

The Children



When her son—conceived with an anonymous sperm
befriended other mothers whose children shared the same biological father
sperm banks, the vital importance of the Donor Sibling Registry, and

Donor

X



ave a mild form of autism, Gwenyth Jackaway went on the Internet and eerily similar diagnoses. **Emily Bazelon** reports on the reliability (or not) of a whole new kind of extended family. **Photographs by Mackenzie Stroh**

When Gwenyth Jackaway and Theresa Pergola met for the first time two years ago, they quickly spotted the resemblances among their children.

Gwenyth's son, Dylan, was 3, and Theresa's triplets, Anna, Anthony, and Joseph, 2. The mothers saw right off that Anthony and Dylan have the same full lips; Dylan and Joseph, broad foreheads and wide-set eyes. As the kids played in her living room, Theresa noticed the three boys bent over their toys in the same posture, backs curved at a similar angle.

Then Gwenyth pointed out more unsettling resemblances between Joseph and Dylan. Neither made much eye contact. And both were absorbed by letters and numbers, unlike Anna and Anthony. Gwenyth also noticed that when all four kids took off their shoes to run around the dining room table, Joseph was walking on his toes, a telltale marker of autism in young children.

Dylan, Anthony, Joseph, and Anna share the same father—Donor X from the California Cryobank, which is among the largest sperm repositories in the world. (The donor's number is being masked at the request of one of the mothers in this story.) At 2, Dylan tested on the autistic spectrum. Two years later, doctors refined the diagnosis to a form of autism called Asperger's syndrome, which means that while he is highly intelligent, unlike many autistic children who suffer from some degree of mental retardation, he shares some of the classic traits of the disorder—social and communication impairments and narrow interests. When Dylan was a baby, he didn't look at Gwenyth. When he learned to talk, he used words only to identify objects rather than communicating wants or feelings, or calling "Mama." As a toddler he could spend hours watching spinning toys, and at around age 3 he became obsessive about subway maps and lists of words and numbers, which still decorate every wall of his room.

GWENYTH, WHO GREW up in a small family, first contacted Theresa out of a longing for Dylan to be part of a larger community. Once the women connected through a Web site called the Donor Sibling Registry, Gwenyth quickly opened up about her son's

autism. Theresa had just begun to notice troubling signs in Joseph. He was 22 months old, and his speech seemed to be shrinking rather than growing. Unlike his brother and sister, he didn't respond when his name was called. And he regularly lined up blocks, videotapes—anything he could. Still, Theresa wasn't sure. "I was a little bit in denial," she said recently. "I kept going back and forth in my head on whether it was really true."

A week after the two mothers hung up the phone, Gwenyth and Dylan were on a train from New York City out to Long Island to visit Theresa and crew in the suburbs. The living room of their three-bedroom Nassau County home, which Theresa shares with her mother and sister, is covered with portraits of the triplets at 9 months. When Theresa broached her fears

about Joseph's development, Gwenyth responded by talking about the traits Joseph and Dylan seemed to have in common—and stressed the benefits that early diagnosis and specialized therapy were having for her son. Theresa couldn't help feeling defensive. "She was being gentle, but it was definitely scary," she remembers.

About a month later, prompted by her own questions and Gwenyth's observations, Theresa had Joseph tested. He, like Dylan, received a diagnosis on the autistic spectrum. Theresa didn't wait to call Gwenyth. She cried, and Gwenyth comforted her, and then they got down to business and talked about how to navigate the special education system to get Joseph the help he needed.

Two years later, they are still strategizing. "In some ways, I look at her as an older sister, someone who listens and guides me,"

TALL, DARK, AND ABSENT: Although the man whose sperm created this family is not here, everyone else was excited to show up for their first group gathering in New York City in January.



Anna, 4

Theresa

Gwenyth

Joseph, 4

Anthony, 4

Dylan, 5

Theresa tells me when the families meet up again for another weekend playdate. "I'd have gone crazy if it weren't for Gwenyth."

