



## Rolling genetic dice with a donor

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There are an estimated one million children living in the United States who were conceived from either a donated sperm or egg.

For many families, donor technology is an answer to their prayers, but critics say the assisted reproduction industry in the United States is one of the least regulated in the world.

That's one reason why some children are born with serious and even deadly genetic diseases.

There are some things you need to be aware of before rolling the genetic dice with a sperm donor.

A mother and her son shared their story with *America Now*, but they asked us to maintain their anonymity to protect their privacy. The woman's child, who is now a teenager, was conceived by his mother's egg being fertilized by donated sperm.

The human body contains thousands of genes, which are pieces of DNA passed on from our parents.

Like the many parts of a puzzle, our DNA determines what we look like and tells us what, if any, genetic diseases we may live with or, perhaps, die from.

What if you didn't know half of your genetic inheritance?

That's what it's like for tens of thousands of children fathered by an anonymous sperm donor. Some



of them are born with serious health conditions.

"I always felt something was off," said the teen who was conceived from donated sperm.

His mother says something was more than off. When he was born, she said her son appeared seemingly healthy, but soon, he was having wild tantrums and suffered from extreme social anxiety.

His mother couldn't find any clues about what was wrong by looking on the few pages of identifying information about the sperm donor except for the man's height, hair color and interests.

Finally, doctors attributed the child's condition to his DNA.

"We came back for the results and she [the doctor] said, 'I think what you're dealing with is Asperger's Syndrome,'" the mother recalled.

Looking back at the pages of documents pertaining to the sperm donor, there was no mention of the sperm bank screening for the genetic condition.

Ironically, the Food and Drug Administration mandates sperm be screened for infectious diseases like HIV, but there is no federal requirement for sperm banks to test for genetic diseases which may explain why babies from what appears to be healthy donor profiles are born with conditions like Cystic Fibrosis, heart defects, and even spinal muscular atrophy.

"Many of those children die before the age of two," said Dr. Bill Meyer, an obstetrician with Carolina Conceptions located in Charlotte, N. C.

Since there is no law limiting how many children a sperm donor can father or rules requiring a family or donor to report updated medical information to a sperm bank, an untested and undiscovered genetic disease could easily be spread to dozens of children.

For most families, the lack of regulation over sperm banks is a reality that many learn about too late.

"You're pretty desperate and you're not thinking as clearly as you might be at the beginning of the process," the teen's mother points out. "They're not just selling a product; they're selling hopes and dreams and future memories."

Future parents should know that some banks have now added genetic screening, but not all of them do this.

"I mean, it's a big commercial enterprise and you have banks that compete against one another," Meyer said.

Another option is for the mother to screen herself.

A simple saliva test can identify her as a carrier for almost 100 different conditions.

"If she is negative for all of those, then it really doesn't matter," Meyer said.

That's because it takes two recessive carriers to create most genetic conditions.

There's also the option of screening the embryos now fertilized with the donor's sperm.

Only those clear of a genetic condition are used.

For families well past that point and are now looking for any DNA information link to their donor, there is a helping hand online called the Donor Sibling Registry.

"It's an amazing network of people out there that want to support each other and know that we are all a family," said the teen's mother.

Searching by their donor ID number, she and her son have been able to find half-siblings around the

country, some of which have the same genetic condition.

For families disheartened to hear that most sperm banks delete donor data after 10 years, the registry has become a social support system and online community to share medical information which is helping to fill in the pieces of the genetic puzzle.

"I had felt distant from everyone else, but when I met my siblings, it helped a lot, because I knew there were other people like me," the teen said.

For others, it's a chance to reconnect with their donors.

Donors who have registered are able to update families on their health.

Some of the donors have found almost 200 children sharing their DNA.

"Then, the question comes up, 'OK, when is enough enough?'" Meyer asked.

For every parent, how much information and testing they want is a personal choice.

Meyer warns that with genetics, there are countless variables and not all conditions can be traced back to a donor.

Largely, human life is always a roll of the genetic dice.

While there are preventative measures parents can take, there are those who say that even if the puzzle didn't turn out exactly as planned, they're grateful for every piece that was put into place.

"Thank you for donating so my parents could have me," the teen said.

Donated eggs pose the same risks as well.

There are hundreds of clinics offering reproductive technology around the country and doctors say most women come with a sperm bank in mind and, usually, its one they found online.

#### Additional Information:

The following information is from Dr. Bill Meyer, an OBGYN & Reproductive Endocrinology Specialist at [Carolina Conceptions](#) in Charlotte, NC.

- The accuracy of how many pregnancies a donor has is unclear. It's up to the fertility clinic to report every pregnancy, but not all of them do or can. Sometimes, clinics never hear from their patients again, making reporting even more challenging.
- Many genetic diseases are transmitted autosomal recessive. If the mom is not a carrier, the child won't get it. It would take two recessive carriers.
- There is the concern that networking online may cause unnecessary stress and worry for parents. Not all health conditions are related to DNA and there are too many variables in the environment. For one donor or family to make a health report and share it online might cause many others to unnecessarily worry over a condition.

