

# saving jordan

My son, the Internet  
and a diagnosis that  
changed his sister's life

by Tammy Harrow



Jordan today with  
mom Tammy and  
brothers Jake and  
Jimmy (right).

Seven years ago, I was at home feeding my then 4-month-old daughter, Jordan, when I noticed a raised line down the middle of her forehead. I gently ran my finger over it, and it almost felt like there was a small serrated knife under her skin.

“Andrew,” I called to my husband. “Come take a look at this.” He walked in and beamed at his little girl. “What’s wrong?” he asked.

I pointed out the ridge. “Don’t you think it’s strange?” He just shrugged.

“She looks perfect to me. You’re really worrying for nothing.”

I wanted to believe him, but I couldn’t help thinking that something was wrong with Jordan. After all, she’d had a difficult birth, and the doctor had needed to use a vacuum extractor to help with her delivery. So a few days later I bundled her up—we were having one of those bad Maryland winters—and drove to the doctor’s office.

In the examining room, a nurse practitioner lay Jordan on the exam table and bent over to get a closer look at her forehead. “I’ve never seen this before,” she said. “I’m sure it’s nothing, but let me grab the pediatrician just in case.”

A few minutes later she returned with the doctor, who quickly declared that the ridge was harmless. When I asked if it could have been caused by the vacuum extractor used during Jordan’s birth, she said it was possible, but that it was nothing to be alarmed about.

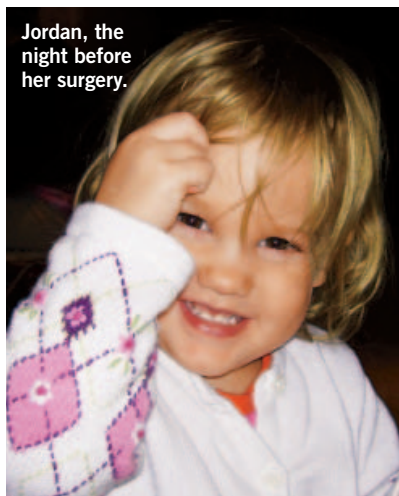
“Are you sure?” I pressed them. They looked at each other and chuckled. “We get so many worried parents,” the doctor said. I blushed. Here I was, just another hysterical mom who was overreacting.

As Jordan got older, the ridge got more pronounced—almost as if whatever was under *(Please turn to 116)*

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CONTINUED her skin was coming closer to the surface. Her head also became slightly elongated, and she was lagging behind developmentally. She didn't crawl until she was 10 months old and didn't walk until she was 15 months. Whenever Jordan had a checkup, I voiced my concerns to several doctors in the group practice and was told that she was just "on the slow end of the curve."

I started to think that maybe they were right. Jordan was a happy baby, and she loved to flip through piles of



Jordan, the night before her surgery.

books and watch Baby Einstein videos. But at 20 months, she stopped forming new words. *Ball* was one of her first words; she'd say "Ball!" and point to just about anything. But a few days later, the word was gone. The same thing happened with *mama* and *dada*. Before long, she wasn't saying any words and was back to babbling. When I told Andrew how worried I was, he got defensive. "Remind me what medical school you went to?" he said. My gut was still telling me something was wrong, but I was at a loss as to what to do.

## finding the answer

Soon after, in July 2004, we moved to Virginia. Late one night I was sitting on the floor, surrounded by dozens of unpacked moving boxes,

when my 13-year-old, Jimmy, came downstairs in his pajamas, looking grim. "What's wrong?" I asked.

"I just figured out what's wrong with Jordan," he said.

"Oh, really?" I tried my best to sound interested, as if my teenage son could have possibly just figured this out.

"She has a condition called metopic craniosynostosis," he said, struggling with the pronunciation as he handed me a stack of papers.

"I'll take a look at these in a little while," I told him wearily.

"You have to look at them now," he pleaded. "There's a surgery that can help. They break open her skull to make more room for her brain."

"OK, I'll read it," I promised, just to get him to go to bed.

Exhausted, I sat down in my makeshift office and began reading. By the end of the first page, my heart was racing and I felt nauseated. This sounded like what Jordan had.

## a rare defect

Craniosynostosis, I learned, is a birth defect in which one or more of the joints (called sutures) between the bones in the skull fuse prematurely, before the brain is fully developed. Without treatment, the brain can't grow properly, which can lead to deformities, vision problems and developmental delays. About 1 in 2,000 children are born with it, and though genetics may play a role in some cases, no one knows what causes it. I later confirmed that it's not caused by using a vacuum extractor during birth.

