'As long as my child is healthy, nothing else matters.' This is a thought many parents have in common. Pregnant women, concerned about birth defects, Down syndrome and other potential dangers, carefully watch what they eat and drink, but no one ever expects something like stroke to happen to her newborn. Yet the truth is that even babies have strokes. So do children and adolescents. In fact, stroke can strike a fetus in the womb.
Samuel Baird was born on Tuesday, September 14, 2004. On Wednesday, he turned blue. By Thursday he was in a neonatal intensive care unit.
Samuel Baird was born on Tuesday, Sept. 14, 2004. On Wednesday, he turned blue. By Thursday he was in a neonatal intensive care unit. After multiple diagnostic tests, including a CT scan, the diagnosis was simply startling — stroke.

Samuel’s mother Jude recalled that day: “In delivering the diagnosis, the words ‘brain damaged and handicapped’ were used, and that’s all I heard. I didn’t hear the word stroke. I have a brain-damaged sister who is institutionalized, in her 40s. I kept looking at Samuel and thinking how could this happen to such a beautiful baby? We were devastated, words can’t even describe how we felt.”

Samuel’s parents learned that about a third of pediatric stroke survivors experience no long-term effects, a third have some deficits and a third require considerable care. “That made us feel somewhat better,” said father Gary. “They said because of the location of the stroke, right-middle cerebral artery, the motor skills on his left side would be affected, but the doctor didn’t know how it would manifest itself. We were relieved to hear that there was a 30 percent chance he would not be cognitively impaired. It seemed something of a blessing and we latched onto that.”

Jude searched the Internet for information on intrauterine stroke. The material she found was either outdated or very hard to interpret without a medical background. It was also difficult to find statistical data about types of injury and prognosis.

The Bairds, who live in Scottsdale, Ariz., enrolled Samuel in the Arizona Early Intervention program, which provides free therapy to children with developmental challenges. At three months, Samuel began physical therapy. Gary did baby massage every night, which Samuel loved and responded to well. By six months, he was seeing three therapists a week and had achieved every milestone.

“At four months, the doctor was very optimistic and felt the cognitive and language centers were likely not affected,” said Jude. “However, to a certain extent it is a matter of ‘time will tell.’ We just feel very grateful that Samuel has done incredibly well to date. The physical, occupational and development therapy have been invaluable.

“He definitely favors his right hand,” said Jude. “We offer him things on his left side, but he still uses his right hand. His physical therapist says he has higher tone on his left side, but I can’t tell when I watch him walk.” Samuel has progressed so well that at his one-year checkup, his neurologist said he had to check the CT scan to know he had even had a stroke.

The Bairds, who are from New Zealand, received support from all over the world. “My parents flew out the day they heard and were a tower of strength,” Jude said. An Arizona-based group called Raising Special Kids also helped.

“They put you in touch with a family who has a situation similar to yours,” said Jude. “I was contacted by a woman whose daughter had had a stroke as an infant, and she was a tremendous support. She answered all my questions. You know, when you’re a mother, your heart’s not your own, so it was very helpful to have someone who had been there.” (Raising Special Kids is specific to Arizona, but there are similar organizations in other states. To find a group in your state, see Parent to Parent USA on p. 32.)

The lack of information about pediatric stroke spurred Gary to action. He has joined Train To End Stroke (TTES) and has raised $9,000 with a target of $25,000. Beyond his fundraising goal, Gary is encouraging the American Stroke Association to make a grant of $150,000 to fund pediatric stroke research and to add related information to its Web
site. “I think it is easier for people to deal with traumatic situations if they have good information that they can understand,” Gary said.

“It’s important for new parents in this situation to understand that a baby’s brain has an incredible ability to rewire,” said Jude. “But it’s also important to get them into therapy as soon as possible.”

A Stroke at Birth

Twins Todd and Josh Anthony of Edmond, Okla., share many things. But only one of them, Todd, has a history of stroke. At birth, Todd had a stroke that affected both sides of his brain (“bilateral infarct”).

At the very beginning, the stroke went undetected. But then while still in the nursery of the hospital, Todd started having breathing problems. Tests uncovered a small hole in his heart called a ventricular septal defect. His condition worsened over the next 24 hours, and he refused to nurse and couldn’t be fed with a bottle.

The Anthonys are concerned about the future. If Todd has disabilities, they wonder, will he be accepted by other kids?

