

## Girl's progress after pioneering brain surgery gives hope to other parents

November 26 2009, By Elizabeth Leland

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Lexi Haas is awakening into a world of new possibilities. Miracle by tiny miracle, she is making her body do what she wants -- instead of her body always controlling her. She looked up at her mother a few weeks ago, pursed her lips and, for the first time in her life, Lexi blew a kiss.

She scribbled with a marker. Sat in her wheelchair without her back arching, her legs going rigid and her mother having to wrestle her down. She touched her hair. Slept through the night. Held her doll.

Parents around the world are watching the engaging 7-year-old from Charlotte, who has an IQ of 160 but cannot walk and has never said aloud more than a few words at a time. Four months after pioneering [brain surgery](#), Lexi has given them something many had lost: hope for a better life for their children.

Her accomplishments may seem small by most standards. But they promise bigger changes for Lexi and other girls and boys trapped inside their bodies from brain damage caused by excessive jaundice as newborns.

Lexi is now undergoing [deep brain stimulation](#) to try to reverse the damage. She has a Facebook page, with 2,609 fans, where other families are following her progress.

"Lexi has given us the first realm of excitement," said Vicki Dornbos of Spokane, Wash., whose 5-year-old son, Zachary, has the same type of

brain damage, called kernicterus.

Zachary, like Lexi, was born healthy. Like Lexi, he suffered [brain damage](#) because his jaundice went untreated until too late. Like Lexi, he has [cerebral palsy](#). When he tries to do anything, big or small, his legs kick, his arms jerk, his head flies back, and there's nothing Zachary can do to stop every muscle in his body from moving erratically or refusing to move. Just like Lexi.

And like Blue, a 4-year-old boy from Fayetteville, N.C., whose kernicterus is so severe he is fed through a tube. And Elliot, a 9-month-old in England, who has trouble hearing.

"We're all focused on Lexi," said Blue's mother, Miriam Iliff. "I had heard about deep brain stimulation. But until Lexi, it had all been speculation."

Deep brain stimulation is working like a pacemaker on Lexi's brain, pumping timed electrical pulses into her damaged basal ganglia. Doctors hoped the stimulation would shut down the abnormal brain activity that causes her erratic movements and allow Lexi to gain control over her body.

"We are seeing encouraging signs," said Dr. Steven Shapiro, a kernicterus expert at Virginia Commonwealth University Medical Center in Richmond, where Lexi had surgery. "She is getting some benefits even earlier than we expected."

Based on how Lexi does, neurologist Kathryn Holloway said they may consider deep brain stimulation for other children with kernicterus.

Lexi's treatment began in July. Holloway implanted electrodes into her brain, then embedded a battery-operated stimulator into her abdomen.

Lexi nicknamed the stimulator "Hope." Holloway activated it in late August. She started slowly, directing a low voltage of electricity to two of eight possible contact points in Lexi's brain.

Holloway warned Lexi's parents not to expect immediate results. But from the moment the neurostimulator was turned on, Lexi's body visibly relaxed. That night, she slept without waking until morning. Her muscles no longer moved constantly so she was able to rest for the first time in her life. Because her muscles no longer move as much, she doesn't burn as many calories and doesn't need to eat as often. And she no longer throws up after eating.

She has returned to Richmond three times to have the voltage turned up. Each time, she has come home with a gift: The strength to hold a marker and push it across a sheet of paper. The coordination to keep her head upright without her neck muscles pulling it off to one side. Breath enough to say "Trick or Treat!"

Before, if Lexi tried to raise her arm, her whole body would set in motion, legs flailing, arms flapping, head jerking, preventing her from doing the one thing she wanted to do. It still takes a lot of effort for her to do something as deliberate as raise one arm. But as often as not, the rest of her body now stays put.

On good days, the possibilities seem boundless in Lexi's imagination. She will walk! She will talk! On bad days, when her body refuses to cooperate, she feels a frustration she never knew. Before, she felt no expectation to do something as simple as hold her doll, or as dramatic as take a step. Now she does. If she fails, she worries she will let everyone down.

The kernicterus affected every muscle in Lexi's body. It's clear from the way her lips move that she knows how to form words, but rarely can she

coordinate her muscles and get enough breath to make herself understood. She communicates by pointing to words and letters taped onto a cookie sheet, a painstaking process.

Asked last week how the deep brain stimulation has changed her, Lexi worked out her answer off and on for several days, letter by letter, her arm struggling against errant muscles pulling it in the wrong direction.

"Hope makes my body feel quieter," she said. "I can hold things better now. I could already talk but my voice is getting stronger. I can ... sit up on my horse at the farm. I also like to use my new swing.

"Sometimes I can't do the things I want and it is frustrating, but mostly my body is getting better.

"I want to cook dinner and tie my shoes myself.

"I would like to walk before my powerchair comes back home so I won't have to use it. That thing is a beast! It has a mind of its own!

"I might be 8 when I am able to walk alone. I promise you I will though. I am absolutely sure. My friends are counting on me."

Nobody's counting on you, her father reassured Lexi. They're cheering you on.

Ken Haas, who is a chiropractor, believes Lexi's determination is a good thing. "In working with patients, one of the things I've found is that wanting something is an absolute must to getting to a goal," he said.

"When people don't think it's possible or lose hope, the healing process shuts down.

"Lexi wants it."

In early November, a week after Dr. Holloway directed voltage to two more contact points, Lexi's mother, Susan, took Lexi as usual to ride on a horse at Misty Meadows Mitey Riders therapeutic riding center near Waxhaw.

Owner Harry Swimmer has always welcomed Lexi the same way. For three years, he stuck out his hand, hoping Lexi might one day reach up to shake it. She would struggle to lift her arm but never could. Harry would then lean over and whisper:

"Say Harry. Ha-ree. Ha-ree."

Lexi would smile and make a sound, though nothing recognizable.

On Thursday, Nov. 5, Harry walked up to greet them as usual. He held out his hand, and Lexi as usual couldn't lift hers. He bent over and whispered:

"Say Harry. Ha-ree. Ha-ree."

Lexi's lips moved. This time, she didn't smile up at him. Her lips opened just a little bit. Her tongue dropped back. She forced air up through her throat and mouth. Then, ever so faintly but clearly enough for everyone to understand, Lexi spoke:

"Ha-ree."

One word, with so much expectation. Everybody around clapped and cheered.

If you didn't know Lexi before surgery, you might not understand the significance of such small improvements.

She still rides in a wheelchair. Her arms still tend to fly about and have to be strapped down. Her head still flops forward when you least expect it. But Lexi Haas today has a different body than before surgery. She doesn't have to fight her muscles constantly the way she once did.

"Her body is so much more manageable," said Gail Fennimore, her physical therapist at Child & Family Development. "It's so much more livable. If she got nothing more than that, it would be worth it."

Lexi wants more.

Dr. Holloway plans to turn up the voltage on the stimulator again in early December, and Lexi is already impatient.

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Citation: Girl's progress after pioneering brain surgery gives hope to other parents (2009, November 26) retrieved 16 April 2024 from <https://medicalxpress.com/news/2009-11-girl-brain-surgery-parents.html>

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