

Unkind Cut

Some Physicians Do Unnecessary Surgery On Heads of Infants

They Remold Lopsided Skull When a Corrective Band May Be All That's Needed

At Fault: Sleeping Position

By BOB ORTEGA

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TUCSON, Ariz. — Within a few months of her birth last spring, Katie Cipriano's head began to flatten in back and bulge in front.

Concerned, her pediatrician referred her parents to a local neurosurgeon, Jack Dunn. His conclusion: The sections of her skull had fused together too soon. She needed surgery — and quickly.

As Katie's mother listened in shock, Dr. Dunn said he would have to saw off the top and back of the baby girl's skull and reshape it, in an operation that would take four hours and leave her, at best, with a scar from one ear to the other. "He said he'd done so many of these surgeries he could tell just by looking," says Kim Cipriano.

Her child is part of what many doctors call a bizarre epidemic. Across America, parents in growing numbers are arriving at hospitals and doctors' offices carrying infants with misshapen skulls. Of 40 pediatricians from 13 states interviewed, all but two say they have seen a big rise in recent years in cases of infants with lopsided heads. "In our practice, we've seen a 400% increase since 1992," says one doctor, Jeffrey Marsh, director of pediatric surgery at St. Louis Children's Hospital.

Major Surgery

Even more surprising is what many surgeons are doing to these babies. Diagnosing them with a rare condition called cranio-synostosis — premature fusion of the skull's bones — the doctors are recommending the elaborate operation prescribed for Katie Cipriano. Thousands of operations for synostosis have been done in recent years. The large majority have been uneventful, but a few babies have

died during surgery, others have been left permanently disabled, and in every case the financial and emotional cost has been tremendous.

Now, the necessity of most of these surgeries is under question. A burgeoning number of pediatric neurosurgeons and cranio-facial plastic surgeons contend that there is indeed an epidemic — of misdiagnosis. In Katie Cipriano's case, two leading specialists whom her parents consulted after getting the disturbing news told them she didn't suffer from synostosis at all, and had no need for an operation.

"There are a lot of kids getting that surgery that never get second opinions, so we'll never know how many may not have needed it," says Jeffrey Fearon, a cranio-facial plastic surgeon in Dallas.

The chief of neurosurgery at Children's Hospital in Los Angeles, J. Gordon McComb, is among several surgeons who say they themselves have operated on infants who, they now believe, didn't need it. "It just drives me up the wall that we have this population that doesn't need surgery that is getting operated on," Dr. McComb says.

Some Need It

A few babies clearly do need skull surgery. In a baby's first 18 months, its brain more than doubles in size, pushing out the separate plate — like bones of the skull. Normally, when this growth spurt ends, the edges of those bones gradually begin to fuse. But in synostosis, some of the plates fuse too soon, making the skull bulge somewhere else, such as the forehead.

Mild cases, where only one small area fuses, can be just cosmetically damaging. In severe cases, where several edges fuse prematurely at once, surgery is imperative, to prevent the possibility of a dangerous pressure buildup inside the head.

But various studies conclude that synostosis affects only one in 3,000 babies; the kind that flattens the back of the head is far rarer — one in 100,000. Yet back-of-the-head flattening is just what doctors are seeing in growing numbers.

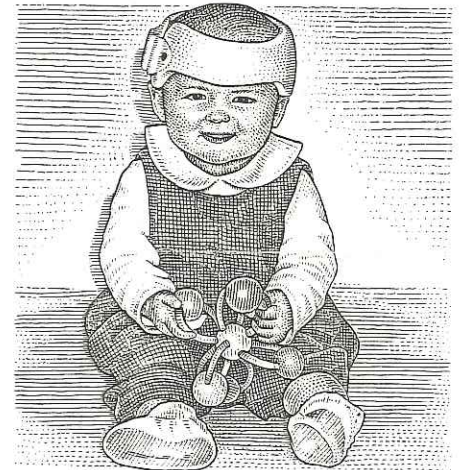
Critical Advice

Now, specialists increasingly believe most such cases have nothing to do with synostosis. Instead, they blame a widely publicized 1992 recommendation that infants — in order to lower the risk of Sudden Infant Death Syndrome — sleep on their backs or sides and not on their stomachs.