“He was inconsolable at times, crying and twitching, but the doctors and nurses were telling us everything was normal for a premature baby,” said Letitia Anthony, Todd’s mother, who had given birth two weeks early. “But on the day we were to be discharged, there was a lot more twitching, and my husband Scott insisted Todd be given more tests before he was released.”

The pediatrician ordered a CT scan and an EEG. Both were abnormal and the doctor ordered an MRI. That’s when they discovered the bilateral infarcts. “Our neurologist told us he had never seen that before and gave us a gloomy prognosis,” said Letitia. “He said Todd might not walk or talk.”

Both Letitia and Scott are physical therapists. “As a physical therapist, you know to start therapy right away, so we started as soon as we got home. I think this has been a lifesaver for Todd,” Letitia said. “He definitely has deficits on his right side, but he is able to use that side. When he falls, he always falls to the right. He just started walking two weeks ago, almost 16 months, which is not considered late, but it’s slower than average. Josh started walking at 12 months.”

Initially, Letitia returned to work and put the boys in daycare, but Todd’s progress seemed to slow, so Letitia decided to stay home. “My first month back, he made huge gains. The physical therapist from Sooner Start (a state-sponsored program in Oklahoma for babies with developmental challenges) would come once a week and show me what to do, and then I worked with him every day. We were fortunate that we were financially stable enough that we could make ends meet. We’re paying bills, but that’s about it.”

At 18 months, neither Todd nor Josh is talking, but both are making sounds. “We get a speech evaluation every two months, and he’s on track. If you ask him what a cow says, he’ll say ‘moo.’”

The Anthonys are concerned about the future. If Todd has disabilities, they wonder, will he be accepted by other kids? What kind of relationship will he have with his brother?

“Right now, they get along very well. Though Todd’s about two months behind Josh, neither one realizes anything is different. They share toys. They fight, just like normal boys. They’re 18 months now and going to day care two half-days a week. We thought the social interaction would be good and also good for them to be away from me. “We’re hopeful and optimistic for the future because in the past 18 months he’s made such tremendous progress,” said Letitia. “But we won’t know if there are cognitive problems until he’s older and in school. Of course, we hope they both go to college, become good citizens, fall in love and get married, but there’s always a ‘what if…’ in the background.”
Cause Doesn’t Change Outcomes

When Ashley Beach was six months old, she woke her parents, Kim and David, one night with horrible screams, but her brother had had a history of stomach problems, and they thought it was probably a stomach virus.

The next morning the pediatrician agreed and sent her home with anti-nausea medicine. “That’s when she started tongue thrusting,” said Kim. “I thought she was thirsty, but it was actually because she was having seizures. At eight that night, she had a grand mal seizure.”

The doctor thought it was a reaction to the medicine, but Benedryl didn’t help, so the Beaches rushed their baby to the emergency room in Tulsa, Okla., where they lived at the time.

A CT scan and subsequent MRI showed the unimaginable — Ashley had had an ischemic stroke.

The doctors were unable to identify a cause, as is often the case with stroke in infants. “I think the biggest thing we’ve learned from all this is that cause doesn’t change outcome, so ultimately the cause isn’t important,” said Kim. “Cause is important for parents at the beginning because they want something to blame, but after awhile it just doesn’t matter because your child is still here.”

Her parents’ next question was: “What kind of life would she have?” They didn’t waste time waiting for an answer: Ashley started therapy before she left the hospital. They enrolled her in Sooner Start, a state-sponsored program in Oklahoma for babies and children with developmental challenges. “They were great because they worked with things that were actually in her surroundings,” Kim said.

Kim suggested to several therapists that a video for parents and grandparents would really help them help their children. One of their physical therapists, Jenna Zervas, took hold of the idea. Together, Kim and Jenna produced a video of exercises appropriate for any developmentally disadvantaged child. Called Baby Builders, the video “helped make something good out of a bad situation,” Kim said. (For more information, see “Baby Builders” on p. 32.)

Ashley turned 7 in July; she’s in the first grade and tests at a level normal for her age. Although she has seizures, they’re small and infrequent and she’s not on medication for them. She’s had two surgeries to lengthen the tendons in her left foot. “She’ll have more surgeries because her brain is telling her tendons to be tight,” Kim said.

