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Sheila Guiter, a registered nurse, measures John Shirley's head as she tracks his growth during a home visit in early September. Guiter said John is meeting, and sometimes surpassing, appropriate milestones. "He's exceeded my expectations," she said.

Iowa's tiniest baby: From birth to birthday

In his short life, John Allen Shirley has claimed two titles — the smallest surviving baby in Iowa and the third-smallest surviving boy in the world.

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John Allen Shirley turns 1 year old today.

In his short life, he has claimed two titles — the smallest surviving baby in Iowa and the third-smallest surviving boy in the world.

When he was born, John weighed less than a can of pop. His dad's wedding ring easily slipped onto his upper arm.

Born at 26 weeks weighing 11.5 ounces, the Knoxville boy was smaller than an average fetus at the same gestation. Lagging four to five weeks behind his peers, his tiny lungs had not fully developed.

He could have died in the womb.

Not only has he survived, he has thrived, thanks to doctors, specialists and his family's care. That is no small feat, considering the slew of mental and physical complications that premature babies battle.

Today, John Shirley — with his big brown eyes, wispy brown hair and penchant for loudly thumping his legs against the floor — is a relative heavyweight, tipping the scales at nearly 12 pounds.

He started out with a 25 percent chance of survival.

Starving in the womb

Full-term babies spend about 40 weeks in the nourishing warmth of their mother's womb.

After 26 weeks, John didn't have that luxury.

He wasn't due until Jan. 18, 2005. But here was his mother, Leslie, six months along in October 2004, with her stomach showing no signs of getting any bigger.

The family practitioner in Knoxville did an ultrasound and saw that John was small for his gestational age. There was little amniotic fluid.

A week before John was born, Leslie and her husband, Aaron, traveled to Des Moines to see Dr. Paula Mahone, a perinatologist, which is a physician specializing in high-risk pregnancies. Mahone helped deliver the McCaughey septuplets in 1997.

"At that time, we knew that there was very significantly decreased fluid," Mahone said.

The ultrasound measured the depth of the deepest pockets of amniotic fluid. A normal amount for a fetus at 26 weeks would have been 12 centimeters, Mahone said. John was floating in a mere 3 centimeters.

The baby was also four to five weeks behind in growth, Mahone said. The placenta was small, and blood wasn't passing properly through the umbilical cord. The condition is called severe intrauterine growth retardation.

John was starving.

One explanation for John's size was blood clots caused by thrombophilia, a genetic condition Leslie has that has been linked to poor fetal growth, Mahone said.

"Whether that was it or not, nobody can say that for sure," she said. "The list is a page long of what it could be."

Leslie was put on steroids, a routine measure in preparing for premature births. The shots help speed fetal lung development and decrease the risk of a brain hemorrhage.

Leslie was ordered on bed rest for a week.

She went home. And waited.

Grim situation

Parents in situations like that of the Shirleys know that their fetus may die before delivery.

But John wasn't ready to throw in the towel.

After consulting with Mahone, Leslie was admitted to the hospital within a week.

A special test was performed to determine whether John had devastating chromosomal abnormalities that could lead to his death hours after birth, Leslie said.

The test results would come in 36 to 48 hours.

But between 1:15 and 1:30 p.m. on Oct. 16, 2004, John's heart rate became abnormal.

Mahone said they had an hour, maybe longer, to deliver him or he would die.

They couldn't wait for the test results.

Leslie said she and her husband were given two options: To give birth, or to let John die naturally inside her.

The couple had tried for three years to have a baby. Leslie has irregular menstrual cycles that make getting pregnant difficult.

They decided to deliver. John was given a 25 percent chance of surviving.

He couldn't wait. It was now or never.

"We wanted to give him at least a fighting chance," said Leslie, who is 23. "What happened after that can't be helped. We weren't going to sit there and do nothing."

The baby is coming

Aaron was optimistic.

Leslie was scared.

"She worries, and I think ahead," said Aaron, 24. "I was making plans for him way down the line, and she was worried about that day. I guess that's the way I try not to think about the negative things."

John was delivered by emergency Caesarean at 2:14 p.m.

His size belied his fighting spirit.

