

# SOUTH COUNTY JOURNAL

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When a stroke strikes the youngest

By [Julie Randle](#)

Jessica Spear wanted to be told she was crazy.

That news would have put to rest her worst fears — that something was wrong with her son.

Instead, those fears were confirmed.

Her son, Brendon, was the victim of a perinatal stroke, a stroke that occurs in the womb or within 30 days of birth.

The stroke left Brendon with mild cerebral palsy, speech difficulties and under-developed back and shoulder muscles on his right side, the result of muscular scoliosis.

“I had never heard of a stroke happening to a child,” said Spear, 36, who conducted admissions and evaluated patients for nursing homes in the mid-1990s. “When I started seeing the symptoms — in hindsight — I looked at him and it looked like he had a stroke.”

Spear had an inkling of what was wrong with her son, but it took 19 months before a doctor finally pinned down a diagnosis.

Spear first noticed something abnormal two weeks after Brendon came home — he never moved his head to the right.

As he grew older, the symptoms accumulated.

She noticed that he sat hunched over in his high chair, he clutched his right hand, his right foot was at a weird angle when he attempted to walk and he used his left hand for everything.

And he said few words. He made noises.

“He said ‘mama’ and ‘dada’ on time and then for months you heard nothing,” she said. “He did noises. Some stroke patients make noises.”

As signs that seemed odd to her appeared, she informed doctors.

One dismissed her claims as something her son would grow out of by age 2 while others reassured her



[Erica Burrus](#) photo/ Brendon Spear, 3, of South County plays in his room. Spear had a pediatric stroke while in the womb and suffers from mild cerebral palsy.

that Brendon was healthy.

But she was right. And she knew it.

Nearly a year and a half after Brendon was born, doctors determined he had suffered a stroke. The diagnosis was confirmed through an MRI.

Along the way to the correct diagnosis, Spear and her son saw eight doctors, including two orthopedists and four neurologists.

The first orthopedist said Brendon was fine. The second orthopedist recognized that something was wrong with Brendon and referred them to a neurologist.

The chain of doctors and the reassurances that Brendon was in good health were not good enough for Spear.

“I needed a reason why he was OK, the foot was the way it was and why he was left-handed,” she said.

Spear and her husband had invited Terry Dollinger, a parent educator for Parents as Teachers, to work with them in their South County home soon after Brendon’s birth.

Dollinger, a veteran of working with parents on child development, saw the same problems Spear had been seeing all along.

Dollinger provided a source of support for Spear, who felt guilty over her inability to figure out Brendon’s problems.

She and her husband, Stephen, 42, a captain with the Webster Groves Police Department, were first-time parents, which added to their anxieties.

Despite her gut instinct that something was wrong, Jessica Spear hoped someone would step forward and tell her she was wrong, that she was imagining her son’s troubles.

Dollinger reassured Spear that she was correct, that Brendon needed help.

“I was her cheerleader,” Dollinger said.

Finally, the walking difficulties and speech signs were too obvious to ignore.

In March 2007, a neurologist conducted an exam. Brendon was asked to reach for toys, grab them and poke them. He was diagnosed with mild cerebral palsy, which includes many neurological disorders that affect body movement and muscle coordination. The doctor wanted to know why the condition occurred.

“He believed the cause was a brain tumor or stroke,” Jessica Spear said. “We were in a race against time. I felt so angry. I was cheated. This started at nine months and this was 19 months. I should have at least known 10 months ago about this.”

The MRI showed that Brendon had damage on the left side of his brain, which affects motor control on the right side of his body.

Doctors believed the stroke happened during Jessica Spear's second or third trimester of pregnancy.

So how does a baby suffer from a stroke?

One possible explanation is that a mother's blood becomes sticky in the body's effort to prevent excessive blood loss during birth.

This can cause blood clots and, later, strokes in babies, said Dr. Brad Schlaggar, an associate professor of neurology and pediatrics at Washington University School of Medicine and St. Louis Children's Hospital.

One baby out of every 5,000 born will have a perinatal stroke, said Schlaggar, director of the pediatric neurology residency training at Washington University School of Medicine. He doesn't consider this rare, but it can be difficult to detect.

"Perinatal stroke is far more common than most people realize, but the manifestations can be subtle," he said.

About half of patients with perinatal stroke are diagnosed because they have seizures within the first several days after being born. The other half of patients are diagnosed because there is something different about their development of motor and/or cognitive skills.

"Brendon hit his milestones on time," Jessica Spear said. "He was a tricky guy."

This is one explanation for the delay in diagnosis.

"If the developmental issue is subtle, the problem may be minimized and a workup will not be carried out," Schlaggar said. "This scenario is the most common reason these days that a perinatal stroke will be detected relatively later."

Today, Brendon attends preschool and receives physical and occupational therapy at his early childhood center in South County.

From time to time Brendon wears a cast on his left arm for two weeks at a time. Last year, the Spears decided to try constraint-induced therapy, which forces the brain to learn to use the other arm and helps Brendon build up strength in his weak arm.

This is his fourth round of therapy. He has sported a cast in December 2007 and in March, May and August of this year.

He also wears a McKee thumb splint on his right hand that forces his thumb out because of the cerebral palsy.

The Spears recently established Brendon's Smile...Raising Awareness for Childhood Stroke, a non-profit organization designed to raise awareness for perinatal and childhood stroke and to advocate for child survivors of stroke.

The Spears wanted to spread the word about stroke so other families are spared what they went through. The Spear family and their story are featured in the September/October issue of "StrokeSmart," a magazine published by the National Stroke Association.

“There’s not enough information about childhood stroke, the prognosis and who it affects,” said Stephen Spear, 42. “We’re using Brendon’s story to propel the bigger issue of childhood stroke.”

For more information visit, [www.brendonssmile.org](http://www.brendonssmile.org).

**Want to go?**What: Brendon’s Smile — Raising Awareness for Childhood Stroke information rally and walk

When: 9 a.m., Sept. 28

Where: The Atkinson Shelter off Grant Road at Jefferson Barracks, 251 Cy Road

Info: Visit [www.brendonssmile.org](http://www.brendonssmile.org)

### **Stroke knows no age**

Signs of possible stroke:

- Seizures in infants that are confined to one area of the body
- Poor feeding in newborns or early hand preference before 10 months
- Delays in motor development
- Tightness or restricted movement in legs and arms
- Language delays
- Seizures or sudden onset of one-sided paralysis are seen in older children



Erica Burrus photo/ Brendon Spear, 3, gives his mother, Jessica, 36, a hug accompanied by a his frog, a stuffed animal. Brendon was diagnosed with a perinatal stroke at 19 months. The stroke occurred while he was in the womb.



Erica Burrus photo/ Brendon Spear enjoys reading a book about fruit. For a while he only made noises, but a speech therapist has been helping develop his language skills.



Erica Burrus photo/ Stephen Spear, a captain with the Webster Groves Police Department, watches as his son, displays dinosaur window adhesives to the front door.