"Before that recommendation, 75% of the kids in this country slept on their stomachs," says Louis C. Argenta, direc-

tor of the division of plastic and reconstructive surgery at Bowman Gray School of Medicine in Winston-Salem, N.C. "Now it's down to zilch."

He and others agree babies shouldn't sleep on their stomachs. But they say parents need to be told to vary babies' sleeping position, because lying the same way every night can mold the malleable head of an infant, in the same way that the Incas once flattened babies' heads by strapping boards to them. Many parents' habit of toting infants everywhere in car-seat carriers worsens the problem, doctors say, by prolonging the time the back of the head presses against a hard surface. Positional molding, as the result is called, often can be treated with a special reshaping headband or helmet, or in some cases just by regularly changing the position of the infant's head.



Katie Cipriano in her headband

At the American Academy of Pediatrics, which issued the sleep-position recommendation, "we've been hearing these reports [about positional molding], too, and it's a concern," says John Kattwinkel, head of a task force on how infants should sleep. He notes that "our recommendations are for infants being put to sleep; putting *awake* babies on their stomachs is a good idea." If heads flatten from too much sleeping on the back, Dr. Kattwinkel says, "neurosurgical procedures are not what they need. The concern is not about how babies sleep but about how the medical community can overreact."

The same problem has arisen in Britain, which likewise has seen a surge in diagnoses and operations for synostosis since adopting a similar sleep recommendation two years ahead of the U.S. Doctors in Canada, New Zealand and several Latin American countries are reporting the same phenomenon.

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The Denver Cases

Indeed, long before the recent spate of cases nationwide — and before the academy's sleep recommendation — the Denver area saw an apparent rash of overdiagnoses of synostosis. In the 1980s, surgeons at Children's Hospital in Denver opened up the heads of 978 infants diagnosed with it. Many cases came through the hospital's program of urging pediatricians and school nurses to watch for signs of the problem.

Kyle Powell's was a typical case. When he was three months old, in 1988, his pediatrician noticed that the back of his head was flattening and recommended a hospital visit. "I'd noticed it, but I hadn't been concerned because he always slept on his back, and I thought that's all it was," says Kyle's mother, Sherrie Bean.

But at Children's Hospital, she says, a surgeon told her Kyle had a rare and serious type of synostosis. "He said [Kyle] could be brain-damaged and/or die from pressure on the brain if he didn't operate as soon as possible," says Ms. Bean. The surgery was done.

The spate of cases led the federal Centers for Disease Control to investigate. More red flags went up when surgeons from the hospital gave a paper at a medical conference, only to have other neurosurgeons question their diagnoses. One skeptic, Joan Venes of the University of Michigan, examined two Denver children diagnosed with synostosis at Children's Hospital; "neither of them, I felt, required surgery," she says.

In 1987, the CDC tentatively concluded that there was little evidence of an epidemic of synostosis but that the Denver hospital's doctors were much likelier than others to diagnose it and recommend surgery. The hospital's diagnoses of the condition fell sharply, as did its surgeries — from 215 in 1986 to 31 last year.

A review of Kyle Powell's X-rays by the head of pediatric neurosurgery at the University of Colorado medical school and of its residency program at Children's Hospital, Ken Winston, found "no evidence . . . of synostosis." The review was done for his parents, who are suing the hospital. They say Kyle, now seven, has short-term memory problems, which they suspect stem from the surgery.

Children's Hospital denies that operations it did were unnecessary or that the children didn't have synostosis. "We were doing what we thought was right and prudent at that time, based on what we knew about cranio-synostosis," says Lua Blankenship, the hospital's president.

Lots More Cases

Although the Denver controversy rippled through professional circles, it didn't ring warning bells elsewhere in the health-care community. In the years since the recommendation on sleep position, as med-

ical centers across the country have seen more and more infants with misshapen heads, many doctors have readily diagnosed synostosis. In hundreds of cases, they did skull surgery; many continue to do so.