He was 3 1/2 inches longer than a No. 2 pencil. His skin was paper-thin. The smallest diaper available — one that fits into the palm of an adult's hand — swallowed his body and had to be folded.

Aaron and Leslie decided long before this tiny baby was born that he would be the namesake to two resilient and influential men in their lives: John, Aaron's grandfather, who died in 2004 after a long battle with prostate cancer; and Allen, Leslie's father, who has struggled with cancer for most of her life.

"We knew from the second he was born that he would be a fighter, that he would be just like his Great-Grandpa John and Grandpa Allen," Leslie said.

"It was a total team effort," said Dr. Joel Stenzel, a neonatologist at Blank Children's Hospital in Des Moines. The delivery included inserting the smallest breathing tube the hospital had — about half the diameter of a pencil — into John's airway.

Preemies have a greater risk for physical and mental complications after birth, including chronic lung disease, stroke and infection, Stenzel said.

John's extremely small body and lung size, compounded by his premature birth, made his situation precarious. The air sacs, or alveoli, in his lungs were not fully formed.

"When he was born, we didn't think he was going to survive," said Stenzel, who cared for John the first five days of his life in the hospital's neonatal intensive care unit. "We did not expect him to live.

"Somebody was watching out for this little guy."

Six months, many obstacles

Despite the size of John's lungs, their function was "amazing," Stenzel said.

However, during his first 90 days, John needed a ventilator to breathe for him. In December, he was switched to a machine that provided less breathing support. On March 8, he began breathing oxygen through nasal prongs.

John had other formidable challenges, including a congenital heart defect in which a vessel that allows blood to bypass a fetus' lungs before birth fails to close.

John rallied with the help of medication, and the blood vessel eventually closed.

Another adversary was an eye complication called retinopathy of prematurity, a potentially blinding disorder affecting premature babies.

John answered by enduring laser surgery.

He had to contend with two urinary tract infections, but he responded well to treatment, with no long-term effects.

His next bout was with bilateral hernias, a condition common in premature babies. He also needed a feeding tube port in his stomach.

John withstood surgery for all of these, and was circumcised Jan. 27.

He is one tough child, said Dr. Onyebuchi Ukabiala, his pediatric surgeon at Blank.

"When you're born that premature, there are so many strikes against you, so many odds against you, so many obstacles to overcome, so many risks, almost on a daily basis," he said.

"When they go through all of that and come out on the end of it, reasonably well preserved, it's a tremendous achievement. Not only on the baby's part, but the family's part, because the stress can be very daunting, and the neonatal team that makes it happen."

The Shirleys have photographs chronicling milestones during their son's first days of life — from hours after he was born and put on a ventilator to the first time Aaron and Leslie held him in their arms when he was 3 months old, and then when he was markedly bigger at 5 1/2 months, clad in a red onesie.

Over the course of John's six-month stay at Blank, Stenzel estimates that more than 100 people — nurses, perinatologists, neonatologists, nutritionists, surgeons, respiratory therapists and others — helped care for him.

Stenzel likened his role to a coach, watching a star athlete run around a track.

"This baby just took it and ran," Stenzel said. "His inherent abilities were there. He got the gold medal. The Iowa Olympics for preemies."

On April 18, John Allen Shirley left intensive care.

He was going home. But not without a hefty cost.

John's six-month stay cost nearly all of the \$2 million for him in his family's insurance plan, the lifetime maximum. The insurance was provided through Aaron's then-employer, American Fence Co. in Des Moines, Leslie said. Aaron now works for Summitcrest Performance Angus, a cattle ranch in Fremont. John is also covered under Title 19, a federal program that provides access to medical and dental treatment through Medicaid.

After the insurance runs out, the family will have to seek high-risk insurance. "That costs a lot," Leslie said.

A mother's challenge

After his release, John was ready to move on to his next challenge — living at home in Knoxville.

The doctors and others charged with his care would need to watch for common lifelong problems in preemies, such as cerebral palsy, mental retardation, vision loss and hearing loss.

Physical therapist Linda Anderson, who helped with the transition from hospital to home, was surprised when she first met John.

"He looked me right in the eye," said Anderson, who works with the Heartland Area Education Agency.

