A HOLE IN THE HEART

ABSTRACT
The first in a series of six parts concerning the lives of Boston residents Greg Fairchild and Tierney-Temple Fairchild and their decisions concerning the future of their Down syndrome fetus is presented.

FULL TEXT
CHOOSING NAIA / A FAMILY'S JOURNEY First of six parts.

Tierney looks radiant in a new black-and-white striped dress, smiling and chatting as she pulls it up to expose a gentle bulge in her normally flat stomach. She lies on a table in a fourth-floor obstetrics room at St. Francis Hospital in Hartford. Her husband, Greg, sits in a chair beside her, watching as a technician begins the routine ultrasound test that is their last task before a weeklong vacation on Martha's Vineyard. The technician, Maryann Kolano, strokes Tierney's belly with a sonogram wand, using sound waves to create a picture of the life inside. Greg studies the video screen, fascinated by the details emerging from what looks like a half-developed Polaroid. An arm here, a leg there, a tiny face in profile. Then the internal organs: brain, liver, kidneys. "I'm having a hard time seeing the heart. Maybe the baby's turned," Kolano says calmly. Then it appears, pumping in a confident rhythm. She stops the moving image, capturing a vivid cross-section, and Greg remembers his high school biology. "All mammals have four chambers in the heart," Greg thinks to himself. "There are only three chambers there." "You know," Kolano says tactfully, "I'm not as good at this as some other people. Maybe somebody else should take a look." She tries to mask her alarm as she leaves the room. The inescapable truth is staring at Tierney and Greg from the silent screen: There is no fourth chamber. There is a hole in the heart. And not just any hole, they will soon learn. It is a tell-tale sign of Down syndrome, a genetic stew of physical defects and mental retardation. A hole in the heart. In their baby's and, suddenly, in their own. The date is July 24, 1998, and Tierney Temple-Fairchild and Greg Fairchild have just entered a world of technological wizardry and emotional uncertainty called "prenatal screening." It is a confusing place where even the name is misleading; abortion screening if more accurate. Most disorders tested for today - including Down syndrome, muscular dystrophy, and cystic fibrosis - cannot be corrected. That means the most common question prompted by distressing prenatal test results is not, "How can we fix it?" It is: "Should this pregnancy continue?"

Those questions are growing rapidly for countless couples who, like Tierney and Greg, would consider abortion under certain circumstances. Researchers say they are within two years of deciphering the blueprint of human development - the genetic code that acts as the operating instructions for creating life. That achievement is expected to drive prenatal screening into the realm of science fiction. Then what? Does a woman carry to term a baby susceptible to mental illness? Cancer? Obesity? Infertility?

Already, hard science has far outpaced the emotional side of the equation. People can learn a great deal about their unborn children, but no one tells them how to handle that knowledge, or what the future might hold.
That void will be filled in days ahead by the competing and sometimes ill-informed voices of Tierney and Greg's family and friends. Some will urge abortion - the choice made by up to 90 percent of people in their situation - while others will be horrified by the idea.

Complicating matters will be pressures of race, faith, and timing - less than two weeks after the final diagnosis, Tierney's pregnancy will reach the stage where abortion is illegal except to protect her life or health, neither of which is at risk.

All that makes theirs a journey through uncharted terrain, filled with fears and tears. Tierney and Greg will be tested and torn, changing their minds repeatedly as they confront a new reality amid the ache of lost dreams.

The morning of the ultrasound test dawned with a cloudless pastel sky, custom-made for a couple on course for an enviable future.

Tierney is 31, as smart as she is attractive, with shoulder-length brown hair, large expressive eyes, and an effervescent laugh. She has a doctorate in education from the University of Virginia, where she also received an MBA. Four years out of school, she works in the corporate contributions department of United Technologies, managing education programs.

Greg is 34, model-handsome, with thick shoulders, a strong chin, and a penetrating intellect. He also received an MBA from the University of Virginia, and is now writing his dissertation for a doctorate in business from Columbia University in New York, where he spends several days each week. The dissertation topic: small business in the inner city.

