

What if It's (Sort of) a Boy and (Sort of) a Girl?

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By Elizabeth Weil

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When Brian Sullivan — the baby who would before age 2 become Bonnie Sullivan and 36 years later become Cheryl Chase — was born in New Jersey on Aug. 14, 1956, doctors kept his mother, a Catholic housewife, sedated for three days until they could decide what to tell her. Sullivan was born with ambiguous genitals, or as Chase now describes them, with genitals that looked “like a little parkerhouse roll with a cleft in the middle and a little nubbin forward.” Sullivan lived as a boy for 18 months, until doctors at Columbia-Presbyterian Medical Center in Manhattan performed exploratory surgery, found a uterus and ovotestes (gonads containing both ovarian and testicular tissue) and told the Sullivans they'd made a mistake: Brian, a true hermaphrodite in the medical terminology of the day, was actually a girl. Brian was renamed Bonnie, her “nubbin” (which was either a small penis or a large clitoris) was entirely removed and doctors counselled the family to throw away all pictures of Brian, move to a new town and get on with their lives. The Sullivans did that as best they could. They eventually relocated, had three more children and didn't speak of the circumstances around their eldest child's birth for many years. As Chase told me recently, “The doctors promised my parents if they did that” — shielded her from her medical history — “that I'd grow up normal, happy, heterosexual and give them grandchildren.”

Sullivan spent most of her childhood and young-adult life extremely unhappy, feeling different from her peers though unsure how. Around age 10, her parents told her that she had had an operation to remove a very large clitoris. They didn't tell her what a clitoris was but said that now things were fine. At 19, filled with rage and feeling suicidal, she started trying to access her medical records and finally succeeded when she was 22. As a means of recovery, she threw herself into her work. She graduated from M.I.T. with a degree in math and then went on to study Japanese at Harvard. Soon after, she moved to Japan and helped found a successful tech company, assuming she'd work really hard for now and be happy later. At 35, realizing that being happy later was not going to happen, she flew to Florida with a list of questions to ask her mother, to whom she was never close. According to Chase's notes from that conversation (both of her parents have since died), her mother maintained that the clitoridectomy had not impacted her daughter's life. “When you came home,” Cathleen Sullivan told Chase about her return from the hospital after surgery, “there seemed to be no effect at all. Oh, yes, wait a minute. Yes, there was one thing. You stopped speaking. I guess you didn't speak for about six months. Then one day you started talking again. You had known quite a lot of words at 17 months, but you forgot them all.”

After that conversation, Chase, an extremely ambitious, focused and analytical individual, decided it was time to heal herself, and she gave herself a year. As part of that project, she moved to San Francisco and started calling and writing to doctors, academics and gender activists — anybody who might have something concrete to say about the predicament of being born part male, part female, or who might be able to tell her why it had been necessary to have her clitoris removed and if she'd be able to get any sexual function back. Along the way, in 1993, Sullivan called Anne Fausto-Sterling, a professor of biology and gender studies at Brown, who had

published several papers on intersex (the term that has come to replace "hermaphrodite") and who was about to publish an article in a magazine called *The Sciences*. Sullivan wrote a letter that was published in the next issue calling for people with intersex conditions to get in touch with her, and she signed it Cheryl Chase, the Intersex Society of North America, though neither a person named Cheryl Chase nor an organization called the Intersex Society of North America yet existed.

Thirteen years later, Chase, as Sullivan began calling herself, is now known throughout the urology and endocrinology establishment as a passionate advocate for the rights of those born with ambiguous genitals, and she has succeeded in stirring a contentious debate among those doctors over how intersex babies should be treated. At the heart of the controversy is the question of whether intersex children should have surgery to make their genitals look more normal. Chase has talked to thousands of doctors and others in the medical profession, making the case that being born intersex should not be treated as shameful and require early surgery. In doing so, she has assembled an impressive intellectual arsenal, drawing on everything from the Nuremberg Code and its prohibition against experimental medical procedures without patient consent to the concept of "monster ethics" — the idea that we perform questionable medical procedures on certain patients, like intersex people and conjoined twins, when we consider those patients to be less than human. Reports on the frequency of intersex births vary widely: Chase claims 1 in 2,000; more conservative estimates from experts put it at 1 in 4,500. Whatever the case, intersex is roughly as common as cystic fibrosis, and while the outcome of the debate Chase has stirred is directly pertinent to a limited number of families, her arguments force all of us to confront some basic issues about sexual identity, birth anomalies and what rights parents have in physically shaping their kids. Will a child grow up to enjoy a better life if he or she is saved from the trials of maturing in a funny-looking body? Or will that child be better off if he or she is loved and accepted, at least at home, exactly as he or she is?

