

50 Surgeries Later: Dunnellon Teen Overcomes Deformed Back, Inability To Eat



50 SURGERIES LATER: DUNNELLON TEEN OVERCOMES DEFORMED BACK AND AN INABILITY TO EAT

By Danielle Prinz

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From the moment Daniel Stephens was born, his mother, Dawn, thought the beginning of his life would be the end.

Needing a ventilator right away, Daniel didn't breathe on his own for his first 59 minutes. Doctors told Dawn they didn't think her newborn would make it through the first night.

"Having delivered children before and hearing that beautiful cry, you know when they take that first gasp," the Dunnellon mom said. "And to have the eerie silence ... and they said they've got to rush him away."

Daniel also had an infant oxygen hood put over his head, and an assortment of tubes and wires were soon attached to his body.

His mother wouldn't be able to hold him for more than a month after birth, eventually getting to do so on Christmas Day 1999.

Despite the doctors' prediction, Daniel would survive, and today, after exactly 50 surgeries to correct a variety of medical issues, the 16-year-old Solid Rock Christian Academy freshman is already preparing for college.

"Joy," Daniel said when asked what word he would use to describe himself.

In addition to being born prematurely, Daniel's spine wasn't fully developed because of kyphosis and scoliosis, severe spinal deformities.

Complications also prevent him from chewing and swallowing, so during meals, he has to pour liquids into a feeding tube that goes through his belly button. Aside from sometimes licking ice cream or a lollipop, he's never eaten through his mouth.

Daniel's dad, Bill, who works at the family's church, Dunnellon Baptist, said the medical problems have led doctors to consistently say that his son wouldn't live long.

"They said the kid might last a week, then we were talking months," he said. "I remember two months. I remember six months."

The family said strength from God has allowed Daniel to march on — even through what he said has been the toughest part: not being able to play sports.

"I remember trying to play football once, but I was always like a free touchdown," Daniel said. "I couldn't really do much."

But Daniel wouldn't be able to try sports — let alone live — had it not been for the regular back surgeries, which have kept his spine from crushing his lungs.

Every six months, Dr. Jonathan Phillips, a pediatric orthopedic surgeon at Arnold Palmer Hospital for Children in Orlando, extends rods in Daniel's back.

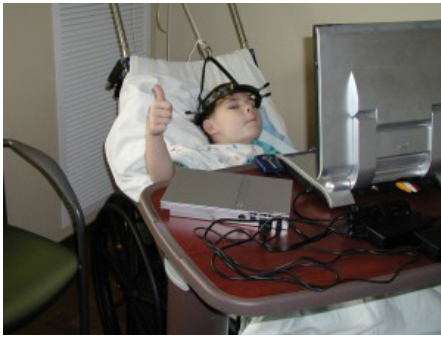
"They are inserted into the bottom of the spine and onto his ribs at the top," Phillips said. "So we actually stretch the ribs out, stretch the rib cage out, and therefore give his chest slightly more volume."

More volume means more breathing room for his lungs, but every once in a while, he still needs a piggyback ride from his dad or a break on the swings to catch his breath.

With each surgery comes fear.



Dawn Stephens holds Daniel for the first time, on Christmas Day 1999. (Photo courtesy Dawn Stephens)



Daniel gives a thumbs up while wearing a halo traction device, which helps keep the neck and spine in line. (Photo courtesy Dawn Stephens)

“I always have that feeling in the back of my mind that I am not going to wake up,” Daniel said. “But I always do.”

Though Daniel was born with kyphosis and scoliosis, he didn’t have rods inserted into his back until he was 6. When he did, Dawn Stephens noticed something wrong.

“He described it like a fire in his tummy,” she said. “He was itching a lot all over. He was clawing at himself.”

Doctors at first thought the symptoms came from a staff infection, but it turned out to be something much different: an allergy to metal.

No one in pediatric orthopedics, which often relies on metal, had ever seen such an allergy, Phillips said.

Phillips coordinated tests with doctors in Europe to confirm which metals Daniel is allergic to, and the results said all of them — except for copper. But copper couldn’t be used because it’s too weak for orthopedic corrections.

“The question then was: How on earth would we get around this problem of trying to support his spine with anything other than metal?” he asked.

For a year, Phillips worked toward a solution by teaming up with NASA; DePuy Synthes, a manufacturer of orthopedic devices; and other organizations.

Meanwhile, with one of the original titanium rods left in his back for support, Daniel suffered.

“Imagine [if] you have a peanut allergy and that is in you all the time, or you think you’re allergic to an ant bite ... and that venom is in you all the time,” Dawn Stephens said.

After a lot of collaboration with other doctors, Phillips remembered hearing what sounded like a sensible idea.

“Somewhere along the line, someone said, ‘Well, why don’t you coat it in carbon?’ he said. “And I said, ‘You can do that?’ And it turns out yes, indeed, you can.”

Acting as a barrier between Daniel’s cells and the titanium, the carbon coating worked, and he now has a metal test strip in his wrist to alert doctors if the coating has worn off and will cause an allergic reaction.

Since the coating solution was applied, Daniel has yet to have any allergy trouble with the rods. And because

longer ones are implanted into his back every few years, he’s able to work toward one of his main goals: grow.

“Now I kind of want to be 5-foot and get my license and hopefully drive a car,” Daniel said.

But for now, Daniel is happy with just driving go-carts, first reaching the 4-foot height requirement for those about two years ago.



Meeting the 4-foot height requirement, Daniel can drive go-carts, and he hopes to someday also get his driver’s license. (Photo courtesy Dawn Stephens)

Despite the bleak start and all the obstacles, Dawn Stephens said she is happy to now be able to picture her son’s future.

“I would love for him to eventually walk at high school graduation and to go on from there to college to pursue his dreams, and then to one day actually live on his own,” she said.

But until then, she said she enjoys seeing what Daniel has already accomplished.

“To see him go to kindergarten that first day and walk him into the classroom just like every other kid was huge because this kid was never supposed to make it,” Dawn Stephens said. “I never dreamed in a million years this kid would actually go to school.”

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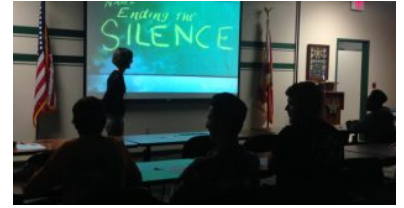
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