It nearly happened with Dion Flannery. Two summers ago she gave birth to twins, Michael and Kyle. When they were three months old, the backs of their heads started to flatten. Ms. Flannery, of Boca Raton, Fla., took them to Miami's Children's Hospital. After CT scans, a radiologist and a neurosurgeon told her both boys needed operations immediately. "The description of the surgery freaked me out," she says.

Determined to get a second opinion, Ms. Flannery flew the boys to Dallas to consult with Kenneth Salyer, a cranio-facial plastic surgeon. He said neither boy had synostosis, and both could be treated more simply. "Bottom line," she says: "In June, Michael came out of his helmet. In August, Kyle came out of his. Now they have beautifully shaped heads, and neither one needed surgery."

At Miami Children's Hospital, Deirdre Marshall, a surgeon but not the one who saw the Flannery boys, says, "Perhaps there was a mistake. It's difficult to distinguish even with CT scans between true synostosis and positional deformations."

Not Easy to Tell

The doctors who read X-rays and CT scans do often find them hard to interpret, surgeons say. Dr. Argenta in Winston-Salem says that of the last 51 infants referred to him with misshapen heads, "our radiologists said they saw abnormalities consistent with varying degrees of synostosis in 38. But only two of the children wound up having cranio-synostosis." The rest were corrected with helmets.

Part of the reason for the difficulty in diagnosis is somewhat paradoxical: According to surgeon Joseph Gruss of Children's Hospital in Seattle, some of the standard medical literature on what to look for is based on cases that now aren't believed to have been synostosis at all.

Another problem: Managed-care systems typically don't employ pediatric neurosurgeons and often are reluctant to refer patients to outside specialists. "There are [only] about 80 full-time, card-carrying pediatric neurosurgeons in the country, and maybe 300 others who do pediatric neurosurgery as part of a broader practice" and clearly understand the difference between positional molding and synostosis, says Harold L. Rekate, a pediatric neurosurgeon in Phoenix. "That leaves about 3,700 neurosurgeons in the U.S. not actively pursuing pediatrics, but who work in centers where they're occasionally asked to do pediatric neurosurgery. They're the ones we're now anxious to reach" to warn against false diagnoses of synostosis.

Katie's Story

Until the word gets out, some parents must fend for themselves, as did Mrs. Cipriano. After surgery was ordered on her baby last September, Mrs. Cipriano, with Katie in her arms, stumbled in tears out of his office. She and her husband decided that if their child needed surgery, they would seek out the best surgeons in the country.

Their search led to the cranio-facial center at Medical City Dallas Hospital. Over the phone, they scheduled surgery. Then they had Katie baptized, hired a photographer to shoot a family portrait and flew to Texas for the operation.

The next morning, Dr. Fearon of the medical center examined Katie and the CT scan brought along from Arizona. Then, recalls Mrs. Cipriano, he said something startling: "I will not operate on her." The bones in Katie's head hadn't fused, he said; she didn't have synostosis.

The Ciprianos, though elated, were also confused. "We wanted to believe him, but it seemed almost too good to be true," says Mrs. Cipriano. They sought a third opinion, from Dr. Rekate in Phoenix.

Dr. Rekate, too, said Katie didn't have synostosis. He said she had positional molding, and recommended that she wear a \$2,000 headband designed to restore the normal shape of her head. She began wearing one, 23 hours a day. "It took seven days in the band and we, with our untrained eyes, could see a dramatic change," says Mrs. Cipriano. At 10 months of age, Katie now is so normal-looking that she may come out of the band this month, Dr. Rekate says.

Dr. Dunn, the Tucson doctor who said she needed surgery, makes no apologies. While declining to discuss this particular case, he says he doesn't operate on most infants he sees with misshapen heads. Still, he says he does do 25 to 30 "cranial vault remodels" — the cutting and reshaping of infant skulls — every year. Dr. Dunn, who notes the difficulty of interpreting X-rays and CT scans, says that even if the deformity turns out to be due to something other than synostosis, surgery sometimes produces a result that is cosmetically superior to headbands.

Some physicians decry that notion, among them Ian Munro, a cranio-facial surgeon at Medical City Dallas Hospital. He doesn't know Dr. Dunn, but, speaking generally, Dr. Munro says: "This is an ego business — surgeons see something wrong, they want to fix it."