ABSTRACT (ABSTRACT)

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FULL TEXT

CHOOSING NAIA / A FAMILY'S JOURNEY FIFTH OF SIX PARTS

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Over the next five hours, if all goes according to plan, Naia's plum-sized heart will be stopped, her blood will be circulated by machine, her breathing will be done by mechanical lungs. Her chest will be sawed open, and her malformed heart will be rebuilt to support her growing body.

And, barring a catastrophe, her life will begin anew.

It is March 31, 1999, the day of the surgery Tierney Temple- Fairchild and Greg Fairchild knew would be needed ever since they decided eight months ago to bear a child with Down syndrome and a major heart defect.

For a few difficult days last summer, fears that the heart problem was a death sentence made them strongly consider abortion. They went ahead with Tierney's pregnancy only after learning that the odds of successful surgery were good.

Now, as they watch Bonnani walk away with Naia, all they can do is wait, and wonder, and pray they made the right choice.

"She'll be OK," Tierney says to no one in particular.
"She'll be OK," Greg repeats, wiping his eyes.

Last night, Greg's mother, Mary Fairchild, gave Naia a leisurely bath, letting her splash around on her stomach as though she were swimming. Tierney gingerly clipped Naia's fingernails and placed her in a battery-powered swing.

Before Naia fell asleep, Tierney read to her from a children's book of prayer. On one page was a pastel drawing of a little bear in bed, a blanket pulled up to her chin. Next to it was the "When I'm Afraid Prayer":

"I'm scared, God,

So please help me,

And keep me in your care.

I always feel much safer,

Just knowing you are there.

Amen."

Then Tierney tucked the book into Naia's cradle and kissed her goodnight. Greg came over and did the same.

With surgery just hours away, Naia was the only one who slept peacefully. Greg sat bolt upright at 3:30 a.m., having dreamt that they overslept and missed the operation. Tierney awoke three times just to check the alarm. It was working fine.

They dressed at dawn and arrived at the hospital at 6:30 a.m. A half-hour later they settled into the preoperation holding area, a hive of activity among doctors, nurses, and parents.

While the adults scurried around, most of the children remained quiet - little ones in cribs, big ones in beds - all wearing hospital gowns adorned with cartoons of Bugs Bunny and Tweety Bird. One father rode his toddler son around the room on a miniature all-terrain vehicle. The mother sat on the boy's bed, trying to muster a smile. Her sad eyes made an unavoidable point: For all the effort to make it seem like a children's playroom, there is no denying the fear here.

Twenty-six children are scheduled for operations today. "For the most part, they're healthy kids coming in for day surgery, pretty minor stuff," said nurse Fran Macoomb.

Naia, facing major open-heart surgery, is the exception. She is also the smallest child in the room. Though more than four months old, she is 8 pounds 8 ounces, smaller than some robust newborns. In fact, Naia is in the bottom 5 percent for growth among children her age with Down syndrome.

At 7:30 a.m., technician Debbie LaBelle came to Naia's metal crib to draw blood, to match her type for a transfusion, and to complete routine presurgery tests. Naia's cries rang through the room as LaBelle tried repeatedly to find a vein. Greg gripped the bars of the crib. Tierney closed her eyes.
When LaBelle finished, Greg sat with Naia in a rocking chair, whispering all the things a father says to a daughter when he’s scared and she’s too young to understand his words. He held one of her hands. In Naia’s other hand was her Elmo doll.

It is 7:45 a.m. when Bonnani arrives, picks up Naia, asks Greg and Tierney to kiss her, then takes her away to Operating Room 3.

It is a 20-by-30-foot room bathed in artificial light. All around are trays of gleaming steel surgical tools covered by sterile blue cloths. There is a bank of flashing monitors, one of which shows Naia’s oxygen saturation - the level of oxygen in her bloodstream. It reads 84 percent. "Normal would be in the 90s. It’s a good thing she’s here," says Cookie Eckel, one of two nurses assisting Bonnani.

A backlit screen on one wall displays X-rays of Naia’s chest, front and side view, taken two weeks ago. To a trained eye, the X-rays reveal an enlarged heart. It’s a side effect of Naia’s malformation, called a complete atrioventricular canal defect.

