## WIRED



Amy Shelton-White and Jeff Johnson

PHOTOGRAPH: BETHANY MOLLENKOF

CAITLIN HARRINGTON

BACKCHANNEL

07.30.2020 07:00 AM

## There's No Such Thing as Family Secrets in the Age of 23andMe

DNA tests are cheap and ubiquitous. For some donor-conceived people, they can unearth long-buried truths about their ancestry—and lead to unorthodox reunions.

JEFF JOHNSON WAS in a hurry. His lunch break was nearing its end, and he needed to catch the 6 train back to Union Square, where he worked an entry-level job at the publisher Farrar, Straus & Giroux. He flew down the stairs to the subterranean clinic on New York's Upper East Side, into a Bond-chic windowless cave of an office. He greeted the nurse—lab technician?—he wasn't sure which, and ducked into an exam room stocked with straight pornography he wouldn't use.

The year was 1974. The clinic, Idant, had opened three years earlier, one of the country's first commercial sperm banks. Johnson had heard through a friend that they were seeking men with twice the average sperm count. He was 21, needed the money, and figured it would make a good pickup line at the bars in Greenwich Village.

The sperm bank had requested some basics: height, weight, eye color, race, religion, education. The health portion of the application comprised half a page: blood type, causes of immediate family members' deaths, a checklist of about a dozen medical conditions, including one simply labeled "mental disorders." He checked a couple lines next to hay fever and nonspecified eye disorders. He didn't provide verification; they didn't ask. It was all anonymous. He could slip out as invisibly as he entered, and no one would know he was there.

Having made his donation, Johnson headed back to work. On the way, he stopped into the fancy French bakery around the corner to buy a pastry before descending into the subway station. He savored the rich indulgence, his reward for a job well done. He didn't know it at the time, but his donation—like hundreds of others collected by Idant—would be sent to a clinic in Michigan.

Three years later, British biochemist Frederick Sanger developed a groundbreaking method for rapid DNA sequencing. Fifteen years would elapse before the World Wide Web was born, and another 14 before scientists finished mapping the human genome. The notion that geneticists would learn to decode our unique genetic fingerprints, that companies would make that information accessible to millions, that vast digital networks of global interconnectivity would render the idea of anonymity quaint—all that defied imagination in 1974.

But technology has a way of creating new consequences for old decisions. Today, some 30 million people have taken consumer DNA tests, a threshold experts have called a tipping point. People conceived through donor insemination are matching with half-siblings, tracking down their donors, forming networks and advocacy organizations. As their numbers grow, more and more of them are banding together to demand regulation of a fertility industry they say has long overlooked their concerns.

In November, Australian health professor Sonia Allan and Belgian advocate Stephanie Raeymaekers led the first delegation of donor-conceived people to Geneva to mark the 30th anniversary of the UN Convention on the Rights of the Child, an international human rights treaty ratified by all member states except the US. Nearly 20 speakers sat two rows deep behind a king-size wood-slatted conference table in a honey-toned meeting room and took turns addressing the convention. Betty Wright talked about feeling "wrong" because she never saw her idiosyncrasies reflected in her family. Damian Adams donned a Phantom of the Opera-style demi-mask to illustrate the mystery half of his identity. Joey Hoofdman spoke of his 75 half-siblings, too many to bond with. Hayley Wilson described her siblings' refusal to date without asking partners to take a DNA test to make sure they weren't related. Joanna Rose told the story of her friend Narelle, who died in 2013 after learning too late about her genetic predisposition to bowel cancer.

They concluded, "We are the products of this industry, and we have not been heard ... We are now grown, and our voices are stronger. We know what is in our best interests and what is not, and we hope you are listening." The audience rose to its feet to applaud.

THE EARLY MORNING sun cast long shadows as Ann walked into the fertility clinic in downtown Birmingham, Michigan, in the summer of 1975. She settled onto a cool exam table and adjusted her legs in the stirrups while the doctor prepared the catheter for insertion. A severe childhood case of the mumps had depleted her husband Norman's\* sperm count, and years of failed attempts to conceive had sapped her morale. So when her gynecologist told her about a new procedure called donor

insemination, she perked up. There was just one catch, the doctor said. If she went through with it, she shouldn't tell him. He didn't want to lie on the birth certificate.

Initially, Norman had balked. Accepting his infertility, not to mention another man's intervention, would mean acknowledging a socially shameful and emasculating fact. But Ann wasn't prepared to go through life without having her own kids. She issued an ultimatum—the procedure or a divorce. After six months of deliberation, Norman relented, under one condition: As long as he was alive, Ann could never tell a soul. (Ann asked me to omit her last name because Norman's brother is not aware of the situation.)

Doctors had faced resistance like Norman's before, and they'd devised a solution. They would inseminate Ann with a mixture of Norman's sperm and the donor's. That way, if she became pregnant, the couple could choose to believe the child was Norman's. (The practice would lead to some bizarre, unintended outcomes, such as triplets with different fathers.)

The young couple huddled together inside the clinic, paging through an oversized binder filled with typewritten pages of anonymized donor data. There were no photos, just a listing of physical attributes and a few biographical basics: height and weight, hair, eye, skin color, religion, occupation, and education. The doctors assured them that the specimens were high-quality: fresh sperm, exclusively from University of Michigan medical students. They spotted one whose characteristics approximated Norman's: 5'10", fair complexion, brown hair, blue eyes. We'll take this one, they said.

After a few failed attempts, the doctors abandoned the sperm mixture and used only donor sperm. Each morning, Ann woke up at 4 am and stuck a thermometer beneath her tongue. When her temperature dropped a certain amount, indicating ovulation was about to begin, she called in sick from her telephone operator job and made the hour and 45 minute drive to Birmingham for insemination. After a few months, she became pregnant. The following summer, she gave birth to a girl. Denise was long and lean, with hardly an ounce of baby fat, nothing like the butterball babies that ran in Ann's family. She marveled at her daughter's striking blue eyes.

Ann rejoiced. She finally had what she'd longed for, a child of her own. But the knowledge that another man had likely fathered Denise plagued Norman. He formed a loving relationship with his daughter, but his marriage grew strained. He took to heavy drinking and extramarital affairs. The couple divorced when Denise was 5, and Ann remarried and had two more daughters, both conceived the old-fashioned way.

