ABSTRACT (ABSTRACT)

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1. THE HAPPY AND PROUD parents celebrate Naia's christening in June. Above left: Godfather [Kyle Rudy] embraces Naia. 2. GREG AND TIERNEY beam as the Rev. [Henry Cody] christens Naia Grace Fairchild at the Church of St. Timothy. 3. NO LONGER AFRAID of exposing Naia to life-threatening germs, Greg and Tierney take her swimming in July. 4. AT 10 MONTHS (top), Naia accompanies Tierney grocery shopping. One month after surgery, Naia gets a bath. 5. ALTHOUGH THERE ARE SIGNS of developmental delays, Naia takes some tentative steps at her first birthday party with help from her grandmother, Joan Temple. 6. BLOWING OUT the candles is a family effort at Naia's first birthday celebration. / GLOBE STAFF PHOTOS / SUZANNE KREITER

FULL TEXT

CHOOSING NAIA / A FAMILY'S JOURNEY Last of six parts

His basket filled with food and diapers, Greg ambles toward the Stop &Shop checkout line. The store isn't crowded, and he could choose any line. But he is drawn to one in particular. He places his groceries on the moving belt and looks past the cashier to a smiling young woman.

"Hello," Greg says, and the young woman looks up from her work as a bagger."Hi," she says sweetly.

Greg wishes he could tell her all the things in his heart. He wishes he could ask a hundred questions about her life, her job, her family. About the friends he hopes she has. He wishes he could tell her about his 6-month-old daughter at home.

He says none of that. It would seem odd, intrusive. When her work is done and his groceries are neatly packed, Greg says, "Thanks." He gives her a warm smile. She smiles back.

The bagger's name is Sarah and she has Down syndrome.

It is June 3, 1999. After all the uncertainty, all the fears, all the medical problems from an emergency birth through open-heart surgery, Greg Fairchild and Tierney Temple-Fairchild have begun settling comfortably into life with Naia.

Still, a day rarely goes by that doesn't include reflections on the choice they made. Not that there are doubts.
Greg’s grocery store encounter merely reinforces his and Tierney’s certainty that they made the right decision 10 months ago about carrying Naia to term.

"In retrospect, it doesn't seem like a big deal. This hasn't crushed us or demolished our relationship or affected anybody in our family in a negative sense," Greg tells Tierney.

"It felt really nice to see she's not closeted in a facility someplace. She's out working, in a productive way, as a member of society," he says of Sarah. "Maybe this is evidence that the days when you didn't see any adults with Down syndrome in the community are at their end."

They know there will be unforeseen problems ahead, obstacles that cannot be corrected by doctors, prayer, effort, or time. But with Naia growing stronger, more active, and more inquisitive every day, Tierney is equally undaunted.

"It's important for us to have high expectations," she says firmly. "I'm preparing myself that there will be developmental delays. It's our job to help Naia through her challenges. How well we do that will determine how she pursues life as an adult."

For all their willingness to tackle the hard work ahead, Tierney and Greg know it's too early to predict how independent Naia might be. It will be years before anyone can fully gauge how the extra chromosome in every one of her cells will affect her mental and physical development.

And yet, there are reasons for optimism.

Two months have passed since the surgery that repaired Naia's damaged heart, and the results are as visible as the tender rolls of fat that have sprouted on her once-frail body.

In addition to the high-calorie formula she still drinks, Naia has begun eating mushy cereal from a spoon. Soon she'll graduate to squash and mashed carrots. She has the energy to laugh more often, and with more vigor. On the other hand, her cries are no longer the weak mews of a kitten. When she's upset, they're full-throated yells.

With each passing day, Naia seems to come more into her own as an individual. She has begun playing a flirtatious game of peek-a-boo with visitors, staring at them until they make eye contact, then quickly turning away. She has begun rolling over and using her pudgy arms to propel herself forward while on her stomach. She uses this precrawl to pursue her new favorite diversion: Onyx the poodle. She's too fast for Naia, but she won't be for long.

Naia's developmental leaps are partly traceable to state-funded visits from therapists with Connecticut's Birth-to-Three System, which provides early intervention for children with disabilities. Similar programs exist in Massachusetts and many other states.

Mary Halloran, a developmental therapist, has been thrilled by Naia's performance during their weekly sessions. "Naia is doing beautifully," she wrote on a May 9 progress report. "Today she rolled, played with her feet and played with her hands at her midline. She's experimenting with sounds and is very aware of what's going on around her."

