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

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 of 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.

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
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 door 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 reddish 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.

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
CONTINUED FROM PAGE 276

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."

THE CHILDREN OF DONOR X
CONTINUED FROM PAGE 253

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, par-
ticularly 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 bi-
ological children because of male infertility.
Many of these families kept their children's
parentage a secret. With a mother and a fa-
ther 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 — espe-
cially 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 en-
terprising 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 par-
ents. 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 Inter-
et to build this new kind of kinship net-
work," 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 knowl-
dge 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 fam-
ilies 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

GAPS IN MEDICAL KNOWLEDGE
BECAUSE OF UNKNOWN GENETIC HISTORY ARE AL-
ways 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 oth-
ers 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 informa-
tion," the father says.

For other parents, the sharing of medi-
cal data has already had real meaning. Vic-
toria 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
and medical information that fami-
lies 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 otherwise medically impor-
tant facts," Kramer says.

Is the bank that sold Donor X's sperm
at fault for failing to catch the genetic de-
fect 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-genera-
tion medical profile that Donor X filled out
for the California Cryobank. The bank
ducts 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.
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 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," Gwynyth 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?" Gwynyth 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 Gwynyth's feelings were clear. She and Theresa hugged and kissed and traded new observations. "See how much better his eye contact is?" Theresa asked Gwynyth, motioning to Joseph. Gwynyth nodded, and then they stood back while the children sang a naming song with Terri Trent, a special education teacher whom Gwynyth 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. Gwynyth and Theresa drank in the music. The notes weren't in harmony, exactly, but then families rarely are. [O, The Oprah Magazine (ISSN 1531-3247), Vol. 9, No. 4, is published monthly by Hears Communications, Inc., 300 West 57th Street, New York, NY 10019, U.S.A. Victor F. Ganzl, President and CEO; George R. Hearst, Jr., Chairman; Frank A. Bennack, Jr., Vice Chairman; Catherine A. Bostron, Secretary; Ronald J. Doerfler, Senior Vice President and Chief Financial Officer. Hearst Magazine Division: Cathleen P. Black, President; George J. Green, Executive Vice President; John P. Loughlin, Executive Vice President; John A. Rohan, Jr., Vice President and Group Controller. Due to the high volume of submissions, the publisher cannot accept or return unsolicited manuscripts or art. Subscription prices: U.S.A. and possessions: $24 for 12 issues. Canada and all other countries: $50 for 12 issues (Canada BN NBR 10321 0943 RT). © 2008 by Hearst Communications, Inc. 0, The Oprah Magazine is a registered trademark of Harpo Print, LLC. Subscription service: Should you have any problems with your subscription, please go online to service.theoprahmag.com, or write to Customer Service Dept., O, The Oprah Magazine, P.O. Box 7186, Red Oak, IA 51591. Periodicals postage paid at New York, N.Y., and at additional mailing offices. Canada Post International Publications Mail Product (Canadian Distribution) Sales Agreement No. 490012499. Send returns (Canada) to Bleuch International, P.O. Box 2542, London, Ontario, N6C 6L2. From time to time, the publisher makes our subscriber list available to companies who sell goods and services by mail that we believe would interest our readers. If you would rather not receive such mailings, please send your current mailing label or exact copy to Mail Preference Service, Box 7024, Red Oak, IA 51591-0024. Postmaster: Please send address changes to O, The Oprah Magazine, P.O. Box 7186, Red Oak, IA 51591. Printed in the U.S.A.}