The secret weighed on Ann. She worried about what would happen when Denise started dating. What if the donor had family in the area? The risk of unintentional consanguinity—the technical term for relatives hooking up—remains small, but it looms large in the minds of those conceived via anonymous sperm donation. In 1992 the tabloid TV show *Hard Copy* aired an episode featuring a donor who was rumored to have fathered 500 children, two of whom believed they nearly married. Last year, a Reddit post went viral after the author claimed he'd discovered via 23andMe that his girlfriend was his half-sister.

From time to time, Ann would notice qualities in Denise—her smarts, her athleticism, her bright blue eyes—and think, she must have gotten that from her donor. She secretly hoped that one day Denise would track him down. She knew it was a long shot, though. The clinic hadn't even given her the donor number.

Norman succumbed to his drinking, and in 2010, at age 60, he died from cirrhosis of the liver. Denise was 32. Freed from her promise of secrecy, Ann prepared to tell her daughter the truth. Arriving home with the family after her youngest daughter's graduation, Ann announced she had news. A thought came to Denise, as if from someone else's mind. "She's going to tell me my dad isn't my real dad." It took her aback. The idea had never occurred to her before.

Ann told her about the mumps, the infertility, the Birmingham clinic, the donor. She handed Denise the receipt from the clinic—for a couple hundred dollars—and a clipping from the Donor Sibling Registry, an organization that launched in 2000 to connect offspring to their donors and siblings. She hoped that Denise could use it to track down her biological father.

But Denise shrugged it off. She already had someone who'd wanted to be her father. "My dad was my dad," she said. "I don't really need another one." OK, Ann thought, surprised. That's that.

THE FIRST WOMAN ever to give birth to a donor-conceived child never knew it. In 1884, an unscrupulous Philadelphia doctor named William Pancoast chloroformed one of his patients, then inseminated her using a rubber syringe loaded with sperm from what he considered his most attractive medical student. He eventually came clean to the woman's husband, but the men agreed the mother would be better off left in the dark. The six medical students who witnessed the procedure were sworn to secrecy; however, compelled by the "peculiar ethics" of the case, one of them published an account of the affair 25 years later in a letter to the publication *Medical World*.

Donor insemination continued largely underground, sans chloroform, until the 1950s. Doctors typically used fresh semen from a limited supply of nearby medical students—or occasionally their own. In 1953, an Arkansas doctoral student named Jerome K. Sherman successfully inseminated a woman with sperm he'd frozen in solid carbon dioxide and preserved with glycerol. For the most part, a combination of stigma, religious opposition, and legal roadblocks kept the practice in the closet. In 1954 and again in 1963, state courts ruled that donor insemination constituted adultery, husband consent notwithstanding. They deemed the resulting children illegitimate.

That changed In 1973, when ULC, a nonprofit that drafts state legislation, introduced the Uniform Parentage Act, which was later adopted by a handful of states. It afforded legal paternity rights to the husbands of women who birthed children from donor sperm. A few years later, scientists developed reliable cryopreservation methods, setting the stage for commercial sperm banks. Freezing sperm allowed banks to stockpile catalogs of donors, ushering in an era of consumer choice.

Frozen sperm became standard in the late 1980s during the AIDS crisis, after several women contracted HIV from donors. A new infection could take months to show up on a test, so freezing kept sperm alive during a quarantine period, after which clinics could retest it. The practice remained voluntary, however; no law mandated it.

All the while, doctors advised couples against telling children the truth about their parentage, warning that it could threaten family unity. It wasn't until LGBTQ parents obtained widespread access to assisted reproduction that the practice started coming into the light. Nondisclosure wasn't really an option, and these children expressed curiosity about their origins.

The Sperm Bank of California, the country's only nonprofit sperm bank, opened in Oakland in 1982, catering to lesbian couples. Responding to requests for more information, they pioneered the first identity disclosure program in 1983: Once donor-conceived people turned 18, they could request their donor's identity and contact information. Commercial sperm banks seized the opportunity to expand their customer bases, adding their own identity disclosure programs.

The industry hummed along in Wild West fashion until 2005, when the FDA began requiring that gamete banks test donors for communicable diseases such as HIV, hepatitis, and chlamydia. (Gametes are reproductive cells, like sperm or eggs.) The agency currently requires testing for eight transmissible diseases, six-month quarantines, and record retention for 10 years post-insemination. Aside from that, US sperm banks are largely free to operate as they please.

COLIN,\* A SCIENTIST, is a sucker for data. He loves the certainty of it, the cutand-dry clarity. So in the summer of 2008, after a coworker's 23andMe test revealed
her genetic disposition to a life-threatening disease, Colin immediately ordered a kit of
his own. He spat prodigally into the funnel-capped plastic vial, mailed it off, and several
weeks later, pored over his personalized library of gene variants. 23andMe also offered
a DNA Relatives feature, but there was nothing unusual in Colin's family tree. His
father had talked of their Norse heritage, and his genetic profile seemed to confirm
those roots. His family was pretty boring.

Years passed, and on August 12, 2015, Colin awoke to a startling message. "It's come to my attention that you're my biological son," it said. Colin figured he was experiencing some DNA kit version of the Nigerian prince scam. When he navigated to 23andMe's DNA Relatives tab, an unfamiliar name topped the list: Jeff Johnson. "50% shared

DNA," the screen read. Under "Relationship," it said, "father." Maybe that message wasn't a scam after all.



Jeff Johnson donated sperm in 1974. He didn't know what offspring he might sire.

PHOTOGRAPH: BETHANY MOLLENKOF

"You have my attention," Colin wrote back, wondering how such a grievous error could have occurred. He quickly began Googling "23andMe breach" and "Spam on 23andMe" but came up empty-handed. He wrote to the company, asking them to investigate the mistake. 23andMe receives so many of these messages that they've since added a warning and a page titled "Navigating Unexpected Relationships" that opens with the message "You're not in this alone."

At 1 pm, Colin called his mother. At 6:30 pm, he called his father. It must be spam, they told him; ignore it. They couldn't believe someone would try and mislead him that way.

Later that day, 23andMe wrote back. They went to great lengths to maintain quality control, they assured him. A mistake was unlikely. Unsatisfied, Colin forwarded his results to a geneticist friend. "I understand this can be shocking," his friend wrote back, "but there's no chance that this is false."