Between visits, Greg and Tierney supplement the work being done by Halloran, occupational therapist Wilma Ferkol, and physical therapist Bonnie Herrin. They do exercises to improve Naia's mobility and strengthen her muscles, which aren't as taut as they should be.
"It might just be that's what parenting is all about, for us or for anyone with children. There's always something else to be working on with your kid," Greg says. "It's not that we're going to be able to work our way out of these deficits, but we'll do whatever we can to be further down the road."

The improvements extend to Naia's medical outlook. Tierney's little brown notebook has taken on a decidedly different tone.

When cardiologist Harris Leopold listened to Naia's heart on May 14, he said, "Sounds good." Tierney happily wrote that down. Two weeks later, gastroenterologist Jeffrey Hyams examined Naia for lingering signs of jaundice. "Looks great," he said, and Tierney wrote that down, too.

One by one, the medicines that once sustained her become unnecessary. By her first birthday, she will need just one, Captopril, which lowers her blood pressure, making life easier for her rebuilt heart. And just as cardiac surgeon Lee Ellison intended, the scar on Naia's chest is fading to a faint white line.

That isn't to say Naia will be free from medical concerns. Sight and hearing problems are common among people with Down syndrome; Naia might need glasses by the time she turns two. More ominously, children with Down syndrome are 15 to 20 times more likely than other children to develop leukemia, and more than 25 percent of adults with Down syndrome develop Alzheimer's-like symptoms of dementia after age 35.

But overall, almost from the moment Tierney and Greg brought Naia home after surgery, their focus has changed. No longer fearful about Naia's survival, they are introducing her to the world. After being kept safely inside nearly all winter and early spring to avoid potentially deadly colds, Naia has become a girl about town, visiting parks, stores, restaurants, and the homes of family and friends.

Naia's public appearances prompt regular cries of "What a cute baby!" from strangers on the street. In the parking lot outside a bagel store, one woman goes on at length about how beautiful she looks in brown. "What a wonderful skin tone she has!" the woman says. Greg smiles. "Thank you," he says.

Some people notice Naia's petite size and ask if she was premature. Rarely does anyone ask about Down syndrome. Some may wonder about it and not want to seem impolite. But Greg and Tierney suspect some people either don't realize she has the disorder or think she has only a "mild" case.

Even Naia's pediatrician, Dr. Della Corcoran, wonders aloud during one visit if Naia might have a rare, less severe form of Down syndrome called Mosaicism, in which not all cells are affected by the extra chromosome.

"No," Tierney told the doctor. "We've had it tested. She has full-blown Down syndrome."

"Well, she doesn't look it," Corcoran said.

In fact, the facial features common among children with Down syndrome are somewhat more subtle on Naia. For instance, her eyes don't slant sharply upward, and they don't have pronounced skin folds at the inner corners. Her tongue only rarely juts out of her mouth, unlike some children with the disorder whose mouths are small and whose jaws are slack, giving their tongues the appearance of being large and protruding.

There's no link between the severity of Down syndrome-related features and the extent of a person's mental retardation. However, Greg and Tierney believe the less Naia exhibits those features, the less discrimination she
might encounter. The notion leaves them with mixed emotions.

"I know she's cute, and I think she would probably be just as cute if she had those features. But would she?" Tierney says. "Would she be as cute to other people? I don't know."

Greg sees the issue through the prism of race.

"It's like the difference between being a visible minority versus an invisible minority. I have no doubt that people who don't like black people will let me know very quickly, one way or another," he tells Tierney. When that happens, he reacts accordingly, deciding whether to steer clear or confront them.

"But when you're part of an invisible minority you don't always have that knowledge of where they stand, and that's not always an advantage," he says. "People might have unreasonable expectations of Naia, based on her appearance. When they talk to her and find out about her condition, they'll have to readjust, and that might be difficult, for her and for them."

With Naia's medical crises resolved, Greg and Tierney decide it's time to formally include her in their spiritual lives.

And so, on June 12, an idyllic day that holds the promise of summer, Naia and her family drive to the Church of Saint Timothy in West Hartford for Naia's christening.

They don't worship regularly at the parish, but the choice is both appropriate and symbolic. Tierney and Greg had come here last July, two days after learning about the problems facing the fetus in Tierney's womb. As they sat together that Sunday morning, sad, frightened and confused, they heard a sermon about prayer and miracles. Only now can they fully appreciate the message.

"Naia is a miracle just as she is," Tierney tells Greg, her eyes welling up. "That's something I feel every day."

As they walk from the parking lot to the church, Naia lets out a stream of happy gurgles. Angelic in a white satin dress with puffy sleeves and a scalloped hemline, she stares at the trees and sky. Nestled in Tierney's arms, she plays with her feet, tugging at tiny green-and-white rosettes on her socks.