In a healthy heart, oxygen-rich blood and oxygen-depleted blood are kept apart by walls that separate the four chambers. But like the hearts of many children with Down syndrome, Naia’s heart has a hole between the upper and lower chambers. Also, it has only one valve, where there should be two, to regulate the passage of blood through the chambers.

As a result of the hole and the valve problem, blood in Naia’s heart that is saturated with oxygen mixes with blood that is not. Mixed blood acts on the body like watered-down gasoline in an engine, causing it to sputter and stall. The heart also has to work overtime to supply the oxygen the body craves, adding extra stress to an already weakened system.

Near the X-ray light board is the machine that will breathe and pump blood for Naia during the operation. And right in the middle of the room is a padded table where Bonnani places Naia.

Surrounded by all the equipment, all the activity, Naia seems even tinier than usual.

She lies on her back, naked, content at first to watch Bonnani and the nurses. Eckel briefly pulls down her face mask and kisses Naia on the cheek. "I just can’t resist," she says.

But Naia’s calm is shattered when Eckel and another nurse pin down her arms for Bonnani to cover her face with a plastic mask, through which flows an anesthetic gas. Naia cries, fighting to get free. "Hey, you are strong," Eckel tells her.

Fifteen seconds later Naia is asleep, a blue pillow supporting her motionless head. Bonnani puts a breathing tube down her throat. He tapes her eyes shut. A nurse inserts a catheter. Warm air is blown over her body to ward off a chill. A pad under Naia’s back forces her chest to arch upward, giving the surgeon the best possible angle to work.

"How’re you doing, sweetcakes?" Eckel asks Naia. "You sure look comfortable." In fact, she looks anything but.

At 8:02 a.m., in walks Dr. Lee Ellison, pediatric cardiac surgeon. Tall and lean, he wears scrubs, white clogs, and a thoughtful expression. He carries himself with none of the stereotypical bluster of some surgeons. Rather, there is a quiet confidence, a low-decibel voice of authority.
He starts by measuring Naia's bony torso. To guide his scalpel, Ellison carefully draws a four-inch line down the center of Naia's chest.

As he works, a song begins to play on a radio speaker overhead. It's the 1960s hit, "Never My Love."

There are now nine people in the room with Naia: Ellison, Bonnani, and a second surgeon, Dr. Chester Humphrey; one scrub nurse; one circulating nurse; a nurse anesthetist; one physician's assistant; and two technicians who run the pump machine that will keep Naia alive while her heart is immobilized. They move quickly in pairs and threes.

Just before the operation begins, Ellison paints Naia's chest with brown antiseptic liquid, then covers her with blue cloths. Only a candy bar-sized patch of skin on her chest is exposed.

At 8:44 a.m., Ellison makes the incision. He takes pride in making a particularly fine line, especially on girls. The scar, in time, will become almost invisible.

The incision made, the blood wiped away, Ellison takes a small power saw and cuts through Naia's breastbone.

While Ellison works, Greg and Tierney take refuge in the hospital cafeteria. It's a round room with 40-foot walls painted to resemble a fantasy galaxy of planets and stars. One of the painters was a Star Trek fan; a tiny Starship Enterprise soars through space in an inconspicuous spot.

They talk about the weather, the war in Kosovo, the coffee, the sunlight that pours through the cafeteria's glass ceiling. But now and then, the conversation turns back to a recent discussion about Naia's future if the surgery goes as hoped.

Lately, Greg has been thinking that as prenatal testing becomes more routine, and as the tests become more sophisticated and less risky, the number of people with Down syndrome will fall. The prospect worries him.

"There's safety in numbers," he says. "When there are other children in the school system who are different, when Naia isn't the only one, it makes it easier in terms of advocacy."

Greg also wonders if advances in genetic therapy might eventually allow doctors to remove or repair the extra chromosome that causes Down syndrome.

"As I sit here now, I'm not sure I'd want that," he says. "I'll bet money that 12 years from now if someone walked up to me and said, 'Would you change who Naia is?' the answer would probably be no. Part of what I love about Naia might be directly related to the fact she has Down syndrome."

Yet Tierney is intrigued by the idea of correcting genetic flaws while a baby is still in the womb.