Together for nine years, married for four, Greg and Tierney live with their poodle, Onyx, in a one-bedroom apartment in a pleasant but unfashionable section of Hartford. Greg's bronzed baby shoes and a sepia-toned photo of him as an infant greet visitors from atop a china cabinet near the front door. They have long dreamed of having at least two children and adopting another.

It has been a busy time in their lives, but Tierney's first pregnancy has gone smoothly after some initial difficulty conceiving. Five months have passed with no morning sickness and enough energy for plenty of jogging through the streets of their neighborhood.

A first ultrasound, in late April, showed a healthy fetus due around Dec. 7, Greg's birthday. A second prenatal test for birth defects, called a triple screen, also was negative. In fact, it showed the odds of Tierney having a child with Down syndrome were unusually low, though the test is accurate only about 60 percent of the time. Still, they had no worries about today's ultrasound, scheduled mainly to confirm the due date.

Tierney left home early for a half day of work. Planning to go straight from the hospital to Martha's Vineyard, Greg loaded their Honda Accord, filling the trunk with bags, books, and a cooler with $100 worth of meat, fish, and a homemade marinade.

Greg picked up Tierney at work at 1:15 p.m. and they drove to nearby St. Francis Hospital. As they walked in, Tierney cheerily mused that their next visit would be for the delivery. It seemed fitting and natural: She was born here, too.
But now, an hour after their arrival, Kolano, the technician, has left them alone in ultrasound Room 1. Budding concerns are pushed aside, muted by Kolano’s comment that she lacks the skill to properly read the results. Tierney’s main worry is that they might miss their 8:30 p.m. ferry reservation.

But then Kolano returns with her boss: Dr. James F.X. Egan, director of maternal/fetal medicine, a vision of authority with silver hair, red cheeks, and blue eyes behind tortoise-shell bifocals.

Egan glances at the screen on the Ultramark 9 ultrasound machine and drops the first shoe: "We're only locating three chambers," he says in a voice that reveals only information, not emotion. He asks them to move two doors down, to Room 3, where he can use a more advanced machine, the Ultramark 5000.

As they begin the move, Tierney starts to cry. Greg takes her hand and says softly, "Stay calm. It's going to be OK. There's not anything to worry about yet."

But the Ultramark 5000 confirms the initial diagnosis in bold color: Their unborn child has a hole between the top and bottom chambers of the heart, a condition that causes a shortage of the oxygenated blood that every cell needs to survive. Also, the heart is situated at a slightly off-kilter angle.

Their baby is fine in the womb, Egan says, because Tierney is providing all the oxygen it needs. But these flaws will require major surgery before their baby's first birthday.

"I'm sorry," Tierney whispers to Greg between rising sobs. "I'm really sorry." She knows it's not her fault, yet she feels guilty. Gently, Greg tells her, "You don't have anything to apologize about."

But "sorry" is more than an apology. Tierney wants to tell Greg she feels sorry for him, sorry for herself, sorry that they won't be having the healthy child they dreamed about. Again, he tells her not to worry.

Then Egan drops the other shoe. This kind of heart defect is associated with Down syndrome, he says. If they want a diagnosis, he could perform a more accurate prenatal test, amniocentesis.

Egan explains he will insert a needle into Tierney's uterus and withdraw a small amount of fluid. Because the fluid contains cells from the fetus, doctors can diagnose Down syndrome with near-certainty by analyzing the chromosomes in the fetal cells. Most people have 46 chromosomes per cell; people with Down syndrome usually have 47. Results take a week to 10 days.

Tierney wants to call her mother. Greg discourages her, saying it would only upset them both, and they still don't know what they're dealing with.

"I feel so bad for you guys," says Kolano, the technician. "This is so tough, but it's better that you find out now."

Greg and Tierney, still trying to absorb the news, wonder what she means and why she seems so flustered. Then Egan offers his sympathy, too, while asking Tierney to sign a release form acknowledging there is a risk of miscarriage from amniocentesis.