Naia's godfather will be Kyle Rudy, a friend from Tierney and Greg's days working at Saks Fifth Avenue in New York. Naia's godmother will be Tierney's sister Tara, whose initial doubts about continuing the pregnancy have been replaced by heartfelt support and endless shows of affection for her niece.

Inside the church, Greg holds a white candle, Tierney holds Naia, and the Rev. Henry Cody blesses her with sacramental oil and water. "She is now called a child of God, for indeed she is," says Cody, who has known Tierney since she was small.

Cody reads from a prayer book that seems written just for Naia. "The parents have generously invited the child into this world by giving a share in the life of their own bodies," it says. "This invitation will be prolonged with every mouthful of food, every drop of medicine, and every inch of shelter they provide."

Naia's grandmothers take pictures. Greg beams. Tierney cries, for joy.
Just when life seems to be calming down, Greg, Tierney, and Naia are forced to confront an unexpected new challenge.

It's June 23, and Greg and Naia are relaxing in their apartment, waiting for Tierney to come home for dinner. Since March, Greg's mother, Mary Fairchild, has been living in the nearby apartment they purchased shortly before Naia was born. Mary and Naia spend most days there while Tierney goes to work and Greg writes his doctoral dissertation.

At 5:30 p.m., the phone at Greg and Tierney's apartment rings. It's Mary.

"Greg, the back porch is on fire," she says before running outside.

A spectacular fire has engulfed a six-story factory building down the street. Embers from the blaze have taken flight, landing on the building housing Greg and Tierney's future home.

No one is hurt, but the new apartment is destroyed, much of it from smoke and water damage. They also lose their good stroller, a baby swing, a playpen, and lots of toys, as well as a computer and several pieces of furniture.

Most of the losses are covered by insurance, but it will take nine months to rebuild. Mary is returning next week to her home in Virginia, and Greg, Tierney, and Naia had planned to move into the new apartment next month. The lease on their current apartment is expiring and cannot be renewed.

They'll have to move in with Tierney's mother, in nearby Avon.

"Last July we found out about Naia. Then the emergency c-section. Then the heart surgery. And now this," Tierney says with a rueful laugh. "I'm at the point now where I think we could handle just about anything."

In a way, she tells Greg, maybe all the trials have been a good thing.

"We've learned that we really are the people we thought we were when we married," Tierney says. "Sometimes it takes a long time to learn how you'll react together in a crisis. I think it's safe to say now we know exactly who the other one is, how we'll react together, how we'll work it out."

For Greg, the key to their future is the way they worked through the decision about Naia.

"Some couples could go through something like this without ever having really agreed," he says. "One person forced their will and the other capitulated. That wasn't the case with us.

"You learn quickly that as long as you're right with the person you're with, even if other people around you don't agree with what you're doing, it's OK. They can hop off the train, because we're going on without them."

In the months ahead, that sentiment will be put to the test, in the form of a confrontation with Tierney's father.

As summer turns to fall and Naia's first birthday approaches, Greg and Tierney are increasingly troubled by Ernie's continued standoffishness. He sends gifts, but during his visits he remains distant from Naia. He still hasn't held her.
It's a sharp contrast from Greg's father, Bob, who gravitates to Naia whenever he sees her, hugging her, playing with her, letting her tug on his beard.

Tierney and Greg's frustration reaches a boiling point when Ernie's girlfriend casually mentions during a phone conversation that he's bouncing her grandson on his knee. They wonder why he doesn't do that with Naia.

On Ernie's next trip through Hartford, on Oct. 20, Tierney asks him that question over pizza at a Bertucci's restaurant.

"I just want to understand what you're willing to do, how involved you're willing to be, how you're going to interact with Naia," she says. "I want to know what your issues are with her."

"I thought they should have been apparent to you," Ernie answers flatly.

It's not the Down syndrome, Ernie says. It's race, the same problem he had a decade ago when he first met Greg. Despite having walked Tierney down the aisle at her wedding, despite the good times he has shared with Greg and Greg's parents, Ernie still disapproves of interracial marriage.

He considers it a betrayal of Tierney's heritage, and his discomfort colors his relationship with his granddaughter.

Tierney is shocked and saddened, a bit sickened as well. Yet she keeps her tone level and tries to point out the illogic of his words, the hypocrisy of his behavior. She uses reason and science to contradict his points, including his suggestion that mixing races might cause physical problems or "sickness," a comment Tierney takes to mean Down syndrome.