"In the papers last week there was a story about a child who had spina bifida corrected to some extent in utero," she tells Greg, referring to the debilitating spinal disorder. "If it's fixable, then why not? Why wouldn't we want every opportunity for everything to go right?"

"It's not that I wouldn't appreciate Naia for exactly who she is," Tierney adds. "But it could become similar to..."
whether or not my child has polio. Of course you’d fix that.”

Greg agrees, as long as nothing changes the Naia they love.

At 10:50 a.m., a woman with a familiar face enters the cafeteria, smiling and heading toward their table. It’s Karen Mazzarella, the cardiology nurse who eight months ago spoke the first encouraging words about their unborn child’s prospects. She arrives with an update from Operating Room 3.

"Everything is going fine. Smooth as silk," she says. "You always like to have a very dull surgery."

Greg’s shoulders relax. Tierney sighs. They touch hands. There’s a long way to go, but signs are good.

At that moment Naia’s grandmothers enter the cafeteria. Greg’s father, Bob, is en route from Virginia. Tierney’s father, Ernie, is home in New Hampshire. He offered encouragement by phone two days ago, but he won’t be coming.

When they hear Mazzarella’s report, Mary Fairchild and Joan Temple bask in the news, making grandmotherly plans for Naia’s future. First, though, Joan voices mock frustration with her granddaughter.

"I didn’t get my kiss from Naia this morning," she says. "I want to get it."

After sawing through Naia’s breastbone, Ellison carefully spreads it apart to expose the pericardium, a leather-like sac that surrounds the heart. With a practiced hand, he cuts through it, setting aside a piece the size of a half-dollar for use later during internal repairs.

With the calm that comes from 25 years of holding life in his hands, Ellison prepares to put Naia on the heart-lung machine.

He inserts plastic tubes with metal ends into the veins that bring blood to her heart. The blood is diverted to the heart-lung machine, where it is oxygenated then returned to Naia’s aorta for distribution to her body, bypassing the heart altogether.

Throughout the operation, Ellison and his team take care to prevent air from entering Naia’s circulatory system. Even a tiny amount could travel to her brain and cause a paralyzing stroke.

Ellison’s next step is to stop Naia’s heart, so he doesn’t have to work on a moving target. He injects a solution into her coronary circulation system that paralyzes the muscle. At the same time, he cools Naia’s heart with ice.

The maneuvers work; Naia’s heart grows eerily still. In precise medical jargon, Ellison calls it "an excellent cardiac arrest." In any other circumstance, it would mean death.

Now, 20 minutes after the incision, the only thing keeping Naia alive is the heart-lung machine. In addition to its work as a pump, the machine cools Naia’s blood, lowering her body temperature to 82.4 degrees Farenheit. Just as people can survive relatively long periods at the bottom of a frozen pond, the cold brings Naia’s system to the point of suspended animation, limiting the risk of brain damage.

His preparations complete, Ellison begins his repairs by opening Naia’s heart. He cuts through the right atrium, the
chamber where depleted blood enters the heart to begin the process of being saturated with oxygen and pumped to the body.

Through tiny magnifying lenses attached to his glasses, Ellison peers inside. With the blood drained and the beating stopped, he can clearly see the hole in Naia’s heart.

To fix it, Ellison cuts a piece of white Dacron cloth to roughly the size of a Chiclet. That’s how much he needs to patch the lower half of the hole, between the left and right ventricles.

He sews the Dacron patch into place, then picks up the piece of Naia’s pericardium that he had set aside. With it, he patches the upper half of the hole, between the left and right atria.

As he sews each patch into place, Ellison uses deft suturing techniques to convert the single large valve Naia had at birth into two separate valves, each of which must open and close thousands of times each day.

As the internal repairs are nearing completion, Ellison begins warming Naia’s body. Then he sews closed the heart and allows blood to return. He watches proudly as the rebuilt muscle grows pink with warm blood. It shivers for a moment then starts to pump on its own, quickly falling into a normal rhythm.

Ellison’s next concern is whether the hole is closed and the new valves work properly. He tests with an echocardiogram, a machine that uses sound waves to monitor heart function.

It shows that Naia’s hole is closed completely. However, as Ellison suspected, the rebuilt valves allow a small amount of blood to flow backwards from whence it came. Ellison calls it a "trivial leak" that won’t affect Naia’s recovery or health.

