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A walking miracle

Doctors said he would not survive. Then they said he would never walk. But Cody keeps proving them wrong.

By Ellen Schroeder

Star-Telegram Staff Writer

Cody McCasland wants to ride the big slide, the 10-foot monstrosity at Emler Swim School in Colleyville.

His mother sizes it up and looks back at him, a 22-pound boy in red swim trunks with the legs sewn shut.

Swim class is over, and Cody, 3, is eyeing his reward. It's not a trip down the tiny 3-foot slide he rode the week before. It's a greased-lightning ride down the big slide -- just like the other children.

"Are you sure?" his mother asks.

"I want to go on it, Mommy," he replies.

An instructor carries Cody up the stairs and positions him at the top. In a flash, he twists down and lands with a splash. The instructor scoops him up and delivers him to his mother.

That adventurous spirit has carried the Colleyville boy through some pretty tough times.

The day he was born, doctors said he would die because so many things were wrong with his tiny body.

IMAGES



STAR-TELEGRAM/KHAMPHA BOUAPHANH

Cody, who is now using his fourth pair of prosthetic legs, got his first set of "stubbies" -- short, unbendable, flesh-colored legs -- in March 2003.



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Mike McCasland kisses his son, Cody, in the morning. Cody was in the hospital for much of his first year of life. On some nights, Mike would sleep in a nearby hotel. On others, he would doze wherever he could find space in the hospital room.

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When he proved them wrong, they said he would never walk because he was missing bones in his lower legs.

When Cody was 15 months old, his parents made a drastic decision. It was the only way they knew to give their baby the best possible life.

They have never regretted it.

Cody's delivery

Tina McCasland was 27 weeks pregnant when her baby dropped into her pelvis and doctors ordered her to bed.

The baby was in the breech position, and his legs were hidden in the birth canal, so sonograms revealed no problems.

Seven weeks later, on Oct. 2, 2001, doctors at Baylor Regional Medical Center at Grapevine delivered Cody by Caesarean section. He was six weeks premature.

In the delivery room, the doctors and nurses were calm and efficient, but as they pulled the baby out, the room fell silent.

Mike McCasland was standing at his wife's shoulder and could see only his son's head. Then Cody emerged, tinier than any baby he'd ever seen. His legs were folded Indian-style, tucked to his body. At just 4 pounds, 2 ounces, he fit in the palm of his father's hand.

Mike counted the fingers. All 10. He counted the toes. There were nine.

We can deal with that, he thought.

As the obstetrician sutured Tina's midsection, he warned Mike not to tell his wife anything. Something was wrong.

The McCaslands would eventually learn that their tiny baby had a dislocated hip, a spine curved at a right angle, a permanently bent left leg, a clubfoot and no anal opening.

But in those first moments, they were unaware of Cody's many problems.

When Tina held her newborn son for the first time, he was swaddled in blankets. To her, he appeared perfect.

Mike gazed at his baby in the incubator.

He's going to die, a doctor said.

Mike went white. Get him a chair, somebody said.

He was crying when he walked into the recovery room. His wife mistook his tears for joy.

Not giving up

Tina began walking the hospital floors six hours after her C-section. Cody had been quickly transferred to Baylor University Medical Center at Dallas. Doctors there had determined that he would live but that he needed a colostomy.

If Tina could walk, they promised her, she could be with her son for his surgery. It would be the first of nearly a dozen.

Mike drove to Dallas. From the neonatal unit, he called Tina and held the telephone near Cody's ear while she talked to her son.

That first week was a blur. Mike was laid off from an Internet company. Cody was scheduled for another surgery, this time for a heart murmur.

Doctors came and went -- surgeons, a neurologist, a geneticist. None offered a diagnosis.

"He'll be in a wheelchair for the rest of his life," one said. He added: "He has a great brain. He can do anything. He can be a doctor if he wants to be."

Tina called her mother, Deborah Sauer.

"What's the worst thing? He's going to be in a wheelchair," her mother said. "He's still fighting. Are you going to give up on him?"

"No," Tina said. "I'm not going to give up on him."

More surgeries

Twenty-three days after Cody's birth, the McCaslands took their baby home. He was so susceptible to illness that doctors warned the couple to keep their son away from people. No grocery stores. No malls. Just stay at home.

The day before Thanksgiving, Tina was at the kitchen sink, with Cody in one arm, rinsing the bottle of milk she had just fed him.

Cody hiccuped, gagged and began choking. Tina patted his back, trying to make him cough up whatever was stuck.

"Cody, breathe, breathe, breathe," she said.

He turned blue, then went limp.

Tina laid him on the counter, cleared his throat with her fingers and began CPR. She tried dialing 911, fumbling with the buttons. She tried again and hit the right ones.

Hurst paramedics arrived quickly. They gave Cody oxygen and drove him to the hospital. Tina called the pediatrician, her mother and Mike, who had just started a new job in Addison.

At the hospital, Cody was diagnosed with severe acid reflux, which forced food into his esophagus, choking him. The McCaslands spent Cody's first Thanksgiving at Children's Medical Center of Dallas, waiting for surgery the next day to correct the problem.

