



Jim Bruce was born with XY male chromosomes but ambiguous genitals. Doctors couldn't be sure if he had a large clitoris or a small penis and were convinced he could never live a "satisfactory life" as a man. So shortly after his birth in 1976, Bruce's external organ and testes were surgically removed and he was raised as a girl.

He struggled for years, preferring "rough and tumble" play and being attracted to girls.

"I was unhappy, but it was really difficult to ask questions," said Bruce, now a 34-year-old writer from California.

At 12, Bruce was given female hormones so his body would feminize. Then, at 18, he prepared for a vaginoplasty - "designed to allow me "to have sex with my husband."

But he knew something was wrong and, battling depression, sought his medical records when he was 19. "I knew that I wasn't a girl," he said.

Bruce's discovery was horrifying. "I was sterilized at birth -- and no one ever told me,"

An estimated 1 in 2,000 children born each year are neither boy nor girl -- they are intersex, part of a group of about 60 conditions that fall under the diagnosis of disorders of sexual development (DSD).

Once called hermaphrodites, from the handsome Greek god who had dual sexuality, they are now known as intersex.

Standard medical treatment has been to look at the genitals, determine the gender and then correct it surgically. But now, many are challenging the ethical basis of surgery, knowing that gender identity is complex, and doctors can sometimes get it wrong, not knowing how a child will feel about their gender assignment when they grow up.

Advocates argue that surgery is irreversible and can have tragic consequences. In Bruce's case, he has been rendered infertile.

In some surgeries on virilized girls with ambiguous genitalia, removing sensitive tissue and vessels can ultimately rob them of sexual sensation as adults.

Bruce was born with a DSD that prevented his body from producing enough testosterone to properly develop his genitals. After discovering the truth, he transitioned back to a man, taking testosterone shots and having his breasts removed.

Today Bruce works with [Advocates for Informed Choice](#), a legal group that promotes the civil rights of those who are born with sex variations.

Jim Bruce, a 34-year-old writer from California, was born with ambiguous genitalia.

"It wasn't that long ago, and parents were often led to believe they were doing the best thing for the child," he said. "They still don't know anything now, and they don't do any follow up."

At first he blamed his parents, but later realized, "they were only kids, 27 and 29, and they were scared. I never had any doubt my parents loved me very much."

As little as a decade ago, the medical community thought of gender as a slate that could be erased and then redrawn.

Today, gender identification is still not well understood, but experts say that when sex cannot be determined, it's better to use the best available information to assign gender, then to wait and monitor the child's psychological and physical development before undertaking surgery, if at all.

Waiting until puberty also allows the child to participate in the decision.

"Our chromosomes don't tell us who we are," said [Dr. Arlene Baratz](#), a Pittsburgh breast radiologist who has two intersex daughters. "We expect XX is pink and a girl and XY is blue and a boy, but we know from children with gender identity conditions that is not always the case, even when their bodies are perfectly typical."

Assign Gender, But Wait for Surgery

"Today, we anticipate how the child will feel as an adult and what they feel inside," said Baratz. "That is called gender identity and the gender role is how we live in society as a man or a woman. So gender assignment is aimed at putting gender identity and role in sync with each other as the child grows older."

Baratz's daughter Katie was born with male chromosomes, but has a DSD called complete androgen insensitivity syndrome (cAIS). Because her androgen receptors are faulty, Katie developed female characteristics. She has a vagina, but no uterus or ovaries. When she was 6, doctors discovered small testes in a hernia sac.

Today, at 26, Katie is married and in medical school hoping to one day be a child psychiatrist. Though she is infertile, she hopes to become a parent through adoption or gestational surrogacy.

"These girls look completely female and they are girls," said her mother. When these cAIS babies are gender assigned as female, 99 percent of them go on to feel like women when they grow up.

But in a similar disorder, partial androgen insensitivity syndrome (pAIS), doctors can't always be sure. Because they have been affected by some androgen, about 50 percent of them do not accept the gender that is assigned to them.