Colin felt the seams of his reality beginning to tear. Every explanation he grasped for disintegrated in his hands, save for the one he wanted desperately not to believe. He ordered three more DNA kits, one for each of his three sons. He wanted to see if their DNA also matched Jeff Johnson's. "I had this feeling that only data could settle my anxiety," he says. But it would be at least a month until the results came back, and he worried he'd unravel in the meantime.

In his office, Colin had access to statistical software called Bioconductor that had a chromosome analysis tool. He approached Jeff with a peculiar request. "Will you send me your genome?" Jeff complied. Colin fed both of their DNA into the program, and almost instantly the results came back. Genetically speaking, they were father and son.

Time slowed. Colin felt adrift. He scoured the internet for advice, other stories like his, a life raft he could grasp to guide his thoughts. He couldn't find his situation reflected anywhere. During his search, he happened upon the website for the Donor Sibling Registry. Its cofounder, Wendy Kramer, was the mother of a donor-conceived child. Frantically pacing an empty cafeteria at work, he gave her a call. She had heard the story before and calmly directed him to some resources.

What Colin didn't know was that his experience was playing out in living rooms and offices and deserted cafeterias across the world. Such incidents have become so common in the past few years that they've earned their own term: NPE, for non-parental event. The explosion of low-cost home DNA tests has prompted a wave of unexpected parentage discoveries, connecting donor-conceived people with their biological parents and siblings without much of a rule book to guide their interactions. (The word *donor* rankles some, as it obscures the transactional nature of the arrangement; some prefer *vendor* or *provider*.)

Therapists have begun to note patterns in the cycle of emotional processing. "Once the shock settles down, it looks a lot like grief," says Eve Sturges, a marriage and family therapist who started an NPE podcast last year called *Everything's Relative* after making her own NPE discovery.

Shock propelled Colin through the grief cycle. "Because it was sudden, it was like a death. It was the death of a secret, the death of a parenthood, and we all went through some stages of grieving."

Colin drove three hours to his parents' house. (He's from Michigan and his parents still live there.) As he sat facing them at the kitchen table where they'd shared countless family meals, unspooling his thoughts, he began to realize something: They thought Colin's father was in fact his biological father. Colin looked and acted quite like him; it wasn't far-fetched to assume they were biologically connected. "It was the only time I'd heard of where a child has to break the news of his parentage to his own parents," Colin says.

Colin's usually composed father grew visibly rattled. He pushed out his chair and excused himself to go for a walk. His mother realized the futility of continuing to deny the facts, and told him the truth: Back when his parents wanted a child, they had struggled to conceive. Colin's father had had a low sperm count, so they tried donor insemination. But since they had continued trying to conceive naturally, they never knew what took. They decided to believe Colin was their natural offspring.

When Colin's father returned, his parents told him they never wanted to discuss the subject again. As long as they were alive, he was not to utter a word of it to anyone. Colin would later chalk this response up to the bargaining stage of grief. He figured it was his parents' way of regaining control of a situation that had so suddenly slipped from their hands.

Colin agreed to keep the secret. "With genetics, you realize that your decisions aren't just yours," he says. He carried the burden of not just his own feelings, but those of his mother, his social father (the term for nongenetic fathers), his brother, his wife and

children, Jeff Johnson, and Johnson's other potential offspring. Johnson hadn't married or had kids, but for donors who had, another set of feelings enters the mix. Decisions reverberate. A family tree becomes a family forest with dizzying speed. Colin shouldered it all alone. "Right now, according to the documents, I'm 100 percent biologically related to my father," he says. "The only person who can screw that up," or at least that illusion, "is me."

THREE YEARS LATER, on a Sunday afternoon in Maine, Denise clicked off her vacuum cleaner and went to check her email. Amid the usual onslaught of newsletters and promotions, a curious message stood out. It appeared to come from the Genographic Project, National Geographic's now-defunct human migration project, where she and her wife had uploaded their DNA results a couple years earlier. A New Zealand woman claiming to be her fifth cousin wanted to connect.

The message struck Denise as fishy, and when she navigated to the Genographic Project's website to investigate, she found no record of the woman. While on the site though, she noticed something else—a new family member match. Based on the shared DNA, it looked like a close relative. She emailed the man, including her phone number. "This says you could be my half-brother or uncle," she wrote. Two hours later, her phone rang. It was Colin.

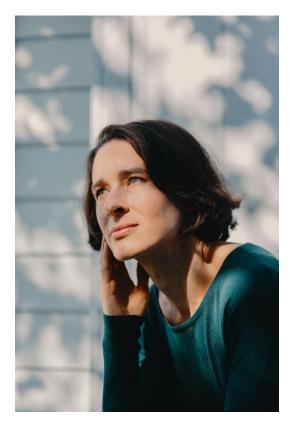
He had been in touch with their biological father, a man named Jeff Johnson, who lived in California. Johnson wasn't a medical student; he'd never even lived in Michigan. And they had another half-sibling, Amy.

**UNIQUE AMONG JEFF'S** offspring, Amy Shelton-White knew she was donor-conceived from childhood. Her mother, Elizabeth, an ardent progressive with an iconoclastic streak, believed in leveling with her children. Like Denise's dad, Amy's father suffered a spermicidal case of childhood mumps, and like Denise's dad, Amy's father swore Elizabeth to secrecy. (They too lived in Michigan at the time of Elizabeth's pregnancy.) But the couple divorced when Amy was a baby, and her father died when she was 4, of non-Hodgkins lymphoma. She remembers hanging around a long-haired construction worker as a 7-year-old while he worked on their Newburyport,

Massachusetts, house. She told him her dad was a sperm donor. He said that made her special. She thought so too.

Adventurous in her own introverted way, Amy had moved to Los Angeles to pursue acting, marrying another actor she met on the set of a B horror flick, *Sasquatch Hunters*. In 2008, as her mind turned to starting her own family, she grew curious about her roots. At the very least, she wanted accurate medical information. The one-two punch of anonymity and nondisclosure means that most donor-conceived people of a certain generation lack access to half their family medical history, at best. At worst, they possess incorrect information from a social father to whom they're unrelated.

Amy had few memories of her dad—his red station wagon, his workaholism. As a kid, she would daydream about what it might feel like to have a father. She pictured someone tossing her in the air. She had little else to go on. "It was like trying to imagine what it would be like to hang out with a Martian," she says.



Amy Shelton-White knew she was donor-conceived from childhood.

