

# Tampa Bay Times

FLORIDA'S BEST NEWSPAPER

tampabay.com

★★★★ Sunday, December 16, 2018 | \$2

## Lincoln's shot



In 2013, Lincoln Avery DeLuna is born with a hereditary disease that limits his ability to breathe, eat and move. It is called X-linked myotubular myopathy.

Courtesy of DeLuna family

## The curse.

A dying boy. A desperate mom. A floppy dog.

BY LANE DEGREGORY • Times Staff Writer

When Maggie's older brother was born, his face was blue, his body limp. He couldn't move anything but his right hand and his eyes.

No one knew what was wrong. Doctors drew his blood, listened to his heart, sliced a sliver of muscle from his thigh.

It took three months to get answers. "Floppy baby syndrome," they finally said. His grandmother had a simpler way to explain it. "A bad baby."

That was 1986, and Maggie Hoyle-Germann's brother, Adam, was only the sixth boy in the United States diagnosed with X-linked myotubular myopathy. It is a fatal, inherited disease, caused by a defective gene, which makes muscles extremely weak. It affects primarily boys; girls can be carriers.

For the first year, Adam never left the hospital. Dozens of doctors, nurses and respiratory therapists studied him and struggled to keep him alive. His family, who lived in Atlanta, went to the library at the Emory

University School of Medicine, searching for information, but found only one page about the disorder in a journal.

Just before Christmas, doctors sent Adam home. There was nothing else they could do.

His grandparents, aunts and uncles sold three houses, six cars and all their jewelry to pay his medical bills. They bought a house a mile from the hospital and moved in together to take care of him.

Maggie was born soon after Adam came home. The family called her "the little light in our dark world."

They settled her into a crib with her brother, who couldn't reach out to touch her but liked to follow her with his eyes.

One morning, when Maggie was 4 months old, their grandmother gave her a bottle. Then she handed Adam his stuffed frog. Maggie was curled in the corner, drifting back to sleep, when Adam suddenly stopped breathing — and died beside her. He was 18 months old.

Maggie's mother, who was only 18, crumpled with grief. Maggie's father wasn't around much, so her aunt had raised her.

Before Maggie started school, two infant cousins died from the same disorder. Relatives buried the three boys beside each other, in caskets the size of coolers.

Her brother became a photo she was shown, a story she was told, about the curse her family carried.

She grew up under the shadow of death.

"When I was really young," Maggie said, "I used to lie in bed at night, cupping my hands over my mouth, to make sure I was still breathing."

She was playing with dolls when her grandmother first warned her that if she had a baby, it would die like her brother.

She started taking birth control pills at 16.

Her grandmother made her promise she would never get pregnant. » See LINCOLN, 10A

THE FIRST  
OF EIGHT  
CHAPTERS

THE CURSE

THE HOPE

THE BOY

THE SCIENCE

THE LIFE

THE RESCUE

THE WAIT

THE ANSWER

### THE SERIES

Chapter One is available to read today at [tampabay.com/lincolnshot](http://tampabay.com/lincolnshot). The entire series will be there on Monday. A chapter a day will run in print through next Sunday.

## With Ybor out, St. Pete is back at bat

The city has been planning to redevelop the old Gas Plant property, with or without a ballpark.

BY JOSH SOLOMON AND CHARLIE FRAGO  
Times Staff Writers

With plans for an Ybor City ballpark trashed by Major League Baseball and buried by the team, any hope for building a local home for the Tampa Bay Rays now appears focused on St. Petersburg.

Rays principal owner Stu Sternberg has said he won't seek an extension of the three-year agreement that allowed him to look outside the Sunshine City for a stadium deal in Tampa. Tampa Mayor Bob Buckhorn says he takes Sternberg at his word that he's not playing a leverage game and dismisses the possibility that any last-minute negotiations will take place before the agreement expires New Year's Eve.

"That's not going to happen," Buckhorn told the *Tampa Bay Times*. » See RAYS, 6A



Populous Architects

A rendering of the \$900 million stadium the Tampa Bay Rays had hoped to build in Ybor City. On Tuesday, the team killed the plan.

### IN BUSINESS 'Dear Homeowner'

As it gets harder to find properties to flip, investors deluge homeowners with offers to buy their houses "as-is" for cash. 1D

### IN OPINION Next steps for the Rays

Apply lessons learned from the Ybor City stadium effort on an improved proposal. 28A, 29A

### IN FLORIDIAN Christmas for the ages

Two local ornament collections celebrate the history of holiday decoration. 2E

### Partly sunny

8 a.m. 59° Noon 70° 4 p.m. 67° 8 p.m. 61°

10% chance of rain  
More, back page of Sports

7 89067 19942 0  
Vol. 135 No. 145  
© Times Publishing Co.