Tierney feels rushed and confused - wasn't it just an hour ago everything was wonderful? - but through her tears she signs the form. Her body shakes as Egan inserts the needle. She cries in fear her baby will be jabbed. But the Ultramark 5000 is still on, and they watch the needle pass harmlessly into the uterus and then back out. Greg helps
her off the table.

Afterward, there is a brief discussion between Kolano and Egan about whether to administer another, quicker test, called fluorescence in situ hybridization, or the FISH test. But Egan decides they won't; it's not accurate enough.

Tierney doesn't catch the remark, but Greg does. "You can't cure Down syndrome, so he has to mean just one thing," Greg thinks. "He must mean accurate enough to decide about abortion."

Despite Egan's misgivings, Tierney and Greg decide they want the FISH test, using part of the sample taken for the amniocentesis.

Insurance forms are signed and Kolano shows them the back way out, so they can avoid the waiting room. "That makes sense," Tierney says to herself. "If we went that way, people would look at us and think, 'Wow, they just got some really bad news about their baby.'"

They drive home in a fog, punctuated by Tierney's sobs. Greg carries in the cooler; they won't be going to the Vineyard tonight.

For the moment, Tierney focuses on the risk of miscarriage. She lies on the couch, asking, "What does this all mean?" Greg tries to be strong, telling her they'll play whatever cards they're dealt.

They make their first call, to Greg's parents in rural Russburg, Va. "We're really sorry for you both," says Mary Fairchild, whose college major was special education.

She talks of faith and holds back the tears she wants to shed for her first grandchild. "You have to face the situation," she explains. "If you are going to cry, you cry later. It blinds your eyes." Greg's father Bob, a retired Army colonel and bank executive, listens intently but says little.

The next call is to Tierney's mother, Joan Temple, a substitute teacher who lives in Avon, Conn. A devout Catholic, Joan tells them, "You need to relax and not think the worst. Remember, it's God's plan." Privately, she will be praying that a miracle heals her first grandchild. Tierney's parents are divorced. Her father, Ernie Temple, won't be told for another 11 days.

The last call is to a genetic counselor, Alicia Craffey, who was referred to them by Egan. She promises to assemble a package of information, books with titles like, "A Time To Decide, A Time To Heal."

They pick at some dinner, listlessly watch TV, talk for hours about everything and nothing, then fall into fitful sleep. Overnight, the ice in the cooler melts. The food left abandoned inside turns rancid.

In the morning, Greg awakens in a dark mood. It is the first of many back-and-forth flips both will make in the days ahead.

He calls his parents again and unleashes a fury of thoughts on being black, on the mentally retarded, and on discrimination against both groups. He knew there would be problems for their child, born to a white mother and a black father. Now, imagining the added hurdles of a heart defect and Down syndrome, he pours out a litany of fears and frustrations.
"I'm just so sick of having to deal with discrimination," he says. "Why couldn't this have been visited on someone who believes discrimination is not a part of life? Why couldn't this have happened to someone who has lived the most privileged life of all?"

He remembers, as a child, watching other boys taunt a mentally retarded girl, asking her to pull down her pants and laughing when she did. He remembers her brother chasing the boys, and now he imagines himself in that role.

He tells his parents he remembers volunteering as a teenager for Special Olympics. He was supposed to hug runners as they crossed the finish line. "I remember my own visceral reaction when you see a child with what I would call extreme Down syndrome - very large glasses, bulging eyes, tongue sticking out of the mouth. I didn't pull away, but you don't feel as comfortable reaching over and hugging. Clearly, after you do it, after you hug the first five, you find out, hey, there's nothing wrong." Still, his initial response makes him wince.

To himself, he thinks, "When I have people over to my house and we have dinner parties, what will happen the moment when the child comes out and the people won't know what to say and do?" He knows he isn't being completely rational, and he will scold himself later, but now the world is spinning and so is he.

After the phone call with his parents, Greg tells Tierney they face a frustrating future in which they can never stop being vigilant, educating the ignorant, battling the cruel.

