the day since Taylor's birth, Brian saw Flake approaching down the hospital hallway, a broad smile on his face. "I can't

believe it went this well!" Flake blurted. "Taylor has almost a 100-percent engraftment. It's incredible!" The doctor appeared on the verge of tears.

Taylor was released from the hospital that day, but Flake urged caution. "It's still early," he said. "We have to see how well he does over the next few months."

Finally, after receiving test results in December, Flake telephoned the Dahleys at home and uttered the words they had longed to hear: "We think your son is cured." ***