

my problem AND HOW I SOLVED IT

Jacob Needed an Angel

by Sharon Johnson O'Donnell

My father and I were standing together at the back of our church near Raleigh, NC, as we waited to take the traditional walk down the aisle. It was my wedding day, and I started to get misty-eyed as I thought of how life had brought me to this point.

Ahead of us was my 3-year-old nephew and ring bearer, Jacob, pacing carefully toward the altar. People smiled as they caught a glimpse of the serious-looking toddler, balancing a ring on his satin pillow. There is a photo of Jacob in my wedding album that always brings back this wonderful memory. He is dressed in a white suit, and his sky-blue eyes have never been bluer. He looks so innocent, and his face is the essence of childhood.

FAST-FORWARD FIVE YEARS to a dreary night in April 1993. The University of North Carolina had just won the national basketball championship, but I wasn't celebrating; I was sitting outside my house in the pouring rain, screaming and crying because I had just been told that Jacob might die.

The phone call came while I was watching the game on TV. "They say it's definitely leukemia," my mother said.

"Oh, God, Mama, no," I moaned. Then I asked about my sister Gail and her husband, Butch—Jacob's parents. "They're devastated," Mama said.

I handed the phone to my husband, Kevin, and ran into the yard. As I sat in the rain, I realized I had used the word

Earlier this year, my nephew Jacob celebrated his fifteenth birthday—an amazing milestone, if you know how close we came to losing him



The author with Jacob: She pitched in when his life was on the line.

devastated much too casually over the years. I could remember saying things like "I'm devastated that I don't have a date" or "I'm devastated about not getting that job." That night, I learned what the word truly means.

Images of my nephew rushed into my mind: Jacob playing Rudolph the Red-Nosed Reindeer in his preschool Christmas pageant; Jacob as a Little Leaguer, waving to us in the stands; and Jacob at the recent church Easter egg hunt, helping his brothers, Sam, 5, and Matthew, 3, look for

eggs. As I looked back on it, I realized he'd been a little pale, but it was hard to believe he was now fighting for his life.

Back in the house, I went to sit by my 2-year-old son, Billy, as he slept. I thought about how fragile we all are, and my feelings of helplessness were overwhelming.

THE NEXT DAY, MY PARENTS WERE ALLOWED to see Jacob at the hospital. Afterward they stopped by our house, and I peppered them with questions. "How is he?" I asked. Daddy's eyes teared up—something I'd never seen. Mama told us that Jacob had the most common type of childhood leukemia, which has a cure rate of about 90 percent; but he also had an extremely high white-cell count, meaning the cancer was very much in command of his body.

My parents have always been very strong people, and I'd grown used to looking to them for comfort. So I wasn't ready when Mama asked, "Do you think he'll be all right?"

I felt my throat get tight. This time, Mama was asking *me* for reassurance, and I struggled for words that would make her feel better. Finding none, I just put my arm around her shoulder and hugged her.

Within a few days, we received another blow: Jacob's doctors found that his cancer cells had a mutation called the Philadelphia Chromosome, which meant the disease would be unusually resistant to chemotherapy and radiation. His best shot, they said, was a bone-marrow transplant. And even that would carry major risks; the

procedure can trigger a war between the donor's marrow and the patient's body. And sometimes transplants work initially, only to fail later. But we had to take the chance; without a transplant, the doctors said, Jacob would die in six months. The clock was ticking.

JUST AFTER THE DIAGNOSIS, JACOB HAD surgery to insert a catheter in his chest. When we came to visit, doctors and nurses were running in and out of his room—he was coughing violently, and we

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weren't sure he'd make it. "He'll be all right," I told Gail. "He's a strong boy." Crying, she answered, "Not anymore he's not." It was a wrenching night for us both.

Now, though, we had to throw ourselves into the search for a bone-marrow donor. Because there are more than 10,000 types of bone-marrow tissue, finding a perfect match was unlikely—but we had to try. Jacob's brothers were tested to determine their type, and we waited a week for the results. I will never forget the morning Gail called, her voice crackling. "They didn't match," she said.

No one else in our family had Jacob's marrow type, so we turned to the National Marrow Donor Program (NMDP) registry. While the registry searched its files for the right donor, Jacob would begin chemotherapy.

Knowing that Gail had all she could handle, the family (including my brother, Sam, and sister Mary) pitched in. Together with Butch's relatives, we took turns driving Gail's younger boys to school, picking them up, and caring for them. But I wanted to do more.

I knew that community groups held

blood and marrow drives for critically ill children. Why couldn't we do the same? Even if it was a one-in-a-million chance that we'd find a match for Jacob, we could help expand the donor registry and, we hoped, save other lives.