This time, Theresa and the triplets—who are 4 now and more portable—have made the trip to Gwenyth's Manhattan apartment, which is chic and artfully spare, the living room painted a cool blue, with a huge Monet print on one wall. Theresa stands in the doorway to Dylan's room, where he and Anthony send cars down a track; Joseph is hunched over another toy in the corner, and Anna tries to open a tube of paint. Gwenyth walks over to help her. A 46-year-old associate professor of communication and media studies at Fordham University, she has red-dish ringlets piled on top of her head and wears a silver choker and toe ring. Theresa, who is 38 and works in human resources, is dressed for schlepping—jeans, a flower-

and-glitter-covered T-shirt, her dark hair falling loose at her shoulders.

With a laugh that is infectious, her speech filled with the sound of Long Island, Theresa says she decided to have a baby when she was in a serious relationship with another woman. They've since split up, but the triplets see their "other mommy" regularly. Theresa also has a new girlfriend, whom she's planning to move in with.

Gwenyth had a string of relationships in her 30s with both women and men, and as each fizzled she toyed with the idea of having a baby on her own. Two months before her 40th birthday, 9/11 hit the city, and she called the

Cryobank. When she gave birth to Dylan, a good friend who'd become her labor coach was there to cheer her through an emergency C-section. He is one of Dylan's two godfathers, but Gwenyth has raised her

son on her own, dating only occasionally in the past five years.

When Dylan was first diagnosed, Gwenyth went through a mourning process. As she puts it, "You have to grieve a child you thought you were going to have. And then this whole new life gets handed to you." In hindsight, though, she thinks the panic she felt could have been at least partly eased. Autism is not a monolithic diagnosis. Some of the children struggle mightily and find their lives constricted as they become adults. Others without impaired intelligence, however, can learn to get along, often with the help of specialized therapy, and even to pass for "normal." Dylan has shown steady improvement, moving from a special-ed preschool to a mainstream one. And in many ways he's exceptional. Before the age of 5, he was reading at a fourth-grade level, playing two-handed compositions on the keyboard, and adding three-digit numbers.

Joseph's status is even more fluid. His diagnosis, pervasive developmental disorder-not otherwise specified (PDD-NOS), is a catchall term for children who exhibit some, but not all, of autism's attributes. In his case, the symptoms seem relatively mild. When he was 2, Joseph received one-on-one therapy five days a week; as he progressed, he only went twice a week. He attends a mainstream preschool with Anna and Anthony; by this summer, his teachers expect he will no longer need special help.

Gwenyth and Theresa have a word for their relationship: sister-moms. When Elizabeth heard it, she began to cry. "They feel like family to me."

Elizabeth and David, 4

Victoria and Victor, 4

Dixie

One couple with 4-year-old twins

David's brother, 2

Sydney, 4

AND THEN THERE'S DAVID. About a year after Gwenyth helped Theresa get through the shock of Joseph's diagnosis, she found herself in an eerily similar phone conversation about another child with developmental problems. Elizabeth (who asked to use only her middle name) is a speech pathologist who lives in western Massachusetts and also conceived with Donor X, twice. Her son David (a pseudonym) was born three months premature with bleeding in his brain, and for a long time doctors thought his behavioral quirks were a result of his birth. But Elizabeth stopped thinking that David would "grow out of it," as one of his teachers said, after she learned from Gwenyth and Theresa about Dylan and Joseph.

When Elizabeth and her son came for a visit last spring, Gwenyth watched David open and close a CD player over and over again. Then Elizabeth walked into Dylan's room. "I saw [CONTINUED ON PAGE 278]"

A LITTLE EMPATHY, PLEASE

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to wail, "Oh my God, you lucky rat! I gained ten pounds...."

But then I stopped myself.

"Um. So how does it feel to have to buy new jeans?" I said.