"Normally, these premature kids with low birthweight, their visual skills are not developed. John just looked right at me, and I thought, 'You know, this kid is in there. He is aware of what is going on.' I did not expect him to focus and be aware of me."

Nonetheless, this round of care would demand medically intensive, time-consuming attention from the Shirleys — especially Leslie, who would be John's main caregiver at home.

Caring for a typical newborn is rough enough. Caring for John at home required extensive medical training and education.

Nothing — from breathing to feeding — came easy.

He was on around-the-clock oxygen, needing 2 liters per minute. Tubes trailed from his nose, secured by round bandages at his temples, tethering him to an oxygen tank. Another cord attached to his foot led to a machine monitoring the amount of oxygen in his blood and his heart rate. Daily nebulizer treatments addressed his chronic lung disease.

He still requires several feedings a day, which his mother administers via a feeding tube using a large, plastic syringe. Premature babies are often too weak to suck on a bottle and breathe at the same time, causing them to spit up or choke on their food.

A feeding tube is a more efficient way to provide the specialized, high-calorie formula designed to help preemies gain weight. An intravenous feed is hooked up overnight.

When John came home in April, he was on six medications — from diuretics to keep water from building in his lungs to breathing treatments for his chronic lung disease. By late September, he had been taken off three.

Leslie toted John to countless doctor's appointments, from pulmonologists to gastroenterologists. As the weeks went by, she could talk with ease about doses, names of medications, symptoms and details of John's progress.

Little victories

On Aug. 14, John was 10 months old and well enough to brave his first visit to the Iowa State Fair. His stay at the campgrounds continued a 40-year family tradition of camping at the fair.

Sheila Guter, a registered nurse who in April began visiting John two to three times a week, said the improvements he has made in his first five months home have been huge.

He has gained weight every week and has slowly been weaned off oxygen to the point that the concentration of oxygen supplement he was getting was just a whiff above that found in room air. By the end of September, John received the OK to go without his oxygen during the day, provided his mother is in the room.

Developmentally, John is at a seven-month level, Guter said, and he is meeting, and sometimes surpassing, appropriate milestones.

"He's exceeded my expectations," said Guter during a late September visit, as John cooed, laughed, rolled over on his green blanket, watched TV and thumped his legs loudly against the floor. "He doesn't have the delays I thought he would have."

Another victory came in early October: John began eating from a spoon. He is now fed half a jar of baby food twice a day.

Having his family's vigilant care and support, especially from his mother, has helped the baby steer clear of the hospital and remain healthy, said Dr. Peter Hetherington, John's pediatrician.

"Our role is just to kind of help them along and look out for them, but we're not there 24-7 like his parents are, and his grandparents, and they have good family support, a major reason why he's done so well," Hetherington said.

In most cases like these, the mother acts as a sentinel, he said.

"She's his gatekeeper, and she's done a great job. I think she's very astute. She knows him probably best of anyone."

A surprise

Small as he continues to be, John will be a big brother soon.

Just as Aaron and Leslie were settling in with 6-month-old John at home in Knoxville, Leslie felt a familiar twinge.

"I started feeling pregnant," she said. "I was in denial. I didn't want to be pregnant. This is very unexpected."

Unexpected because she was using birth control. Ironic because she was told that getting pregnant would be difficult.

After Leslie gave birth to John, Dr. Paula Mahone, the perinatologist, had suggested they wait three to four years before having another baby. Doctors told her she should stick to having two to three kids.

Now, the Shirleys will be having two kids, sooner rather than later.

In fact, they'll have two boys.

"I was really freaked out," said Leslie. "If something happened, I couldn't handle two babies that

consumed that much time. I was worried that the baby would have to be in the hospital, and it would be small again."

So far, this second child seems to be on the road to a normal delivery. Leslie, who is due Dec. 12, is past the 26-week mark that heralded John's arrival. She's been injecting herself twice a day with a blood thinner to avoid the clot problems she experienced with John.

Leslie was told in early October that the baby weighed 3 1/2 pounds and was doing well. An amniocentesis is scheduled for Nov. 22 to check on the maturity of the baby's lungs, she said. A C-section will be scheduled that week.

"I'm ready for it to happen," Leslie said. "I'm hoping they'll be like twins."

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