PHOTOGRAPH: BETHANY MOLLENKOF

Amy harbored no illusions that her biological father would fill that role. At 33, she was long past tossing age; no amount of bonding would reverse that. But she hoped he'd be cool. She hoped he'd approve of her. If she were honest, a small part of her even hoped that he would become family. But she tried not to indulge that hope. For all she knew, he could be a total cad.

After Elizabeth recalled the fertility doctor's name, Amy started cold-calling clinics in Michigan. Several stumbling, awkward conversations produced dead ends. She finally reached a veteran nurse in Birmingham, whose memory Amy's story sparked. Patient confidentiality prevented her from sharing files with Amy, but she told her to have her mom call. Hurry, she said. They were in the process of destroying old records.

Elizabeth called, and the clinic gave her the donor number and the name of the clinic they obtained the sperm from: Idant. She called the New York sperm bank, and a clerk told her they had the full profile of Amy's donor and offered to mail her a copy. When Amy opened the envelope, she found that they had accidentally enclosed the unredacted version along with the anonymized one. There, in her hands, lay everything: Jeff Johnson's name, his donor number, his previous addresses, his former employer. (The Michigan fertility clinic has since closed, and Idant closed for good around 2015 after multiple lawsuits and a health-code-related suspension. Its parent company paid a \$250,000 settlement last year to a mother who alleged that her sons were part of a donor-linked autism cluster.)

Armed with this new-found information, Amy set out to track down Johnson. She flirted with the idea of hiring a private detective, but while casting about online, she happened upon the Donor Sibling Registry. Home DNA kits hadn't yet hit the mainstream, and the DSR was the main way for donors and offspring to connect. She created an account.

Years earlier, Johnson had read about the DSR in the news and entered his donor number, mostly out of idle curiosity. Years passed without event, so when he received a message in the summer of 2008, "it felt like the ground shifting under my feet." He hadn't thought much about what he'd do if a match materialized. He asked himself what he would want if the roles were flipped. With some apprehension, he sent a reply.

Amy and Jeff began by exchanging photographs, nearly identical ones, each of them kneeling beside a stream. They discovered they both lived in the Los Angeles area, so two days later, they arranged to meet at a restaurant, with Amy's husband, David, in tow. Amy had heard stories of donors and offspring meeting and becoming flooded with a sense of instant recognition. But with Jeff, the similarities took time to reveal themselves. She would begin to notice their even-temperedness, their craftiness. Elizabeth later commented on their intuitive sense of other people's needs. David said they walked the same way.



Amy Shelton-White still doesn't call Jeff Johnson "Dad," but her kids, who have always known him, call him Grandpa Jeff.

PHOTOGRAPH: BETHANY MOLLENKOF

**ONE NEEDN'T LOOK** much further than 23andMe's <u>Traits page</u> to see that the genetic claw reaches much further than skin-deep. The company can tell you if you've got a gene-encoded hatred for the taste of cilantro, a biological predisposition to fear heights, an inherited tendency to stay up late, a hard-wired disgust for the sound of chewing. By studying the incidence of certain traits in identical versus fraternal twins, who share half as much DNA, scientists can zero in on which characteristics are genetically, as opposed to strictly environmentally, influenced.

In perhaps the most famous nature versus nurture project, the Minnesota twin study, researchers found that twins reared apart and reunited as adults exhibited greater similarities than genetically unrelated siblings raised together. In some cases, the specificity bordered on paranormal. One pair of twins reunited as 21-year-olds discovered they both read books back to front, flushed the toilet before and after using it, and amused themselves by scaring strangers with a thunderous sneeze. Another pair known as the "Jim twins" found that they'd both named their sons James Allan/Alan and their dogs Toy, worked as part-time deputy sheriffs in Ohio, and vacationed at the same three-block-long beach in Florida.

Critics note that playing "spot the similarities" runs the risk of confirmation bias. Any two people are bound to share some traits if you look hard enough. But twin studies have helped identify some surprisingly heritable qualities. A trait is considered heritable if there's a larger chance that you'll share it with a relative than with the population at large. For example, IQ has been estimated to have a heritability of around 0.5 on a 0 to 1 scale. This does not mean that you get 50 percent of your smarts from your parents and the other half from the environment; it means genes account for about half of the variability in IQ amongst the population.

Some heritable traits are mediated by other, underlying traits. For example, extraversion is partly mediated by height—turns out we tend to treat taller people more favorably, positively reinforcing their social interactions. Political party affiliation: also heritable, thought to be mediated by ambiguity tolerance. (Higher tolerance correlates with progressivism).

After meeting Jeff and several of his LGBTQ family members, Denise wondered whether she might have inherited her sexual orientation. While no single gene encodes sexual preference, studies have indeed shown a small degree of heritability—between 8 and 25 percent—in same-sex orientation.

Despite their spooky similarities, meeting Jeff confirmed for Amy that he wasn't Dad. "I grew up without a dad, and that was a huge part of my identity. It doesn't get undone by meeting my donor when I'm 33." Nevertheless, she had space in her life for—if not a father, then some labelless new sort of family relation. She invited Jeff to the hospital when both of her children were born. They began celebrating holidays together. She says she began to feel "more settled into myself." She still doesn't call Jeff "Dad," but her kids, who have always known him, call him Grandpa Jeff. Skipping straight to grandfatherhood meant Jeff "had to grow into his parental instincts," Amy says.

Although Johnson's offspring were scattered throughout the country—Denise on the East Coast, Colin in the Midwest, Amy in California—they began to meet and swap stories and study one another with acute interest.

While protective of his parents' feelings, Colin lamented having to keep his old and new families apart. He had three-hour-long phone conversations with his newfound relatives, trying to make up for lost time. He admired Jeff and Amy's relationship, but envied their closeness. "It's like a missed opportunity," he said. "But should you feel bad about a missed opportunity you didn't know you had?" For Amy, she enjoyed her new relationships but had limited bandwidth to foster them. She wondered if other siblings would come along.

Like Jeff, many sperm donors express a willingness, even an eagerness, to know what came of their genetic material. But not all. Andrea Braverman, former chair of the American Society for Reproductive Medicine's Mental Health Professional Group, sometimes hears from these men. "I just had a conversation at a cocktail party," she says. "The man was a sperm donor in medical school and never thought about it much. Now he's got kids and a wife. He was reached out to by an adult offspring recently and shut her down. He freaked out."