There were six more surgeries in 2002.

One, in July 2002, stabilized a dislocated hip.

After that, Cody wore casts on his legs for three months during the heat of summer. In the mornings, his parents pulled him around the neighborhood in a little wagon. When it was hot, they hauled his wagon around the air-conditioned Grapevine Mills mall.

Life in the hospital

Before they were married, Tina and Mike's favorite TV show was *Trauma: Life in the ER*.

After Cody's birth, they lived it.

He spent so much time in the hospital that they developed a routine.

Page the pediatrician. Pack the bags. Grab Cody's favorite CD, Kenny Loggins' *Return to Pooh Corner*. Bring the portable CD player. In the chaos of the emergency room, Tina would create a little island of calm, holding Cody as the music soothed him.

Some nights, Mike stayed at a hotel near the hospital, and Tina slept next to Cody. Other nights, Mike dozed wherever there was space in the hospital room. On the linoleum floor. In a chair, his head between his knees.

In the morning, he would go to work. It was a relief to get away from the stress of the hospital for a few hours. He could barely stand to hear his son scream as nurses searched for another vein to insert the intravenous needle. They tried his arm, his foot, even his head. Cody thrashed his arms and legs, sweating so hard that he soaked the paper on the hospital bed.

Tina sang to calm him, cooing *Mary Had a Little Lamb* or *Twinkle, Twinkle, Little Star*.

During the day, Cody played with rattles and mobiles. His mother read him *Hop on Pop* and *Goodnight Moon*.

Tina took meticulous notes in a composition book. She made schedules to keep track of Cody's feedings and medications. Sometimes he had to take 12 at a time. She typed his medical history -- an ever-growing list.

When Cody wasn't in the hospital, Tina spent up to seven hours a day on the phone with insurance companies. She hired a registered nurse to watch him as she sifted through medical bills and insurance forms.

The bills were huge. That first year, they grew to about \$750,000 before insurance

reimbursements. The McCaslands paid about \$10,000 in 2001, \$17,000 in 2002 and \$8,500 last year.

To care for Cody, Tina quit her job helping adolescents at the Phoenix House, a nonprofit devoted to treating and preventing substance abuse. Friends and relatives sent money to help pay the medical bills.

At the same time, Cody's progress was amazing and delighting his parents. At 6 months, he was jetting around the house in a combat crawl, pulling himself with his forearms and dragging his legs behind him, laughing as his parents chased him. He said his first word -- "mama" -- before he was a year old.

By his first birthday, Cody had spent about a third of his life in hospitals. But there was still no diagnosis for his leg problems.

An acquaintance who worked for Texas Scottish Rite Hospital for Children in Dallas thought it might be sacral agenesis, a disorder affecting the lower spine. The McCaslands began researching the condition on the Internet.

Doctors at Scottish Rite recommended amputating Cody's right leg through the knee because of the missing bones. They wanted to do exploratory surgery to determine whether his left leg could be saved.

The McCaslands needed a second opinion. A doctor at Children's Hospital of Philadelphia agreed to examine Cody in November 2002. There, the family got the formal diagnosis: sacral agenesis caused by a spontaneous gene mutation.

An MRI showed that bones were missing from both legs. It would be best to amputate both just above the knees.

Without the surgery, Cody would always be in a wheelchair. His misshapen legs would make it difficult to even get dressed.

"That confirmed it, that amputation was the right way to go," Mike said. "No reason not to do it, get it done as soon as possible."

The surgery was Jan. 21, 2003. Cody was 15 months old.

A big first step

Without his legs, Cody could at last learn to walk.

He got his first set of "stubbies" -- short, unbendable, flesh-colored legs -- in March 2003. He took his first steps the same day he got them, a stiff-legged walk while holding a hospital worker's hand.

His first independent steps came in September 2003 at his grandparents' home -- much to the disappointment of Tina and Mike, who missed the moment.

The next day, Tina, Mike and Cody went outside to play in their back yard. Cody took a few steps, smiled proudly and fell down.

This September, Cody got his first set of knees -- bendable joints on red, purple, blue and gold metal legs.

He has a freely bending knee on his right leg. The left leg has a knee that he can bend, but only while sitting and tugging on a band connected to the mechanical joint.

Doctors believe that within a year Cody will have enough strength and coordination to have two freely bending knees.

"He's just so energetic and pleasant, it amazes you," said Dr. Tony Herring, chief of staff at Scottish Rite and Cody's orthopedic surgeon. "I think a lot has to do with the parents -- the support he got and the positive attitude."

Swim lessons at Emler and horseback-riding sessions at Keller's Rocky Top Therapy Center help Cody build strength, balance and coordination.

At Glenhope Elementary School in Colleyville, Cody attends morning preschool for children with disabilities. He knows his ABCs and how to count to 10. Whether it's cutting and gluing craft projects or walking down the hall, he wants to do it by himself.

"We've tried pushcarts. He didn't like that much," said his teacher, Laura Fillmore. "We've tried a walker for him for long distances. He doesn't want to do that so much anymore. He just really wants to walk. He's got a great attitude about everything."

