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STYLE DESK

## When Gender Isn't a Given

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AT the moment after labor when a mother hears whether her new child is a boy or a girl, Lisa Greene was told she had a son. She named her baby Ryan and went home. Ms. Greene learned five days after the birth that her baby was really a girl.

Doctors who ran tests diagnosed congenital adrenal hyperplasia, a condition that, put simply, can make baby girls' genitals look male. As the young mother struggled to get over her shock, to give explanations to relatives and put away the blue baby clothes, she also had to make a decision: whether to subject her daughter to surgery to reduce the enlarged clitoris that made her look like a boy, or leave it alone.

Thus Ms. Greene, a 26-year-old cashier in East Providence, R.I., was thrown into a raging debate over a rare but increasingly controversial type of cosmetic surgery.

For decades, parents and pediatricians have sought to offer children whose anatomy does not conform to strictly male or female standards a surgical fix. But the private quest for "normal" is now being challenged in a very public way by some adults who underwent genital surgery and speak of a high physical and emotional toll.

Some of them gave tearful testimony at a hearing last May before the San Francisco Human Rights Commission, which has taken up the surgeries as a human rights issue and is expected to announce recommendations before the end of the year. They spoke of lives burdened by secrecy, shame and medical complications: some said the surgeries robbed them of sexual sensation and likened the procedures to mutilation; others said they were made to feel like freaks when nothing was really wrong with them.

But a more common argument was that the surgeries are medically unnecessary and should at least wait for the patient's consent. Some doctors are starting to agree.

"Everyone's rethinking this," said Dr. Bruce Buckingham, associate professor of pediatric endocrinology at Stanford University. "We're probably a little less aggressive than we used to be. There's a lot of opinion."

But more opinions and inconsistent medical practices have made the decision tougher than ever for parents, many of whom are confronted with the word "intersex" for the first time. The term describes cases that arise from a host of conditions that cause sex chromosomes, external genitals and internal reproductive systems not strictly to fit the male or female standard.

Although no national statistics are available on the surgeries, some pediatric urologists and surgeons say they are doing fewer of them early. Doctors say the majority of cases involve girls with congenital

adrenal hyperplasia, or C.A.H., a hereditary disorder that affects the synthesis of adrenal hormones and leaves girls with high levels of male hormones. The condition may cause not only male-looking genitals, even in the presence of fully formed ovaries and uterus, but also personality traits and interests typically associated with boys.

The incidence of anomalous genitals in C.A.H. patients is not known precisely, but some studies indicate it may occur in as few as one in about 30,000 births because only girls are affected. Surgeries for other intersex conditions are even rarer, doctors say. But for the minority of parents who must choose whether surgery is the best course of action, the decision is unlike most others they may make on behalf of their children.

Some parents say they choose largely in the dark because there are no comprehensive long-term studies showing how patients fare as they grow up, with or without genital surgery: data on sexual function, for example. At the same time, some parents note, some doctors inform them of the option to do nothing, while others advise to do the surgery right away.

There is the steady drumbeat of opposition to surgery from a vocal intersex movement, but some parents wonder whether there is a silent majority of satisfied patients. And then there is the question: What would the child want them to do?

Worries about such an intensely personal matter often surface anonymously on computer message boards. "It's very hard to know what her feelings will be when she is older," read one message posted this summer on a Web site for families affected by congenital adrenal hyperplasia. "Will she hate us for letting her have the surgery? Or will she thank us for having it done when she was young enough not to know?"

In Rhode Island, Ms. Greene said she was confused and overwhelmed at first, not just with the news of her baby's change of gender but also with medical problems related to C.A.H., which kept her daughter in and out of the hospital for the first year. Ms. Greene said that at first she was determined to do a clitoroplasty, or reduction of clitoral size, fretting over whether people would call her daughter hermaphrodite, a term from Greek meaning one with male and female sexual organs, and suggestive, in modern times, of a sideshow attraction.

"She looked identical to a boy," said Ms. Greene, explaining that in addition to a large clitoris, her daughter's labia was fused together and she had no vaginal opening. "It's hard for a parent not to think of the psychological damage." She said she was speaking candidly because "in a way, I'm telling other parents that it's not something to be ashamed of."

Ms. Greene said her child's doctors recommended against surgery, warning her of risks like possible nerve damage. Skeptical, she went to the library to do her own research and on the Internet, where she said she sent e-mail messages back and forth with adults with the same condition.

In the end she consented only to creating a vaginal opening and rebuilding the urethra last year. Although whether vaginoplasties should be done early is also a subject of debate, Ms. Greene said her daughter, now 4 1/2, would have needed to undergo the procedures sooner or later to menstruate and for heterosexual intercourse. Ms. Greene deemed them medically and psychologically easier on the child if done early.

But Ms. Greene said she opted to wait for her daughter to grow old enough to make other decisions for herself. "They tell me that what I've done is the best compromise," she said.

Some parents weigh the same pros and cons and come out in favor of surgery, however. In San Jose, Calif., the 28-year-old mother of another girl diagnosed with the same congenital condition said doctors told her that today's surgical techniques spare nerves and are less extreme.