Such potential rejection infuses unknown-parent searches with gut-churning suspense. Oftentimes, people discover their genetic parents without even meaning to, as Colin did. For others, all they need to get started is the DNA of a couple distant relatives and the help of a genetic gumshoe.

**DAVID NEAL IS** a search angel. "We believe that everyone has the right to know who their biological parents are," he says. A retired software engineer and amateur genealogist, he volunteers for a nonprofit called Search Angels, helping clients—adoptees, children of affairs, and, increasingly, donor-conceived people—find their birth parents. That last group, he says, "are kind of shattered, because they've been told a story their whole life, and they find out it isn't true."

Neal relies on the same methods police use to solve high-profile cold cases: old school genealogy tools such as census records, obituaries, marriage and death certificates, any documents linking parents and children, as well as home DNA tests. Ancestry has the biggest customer base, but if clients can afford to test on multiple sites—Ancestry, 23andMe, My Heritage, and Family Tree DNA are the biggest—it can increase their chances of finding a close relative. Uploading results to third-party sites like GEDmatch also widens the pool. "We call this fishing in all the ponds," he says.

Most consumer genetic testing companies use a technique called autosomal DNA testing, which analyzes chromosomes 1-22, the ones you inherit from both parents. Based on the amount of DNA you share with another person, measured in units of centimorgans, you can predict your relationship. There's a range, but on average, you share about 3,500 centimorgans—roughly 50 percent—of your DNA with each parent, 1,785 with your half-siblings, 125 with your second cousin once removed, and so on. The ranges for certain relationships overlap, which is why, for example, Denise couldn't tell if Colin was her uncle or half-brother.

The math of unknown-parent search goes like this: If DNA testing identifies two people who are genetically related to you and each other, you must share a common ancestor. If they're unconnected to anyone on your known parent's side, they're probably related to your unknown parent. Pinpointing the most recent common ancestor between you

and these relatives kicks off the search. You and your siblings' most recent common ancestor, for example, is your parents; for you and your cousin, it's your grandparents; for a third cousin, it's your great great grandparents, and so forth.

A 2018 <u>Science paper</u> showed that a genetic database only needs 2 percent of the population to provide a third-cousin match to just about anyone. Ancestry says customers average 64 third-cousin-or-closer matches. Ninety percent of 23andMe users get at least one second cousin match.

Neal then gets to work building a family tree, filling out the branches using historical records, People Search websites, and trees people create themselves on Ancestry. When he reaches the time frame that the birth parent was likely born, he begins generating candidates. Most donor-conceived people have some additional information—rough age, ethnic background, general location, medical student—that helps narrow the list. Neal can often get to 95 percent confidence; to reach 100 percent, the candidate has to get a DNA test themselves. Of the 50 cases he's gotten so far, Neal says he's solved two-thirds. The remaining third "are the hard ones," he says.

About half of Neal's clients attempt contact; the rest just want to know. (A <u>study</u> of the Sperm Bank of California's Identity Release program found that just 35 percent of offspring requested their donor's identity, although the study stopped at age 27, before many people become parents, a potential motivating factor.) For those who reach out, he suggests writing a letter containing some basic biographical information and stating what they want—typically medical information, not money, sometimes a connection, but only if both parties agree. "I don't suggest coming out and saying, 'You're my birth dad,' because we don't know for sure, and it can be overwhelming."

Responses have ranged from warm receptivity to threats of legal action. Roughly threequarters of the parents Neal has identified have expressed openness, or at least have gotten there eventually. "It evolves over time. Even if they put a wall up initially, it can start dissipating. Sometimes the first reaction is, 'I was told no one would ever know.' The next reaction is often, 'How will the rest of my family react?' There was a period of time where this was very shameful. The nice thing is that society has evolved. The younger generation is unfazed. They're like, OK, so Grandma had a life.' Cousins are like, 'Cool, another Facebook friend. Welcome to the family.'"

As more and more people get tested, the "hard ones" will become fewer and farther between. "One of the things that happens is we have a case where we're stuck," Neal says. "But then someone else gets tested, and we have a breakthrough. Within 10 years, we'll probably be able to solve for almost everybody."

In the meantime, he's using his software know-how to build an app called DNA2TREE, which automates the detective work. He's already written a program that can execute the most-recent-common-ancestor search, and he's working on adding the family tree component. "I just think sometimes, what if you could run an app, and in 10 minutes it gives you your birth parent?" he says. "That's spooky crazy. And not that far away."

INSIDE THE CALIFORNIA Cryobank (CCB), the largest sperm bank in the US, orderly rows of rotund silver tanks hold thousands of vials of precious genetic material, like a lab-grade brewery. It's hard not to think that one wrong move, one leaky valve, could doom the most cellular-level dreams of countless hopeful parents. Strategic Alliances VP Scott Brown uncaps one of the tanks, unleashing a cloud of liquid nitrogen that dissipates to reveal a bath of four-by-four grids cradling tiny hand-numbered vials.

Sperm banking has come a long way from the loosey-goosey basement clinics of the 1970s. In 2018, its global market size was <u>estimated</u> at more than \$4 billion; 44 percent of donors were anonymous. Two-page self-reported donor sketches have given way to criminal background checks, psychological evaluations, genetic disease screenings, college education, and height requirements (CCB's minimum cutoff is 5'8") plus optional upsells, like donor poetry, personality tests, and voice recordings.

Log onto CCB's online search portal and you can browse sperm donors like you shop for loafers—filtering by characteristics such as ethnic origin, hair texture, area of study, and celebrity look-alike (degree of resemblance may vary). The cost of four vials—

roughly the average number needed to achieve pregnancy—runs about \$4,800, including shipping. While some banks are laxer, CCB—which Brown has called the <u>Harvard of sperm banks</u>—accepts fewer than 1 percent of applicants. As its website crows, "Good isn't good enough."

As medicine has advanced and access to assisted reproduction expanded, client bases have changed considerably too. About 80 percent of CCB's clients are now same-sex couples and single mothers by choice. "A lot of heterosexual couples don't need us anymore," Brown says. With newer fertilization methods like intracytoplasmic sperm injection, doctors can extract a single sperm cell and inject it directly into an egg, overcoming low sperm counts or motility (swimming ability) and obviating the need for donor sperm.