The following details are from our interview with the mother.

- Around first grade, her son started exhibiting wild temper tantrums where she would have to physically pick him up and remove him from the room. He could not function in school and while they were thrilled how studious he was, she felt something was not right.
- During fifth grade, her son went through extensive testing and was finally diagnosed with Asperger Syndrome, Anxiety Disorder, and Dysgraphia (a learning disorder).
- The family has used the Registry to reconnect with her son's half-siblings. They have traveled to meet them and, sporadically, keep in touch.

The following details are from our interview with the son.

- He explains Asperger Syndrome as a disorder in which a person takes everything "literally." For example, if you told him to put his dishes away, he might put them in the cabinet unclean as opposed to placing them in the kitchen sink or dishwasher.
- Those with Asperger have hard-to-read facial expressions and difficulty understanding humor.
- He says the registry has helped him feel more comfortable about himself knowing that there are others out there just like him.

The following information is from the [Donor Sibling Registry](#):

- The Donor Sibling Registry (DSR) was created in 2000 by Wendy Kramer and her son, Ryan.
- The site averages more than 10,000 unique visitors each month and is a worldwide organization.
- The purpose is to assist those conceived via sperm, egg or embryo donation with making mutually desired contact with those whom they share genetic ties (both donor and siblings).
- Users may stay anonymous and use a "throw away" or "untraceable" email address when communicating.
- Egg and sperm donors are encouraged to contact and communicate with their recipients.
- A yearly membership fee to post and contact is \$75. Permanent membership is \$175.
- The DSR is not funded by any outside organization and is a 501(c)(3) non-profit.
- Searches are done by donor birthday, type (sperm vs. egg vs. embryo), donor ID#, facility.
- Approximately 75% of all surveyed donor offspring would recommend parents as a known or willing-to-be-known donor.
- Advises choosing an "open" donor who is willing to have later contact with the children, which may facilitate exchange of medical information.
- Questions to ask when choosing a bank:
  1. What compensation is there if your vials are lost by the sperm bank? What about the storage fees?
  2. What compensation is there if your vials have low motility or what if they are contaminated? What type of refund policy is there? What about storage fees?
  3. What compensation is there if it is found that children born from your donor, or the donor himself, has medical issues? What is the refund policy? What about storage fees?
  4. What type of records do they maintain? Paper? Electronic? How long are they promising to keep records for?
  5. How will they notify you if they become aware of a child born through your donor with medical or genetic issues? Will they only contact your doctor? You directly?
  6. How will you be notified if a donor reports a medical or genetic issue? Will they contact your doctor? Or you directly?
  7. Will they notify you if your donor tests positive for HIV after you have already bought vials? Will they contact you directly?
  8. What is their policy on creating large sibling groups? (Fairfax has the largest number of large sibling groups on the DSR.) What tracking system do they have in place?
  9. Do they ask donors if they have donated anywhere else? (Research shows that between 22-27% of donors donate to more than once facility).
  10. Can people view their premises? See where the vials are stored?
  11. Can they confirm which types of screening have occurred on your purchased vials, and provide proof?
  12. How do they verify a donor's medical information?
  13. If a donor is found to have lied on their application, is the donor pulled from the system? Are families notified? If yes, how?
  14. Are they in compliance with all HIPPA and FDA regulations? Are all patient records maintained on the premises and not accessed from remote locations?
  15. How does the sperm bank access donors?

The following information is from an article entitled ["Are Sperm Banks Unethical?"](#) published by Salon Media Group:

- The first commercial sperm banks using frozen sperm appeared in the 1970s. During the AIDS epidemic, sperm was tested for diseases.
- Every ejaculation contains up to 500 million sperm. Regular donation can produce mass offspring.

The following information is from the Center for Bioethics and Human Dignity:

- According to The Center for Bioethics and Human Dignity the assisted reproduction industry in the United States is one of the least regulated.
- While many of the 400-500 clinics offering assisted reproductive technologies are members of professional organizations and follow ethical guidelines, the majority do not.