In May 1993, I joined 15 friends to form a group we christened Jacob's Ladder, organizing drives through schools and churches. I'd worked in media relations, so I used my contacts to get on TV and radio to talk about the need for donors and to persuade newspapers in our area to do stories about transplants. When he was feeling up to it, Jacob helped us out—pitching in at drives or doing radio interviews.

Pregnant with my second son, David, now 5, I became obsessed with our campaign—so much so that my husband began to worry about me. I couldn't explain why Jacob's Ladder was so important until the Sunday when we held a drive at a local Catholic church. I spoke during the service, then returned to my seat as an unfamiliar hymn began. I became captivated by the lyrics: *Here I am, Lord/Is it I, Lord?/I have heard you calling in the night/I will go, Lord, if you lead me/I will hold God's people in my heart.* The words vividly expressed something I had sensed but had not been able to articulate. I felt literally pulled

toward my work; at that moment, I realized it was God who'd given me the call.

ONE MONTH AFTER STARTING CHEMOTHERAPY, Jacob surprised us by going into remission. But the chemo and steroids had taken a toll: Jacob's curly blond hair was gone, and his face became swollen. The bald head and puffiness never seemed to bother him—he just wore a baseball cap and big shirts. The catheter box in his chest, though, made him feel self-conscious.

Every Wednesday, Gail and Jacob spent the day at the hospital while he got needle sticks from all directions. Marrow aspirations, blood tests—I knew she flinched each time he held out his arm. Sometimes I went with them, and I always came away with a fresh perspective on what was important in life: In the cancer ward, one of the most wrenching scenes I saw was a mother lying in bed beside her sick child, holding her, gazing at her, as if she were drinking in her child but unable to quench her thirst.

In October, we heard the most beautiful words in the English language: "We've got a match." Somewhere, there was a man who decided to join the NMDP registry, and who ended up being Jacob's miracle. (To our disappointment,

we were never able to learn who he was.)

Our prayers were with Jacob when he entered the Pediatric Bone Marrow Transplant Unit, a part of the Children's Health Center at Duke University Hospital in Durham. For two weeks, he underwent radiation treatments to rid him of as many cancer cells as possible. The transplant was performed on the night before Thanksgiving. Then another wait began, to see if Jacob's body would accept the life-giving graft.

Jacob got pretty sick during the next ten days—mostly with stomach problems. He had to be very careful not to get any infections, because his immune system was nonexistent. After about two weeks, new white cells began to appear in his blood—meaning that his body seemed to be accepting the donor marrow. We were thrilled, but we knew it was still very much a day-to-day thing.

One month after the transplant, doctors told Butch and Gail that Jacob could come home. On Christmas Eve, we gathered outside their house. A TV crew was on hand, and a WELCOME HOME, JACOB banner was tied between two trees. Jacob stepped out of their van wearing his familiar baseball cap; he walked stiffly, his steps a bit unsure. His brother Sam gave him an awk-

ward hug—a rare show of all-boy affection—and we knew we'd just been given the greatest Christmas gift we'd ever receive.

DURING CHEMO TREATMENTS, JACOB FOUND a friend in Johnny—an 11-year-old who had aplastic anemia and also needed a marrow transplant. The boys had a lot in common—especially a playful sense of humor. They went to the movies together and slept at each other's houses, and Gail became close to his mom.

After his procedure in November 1994, Johnny did great—for awhile. In January, though, his speech became slurred. The doctors couldn't pinpoint the problem, but they thought a virus or a fungus was involved. Back at Duke, Johnny slid into a coma; in early February, he died. It was so hard to believe that the transplant that began with such hope had ended with such sorrow.

Jacob didn't say much, but we knew he was grieving. For me, Johnny's death was a real blow: I was still spending about 30 hours a week on Jacob's Ladder, and I was getting burned out. I began to feel powerless again; Johnny was gone, and there was nothing I could do.

I almost skipped church that Sunday, but I went anyway. At the end of the

service, I stood, waiting impatiently for the choir to sing the regular benediction. Instead, they closed with "Here I Am, Lord," the song that had spoken to me so powerfully before. Tears instantly filled my eyes. As others began to file out, I stood motionless, my body tingling. I knew there was still work to be done.

LAST NOVEMBER, JACOB PASSED THE FIVE-year post-transplant mark, which his doctors consider a cure. Because of the radiation therapy, he's still on medications to regulate his growth. But he's a happy, healthy 15-year-old—a high school sophomore who sometimes picks on his brothers and has a passion for computers. He visits children who need marrow transplants, and he works at our annual "Marrowthon" drives. Basically, though, he just wants to be one of the guys.

No one in our family will forget what he went through, but my dreams for Jacob focus on his growing up and leaving his illness behind. I want to see him graduate from college; I want him to fall in love with a special girl. And I hope that, one day, I'll be at Jacob's wedding, fighting tears as I watch him at the altar, waiting for his own ring bearer to take that slow walk down the aisle. ★