Inside a narrow ground-level waiting room, a baseball-cap-clad guy, who looks to be about college age—presumably a potential donor—balances a clipboard on the side of his sneaker. One floor up, CCB's chief medical officer, Jaime Shamonki, occupies a modest second-floor office, splashed with endearing photographs and paintings of young people. Sporting a stylish pixie cut and backlit by floor-to-ceiling windows, Shamonski launches into a narrative of then versus now, a reproductive dark ages of secrecy that's given way to a more enlightened present.

The Donor Sibling Registry's <u>dossier</u> on California Cryobank challenges that tale. The 61-page compilation of customer experiences, spanning 20 years, reads like the Yelp page of a one-starred restaurant. Comments on an FDA petition the DSR filed list allegations ranging from offspring numbers exceeding what the bank <u>promised</u>—as many as 35 children, although sibling groups from other banks have risen into the hundreds—to surprise genetic <u>disorders</u> to failures to obtain updated health information for a child with <u>cancer</u>.

A spokesperson with CCB later said it "maintains a maximum goal of 25-30 family units per donor." (A family unit can include multiple siblings.) They wouldn't comment on specific cases but noted that "it is not possible for anyone to prevent the birth of a child with a genetic disease, regardless of the mode of conception." However, the

spokesperson said, CCB employs a team of genetic counselors "who evaluate all reports of medical issues in offspring of our donors, as well as any new medical information involving a donor and his family members. If a significant increased risk for a specific condition is identified, we attempt to notify all clients to whom the information may be relevant, while also maintaining the original family's privacy."

As anonymity in the age of DNA testing becomes impossible to guarantee, some banks have begun phasing it out. CCB stopped accepting anonymous donors in 2015. "It occurred to me that you can't promise anonymity to somebody in today's day and age," Shamonki says. However, they continue to sell anonymous sperm from donors who predated the change, as well as a kind of Anonymity Lite called Open Donorship. Under this option, contact is permitted once the child turns 18, but the donor's identity remains concealed. That is, the cryobank won't release it.

Activists have long advocated for increased regulations, such as limits on the number of births per donor and stricter record-keeping requirements. "I would be fine with it," Shamonki says. "Anytime I want to do something that sounds like it'll be harder to recruit donors, but it's better, we always do it. But if you look at the major sperm banks in the US, I don't see those as being pervasive issues."

I bring up the case of Danielle Teuscher, a sperm-donor recipient who is suing Northwest Cryobank, CCB's affiliate in Spokane, Washington. Teuscher's daughter matched with her biological grandmother—her donor's mom—on 23andMe, so Teuscher sent her a message. In response, Northwest revoked the four vials of sperm she had purchased for future use, changed the donor's status from open to anonymous, and threatened Teuscher with a \$20,000 fine.

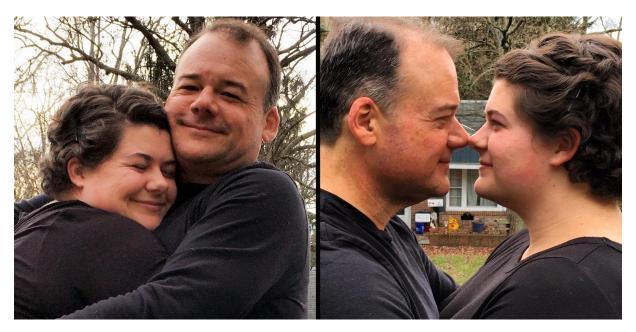
Shamonki declined to comment on the specific case, "but this relates to the conversation around the mutual respect of privacy. If we agree to a set of terms, then there's absolutely opportunity to have potential contact in the future. But if you don't respect those terms, then it makes it difficult for other people who were playing by the expected rules." (A spokesperson for Northwest Cryobank later said, "Our clients have contractually agreed to not independently seek the identity or attempt to contact

[donors or their families]. We do not become aware of breach-of-contract situations unless a complaint has been raised. The parents who have benefited from the generous gift of gamete donation must remember that there is a human being on the other side of the gift with partners, parents, jobs and children of their own. Our policies are set forth to protect the health and well-being of all participating parties.")

Just last month, in an attempt to curb accidental DNA discoveries, California Cryobank rolled out its own ancestry testing, mandatory for all new sperm donors. "I didn't want to use one of these genetic testing companies like Ancestry," Shamonki told a writer for <u>LeapsMag</u>, a Bayer-sponsored digital publication. "The whole thing we're trying to accomplish is also privacy," she says.

Some activists oppose requiring offspring to wait until age 18 for contact, arguing that identity formation begins well before that. Alice Ruby, the Sperm Bank of California's director, tells me the reason for the rule is legal concerns; parents worry donors might try to assert parental rights. Shamonki brushes aside the suggestion, chalking it up to maturity. "We give people autonomy when they're majority age, of voting and joining the military. That's the time when they're adults."

I think about my conversation with Jason Frankel, a sperm donor who never had his own children, and Joanna Collins, his biological daughter raised by a single mothe. The two of them met when Joanna was 23 and had one of those sparks-fly moments Amy had read about. (They dubbed their initial running-start embrace "the flying hug.") They've since been traveling to meet each other and talking frequently by phone, making up for lost time. For them, it's bittersweet. "We're mourning the loss of the time that might have been," Frankel says.



"We're mourning the loss of the time that might have been," says Jason Frankel, who met his biological daughter, Joanna Collins, when she was 23.

PHOTOGRAPH: JASON FRANKEL

"It's hard not to think about all the things that would have been better if he'd been there when I learned to ride a bike and got my knee skinned, or for my first school play," Collins says. "I would love to give him all those experiences."

Then I think about Denise's response to discovering she was donor-conceived. "I wouldn't want to find out as a kid or while my dad was alive. I wouldn't have known how it mattered, and at this point, it doesn't matter who my genetic father is. As a younger person, I would have thought, what is he feeling about this now that he knows I know?"

The dynamics that make up our closest relationships, what we long for, what we miss, what we mourn, are so individual. Anonymity worked out OK for Denise; it left Jason and Joanna with a hole they can't quite fill. It feels impossible to know which way a child will lean.

At the end of our talk, Shamonski brings up a woman she knows who has begun thinking about sperm donation. "She's in a relationship with a woman, and they talk about having kids someday. They're far away from when they actually want to conceive, but they know the path they're going to take: not a known donor, a sperm

donor from a sperm bank. Being in that generation, they have years to wrap their heads around it and think about what's right for them. So, it's nice."

"So they're opting for an open donor?" I ask.