Despite these challenges, Ashley is active: she has taken classes in tap dancing and cheerleader-gymnastics, and has played soccer. She loves to go 4-wheeling with her family and walk the ruins at Mesa Verde National Park near the Beaches’ home in Durango, Colo. “Physically, she doesn’t know any different, but she does get tired of being the slowest at things. Emotionally, she feels like she’s the only kid who ever had a stroke.”

Ashley’s situation has affected her brother Chris, who is two years older. “When he was five, he asked his pediatrician what he had done to cause his sister’s stroke,” Kim said.

“Poor little guy, he had carried that a long time. I feel like he lost his childhood by going to the hospital all the time. He learned to count by touching numbers in the elevator.

“He’d get jealous during therapy because she got all the attention. Every once in a while I see he’s tired of everyone always asking about his sister.

“Early on, I got a call from a mother of a pediatric stroke survivor, and she said that I had to grieve. I said, ‘Why? Ashley’s still alive.’ And the woman said, ‘Yes, but all your dreams have died.’ And I realized that was true, all the dreams we’d had for the child born in July had died in January. We had to develop new dreams.”
A Summer to Remember

On May 19, 2003, Dale and Tanya Koller put their 11-year-old daughter Kasey on the bus for her last day of fifth grade in Panama City, Fla. Later that morning, they received a call from Kasey’s school. Kasey was having convulsions and needed them right away.

By the time they got to the school, however, their daughter had already been taken to the hospital, where she was admitted with stroke-like symptoms.

Many hours later, ultrasound imaging revealed the agent of the terror — an inch-long tear in her carotid artery. “Kids damage the carotid all the time,” said Dale, “but something happened that caused the artery to crimp. Running caused her blood pressure to rise and that burst the artery down deep near the aorta, where a tear could have been fatal.

“When the doctors came back with a stroke diagnosis, I thought it had to be a misdiagnosis,” said Dale. “They said on a scale of 1–10, her stroke was an 8.”

Because of the severity of her situation, Kasey was transported 200 miles by ambulance to another hospital. She was alert when she arrived, but on the second day she went into a coma. “She was asleep and motionless and completely unresponsive,” said Dale. “The doctors couldn’t answer any of our questions, but they said if she woke up and started moving, that would be a good sign.”

Two days later she awoke, but couldn’t move her right side. The stroke had injured areas that controlled comprehension and dexterity as well. The worst-case prognosis was that she would never again walk or talk; the best-case was being released to rehab in a week.

“When she first came to, she could only say ‘ce-ce’ and try to move. Her facial muscles were paralyzed, too. I thought it was bad, but the doctors said it was good that she was making sounds,” Dale said. “All the doctors agreed that age was on her side.”

Within two days she was learning to walk and talk again — one step and one word at a time, but it was a miracle to her parents. By the third day she was walking on her own and speaking fragmented sentences. The following weekend she was released to rehab — the best case had been realized.

With summer just beginning, Kasey’s goal was to return to the sixth grade on time. With a lot of hard work, she made it. “I’d say she’s 90 percent recuperated, making A’s and B’s,” Dale said. “She’s gotten her walk back, but her right arm is still weak. The doctors say she can get that back, but it’s up to her. At 13, she’s a little embarrassed by it and compensates with her left hand.

“We were scheduled to attend a seminar on the Saebo glove because they say with that she’ll be able to get her hand back. Unfortunately, the seminar was in New Orleans the weekend Katrina hit. But the fact we’ve got her back mentally, we couldn’t be more pleased.”

Learn more at StrokeAssociation.org/strokeconnection:
• Rehab psychologist Mark Sandburg discusses emotional and cognitive recovery of child survivors.
• An update on Brandon Zimmerman (SCM March/April 2002) who had a stroke when he was 6 months old.

Stroke in Children

Stoke in children peaks in the first 30 days after birth. The rate of stroke for infants less than 30 days old is 26.4 per 100,000 live births per year: (17.8 ischemic stroke, 6.7 hemorrhagic stroke).

For children between ages 1 and 14, the rate is 2.7 per 100,000.

The outcome of childhood stroke is moderate or severe in 42 percent of cases.

Compared to white children, black children have a higher relative risk of stroke of 2.12.

One out of 10 children with ischemic stroke will have another stroke within five years.

Cerebrovascular disorders are among the top 10 causes of death in children, with rates highest in the first year.

Stroke mortality in children under age 1 has remained the same for 40 years.

Source: Heart Disease and Stroke Statistics — 2005 Update