The following information is from an article entitled ["In Choosing a Sperm Donor, a Roll of the Genetic Dice"](#) published by The New York Times:

- Sharine and Brian Kretchmar of Yukon, OK used artificial insemination with a sperm donor chosen from the New England Cryogenic Center in Boston.
- Their son was born with Cystic Fibrosis.
- They later discovered the sperm was decades old and originally came from a lab halfway across the country.
- Genetic illnesses from donors include heart defects, spinal muscular atrophy and neurofibromatosis type 1, among others.
- Donated eggs pose a risk as well.
- Sperm donors are no more likely to carry genetic disease than anyone else, but they can father far more children, making the genes more pervasive in the public.
- How many children are born each year using a sperm donor is unknown since mothers are not required to report their births.
- The FDA requires sperm donors to be tested for communicable diseases, but there is no federal requirement for banks to screen for genetic diseases.
- The American Society for Reproductive Medicine encourages banks to test for conditions like Cystic Fibrosis and mental retardation when there is a family history of disease.
- Usually the donor is tested, not the sperm.
- Compliance with the guideline is not obligatory.
- The Society points out that reproduction is inherently risky and testing will never be able to catch everything.
- Families and donors are not required to report births or illnesses to banks so the bank may continue to use the sperm.

The following information is from an ABCNews online report entitled ["Sperm Donor's 24 Kids Never Told About Fatal Illness"](#):

- Experts speculate that there are about one million donor-conceived children in the US.
- The FDA requires sperm to have no "relevant communicable disease or agent", but there is no limit on how many donations can be made by one person nor is there any sharing of medical information between the donor and the child's family.
- The FDA mandates that clinics keep records for only 10 years, but the American Society for Reproductive Medicine (ASRM) recommends it be permanent.
- By law, donors need only be screened for sexually-transmitted diseases and some communicable diseases.
- Donors are usually anonymous and only have a number.
- The American Academy of Adoption Attorneys say adoption processes are a good model.
- All details on the social and medical history of the biological parents must be kept in court records in case of a medical emergency (i.e. when the child needs a bone marrow transplant or a blood transfusion).
- What would happen to the records if the clinic went out of business?

The following information is from an online article entitled ["Preimplantation Genetic Diagnosis and Screening: PGD and PGS"](#) published by Fertility Authority:

- Preimplantation genetic screening (PGS) or preimplantation genetic diagnosis (PGD) screen embryos for single gene defects of chromosomal abnormalities.
- Screens for single-gene defects that may cause genetic disorders.
- Offered to patients at high risk of transmitting a known genetic disorder to their child.
- PGD can screen for: Cystic Fibrosis, Hemophilia, Huntington's Disease, Muscular Dystrophy, Sickle Cell Anemia, Marfan Syndrome, Tay-Sachs Disease.
- If a problem is found, the woman can decide to transfer only the "good" embryos.
- Screening is not 100% accurate nor is it an alternative to amniocentesis and chorionic villus sampling.
- PGS and PGD cost from \$2,500 to \$7,000 and are not covered by most medical insurance policies.

The following tips are from an article entitled ["How to Carefully Choose a U.S. Sperm Bank"](#) published by Choosing Single Motherhood:

- In choosing a bank, you may want to ask the following:
  - What kind of identity option do you want?
  - What kind of information they release, if and how donor information is maintained, if there is support for families and donors.

The following information is from an ABCNews online report entitled ["Your Saliva: A Crystal Ball to Your Offspring?"](#)

- A kit lets users -- women and men -- spit into a tube and then send it off to a lab that analyzes the DNA in about 10 weeks.
- A company called "23andMe" charges a \$399 fee to map your DNA and tell you if you're predisposed to as many as 90 different conditions, such as lupus or lactose intolerance.

The following information is from a [Curiosity.com/Discovery Communications](#) online article:

- Inner cheek skin cells house chromosomes containing DNA.
- Saliva containing those cells can be used to "read" our DNA.
- There are more than 900 different ways to test your genetic makeup, but saliva is one of the simplest.
- At-home testing kits are available through companies like "23andMe", Navigenics or deCODEme.
- Collect two tablespoons of saliva into the enclosed cup or tube and mail it back.
- A company representative will call you to discuss the results.
- It can look for genetic markers for things like arthritis, asthma, depression, cardiovascular disease, multiple sclerosis, osteoporosis, schizophrenia, thrombosis, diabetes and more.

The following information is from an [Asperger Syndrome Fact Sheet](#) published by the National Institute of Neurological Disorders and Stroke:

- Asperger Syndrome (AS) is a developmental disorder that is characterized by: <sup>1</sup>limited interests or an unusual preoccupation with a particular subject to the exclusion of other activities; repetitive routines or rituals; peculiarities in speech and language, such as speaking in an overly formal manner or in a monotone, or taking figures of speech literally; socially and emotionally inappropriate behavior and the inability to interact successfully with peers; problems with non-verbal communication, including the restricted; use of gestures, limited or inappropriate facial expressions, or a peculiar, stiff gaze; and, clumsy and uncoordinated motor movements.
- Parents usually sense there is something unusual about a child with AS by the time of his or her third birthday, and some children may exhibit symptoms as early as infancy. Unlike children with autism, children with AS retain their early language skills. Motor development delays – crawling or walking late, clumsiness – are sometimes the first indicator of the disorder.
- Experts in population studies estimate that two to six out of every 1,000 children have the disorder. Boys are three to four times more likely than girls to have AS.

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