There was a silence on the line. Then Lisa started laughing. "Wonderful," she said. "Absolutely wonderful." **Q**

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that he had lists of numbers and Spanish words on the wall," she tells me later when I reach her on the phone. "As soon as David learns something, he wants to know all about it. He learned quickly how to count to 100, and then to 40 in Spanish."

Last June, soon after his fourth birthday, David got the same diagnosis as Joseph: PDD-NOS. Like Theresa, Elizabeth called Gwenyth before she told her family—it didn't matter that the women had met only once. They stayed on the phone for more than an hour.

Gwenyth tried to say what she wished someone had said to her—that an autism diagnosis isn't a terrible lifetime sentence, that a range of outcomes is possible, particularly for bright kids who get help at a young age. "It was easier to talk to Gwenyth than anyone else because she understands what this diagnosis means," Elizabeth says. Gwenyth and Theresa have a word for their relationship: *sister-moms*. When Elizabeth heard it, she started to cry. "They feel like family to me," she said, her voice breaking.

IN THE 1970S AND '80S, THEIR EARLY days, sperm banks primarily catered to couples who could not have their own biological children because of male infertility. Many of these families kept their children's parentage a secret. With a mother and a father accounted for, there was no particular call for honesty. As late as 1995, one study found that none of the parents in 45 sperm donor families planned to tell their children the truth about their genetic origins. Today, however, at least 60 percent of sperm bank users are single mothers or lesbian couples, according to Liza Mundy, author of *Everything Conceivable: How Assisted Reproduction Is Changing Men, Women, and the World*. These women can't fudge the father question so easily, and they've fueled an increasing push for connection and information—especially medical information.

For the Donor X mothers, the drive to find out about the paternal side of their

kids' family tree eventually led them to the Donor Sibling Registry (DSR). Started in 2000 by Wendy and Ryan Kramer—an enterprising mother and her sperm donor son—the DSR has gone from a small Yahoo discussion group to a sprawling Web site that has matched more than 4,000 children with their half-siblings or biological parents. The site is a nest of personals ads—it's just that the sought-after partner isn't a lover, but a parent, child, brother, or sister. Or perhaps, a "sister-mom," since many of the ads are placed by mothers on behalf of their children. "Some women use the Internet to build this new kind of kinship network," Mundy says. "They're raising their children on their own, but they feel like they have an extended family. The families are often far-flung, and yet the women have these intimate relationships."

Through the DSR, Gwenyth, Theresa, and Elizabeth found each other as well as two other single mothers, a lesbian couple, and a husband and wife who all chose Donor X. For some of them, the decision to join the site was made with a great deal of angst. One mother, who lives in Florida with her 5-year-old son, says that when friends told her she could look for his half-siblings, she wanted nothing to do with it. But later she started reading blogs written by mothers who had connected with the families of their kids' half-siblings, and she found herself craving the kind of knowledge they had. "We get to know the donor by getting to know the other children," she says.

The married couple, who have twin 4-year-old boys, went through a similar change of heart. At first, registering on the DSR felt "like jumping off a bridge," the mother says. Her kids would never wonder on their own where their father is. What would they make of all these half-siblings, when they were old enough to understand? And yet, once she knew the DSR was out there, the pull was irresistible. Last spring, after initial contact over e-mail, she and her husband conquered their fears and met up with Theresa and her kids when they came to Florida to go to Disney World. The families got together in a park, and as Gwenyth and Theresa had, the three adults marveled at the kids' similarities. Anna and one of the twin boys mirrored each other's facial expressions. They broke the crust off their sandwiches with the same precise gesture. And when they squinted in the sun they looked as if they could be twins.

So far, the DSR has connected seven families who used Donor X. They live in five states and have 11 children, two of them

girls, nine of them boys (with one more on the way). The odds that three of these kids would fall on the autistic spectrum is about 45 times higher than the chances for the general population.