Cody walks slowly but steadily now, often holding someone's hand or touching the wall for balance. Sometimes he doesn't want to wear the prosthetic limbs and asks an adult to take off his "shoes," as he calls them.

Then he's off, scampering across the floor, lightning-fast, on his hands and stumps.

Seeing no limits

Someday, Mike knows, Cody will ask why he has no legs.

"The questions are going to be hard," Mike said.

His voice quavers, and he wipes his eyes with a Thomas the Tank Engine napkin, left over from Cody's third-birthday party. "Hopefully, he will ask Tina."

She's ready.

Before Cody's amputations, his parents had molds made of his feet. Tina will show him the molds and photographs of his one year with legs.

She keeps Cody's three former sets of prosthetic legs on a high shelf in his bedroom closet.

She will pull them out over the years and show them to her son, marveling at how he's grown and how technology has advanced.

"Prosthetics have come so far now; he'll be able to do whatever he wants to," Tina said.

She and Mike see no limits. Cody will be able to ski, scuba-dive or climb a mountain.

Tina will help him get in touch with others across the country who have sacral agenesis so he does not feel alone.

Yes, some children stare and call Cody "Robot Man." He doesn't seem to mind.

"It would be very easy to retreat into a 'woe is me' depression kind of thing. Maybe even a little hate could come from that," said Cody's stepgrandfather, Mike Sauer. "I don't think he's going to do that. I haven't seen that yet."

One recent morning, Cody watched intently as the other children on his school bus walked down the steps.

Me, too, he said. Me, too.

As a teacher's aide waited at the bottom, the driver lifted him off one step and onto the next. Cody moved forward.

One step at a time.

IN THE KNOW

Sacral agenesis

- The rare disorder involves abnormal development of the lower spine. It can include a wide range of abnormalities, from partial absence of the spine, causing no apparent symptoms, to extensive abnormalities of the lower vertebrae, pelvis and spine.

SOURCE: National Organization for Rare Disorders, www.rarediseases.org

IN THE KNOW

How to help

- Cody McCasland is junior race director for the Dallas White Rock Marathon on Dec. 12. The race begins at American Airlines Center and raises money for and awareness of children with orthopedic conditions like Cody's.

- Proceeds benefit the Texas Scottish Rite Hospital for Children in Dallas, where treatment is free.

- The McCasland family hopes to raise \$10,000 for Scottish Rite -- a portion of the cost of

Cody's \$50,000 prosthetic legs.

ONLINE: www.runtherock.com

www.active.com/donate/tsrhc/ teamcody

STAR-TELEGRAM.COM

A difficult journey

On the Star-Telegram's Web site you can see more photos of Cody McCasland and hear his mother talk about his remarkable story.

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IMAGES



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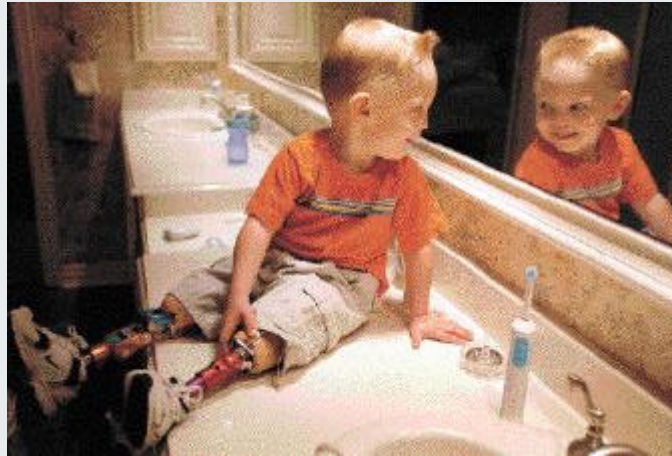
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would sleep in a nearby hotel. On others, he would doze wherever he could find space in the hospital room.



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After his mom fixed his hair for school, Cody McCasland admires himself in the mirror. Cody, 3, had his legs amputated when he was 15 months old because of sacral agenesis, a rare disorder affecting the lower spine. The day he was born, doctors said he would die because so many things were wrong with his body.



STAR-TELEGRAM/KHAMPHA BOUAPHANH

Physical therapist Kellie Shay works with Cody on bending his knees when he walks using his prosthetic legs at Glenhope Elementary. Cody has a freely bending knee on his right leg.



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Instructor Iris Melton, right, and assistant Morgan Havard work with Cody as he rides a horse for physical therapy. The riding sessions help Cody build strength, balance and coordination.



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Tina walks Cody to the school bus recently. "Prosthetics have come so far now; he'll be able to do whatever he wants to," she said.



At right, 3-year-old Emily Weimer watches as Cody's mother, Tina McCasland, picks him up after swim lessons.



Cody McCasland



STAR-TELEGRAM/KHAMPHA BOUAPHANH

Tina McCasland helps her son, Cody, put on his prosthetic legs in the morning before school. Cody attends preschool for children with disabilities at Glenhope Elementary School in Colleyville.



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Cody waits for swim lessons at Emler Swim School in Colleyville.