"If we have this baby, just get ready for the onslaught of stupid, maybe well-meaning, but stupid comments. We're going to have to deal with them for the rest of our lives," he tells her. "Tierney, we're going to have to go into our child's school, fighting with administrators, changing this and that. I'm going to have to make sure people aren't abusing my child, putting him in the back of the room or locking him in the closet. This is what we're going to have to do. But I'm mad about it."

He is leaning toward abortion.

But Tierney has awakened more peacefully. For the moment, her confusion and sadness have passed with the night. She tells Greg: "We both consider ourselves to be pretty strong people. If this is going to be a worst-case scenario, then maybe we're the right parents to take this on." She also reminds him they still don't have a final diagnosis - either about the heart defect or Down syndrome - so they should just wait and see.

Tierney leaves to get the information assembled by Craffey, the genetic counselor. Then they read it together, huddled on their living room couch.

They learn that no one knows why Down syndrome occurs or how to prevent it. It appears in all races and in all countries, and is the most common chromosomal abnormality in humans. The only clue to its likely occurrence is the mother's age: women over 35 are significantly more likely to have babies with Down syndrome.

But Tierney is only 31, and that leads them to a surprising discovery. Of the 5,000 or so babies with Down syndrome born each year in the United States, 75 percent are born to mothers under 35. The main reason is that most babies are born to younger mothers. Their low odds of having a baby with Down syndrome are offset by the proportionately larger number of babies they bear.

That helps to explain why the number of children born with the disorder has remained stable for decades, despite the high abortion rate among women who know in advance. Because younger mothers undergo fewer prenatal
tests, most don’t know their unborn child has an extra chromosome. Also, the number of older women having babies is rising, increasing the overall incidence of Down syndrome.

From the literature, Tierney and Greg also learn that children with Down syndrome are as varied as other children, though they have certain consistent features. All are mentally retarded, most with IQs between 40 and 70 on a scale that considers 100 to be average.

Though often stereotyped as relentlessly happy, they have the same range of emotions as other children. Most have poor muscle tone, upward-slanting eyes, and faces that are broader and flatter than those of other children. Life-expectancy is 55 and rising. Many have vision problems, and heart defects are common, occurring in nearly half of all children with Down syndrome.

Greg and Tierney learn that surgery can correct the type of defect spotted in their unborn child's heart, but success is not guaranteed; some babies are doomed from birth.

When they awaken the next day it is Sunday and both feel drawn to church. Greg, raised a Baptist, and Tierney, a Catholic, consider themselves religious. And yet, they depart from church doctrine on key matters, most notably abortion rights, which they strongly support.

With no church of their own, they drive to the Church of Saint Timothy in West Hartford, where Tierney’s mother sometimes worships. It is a fine brick building, surrounded by tall, strong trees.

Sitting in a pew, bathed in sunlight passing through stained-glass windows, Greg and Tierney hear a sermon about the role of prayer. It resonates so deeply it seems written just for them. "The miracle you pray for," the priest concludes, "may not be the miracle you receive."

From this moment on, there will be no more prayers for the baby not to have Down syndrome. What’s done is done, they decide, and such a diagnosis might somehow be a miracle in itself, in ways they cannot yet fully imagine. Instead, Tierney and Greg will pray the heart heals or can be fixed by surgery.

Back home, Tierney begins to feel claustrophobic. With days until the test results come back, she wants to begin their delayed vacation on Martha’s Vineyard. Reluctantly, Greg agrees.

Greg spends the ferry ride napping in the car, too tired and depressed to venture out on deck. It is a pattern that continues on the island. The first few days, Tierney goes alone or with Onyx the poodle to Philbin Beach, near the Gay Head Cliffs, to read and reflect under blue skies and a healing sun. Greg stays holed up in their rented house, slowly coming to terms with what their future might hold.

Then, on Thursday, they get a phone call from their obstetrician, Dr. Michael Bourque, with news about the FISH test.

"I’m really sorry to have to tell you this, but it came back positive," Bourque says. Chances for a different result are slim, he says, but the diagnosis won't be final until the amniocentesis results arrive next week.