To her the psychological issues seemed more crucial than the physical risks and her daughter underwent a clitoroplasty last month at the age of 4. "My problem is the adolescent period," said the mother, a medical assistant who spoke on condition of anonymity to protect the privacy of her family. "Growing up a teenage girl is hard enough. I never want her to feel different. I never want her to have extra issues to deal with."

"When she's a teenager, and she's in a girl's locker room, it's not going to be a cute situation," the mother said. "Society is a big issue here. I tell my husband, if we lived in a deserted island she'd never need this."

Jeff Spear, 37, a farmer in Maine whose 11-month-old daughter underwent a clitoroplasty along with other surgical procedures six months after birth, said he hardly considered the surgery cosmetic given how male she looked. Mr. Spear rejected the idea of waiting for his daughter's consent. "You're the parent, you make the decisions," he said. "We felt this needed to be done right now."

The more "virilized" the appearance, the more likely parents will choose surgery, said Kelly R. Leight, executive director of the Cares Foundation, a support and educational group for families affected by congenital adrenal hyperplasia. While more parents are beginning to question the surgeries, more often than not they choose to operate within the first year, said Katrina A. Karkazis, a medical anthropologist and research associate with the Stanford Center for Biomedical Ethics.

Ms. Karkazis, who interviewed parents, doctors and people who had undergone early surgery of the clitoris, vagina and testes because of C.A.H. or androgen insensitivity syndrome, another condition that affects the development of genital organs, said doctors and parents who favored genital surgery were driven by cultural factors, like their own values about appearance and worries about how the child would be treated by others. Most of the adults who had undergone the surgery as children, however, told Ms. Karkazis they were unhappy with the results and complained of lack of sensation or pain, of the need for repeated surgeries and of the fact that they had thick scarring and the genitals never looked "normal." Few were in intimate relationships, she said.

Since the 1990's, adults unhappy with the operations have been raising their profile, denouncing a standard of treatment they say is based on cultural biases, and on arbitrary ideas of male and female and of the ability to assign gender.

The most famous case of "gender management" was not intersex but illustrated the point: David Reimer, raised as a girl after a botched circumcision, rejected the identity assigned to him later on in life and lived his teenage years and adulthood as a man, proving wrong researchers who believed sexual identity is made rather than born. He shared his story in a 2000 book, "As Nature Made Him" by John Colapinto, and appeared on "The Oprah Winfrey Show." Last May, depressed after losing a job and separating from his wife, relatives said, he committed suicide at 38.

Some doctors say that even when gender seems certain, as in the case of C.A.H. patients, who can also be fertile and bear children, there are questions surrounding the effect on the girls of high levels of androgens.

Dr. Patrick H. McKenna, chairman of the division of urology at Southern Illinois University School of

Medicine and a member of an intersex task force of the American Academy of Pediatrics, said that both the mixed results of surgery on sexual sensation and the idea that some patients may identify more with the opposite gender upon growing up has led him to recommend against early surgery in intersex cases.

He and other doctors said medical centers are increasingly involving psychologists and other specialists in handling intersex cases because of their complexity.

"There's no good scientific data, and more and more we're leaning toward waiting," he said.

The Intersex Society of North America, a group representing intersex adults founded in 1993, advocates that children with anomalous genitals be raised in a specific gender even without surgery, but not be regarded as "a social emergency," as pediatric guidelines have called these cases in the past.

Cheryl Chase, the group's executive director, said its efforts are now focused on influencing how medical schools teach the intersex subject; she said that if doctors learned alternatives to early genital surgeries, including a treatment model that incorporates psychological support for families, they would in turn help parents see their children's condition more as a natural variation than a cause for panic.

In many cases, opponents of the surgery say, parents have hidden the medical history from their children. Betsy Driver, 40, a television news freelancer from Easton, Pa., who runs an online support group, Bodies Like Ours, said she underwent an extreme form of clitoral surgery as an infant because of congenital adrenal hyperplasia but did not fully learn the details of her condition until her 30's.

"I felt my parents could not love me the way I was," she said. "There was nothing wrong with the genitals. They just looked different."

It took her years of therapy to come to terms with her intersex condition, said Ms. Driver, who said she was left with no clitoral sensation. "Dating was exceptionally difficult," said Ms. Driver, who is gay and said she did not start dating until her 20's. "It was body image, fear of rejection and not being able to explain why I was different. Now, because I can explain, it's no big deal."

But she added, "Not doing the surgery is not a magic bullet." Parents need to talk openly about their children's bodies and teach self-esteem, she said.

Ms. Greene said she was trying hard to do just that. She said her daughter was old enough to be curious and constantly asked questions about the way she looked. "Bigger means better," Ms. Greene tells her.

Ms. Greene said she had warned preschool teachers about her daughter's physique "so they're not surprised" if she ever has an accident.

She said she was compiling a huge folder with information so her daughter had the facts as she grew up. "We're not ashamed of it, and she should not be ashamed of it," Ms. Greene said.

"I just came to the conclusion that we'd raise her with as much confidence as we can," she said. "If she chooses as an adult to have the surgery, I'll support her."

Photos: CHOICES -- Lisa Greene, above, found a compromise for her daughter; Jeff and Jody Spear, above left, chose reconstructive surgery. (Photos by Lawrence Frank for The New York Times; left, Herb Swanson for The New York Times)(pg. 6)

Drawing (Drawing by Mark Bodnar)(pg. 1)