GAPS IN MEDICAL KNOWLEDGE BECAUSE of unknown genetic history are always a concern, but when a child has health or developmental problems, the issue feels especially pressing. Among the Donor X families, the reports of autism have drawn some of the parents closer—affecting even those not directly touched by it. For the married couple, seeing how much the others were getting from these relationships has strengthened their intention to tell their own sons when they are older that they were conceived with donor sperm—and also, as it happens, donor eggs. "I don't want to mislead them or have them make medical decisions based on faulty information," the father says.

For other parents, the sharing of medical data has already had real meaning. Victoria Boyd conceived a son named Victor with Donor X. When he was about 2, he had a speech delay and significant trouble chewing and swallowing food. Now at 4, the problems have mostly resolved, thanks to early intervention. But Victoria has been grateful to know about Dylan and Joseph, because the information has given her more to go on. "These are his blood siblings, so that was important," she says.

This is familiar terrain for the DSR's Wendy Kramer. "I wanted to respond to our members' stories about struggling to get medical history that the banks won't give them," Kramer says. And so she recently added a new option to the registry. It's a page designed to collect all relevant genetic and medical information that families who used the same donor wish to share among themselves. The donor can also post, anonymously if he chooses. "I wanted to create a safe place where the donor can let the families know if his father dies of a heart attack, or other medically important facts," Kramer says.

Is the bank that sold Donor X's sperm at fault for failing to catch the genetic defect he appears to carry? (None of the mothers of affected children has family members with autism.) No history of the disorder showed up on the three-generation medical profile that Donor X filled out for the California Cryobank. The bank conducts DNA testing for conditions like Tay-Sachs, cystic fibrosis, and sickle-cell anemia, which are primarily caused by a single mutant gene. Autism is a different

story. The disorder clearly has a hereditary component (if one identical twin has it, the odds the other will, too, are between 60 and 90 percent), "but there is not a genetic test for autism because we have not yet identified enough genes that might cause it," says Peter Szatmari, MD, a veteran autism researcher and psychiatry professor at McMaster University in Hamilton, Ontario.

There is at least one other case, reported in 2006, of a high rate of autism and related disorders among children with a common sperm donor—four of the seven known children of California Cryobank donor 3066. Other accounts of shared medical problems among donor children have cropped up. Mundy writes of a group of mothers on the DSR who used Donor 1476 of the Fairfax Cryobank in Virginia, and discovered that while he had claimed to be allergy-free, several of the more than 35 children he produced have problems with asthma. And in Michigan, pediatric hematologist and oncologist Laurence Boxer, MD, diagnosed five children born into four different families with the same genetic disease, severe congenital neutropenia, a blood abnormality that highly increases vulnerability to bacterial infections and raises the risk for leukemia. In treating the children, Boxer discovered that all of their parents had used the same sperm donor, from a Michigan sperm bank. The rate of severe congenital neutropenia is one in five million children in the general population, but a genetic carrier has a 50 percent chance of passing it on. Boxer, writing in the *Journal of Pediatrics*, surmises that the donor's malfunctioning gene only showed up in his sperm—a condition known as a gonadal mosaicism—and without genetic testing, he would have seemed perfectly healthy.

The sperm banks have taken hits as a result of these cases. Some parents say they have phoned in their concerns, describing their children's problems and asking if any similar accounts had been filed, only to learn later that the banks kept no record of their calls and continued to sell the donor's sperm. That has not been the experience of the Donor X group. When Dylan got his diagnosis, Gwenyth called California Cryobank and had a long talk with a genetic counselor, Mindy Bukrinsky, who worked there at the time. "She asked a lot of questions. I felt they took it seriously," Gwenyth says. Theresa, Elizabeth, and Victoria followed up with calls of their own. Persuaded that this donor posed a higher-than-average genetic risk, the bank pulled his sperm from general circulation. Cryobank also

notified families that had vials in storage about the autism—and contacted the donor himself. "We wanted him to know for his own future reproduction," says Bukrinsky.

