

Lincoln's shot

CHAPTER EIGHT: THE ANSWER



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After waiting two years for her son to get gene therapy, Maggie is starting to lose hope. Here, she pours herself a vodka and Coke Zero as she and Anthony discuss their options.

“I told her that if I needed to get Lincoln to Timbuktu, I’d swim him there tomorrow,” Maggie said.

» LINCOLN

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“We need an ambulance. He’s not going to make it!” Maggie screamed from the driver’s seat. She pulled into a Costco parking lot and dialed 911.

Anthony was behind her, on the floor of their van, trying to get Lincoln to breathe.

That morning, at the end of August, a nurse had changed his feeding bag and, somehow, liquid had gotten into his lungs. He was gasping.

“Help him!” Maggie sobbed. “He was so fine last night, playing with his puppets ...”

Paramedics eventually stabilized Lincoln enough to transport him to St. Joseph’s Children’s Hospital. There, doctors discovered that his heart rate was dropping, his organs were shutting down.

They whisked him into surgery, gave him oxygen and a blood transfusion, threaded thin tubes between his ribs. Once they’d drained his lungs, they discovered that the tissue already was hardening, dying. And they found widespread infection: staph and MRSA.

For nine days, Lincoln was unconscious. Maggie and Anthony sat beside him, surrounded by silver balloons and beeping alarms.

“How you feeling, bubba? Did you get some rest?” Anthony asked on a morning in September, after Lincoln had awoken. His face was still ashen. He was too weak to sign. “Don’t worry,” Anthony said. “We’ll get it all fixed.” He uncured Lincoln’s right hand and put his finger on his son’s palm.

Maggie bent over his bed asking, “Can you give your mama a kiss?” Lincoln couldn’t.

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When they finally got to bring him home, 19 days later, after they settled him into clean sheets, plugged in all his machines, checked the monitors, suctioned his mouth and nose, squeezed drops into his eyes and found his favorite puppet, Mr. Owl. Maggie ducked into the kitchen and called UF.

She kept thinking that, if Lincoln had gotten his shot, he probably wouldn’t almost have died. Again.

Lincoln was scared this time, Anthony said. He’d never seen him like that.

“That was the worst part,” he said.

Days later, Dr. Barbara Smith returned Maggie’s call. UF was still battling the drug company, Audentes.

Other hospitals were going to dose more boys, Smith told Maggie, so she put in a request to transfer Lincoln to another site.

“I told her that if I needed to get Lincoln to Timbuktu, I’d swim him there tomorrow,” Maggie said. “And she said I should email them, too, put in some pictures, tell them how great Lincoln is. So now I have to make a case for my son?”

Before Audentes would agree to treat Lincoln at another location, the doctor told Maggie, scientists there wanted to see the hospital records



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Anthony reassures Lincoln at St. Joseph’s Children’s Hospital in Tampa. “Nothing’s wrong,” he said, before doctors sedated the boy for an MRI.

from when his liver was bleeding.

“Are they just trying to find a reason to disqualify him?” Maggie asked Anthony.

It took hours for her to write the email. How do you convince the company that holds the cure that your son is worth saving?

She laid out his history with the trial, all that he’d been through.

She attached videos of Lincoln moving his feet slightly, which she called running. “He is brilliant and recently

was evaluated for preschool and was testing at a 7-year-old level when he is only 4.5 years old ... He is self-motivated and speaks fluent American Sign Language. He also knows bits of French, Hebrew, Spanish and Arabic. He understands, unequivocally, that he has been participating in these trials to get an experimental drug that may make him stronger ...

“I would like Audentes to consider transferring him as soon as possible,” Maggie typed in bold, “and bumping

his name to the top of the list.”

As she hit send, she prayed, “Please, God, don’t abandon us!”

Of the 16 boys who were part of the initial research, Maggie knew, only two had been treated. Three others had died. Some of the moms thought the company was choosing babies, because they showed better results. One was even meeting milestones for his age, as if the disease had been completely reversed.

Of course, there were other MTM

boys out there who were too old, or too sick, to qualify for the clinical trial. And plenty who weren’t chosen. Or whose families didn’t know about it.

But Maggie couldn’t help feeling that her son had been cheated.

She couldn’t sleep. Wouldn’t eat. Lost 11 pounds. She couldn’t concentrate on her job as a social worker, couldn’t help other people with their problems. Neither UF nor Audentes had provided a social worker to see families through the clinical trial.

Maggie’s therapist diagnosed her with post-traumatic stress disorder and told her to take a medical leave from work.

“I’m becoming radicalized,” Maggie told her therapist. “I can see how, when people are oppressed, mistreated and lied to, they do things they would never have considered before. I’m not above showing up in San Francisco in person, making them come through on their promise. I would do anything for my child. He’s worth dying for.”

When she got really upset, which was happening more often, Maggie crept into her room and closed the door. But Lincoln saw her tears, felt her sorrow. He signed funny stories about his stuffed monkey, trying to make her laugh, stuck a piece of tape on her shirt, blew kisses.

Weeks dragged on.

On a Friday afternoon in late September, Maggie called Audentes. Again. Though the company hadn’t yet gotten Lincoln’s medical records, a woman told Maggie that because of the liver bleed in February, it looked like he would not be a good candidate.

“How dare you!” Maggie yelled. “My son deserves a shot.”

If he didn’t get to be in the clinical trial, he would have to wait until the Food and Drug Administration approved the product for market. Which could take years.

“I never thought it would end like this,” Maggie sobbed to Anthony.

She poured Coke Zero into a red Solo cup, added two shots of vodka and swallowed a Valium. He called Barry Byrne, the doctor at UF who had pioneered treatments for muscular disorders. A nurse was watching Lincoln, so they retreated to their room and shut the door.

“He said there’s another company, another drug he feels good about that will be safer and more effective,” Anthony told Maggie. “He sounded really hopeful.”

“But how close is that? What if we don’t have a few more years with Lincoln?”

Maggie reminded him of all that had happened in the last year.

Anthony tried to reassure her. If UF could get them into another clinical trial with another company sometime down the road, he said, they should just do that. “I think we should disenroll from this trial,” he said, “and trust UF to make it right.”

“What if this new treatment won’t accept older kids?” Maggie cried. She argued for waiting on Audentes, to see if it would give Lincoln a dose. “Look at the outcome. There are boys off ventilators.”

» See LINCOLN, 12A



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When Maggie and Anthony retreat to their bedroom during an argument, Lincoln watches them in his mirror.