Overall, Ellison is satisfied, calling it "an excellent result." He believes there is little chance Naia will need future heart surgery.

Ellison sutures closed the pericardium, then uses stainless steel wires to rebuild Naia’s breastbone. Then he sews her skin back together, taking care to make the scar as straight and small as possible.

At 11:35 a.m., while Ellison is still patching and sewing, Greg, Tierney, and their mothers move from the cafeteria to a waiting room near Operating Room 3.

Toys are scattered around, along with poignant memorials to children who didn’t survive. A wall plaque is engraved with a lost child’s name and a passage from a favorite children’s book: “In memory of Jason Michael Cianci. Love you forever, love you for always. As long as I’m living, my baby you’ll be.”

As they wait, no one mentions the memorials. The grandmothers chat about how wonderful Naia is. Tierney recounts the first stroller ride she gave Naia, only last week, when the weather warmed enough to risk taking her outside. Greg says little.

At 12:55 p.m., Ellison walks in. Everyone stands. He smiles.

"She's all done," the surgeon says warmly. "We did exactly what we talked about, and so far everything looks just right." He explains her need for a blood transfusion and more sedation, describes the breathing tube still in her
throat, and mentions that the rebuilt heart valves show small signs of leakage.

All Tierney and Greg hear is that their daughter is OK.

"That's great," Greg says. The tension drains from their faces, their bodies. They embrace.

"Yay for Naia!" Tierney calls out. "Naia the great!"

As he leaves, Ellison turns and warns them not to be alarmed by how Naia looks. "Just treat her like you're at home," he says. "Just smooch her."

A half-hour later, Naia's parents and grandmothers are escorted to Room 306 of the pediatric intensive care unit.

Naia lies on her back, motionless, her eyes closed. She has lines attached to all four limbs, her torso, and her head. She looks like a crumpled marionette.

A breathing tube brings air to her lungs. A drainage tube removes blood from her chest. An intravenous line supplies nutrition to her depleted system. A nasogastric tube is in her nose for future feedings. A catheter takes away her urine. An arterial line in her wrist checks her blood pressure. A pulse oximeter measures the oxygen level in her blood. It reads 96 percent, just where it's supposed to be.

It makes them cry to see her like this. Greg fingers Naia's fine hair. Tierney follows doctor's orders and kisses her.

A nurse, Wendy Lord, comes in to check Naia's pupils and adjust the monitors. Mostly for modesty's sake, she puts a doll-sized diaper on Naia. Lord wears a Black Dog T-shirt, the unofficial symbol of Martha's Vineyard. For Greg and Tierney, it sparks rueful memories of the day last summer when an ultrasound test changed their lives, just hours before they planned to leave for a Vineyard vacation.

Nurse Cookie Eckel comes by to see how Naia is doing. "She's one feisty little lady," Eckel tells Greg and Tierney. Eckel says the surgery was flawless, and necessary. "She had a big hole in there. You got your money's worth."

Greg and Tierney can't help but smile.

Eckel leaves and Tierney's mother takes care of her unfinished business. Tears streaming down her face, Joan bends low and kisses Naia on the forehead.

"Grandma loves you," she whispers.

It is April 4, Easter Sunday, four days after the operation. Naia's recovery has gone slowly.

She's still in the pediatric intensive care unit, two days longer than Greg and Tierney expected. She'll be here at least one more day, breathing with help from a ventilator. She's fighting a fever, and her blood pressure is low. She remains sedated with morphine.

Naia has resisted attempts to get her to breathe on her own. When the doctors turn down the respirator - hoping her own breathing system will kick in - she barely responds. Today, though, they hope to wean her from the respirator entirely.
The day begins with a visit from a nearly six-foot Easter Bunny who leaves a basket of toys and a blue-and-yellow quilt sewn by Girl Scout Troop 988. Naia sleeps through the visit.

At 11:30 a.m., Ellison removes the drainage tube from Naia's chest. Then, at 4:30 p.m., he returns to remove the breathing tube. Naia is deep in a morphine-induced sleep.

Greg and Tierney expect Naia to scream when the tube comes out, but there is only silence. They fear the worst. "It's like her birth, when she didn't cry," Tierney says.