The bank's handling of this particular case seems fairly unassailable. But that doesn't mean the same is true across the industry. In the United States, sperm banks are virtually unregulated. As a result, they function much as adoption agencies did a half-century ago: Secrecy is the norm—the concern more about protecting the donors' anonymity than helping families solve health problems that develop as their children grow. California Cryobank facilitates the updating of a donor's medical history over the years for the benefit of its clients. But as the DSR's Wendy Kramer points out, this is rare. In most cases, the purchase of sperm is a one-time transaction.

California Cryobank allows up to 25 families to purchase the sperm of one donor.

Sometimes the banks go to seemingly unreasonable lengths for the sake of a donor's privacy. In 1991 Diane and Ron Johnson wanted to have a second child. So they went back to the California Cryobank for more vials of sperm from Donor 276, with which they'd already conceived a daughter, Brittany, in 1989. The second time around, the bank told the Johnsons that Donor 276 had a family history replete with kidney disease—his mother and aunt both suffered from it. The bank had evidence of this ever since the donor filled out a profile chart in 1986. Brittany became sick with the illness (autosomal dominant polycystic kidney disease) four years later, at the age of 6. The Johnsons sued the bank for initially failing to disclose the information, and to compel Donor 276 to testify about it. They argued that he had information that was crucial to future decisions about their daughter's treatment.

When the donor refused to come forward, the sperm bank joined him in fighting the subpoena. In 2000 the California Court of Appeal rejected the bank's argument and forced the donor to testify, ruling

that he could do so anonymously. "There may be instances under which a child conceived by artificial insemination may need his or her family's genetic and medical history for important medical decisions," the court wrote.

By protecting the donor's privacy while demanding that he testify, the California court sought to help Brittany without shredding the guarantee of anonymity. That's what donors are promised in the contracts they sign. Identity protection also appears to be key to a thriving donor market. Despite the financial incentive—at California Cryobank, donors can make almost \$8,000 for a year of twice weekly visits—sperm is now in short supply in Australia, the Netherlands, and the United Kingdom, where laws have been changed to give donor offspring the right to know who their fathers are. Faced with long waiting lists, some foreign banks have even resorted to importing sperm from abroad.

The fear of scaring away future donors complicates the question of sharing medical histories with donor children. Still, advocates argue that there is plenty of room for reform. Wendy Kramer wants the banks to take a first step by tracking live births. As it stands, California Cryobank admits that it doesn't hear back from many of its clients. Meanwhile the bank allows as many as 25 families, each of which may have multiple children, to purchase the sperm of any one donor; after that, he is retired. Without a complete record of births, it's nearly impossible for the banks to notify all the potentially affected families when evidence arises of a genetic risk like Brittany's kidney disease, or Dylan's, Joseph's, and David's autistic spectrum disorders. This is where Kramer hopes the DSR's new medical page will come in. The details of a family's history can prompt a mother to get a child tested, as Theresa and Elizabeth did—no small thing, because with autism, early intervention can matter. And then there are the decisions that parents make about their family's future. The Florida mother whose 5-year-old son has developed normally recently elected to use Donor X's sperm again. Pregnant with a second son and in a long-term lesbian relationship, she says, "I wanted my two boys to be related in every way possible. Since my partner and I can't reproduce without the assistance of a donor, we felt that choosing the same donor was the only logical way to go." But a second Donor X mother, Dixie (she did not want her last name printed), says that she will use the sperm of a different man if she has more children. Her daughter, Sydney, ▶

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now 4, looks like Theresa's daughter, Anna, and has the donor's professed aptitude for music. Still, Dixie doesn't want to take her chances with autism, now that she knows about the risk. "Not that you wouldn't love the child, but why would you want to stack the odds against yourself like that?" she asks.

NATURAL AS THAT QUESTION IS, TOO much focus on a donor's medical history can make a sick or disabled child seem like faulty merchandise. "There is no certainty in a baby. It does not come with a ten-year warranty," warns David Plotz, author of *The Genius Factor*, the history of a sperm bank established to propagate the genes of Nobel laureates and other prodigies. When parents have only their own genes to hold accountable, are they less likely to feel burdened or cheated by a child with health problems?

