

# Lincoln's shot

CHAPTER ONE: THE CURSE



Photos courtesy of DeLuna family

Maggie's older brother, Adam Hoyle, died in the crib beside her in 1988. He was the sixth boy in the United States diagnosed with X-linked myotubular myopathy.

## » LINCOLN

continued from the front page

...

Maggie met Anthony DeLuna her senior year, in show choir at Bloomingdale High in Tampa. He was smart without being stuck up. Sturdy, dependable, the friend everyone leaned on. Classmates voted him: "Most Likely to be Super Dad."

She was beautiful, Anthony said, "way out of my league. So positive and passionate and just magnetic. Everyone was drawn to Maggie."

They started hanging out at rehearsals, going to Mimi's Cafe afterward. She learned he played the cello. He found out she danced ballet.

"We dove in deep from the get-go," Anthony said. "We talked about everything: Space, God, life, what it means."

The first time Maggie brought Anthony home, before they could play Mario Bros., her grandmother sat him in the living room, across from a photo of Adam. She pointed to the boy's long face and sad eyes — and warned him about the family's fate.

"I heard her. But it didn't matter," Anthony said. "We were so young, and we weren't even really dating. All I wanted was to be with Maggie."

She went off to Mercer University in Georgia, to study psychology. He enrolled at the University of South Florida, to major in business.

When Maggie finished college, she moved back to Tampa to get a master's in social work — and to be with Anthony.

They started planning a life together: good jobs; a comfy house with a big back yard; two cats, at least. They were going to camp with fireflies in Tennessee, hike along fjords in Norway.

Anthony's dad had been divorced six times, so Anthony told Maggie he didn't believe in marriage, but he wanted to be with her forever. And he longed to be the father he never had.

He kept telling her he didn't care about the curse. They could adopt. Plenty of kids needed families.

Maggie always felt she was meant to be a mom but knew she couldn't risk having her own children. She was faithful about using birth control.

So when she missed her period in the spring of 2013, she was shocked. She took three drug store tests but still didn't believe it.

A doctor confirmed the pregnancy. She and Anthony were horrified. And overjoyed. They worried for two months, until they learned they were having a girl.

Then they thanked God and called their parents.

In the evenings, after work, they spun visions of their daughter's childhood: music and dance lessons, trips to the zoo, art museums. Of course, she would be beautiful, like her mom. And as brilliant as her dad. They decided to name her Adalynn, after Maggie's brother.

Maggie talked to her unborn child constantly, but she never felt the baby move.

She kept obsessing about the curse. She felt guilty for even daring to have a child. And what if they'd read the sonogram incorrectly. What if she was a he?

When she was five months pregnant, Maggie demanded another sonogram. It took a long time to find the heartbeat. Finally, the nurse said brightly: "Congratulations! It's a boy!"

The doctor had misread the first video. This time, there was no doubt.

Maggie started weeping. Anthony felt sick, but he tried to console her. There was still a chance, a 50 percent chance, that their son wouldn't have the defective gene.

He tried to paint that picture, of a healthy, thriving boy.

Maggie only saw her brother.

They emptied their savings to spend \$3,000 on genetic tests. They didn't tell anyone until they were sure. Weeks later, the results confirmed their fears: Maggie was a carrier of the disease, and their child had the defective gene.