"Yeah, well, it's called something different at every sperm bank. But they don't want to use their brothers-in-law or their guy friends. It's sort of the Thanksgiving test. Like, do you want to have these people at your Thanksgiving or not? They know where they want to draw their boundaries."

My mind goes back to Jason, Joanna, and Denise. I wonder which side this child will come down on.

THE DESIRE TO know one's biological heritage runs deeply through our culture. PBS's hit show *Finding Your Roots* features genealogists helping celebrities trace their genetic lineages, often leading to tears. Cultural phenomena like *Star Wars* are shot through with NPE revelations. Ancestry suffuses our national origin story, our politics, our myths.

Some bioethicists challenge the privileging of genetics-based identity. Last year, at an NYU conference on donor conception, Cornell medical ethics professor Inmaculada de Melo-Martin argued that deprioritizing genetic identity could help destigmatize "families who don't conform to biogenetic norms," and "eliminate the harms that lack of access to genetic information can have." Either way, critics point out that anonymity sets up a double standard. Texas activist Eve Wiley puts it this way: "If parents valued and desired to have a child of at least 50 percent biological relation, we must also value that offspring's desire to know the other 50 percent of their genetics. It's either valued or it's not."

Last year, Wiley discovered that her mother's fertility doctor was her father; he secretly inseminated her mother with his own sperm. Wiley's experience is growing increasingly common—she hears of new "doctor daddy" discoveries weekly. When she tried to pursue legal action, she was shocked to discover the practice was not a crime. So she set out to make it one. In June, Texas became the second state, after Indiana, to

establish a new felony called fertility fraud. Florida, Ohio, and Colorado have all since introduced or passed similar bills. Wiley set a goal of reaching 10 states before bringing her efforts to the federal level.

Activists see fertility fraud, which they deem an egregious violation of trust deserving of sanction, as an opportunity to bend legislators' ears and educate the public about donor conception practices more broadly. A few mild state-level laws have passed, such as ones in Washington and California requiring gamete banks to notify all donors if their offspring requests contact at age 18. Bills in <a href="New York">New York</a>, <a href="New York">New Jersey</a>, and <a href="Illinois">Illinois</a> have called for tougher regulations, like registries and anonymity bans, but none have made it out of committee.

When I tell donor-conceived advocate Nick Isel I'm writing a story involving anonymity, he says, "So it's a eulogy?" Isel was featured in David Plotz's book *The Genius Factory* about the Repository for Germinal Choice, a sperm bank associated with eugenics. After tracking down his father with Plotz's help, Isel began advocating for new laws regulating gamete banks. In 2016 he filed an <u>FDA Citizen Petition</u> calling for record redundancy and 50-year record retention, given that many inherited diseases present later in life. It also called for a formal end to anonymity. The FDA denied the petition in 2018, then denied a revised version in March, stating that its authority to prevent the spread of communicable diseases does not include genetic diseases. "In response to that, I didn't know what else to do except send them a high school biology book," Isel said. He and his attorney filed for one final internal review, which the FDA denied in late July. Now he's planning to take the agency to court.

When asked who has the authority to regulate genetic disease risk, if not the FDA, a spokesperson wrote, "We are not aware of a federal regulatory agency that does. We recommend contacting [professional] associations for information on their clinical guidelines."

But these professional associations—the American Society for Reproductive Medicine, the Society for Assisted Reproductive Technology—represent the very industries Isel wants regulated. "It's the fox watching the henhouse," he says. When a more

expansive version of Florida's fertility fraud bill began making its way through the legislature, the two associations coauthored a private letter to state representatives, opposing requirements for clinics to develop sperm storage best practices and submit to annual health inspections. "The requirements of the bill will only add costs to the provision of health care involving assisted reproduction," the letter said. "Should the language remain intact as it is, we will have no choice but to publicly oppose SB 698." Those provisions were ultimately stripped from the bill.

"OUR POSITION IS simple," says Sean Tipton, the American Society for Reproductive Medicine's spokesman and lobbyist. "People ought to be able to avail themselves of the family-building services that they need. We get nervous about proposals to have politicians and bureaucrats getting to make those decisions."

Tipton betrays little sympathy for donor-conceived activists' concerns. "No one can consent to the circumstances of their own conception," he says. "Donor-conceived offspring are not in some kind of privileged position, or they shouldn't be, where they're entitled to know their genetic roots in a way that doesn't apply to everybody. If I'm raising a kid as my son who maybe is not my genetic son, and I don't choose to tell him that, I should have that right." (Officially, the organization encourages disclosure, citing open adoption trends. Research has shown that openness benefits children's well-being.)

"So you wouldn't view a donor-conceived person as being at a disadvantage compared to the rest of the population," I ask, "given that the rest of the population, for the most part, knows—"

"That 'for the most part' is very, very important!" Tipton says, interrupting me. "I don't think you should assume people know their full genetic ancestry. People are wrong about who their fathers are. The human species has a long history of not being completely upfront about who they're having sex with."

To minimize the risk of inadvertent consanguinity, the society recommends limiting births to 25 for every 800,000 people in a given area (which can add up, given that

banks ship internationally). But while some banks offer incentives for reporting births, the practice remains voluntary—as are the limits themselves. Tipton calls the prospect of a mandatory registry "an enormous privacy issue." He raises similar concerns about increasing the longevity of record retention. "Being able to protect that record is very, very difficult," he argues. "Medically there's not a lot of justification. Your genome is far more determinative of your health than your parents' genomes are."

Brianne Kirkpatrick, a genetic genealogist who counsels donor-conceived people, disagrees. "His argument ignores the huge limitations of genome testing," she wrote in an email. Thousands of genes are understudied or unstudied, and not all genetic conditions have tests. Given that some variants cause disease in some families but not others, Kirkpatrick says, "without family pedigrees it can be impossible to tell the difference." Additionally, many inherited conditions stem from multiple factors. "We need to know family history for the various types of diabetes, for example," she says. "We can't just do a DNA test."

WHILE THE AMERICAN Society for Reproductive Medicine balks at regulations, they're well underway abroad. The UK and Australia, which have dedicated regulatory bodies overseeing reproductive tissues, ban the sale of gametes, so sperm donors are donors in the true sense of the word. Both countries outlawed anonymity in 2005. In 2018, the Australian state of Victoria went a step further, applying the ban retroactively, so previously anonymous donors must register their information. These men can impose contact vetoes, however, letting them limit communication or forego it entirely.