Ellison calms them, telling them to "look at the big picture." In fact, though she remains asleep, Naia has begun breathing for herself.

As the hours drag on, Naia confounds expectations and continues to sleep. The doctors order an antidote for the morphine, called Narcan, and she finally begins to stir. Then she starts to thrash, pulling at the tubes in her nose and on her foot. After a few scary moments, she settles down.

At 11:30 p.m., Greg and Tierney go to a nearby parents' room for a dinner delivered by her mother. Like the Thanksgiving after Naia's birth, their Easter dinner is another holiday meal eaten in the sanitary confines of a hospital. Exhausted, they quietly savor lamb, Swiss chard, mashed potatoes, and black olives, a family favorite.

The days go slowly. A planned five-day stay stretches to 10. But with the extra time and extra care, Naia's strength gradually begins to return.

Now, on April 9, it's time to go home.

Greg and Tierney are buoyant. Naia is snuggled in pink-and-green pajamas. There is something different about her. It's partly the silky ribbon a nurse has tied to a lock of her hair. And it's partly the smiles she showers on passersby like rice at a wedding. Most of all, though, it's her coloring.

Now that her heart is working well, Naia's skin has taken on a healthy glow. It's not the white of her mother, nor the black of her father. It's not the yellow of jaundice, nor the blue of heart failure, nor the pink of a photo clerk's baby ideal.

It's her own unique color.

TOMORROW: Life with Naia

Illustration
Caption: 1. DR. LEE ELLISON, a cardiac surgeon, draws a line down the center of Naia's chest to guide his incision as he begins open-heart surgery on March 31, 1999. 2. NAIA CRIES as Dr. Craig Bonnani, an anesthesiologist, and Cookie Eckel, a nurse, prepare to sedate her before surgery. 3. A TIRED TIERNEY awaits the outcome of Naia's surgery near a rocking chair that commemorates a child that died. 4. DR. LEE ELLISON, the pediatric cardiac surgeon who performed Naia's surgery, brings good news to Tierney, Greg, and their mothers, Joan Temple (left) and Mary Fairchild. 5. JOAN TEMPLE and her daughter Tierney watch over Naia in the intensive care unit following the successful surgery. 6. TIERNEY WHISPERS words of encouragement to Naia, whose upbeat prognosis belies
her appearance. Photographs by Suzanne Kreiter

**DETAILS**

<table>
<thead>
<tr>
<th>Subject:</th>
<th>Birth defects; Families &amp; family life; Series &amp; special reports; Babies; Heart; Surgery</th>
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<td>Location:</td>
<td>Connecticut</td>
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<tr>
<td>People:</td>
<td>Temple-Fairchild, Tierney Fairchild, Greg</td>
</tr>
<tr>
<td>Publication title:</td>
<td>Boston Globe; Boston, Mass.</td>
</tr>
<tr>
<td>Pages:</td>
<td>A, 1:1</td>
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<tr>
<td>Number of pages:</td>
<td>0</td>
</tr>
<tr>
<td>Publication year:</td>
<td>1999</td>
</tr>
<tr>
<td>Publication date:</td>
<td>Dec 9, 1999</td>
</tr>
<tr>
<td>Section:</td>
<td>Metro/Region</td>
</tr>
<tr>
<td>Publisher:</td>
<td>Boston Globe Media Partners, LLC</td>
</tr>
<tr>
<td>Place of publication:</td>
<td>Boston, Mass.</td>
</tr>
<tr>
<td>Publication subject:</td>
<td>General Interest Periodicals–United States</td>
</tr>
<tr>
<td>ISSN:</td>
<td>07431791</td>
</tr>
<tr>
<td>Source type:</td>
<td>Newspapers</td>
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<tr>
<td>Language of publication:</td>
<td>English</td>
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<tr>
<td>Document type:</td>
<td>Feature</td>
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<tr>
<td>ProQuest document ID:</td>
<td>405322473</td>
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<tr>
<td>Copyright:</td>
<td>Copyright Boston Globe Newspaper Dec 9, 1999</td>
</tr>
<tr>
<td>Last updated:</td>
<td>2017-11-10</td>
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<td>Database:</td>
<td>Boston Globe</td>
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