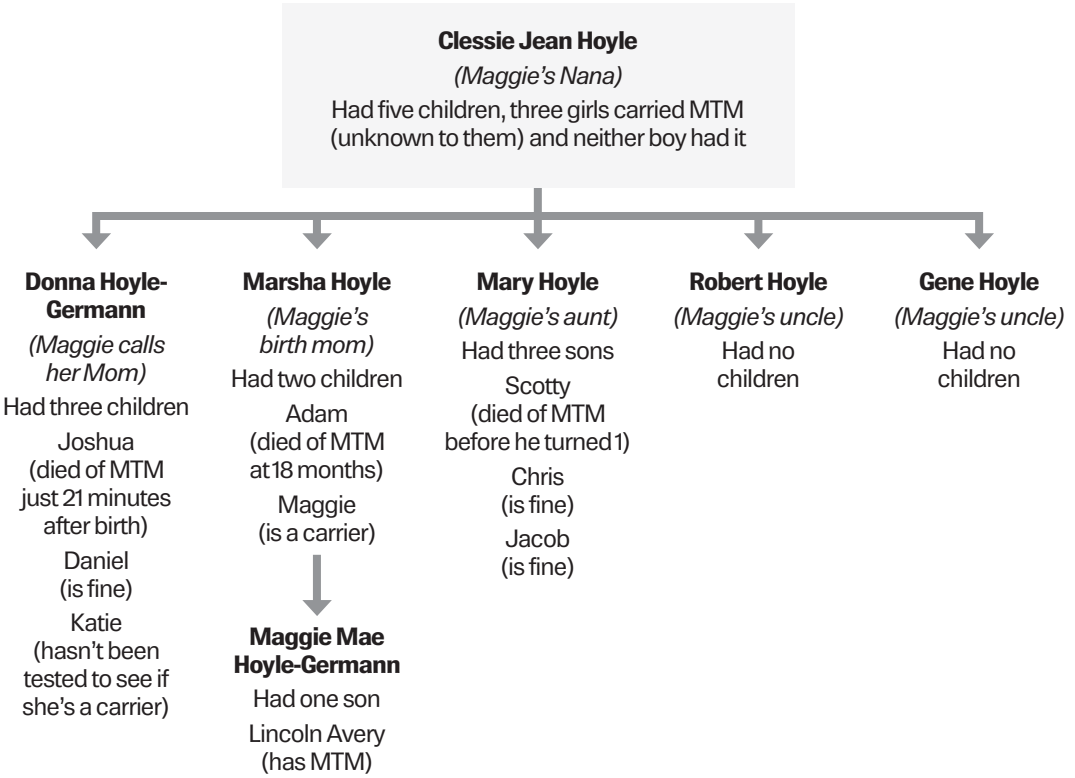
Her family was furious. Her uncle wouldn't talk to her. Her aunt asked, "How can you do this to us?"

By then, it was too late for an abortion. Doctors told her she could have the fetus taken out right away or try to carry it to term. If the baby wasn't stillborn, they said, he would likely die at birth.

Maggie didn't hesitate. She had become attached to the life inside her. She knew this was the only chance she would have to deliver a child. She wanted to meet her son.

She refused to have a baby shower. She didn't buy a crib, or even diapers. She was sure she would never be able to bring her boy home.

## FAMILY TREE OF MAGGIE MAE HOYLE-GERMANN



...

When their baby was born, on Dec. 14, 2013, doctors told Maggie and Anthony to let him die. He would never be able to eat, sit up or cry out loud. He couldn't even breathe on his own.

Maggie, then 26, and Anthony, 25, clung to each other, sobbing.

They screamed at everyone who kept asking: We won't take our son off life support.

"Please, do whatever you have to," Maggie begged. "He's here. He's ours. We have to try to keep him alive."

Doctors at St. Joseph's Children's Hospital in Tampa pressed on their son's sunken chest, trying to force air into his lungs. Then nurses swept him away in a sea of towels and tubes, out of the dark delivery room, into the bright hall.

Maggie and Anthony didn't get to hold him that day or even take a photo.

For the next week, they hovered over his plastic cube in the neonatal intensive care unit, willing him to move a finger, wiggle a foot, at least open his eyes.

They stared at his black curls, long eyelashes and pale lips. They counted his perfect toes. They gave him a name, the name of a fighter, a leader: Lincoln.

...

In the hospital, Maggie and Anthony read everything they could find about the diagnosis. Doctors had learned so much in the years since Adam had died.

The broken gene is called MTM1 and is carried on the X chromosome. Since girls have two X chromosomes, the good one generally overrides the bad. But boys only have one X chromosome, so if the gene is defective, they inherit the disease. Only 1 in 50,000 boys has the condition. The only way to diagnose it is with a muscle biopsy.