Detractors often warn that removing anonymity will create a donor shortage; however, both countries rebounded after temporary dips. Sonia Allan, the Australian professor who co-led the UN delegation and helped draft her government's open identity laws, noted a shift in the type of people who donate. "They tend to be slightly older than the 18- to 24-year-old donating for a few dollars. They're men who were involved in infertility treatments with their own wives, or who have friends who have been through it." Post-retroactive ban, Allan says, the majority of donors—around 85 percent—were happy to share information. "About 10 to 15 percent are saying, I was told this was anonymous. I'm really angry you removed it."

Allan first became interested in this area while sitting on expert panels crafting reproductive policy. "What really struck me was that often when [donor-conceived] people would leave the room, someone left at the table—commissioners, doctors, people involved with the industry—would make a comment like, 'She's just an angry teenager,' or 'These are just a disgruntled few. Not all donor-conceived people feel like that.' I was thinking, this is really strange and actually quite unacceptable to deny somebody how they feel. If donor-conceived people are saying they're angry, because they need information about where they come from, or they're hurting, then we need to do something about that."

EARLY LAST YEAR came the latest addition to the Johnson clan. Ben learned the news through a half-disbelieving phone call from his brother, who'd received a 23andMe kit for Christmas. "Haha," he said, "We're not related." Logging on, Ben saw Jeff Johnson appear as his father. To Ben, affable and easygoing, it felt like a missing puzzle piece falling into place. His bright blue eyes and tall, lean build were a mismatch with his dark-eyed, darker-skinned, stockier family members. They regularly joked that he was adopted.

Ben's excitement grew in proportion to his family's sense of loss. "I gained a whole new family," Ben says of his brother, "while he lost half a brother." His mother—who, yes, was living in Michigan when she became pregnant—pleaded with him to keep the news from his father and wait until he dies to tell his children. But Ben wants to give them new cousins, aunts, and uncles without lying about their identities. "I just think this would be a great new adventure," he says. "I can't see how fewer connections are better than more connections." He hasn't decided what to do.

So far, Jeff Johnson's brood stands at four. It could stay that way, or it could climb to half a dozen, or dozens. With no birth limits and no mandatory tracking, many donor-conceived people live with the sense of waiting for untold other shoes to drop. "I know at any point I could be connected with a half-sibling," says Erin Jackson, who founded a resource center called We Are Donor Conceived. "Every time that happens, I go through the grief cycle all over again."

I CAN'T HELP but reflect on the idea of lost time as Amy's mom Elizabeth describes her new extended family. "It's just been a miracle. Every time I see Jeff, I say thank you. I've had an amazing, multifaceted life, but the best part is now. I'm 78, and they come for Thanksgiving, and it's heaven."

At the NYU conference, philosophy professor Elizabeth Brake argued the benefits of expanding typical all-or-nothing views of parenthood, citing bell hook's description of "revolutionary parenting" in black communities. "Rethinking the parental role will allow us to decrease parental burdens by spreading those burdens among willing individuals ... A parenting model that resembles the extended family rather than the nuclear family ... could allow gamete donors or other individuals to be considered third or fourth parents or quasi-parents."

Such a vision may threaten some parents, however. Wendy Kramer hears from parents who struggle with fears of being replaced, particularly social parents. "It's not taking away; it's adding," she counsels. "When kids are told the truth, they usually become closer with their nonbiological parents. They think, it must have been hard to raise me having no biological connection, yet you raised me as if you did." Colin, for one, came around to this sentiment. "Overall, I gained more appreciation for my dad. He knew this whole time that this was a possibility, and he was a great dad."

Of course, where family relationships are concerned, reactions run the gamut. Matt Doran, who founded the social network Donor Children, made his NPE discovery at 25. Doran tracked down his biological father in 2014—the rumored mega-donor from *Hard Copy*—and now plans to change his last name to match. He's among a cohort that privileges genetic relatedness, opposing donor conception altogether.

A deceptively simple question underlies these experiences: What makes someone family? How much is the shared genetic material that tethers us together, drives our behaviors in uncannily similar ways, enables near-telepathic intuition, reflects a nose, a pair of eyes, a peculiar smirk or canted brow, in the face of another? How much is choice, commitment, shared history, the hard work of providing and role-modeling, of

caretaking and loving? What is one without the other? And perhaps more importantly, should a sperm bank, or even a parent, decide that for someone else?

I ask Jeff and Amy, "What if you discovered there had been a mistake, and you weren't actually genetically related? Would that change how you thought about one another?"

Amy considers it. "No," she decides. "He's put in the time."

**ALTHOUGH DNA TESTING** is making anonymity a moot point, gamete banks continue to offer it, placing the burden on curious offspring to splash their DNA all over the internet, construct elaborate family trees, set out on anxious hunts to track down donors who may or may not be receptive to their surprise overtures, and sometimes, shoulder family secrets.

But secrets have a way of coming out. Reflecting back on her sudden hunch, Denise says: "Somewhere in my subconscious I knew the whole time." Another man analogized it this way: "I think the feeling that went through me was—You know in *Return of the Jedi* where Luke tells Leia she's his sister? And she says, 'I know. Somehow I've always known."

In her recent memoir, *Inheritance*, about her surprise discovery that she was donor-conceived, author Dani Shapiro framed her revelation through a concept coined by psychoanalyst Christopher Bollas, "the unthought known." Bollas wrote, "There is in each of us a fundamental split between what we think we know and what we know but may never be able to think."

Back when Colin was cycling through his bargaining phase, turning to data for solace, his three young sons casually went along with the DNA tests he bought them, forgetting the episode soon afterward. They haven't thought much about 23andMe since that summer day in 2015. But their genetic code sits on a server, an open secret that will last only as long as their forgetting, like a smudged lens, waiting to be wiped clean.

\*Pseudonyms used to protect family secrets

Updated 8/3/2020 5:10pm ET: A previous version of this story incorrectly stated Australia outlawed donor anonymity in 1995; it was 2005. The story has also been updated to clarify that a body temperature drop indicates the imminence of ovulation.



Caitlin Harrington is a contributing researcher at WIRED and also writes for the magazine. Before coming to WIRED as a research fellow, Harrington worked as an editorial fellow at San Francisco magazine and as a certified medical dosimetrist in the radiation oncology field. She earned her bachelor's degree in English... Read more