I was amazed that Jimmy was able to match Jordan's symptoms with a diagnosis, though he's always been a bit of a whiz with computers. He later told me he started by Googling skull deformities and eventually ended up on medical sites that led him to figure it out. [For tips on finding medical info online, go to [womansday.com/info](http://womansday.com/info).]

By now Jimmy was asleep, as was

Andrew. I ended up spending that night alone in the office, devouring the rest of what Jimmy had printed. I anxiously kept glancing at the clock, waiting until morning.

At 8 A.M. on the dot, I phoned our pediatrician's office and explained to one of the doctors what Jimmy had found. She offered to refer me to a specialist—something I should have insisted on a year before.

When Andrew woke up, I told him what had happened, and he was stunned. Three days later we made the four-hour drive to Baltimore to see Benjamin Carson, MD, a renowned pediatric neurosurgeon at Johns Hopkins Children's Center.

## finally, a diagnosis

Dr. Carson examined Jordan, ordered a CT scan and told us to be patient; it could take a week or two to get the results. But the next morning the phone rang. The scan showed that Jordan's brain was under extreme pressure inside her skull, and the diagnosis was just as Jimmy had predicted: craniosynostosis.

Dr. Carson told us that he would remove pieces of Jordan's skull and, with the help of a plastic surgeon, reshape those bones to create a new forehead. I shuddered to think about my daughter's head being cut open, but it was the only way to help her.

Andrew's face dropped when he heard the news. Jimmy was relieved. "I was worried that if I was wrong it meant that Jordan was going to be slow her whole life," he later said. I, too, was relieved that we now had some answers, but of course I was also furious—with the pediatricians for missing the signs, and with myself for not insisting that my concerns be taken seriously. But there was no time to dwell.

## the surgery

A week and a half shy of Jordan's second birthday, we returned to Baltimore for the surgery. At one point, about an (Please turn to 119)

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CONTINUED hour into the eight-hour procedure, I spotted a nurse coming toward me in the waiting room. She handed me a biohazard bag and said that although they had intended to shave just a thin strip of Jordan's hair for the incision, they ended up having to shave her entire head. I looked at the bag filled with my daughter's beautiful golden hair, sat on the floor and cried my eyes out.

After an agonizing wait, we were led to the pediatric intensive care unit to see Jordan. Even though I had looked at pictures online of other kids post-surgery, nothing could have prepared me for what I saw: Jordan was extremely pale, and her tiny body was covered by wires and tubes. Her head was swollen to what seemed like twice its normal size and was covered by a gauze turban. A thick tube drained blood from beneath her scalp, and her eyes were blackened and swollen shut. I held the wall to keep from fainting.

Jordan remained asleep for a couple of days after the procedure, so when I entered her room on the morning of the third day, I was surprised to find her thrashing around in her crib. I pulled back her blanket and shrieked: There was blood and fluid everywhere. Her IV lines had come out at some time during the night, and within minutes she was screaming inconsolably. She had to be restrained in order for the nurses to get her lines back in. I was shaking and crying so hard, the nurses forced me to leave the room, though I could hear Jordan screaming, "No, no, pwease no!"

Stunned, I suddenly felt like a weight had been lifted: Although she looked horrible and I couldn't do anything to ease her pain, my little girl could talk!

### a surprising recovery

It wasn't long before Jordan started talking like a normal 2-year-old. The day before she left the hospital,

I took her to the playroom, where she spotted a mirror. She examined her reflection, saw the turban on her head and said, "My pretty white hair." I was so happy I almost cried. All the words just came flooding out, as if they had been stuck in her head the whole time. Dr. Carson told us she was now able to speak because the pressure had been released from the frontal lobe of her brain.

Fortunately, Jordan never needed any therapy; in fact, an early-childhood special education team came to evaluate her shortly after we returned home from the hospital and determined that she knew all her numbers, letters and colors. So all along she had been learning—she just hadn't been able to express it.

In the years since her surgery (she's now 8), Jordan has been doing phenomenally well. Other than her scar, which can occasionally be seen through the part in her hair, there are no visible signs that she ever had craniosynostosis. She's been reading since she was 4, and she was just accepted to the gifted program at her elementary school.

Jimmy is now in college; he's majoring in criminal justice but is thinking of minoring in biology, in case he decides to go to medical school. After he figured out what was wrong with Jordan, he developed an interest in medicine and helping others. He even took some EMT classes and really enjoyed them.

He's living at home, which means that he still gets to spend a good amount of time with Jordan. Because of their big age difference, and perhaps because of his role in her diagnosis, he's always been very protective of her. Recently, Jordan came home crying because she was being bullied by a girl on the school bus, and Jimmy was ready to march over to that girl's house and have a chat with her parents. I stopped him, but just seeing how angry and upset he got reminded me that they'll always have a special bond. **wd**