The disease prevents production of a protein called myotubularin. Muscles are intact but, without the protein, can't communicate with the brain. The boys' minds usually are fine — but they are trapped, in bodies they can't make move.

A few boys with the disease had survived into their teens.

Most die by their second birthdays.

Still no treatment. No cure.

...

Maggie and Anthony didn't know yet about the manager of Guns N' Roses, the NFL star or the mice in France.



Maggie and Anthony at a wedding in 2008, on the night the long-time friends became a couple.

“We can do this,”  
Anthony kept saying.  
“We have to,”  
Maggie agreed.

## WHAT IS X-LINKED MYOTUBULAR MYOPATHY?

A rare, fatal condition caused by an abnormality on the X chromosome. Mostly boys are affected. Girls — who have two X chromosomes — usually can override the faulty gene, though they can be carriers.

Boys with the disease can't make myotubularin, a protein that connects the mind to the muscles, so they can barely move, swallow or breathe. Most spend their lives on ventilators. One in 50,000 male infants is born with MTM, also known as floppy baby syndrome. More than half die before they reach their second birthdays. Few survive into their teens.

Source: University of Washington

They hadn't heard about venture capitalists or clinical trials.

They had no idea that, while their son was tethered to machines in Florida, researchers on the other side of the country were studying the same condition in animals — and fixing puppies that had been doomed to die.

Maybe Lincoln would be lucky.

He was born just as research, money and medicine were braiding to repair rare genetic disorders.

For the first time in nearly two decades, the federal government was considering approving controversial treatments that would alter human DNA.

Could Lincoln live long enough for science to come up with a cure?

...

Maggie got to hold Lincoln for the first time when he was 8 days old. Nurses untangled all his wires, moved the machines and lowered him, gently, into her arms. She sat as still as she could, careful not to jostle the spaghetti-sized lifelines taped to his face and belly, terrified she might hurt him. She cradled him, smelling his sweet, soft skin, feeling his heart beating against hers.

"Mommy's got you," she cooed like any new parent. "Daddy's here. We won't let anything happen to you."

After a few moments, she felt her baby relax in her arms. The monitor showed his heart rate slowing. "Maybe he knows me," she thought. Then, finally, her son opened his eyes. They were brown.

Lincoln's lungs were too weak to take in enough air. So when he had survived a month, doctors opened his throat and inserted a breathing tube. He couldn't swallow, so doctors plugged a feeding tube into his stomach. Every few hours, someone had to put drops in his eyes since it was hard for him to blink. Every few minutes, someone had to suction the mucus from his nose and saliva from his mouth so he wouldn't choke.

Flashing red and blue numbers tracked his breathing, heart rate and blood pressure. Maggie and Anthony got used to the hiss of oxygen, the beeps of monitors, the hum of the feeding pump. But every time an alarm went off, Maggie was sure Lincoln was going to die.

Some people urged them to put their son in a nursing home. They wouldn't consider it.

"We can do this," Anthony kept saying.

"We have to," Maggie agreed.

At five weeks, Lincoln was stable enough that Maggie and Anthony could go back to their apartment for a real shower. They kissed their boy and promised they would be right back.

Jan. 22, 2014, just after 2 a.m. Maggie remembers the exact moment.

She was drying her hair, scrolling through Facebook on her phone, when she came across a new YouTube video, with only nine views. A silver-haired man wearing a striped tie was talking in front of a wall covered with diplomas. Words beneath him said, "Gene therapy defeats muscle disease in tests."

Maggie watched for three minutes. She saw a 12-week-old black Labrador wriggling on a tile floor. It looked like a bean bag and was unable to stand. A label below said, "XLMTM dog."

In the next scene, filmed weeks later, the same puppy was running around, wagging his tail and playing tug-of-war with a towel. The scientist on the video said, "This has never happened before in these fatal disorders."

Maggie fell to her knees. "Anthony!" she shrieked. "Come see this!"

Times senior news researcher Caryn Baird contributed to this story. Contact Lane DeGregory at ldegoregory@tampabay.com. Follow @LaneDeGregory.