Gwenyth, Theresa, Elizabeth, and Victoria voice no such regrets. Donor X appealed to all the mothers (and the one father) who chose him for a variety of reasons. Theresa and Elizabeth were attracted to his part-Puerto Rican heritage, which he had in common with the women who were their partners when they became pregnant. Victoria is African-American, and the bank offered her few donors of color; Donor X was the one with a strong academic record who presumably looked the most like the men in her family. For other parents, the donor's IQ was his primary selling point: They mention his degree in economics and that he'd also studied astrophysics—although the form he filled out doesn't name the schools and the bank doesn't verify such information as courses taken.

A common perception about autism—especially Asperger's—is that it runs in the families of scientists. Astrophysics, then, could seem like a telling clue in retrospect. But the parents who chose Donor X don't think they missed any obvious warning signs. On paper and in the audiotaped interview he did with the sperm bank, they all say, he came across as socially adept and quintessentially well rounded. He made jokes, said he loved to travel, play basketball, listen to music, and was curious about moviemaking.

For Gwenyth, the deciding factor was the evidence of his imagination. "They asked him, 'Where do you like to travel?' and he wrote, 'To the farthest reaches of the universe.' Some people might think that's weird. But I'm also philosophical and

I like to think big picture. For me, that was it." Rejecting the idea that she would have screened him out as a father if she'd actually met and dated him, she told me the first time we spoke, "I feel nothing but a huge, huge debt of gratitude to the donor who helped me create Dylan. This is the luck of the draw, and there are all kinds of happily married adults with autistic children. I hope someday I get to kneel at our donor's feet and thank him. He brought me the best gift of my life."

Still, even if Donor X were the type to have children on his own, he almost certainly would not have had a dozen of them. "It's true that if you marry someone and have a child, you never know the whole picture about genetic risk," says *Everything Conceivable's* Mundy. "But because sperm donation has become an industry, a greater number of people will be at risk from a

"I hope someday to kneel at our donor's feet and thank him. He brought me the best gift of my life."

single person's genetic makeup. It's like E. coli at a big hot dog plant as opposed to a small farm: The danger is dispersed over larger numbers of people."

And yet the extended web has its benefits: "I find it comforting to know that Dylan's siblings have similar challenges," Gwenyth says. "It tells me that there's nothing I did that made this happen to him. This is just the luck of the gene pool." She and Theresa see themselves as the driving engine of the Donor X families. Or is it one big family? In January many of the parents met for the first time—a great thrill. The kids are still young, and it remains to be seen whether or not they will decide to forge ties with one another as they grow older.

In the meantime, it's the mothers for whom these relationships are paramount. "Are you excited to see your brothers and sister?" Gwenyth asked Dylan three times when Theresa and her kids were on their way over the afternoon that I spent with them. Dylan didn't answer, and it was hard

to imagine what he thought about the idea of siblings. But Gwenyth's feelings were clear. She and Theresa hugged and kissed and traded new observations. "See how much better his eye contact is?" Theresa asked Gwenyth, motioning to Joseph. Gwenyth nodded, and then they stood back while the children sang a naming song with Terri Trent, a special education teacher whom Gwenyth had asked to help with the visit. When it was Joseph's turn, he looked directly at Terri and said, "My name is Joseph." Theresa beamed.

Dylan played his part in the song, too. Last year, when Terri started working with him in preschool, he was isolated and couldn't find the words to talk to other children, despite his advanced reading and cognition. At almost 5, Dylan made his first friend in preschool. Socializing still isn't easy for him. He got upset when the triplets wouldn't sit still and listen to him play an eight-song concert on his keyboard. But before that frustration came a peaceful interlude. All four kids played on the keyboard together. Anna and Anthony and Joseph tapped away. Dylan held down a bass note. Gwenyth and Theresa drank in the music. The notes weren't in harmony, exactly, but then families rarely are. **O**

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