But she knows there's no convincing him, and she'd rather be back home with Naia and Greg than hear any more of this.

When he hears about the dinner, Greg is disgusted and shocked by Ernie's comments. "This guy has done such a good act around me, my parents, that I thought maybe he had gotten over those views. I feel duped," he says.

At the same time, Greg and Tierney see the bitter irony: Naia is a victim of garden variety discrimination. Ernie would reject any child of theirs, not just one whose genetic disorder once made them consider abortion. Perhaps the "tragedy" Ernie had envisioned last summer had nothing to do with Down syndrome.

In a phone conversation nearly a week later, Tierney spells out a set of new rules to her father. "I can't have my daughter in an environment where she is going to be discriminated against, especially by her grandfather," she says. "If you can't tell me how long it will take for you to warm up to her, then I have a problem."

Two days later, Ernie calls back with an apology. He was too blunt, cruel even, and the comments he made at Bertucci's don't reflect how he really feels, he says. He might not agree with Tierney's choices, but he says he will respect them.

"Respect is absolute," Tierney says. "It's black and white. It's not gray. If you want to have a relationship with us, what's most important is that you respect my child, and that you demonstrate that with your actions."

Ernie says he understands. Tierney and Greg, hurt by his words and protective of their daughter, are skeptical. But
they will give him a chance, knowing that only time will tell.

It's Sunday, Nov. 21, Naia's first birthday party. Tierney has baked a cake using her grandmother's recipe, and Joan's house is awash in presents. There's plenty to celebrate.

This week, Naia received an encouraging one-year assessment from the Birth-to-Three therapists. "Naia's strength has improved greatly over the past few months," it says. "She visually explores and takes in much of what is happening in her surroundings. . . . Naia is a very friendly little girl who greets her visitors with a broad smile and vocalizations, often 'hi.'"

Even better, for several months she's been calling Greg "da-da." And just days before her party - at long last, as far as Tierney is concerned - Naia looked to her and said, "ma-ma."

Still, there are signs of developmental delays. The therapists estimate she is at the level of a 9-month-old in terms of gross motor skills; a 7- to 8-month-old for fine motor skills; and a 10-month-old for "expressive language."

More upbeat is Naia's one-year medical report. After routinely depressing visits to doctors early in Naia's life, this one is remarkably different. Greg goofs around, wearing Naia on his head like a hat. Naia laughs, pulling his hair. Then Corcoran, her pediatrician, bursts into the room with outstretched arms and a hearty "Happy Birthday!"

Corcoran says she's "astounded by Naia's development," including Naia's newly acquired ability to pull herself to a standing position, a precursor to walking.

"If I didn't know she had Down syndrome, I wouldn't make a referral to Birth-to-Three," Corcoran says. When Tierney suggests that Naia's progress is probably a result of the therapy sessions, Corcoran says there's more to it.

"This isn't Birth-to-Three. This is Naia," she says.

Adding to their delight, Naia weighs 17 pounds 10 ounces, and is 28 1/4 inches tall. She has gained nearly 12 pounds and grown more than 10 inches since birth.

This baby who flirted with death, who arrived for surgery eight months ago near the bottom of the Down syndrome growth chart, has made a stunning reversal. She is now in the 50th percentile for weight and the 75th percentile for height among children her age with Down syndrome. Naia has even grown her way onto the standard growth charts; she's on the low end, but she's there.

As they look back over the past 16 months, Tierney and Greg remember the painful knowledge gained from prenatal testing. But now that pain has been replaced by pleasure. When they think about the summer of 1998, there's a sense of confusion, a shared bewilderment: "How could anybody not want Naia?"

Still, they are grateful to have learned about Naia in advance. "The diagnosis she got in utero is exactly what happened," Tierney says. "Being prepared for her to have special needs allowed us to adjust our expectations, to deal with the grief and to reach acceptance. When she was born, we were ready. We were ready to celebrate Naia."

As the birthday party gets under way, Naia positions herself in the midst of her presents, pulling at the shiny wrapping paper and taking an occasional lunge at Onyx the poodle. Using the couch for balance, she pulls herself to a standing position.
Tierney and Tara stand close together, wearing their matching "hope" necklaces. Lately, Tierney hasn't worn hers quite so often. She has traded hope for something more concrete, an amber locket that opens to reveal tiny photos of Greg and Naia.

She soon might have to buy a bigger locket: Tierney and Greg have begun making plans for another child. They hope Tierney will be pregnant again by spring.

Greg takes Naia's hand, and she lets out a squeal of "DA-DA!" She takes one tentative step, then another.

END OF SERIES

Illustration
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