Baratz, who works with advocacy groups like the [Accord Alliance](#) pushes for more support for parents and children dealing with intersexuality.

"They are made to feel ashamed," she said. "It would be good for families if someone said there may be an issue, but there is support for this. They are made to feel, even by the medical community, as something shameful." "A lot of urologists argue strongly for surgery," she said. "There is a place for waiting and allowing children to have some voice in the decision and wait for long term effects or until something better is available. It's important to talk to them about what we don't know."

Stanford University has set up a multidisciplinary committee to explore these ethical issues and hopes soon to launch a DSD clinic.

Dr. Hsi-Yang Wu, a pediatric urologist at Stanford, sees a case of intersex about "once or twice a year," but endocrinologists may consult with two or three families a month.

"The surgical approach has become much more nuanced in terms of who needs surgery," said Wu. "Early on, we assumed all children with DSD got surgery. But things have changed."

The spring issue of [Stanford Medicine magazine](#) describes a baby with a potentially life-threatening form of the endocrine disorder, congenital adrenal hyperplasia.

Born with XX female chromosomes, the baby had ovaries, a uterus and fallopian tubes, a clitoris that looked more like a penis and partially fused labia.

The condition accounts for about 60 percent of all DSDs. The adrenal glands lack an enzyme to make the hormones cortisol and aldosterone, and so the girls' bodies create more androgen.

As a result, their genitals, and some say their brains, are masculinized and they must take daily hormone medication to stay alive.

At the age of 6 months, the baby had surgery to reduce the size of her clitoris and open her labia. She'll need another one at puberty to widen the vaginal canal.

Wu said doctors no longer use a surgical technique that pulls the clitoris under the pubic bone, which can cause painful orgasms in adulthood. He uses a nerve-sparing technique that removes the erectile portion of the clitoris.

"In this kind of case, she didn't fit into the typical DSD classification and it made it challenging," he said. "We try to predict what the gender identity will be, and three or four years later, the child psychologist can give us some kind of idea."

Parents are also confused. "It's so hard to accept that my child will look different to anyone who changes the diapers," said Wu. "Some parents are so torn by the fear that they will make the wrong choice and mess up the child forever."

Hormones are identical in children until they reach puberty, but by the time they are about 12 their bodies can change.

"The thing we worry about is if something starts to kick in when they age and they are not the sex we raised the child," he said. "What do we do then?"

Who Protects the Child's Rights? Anne Tamar-Mattis, executive director of [Advocates for Informed Choice](#), worries about the legal side of this complicated issue, especially when it involves sterilization without a child's consent.

"We don't weigh in on what medical decisions people should make," she said. "We weigh in on children's rights. If the decision involves sterilization, the child has a right to court oversight."

And when parents are making these complex decisions to remove the child's reproductive organs, they must be fully informed. Often, they are not, she said.

Katrina Karkazis, senior research scholar at Stanford's Center for Biomedical Ethics and author of ["Fixing Sex: Intersex, Medical Authority and Lived Experience,"](#) agrees that "the child can't speak for him or herself."

The American Academy of Pediatrics' Consensus of Care was established in 2006 to address treatment of intersex disorders.

"Everyone agrees there must be gender assignment," she said. "In a good scenario, the physician makes a decision with a lot of reflection and without rushing in to anything and in consult with the parents."

The number of children who don't accept their gender assignment is small, according to Karkazis. (This is no longer believed to be necessarily true. Many older patients attest to a wrong medical decision at their birth) "What's missing is these families and kids don't get the appropriate social and psychological support."

She recommends that doctors "check in" with the child over his or her life span and "find out what they are feeling."

Behavior is not always the best indicator. "Pay attention to what child a child is **telling** you -- there may be a switch which needs to be evaluated with expertise," she said. "Plenty of kids go through phases -- I am a girl or I am a boy -- and it ends after a year. But one thing that is irreversible is surgery."

"Once you've removed the tissues, you can't put them back," she said. "It's infinitely more complicated and for the most part, you cannot replace a phallus."