Greg takes it hard, even though he had expected the news. It’s worse for Tierney.

"I was dealing with it and trying to stay strong, and appealing to my better half that I could handle it," Tierney tells...
Greg. "Now, all of a sudden, it is going to be us."

There are tears to shed, more hard news to share with family.

The next day, Friday, exactly a week after the ultrasound, Tierney's sister Tara joins them on the Vineyard. Her visit unleashes new tensions.

Tara is a year older than Tierney, single, a veterinarian in Worcester. The two look and sometimes act like twins. They wear identical necklaces, presents Greg brought home from a trip to Ghana. Each necklace has a single pendant, an African symbol for "hope," that dangles over the heart.

Tara was the first person Tierney told that she was expecting. Tara has been kept informed about the difficult news by phone.

Before heading to the Vineyard with her golden retriever Winnie, Tara spent a night in Boston with their older brother George, 36, an architect and former Air Force captain, and his wife Allison, an anesthesiologist. Based on a discussion of medical information gathered by George and Allison, the three had reached a consensus: Tierney and Greg should abort.

Tara drops this bombshell when Tierney meets her at the ferry.

The conversation fuels Tierney's worst fears. She loves the unborn child kicking inside her, but if the heart defect is irreparable, maybe abortion is the right choice. Still, hearing it from Tara is devastating.

When Tierney and Tara reach the rental house, their reddened eyes are turned from each other. When Tara goes inside, Tierney tells Greg on the porch: "They think this is a big tragedy."

Tara walks back outside and into a confrontation with Greg, whose reading about the heart defect has made him more optimistic. He believes Tara, George, and Allison are overstating their medical fears to justify abortion. He suspects they really want to spare Tierney and Greg - and perhaps, even themselves - the difficulties and discrimination that come with Down syndrome.

"You know," he says sharply, "when this is all said and done, if it turns out more positively than everyone expects, some people will see us as having been pioneers."

Tara shoots back: "And if it doesn't turn out as positively as you expect, some of them will see you as having been stupid."

The next morning, Tara and Tierney have a talk that brings them full circle. After Tara apologizes, Tierney wistfully mentions that the children on Martha's Vineyard all seem so perfect.

Not true, Tara says. On the ferry, a pretty 4-year-old girl with Down syndrome came over and asked to pet Winnie. "She was so cute and so sweet," Tara says.

"Oh, Tara!" Tierney cries. "That's what God wanted you to tell me all along. That's what I needed to hear."

With that, Tara begins to understand how her sister feels, and what she needs.
TOMORROW:

Reaching a decision

Illustration
Caption: 1. Greg Fairchild and Tierney Temple-Fairchild, whose unborn child has Down syndrome and a severe heart defect, at Hartford’s St. Francis Hospital in September 1998. 2. TIERNEY CRIES at her dining room table while discussing the unexpected difficulties of her pregnancy and the painful choices that followed. 3. The three-chambered heart (circled in red) on this ultrasound image triggered Greg’s fears about their unborn child. 4. Greg and Tierney ponder the fate of their unborn child at St. Francis Hospital. 5. Tierney confers with Dr. Wendy Amblo, an obstetrician, about the difficulties of her long-planned pregnancy. PHOTOGRAPHS BY SUZANNE KREITER

DETAILS

| Subject: | Series & special reports; Downs syndrome; Parents & parenting |
| Location: | Boston Massachusetts |
| People: | Fairchild, Greg Temple-Fairchild, Tierney |
| Publication title: | Boston Globe; Boston, Mass. |
| Pages: | A, 1:1 |
| Number of pages: | 0 |
| Publication year: | 1999 |
| Publication date: | Dec 5, 1999 |
| Section: | National/Foreign |
| Publisher: | Boston Globe Media Partners, LLC |
| Place of publication: | Boston, Mass. |
| Publication subject: | General Interest Periodicals–United States |
| ISSN: | 07431791 |
| Source type: | Newspapers |
| Language of publication: | English |
| Document type: | Feature |