The old protocol for dealing with an intersex birth, the protocol Chase was subjected to as a child, was based on the belief that children should be saved from the anguish of looking weird, or of even knowing they were born looking weird. This would come to be known as the "optimal gender of rearing" protocol and was put forth by John Money, a psychologist who in 1965 founded the Johns Hopkins Gender Identity Clinic, which specializes in transgender surgery. Money's protocol guided doctors to perform genital surgery on intersex babies and then discourage families from discussing the child's ambiguity, for fear that the child would grow up questioning his or her sexual identity.

This protocol held for 40 years, until Chase began agitating against it in the mid-1990's. For a dozen years, she chipped away at its logical underpinnings, and last month Money's protocol officially fell. The journal *Pediatrics* published a paper signed by 50 international experts, primarily doctors but including Chase, titled "Consensus Statement on the Management of Intersex Disorders." The consensus promotes the traditional idea that every child should be assigned a gender as soon as possible after birth, and that this should be done by doctors examining the baby's genes, hormones, genitalia, internal organs (via ultrasound), electrolytes, gonads and urine. These doctors then make their best guess as to whether that child will want to live his or her adult life as a man or a woman. Where the consensus departs from tradition is that it also instructs doctors to discourage families from rushing into surgery. The paper is a bit vague on this point; it doesn't directly tell doctors not to

operate but does state that no good scientific studies prove infant cosmetic genital surgery improves quality of life.

Chase says she believes that every child should be assigned a gender at birth but that the assignment should not be “surgically reinforced” and that parents and doctors should remain open to the idea that they may have assigned the wrong sex. She contends that the most important thing is for a child to feel loved by her parents, despite her difference. An operation, she says, should not be done to assuage parental embarrassment or anxiety; it should be chosen, if it is chosen at all, by an intersex individual who is old enough to make her own decision and give proper consent.

The consensus is a major victory for Chase. Yet making progress from here may prove extremely difficult. Chase now must take her arguments not just to medical professionals but also to parents of intersex children, almost all of whom will be feeling intensely stressed and almost none of whom will have considered the complexity of raising an intersex child. One doctor, who didn’t want to be named, put her chances of persuading parents not to choose surgery for their intersex children at “honestly, zero.” From the parents’ perspective, the argument for surgery is almost impervious to reason. As one mother of an intersex girl wrote on a message board: “How can anyone possibly think that a child can grow up and feel confident of her sexuality looking down at her genitals that look like a penis? Come on.”

One day last spring, Chase traveled from her home in Sonoma County, Calif., to Chicago to tell her story to a group of genetic counselors and to distribute the Intersex Society’s latest handbooks, one for medical professionals and one for parents. On this morning, Chase, who is 50, has short white hair, fashionable glasses, intelligent eyes and a strong build, was wearing a wide-necked sweater meant to fall off her shoulders, exposing a black bra. She lives as a woman and as a lesbian, and while she imagines she doesn’t look or feel exactly as other women do — for instance, she can’t find any gloves made for women that fit — she has no desire to be a man.

Chase had been invited to speak by Rebecca Burr, a genetic counsellor who several years ago found herself dealing with a 26-year-old woman who’d never menstruated, knew she’d had multiple operations as a child but didn’t know that she was intersex. Burr felt ill prepared to handle the case and tracked down the Intersex Society. In Chicago, Chase stood in front of 30 members of the Genetic Task Force of Illinois, telling them about the parker house roll, the trashing of her baby pictures, the hospital stay at age 8, when she was told doctors would be helping her stomach aches but when she really had the testicular part of her gonads removed.

When Chase began her activism, more than a decade ago, few doctors were open to her ideas about the way intersex babies should be treated. “When I first started doing this, it took some extreme kinds of conversation to get people to listen up,” she told me. She also organized a picket of a pediatric convention; she sneaked into medical conferences and buttonholed attendees. In 2000, however, the esteemed Lawson Wilkins Pediatric Endocrine Society finally invited her to speak, and since then Chase’s technique has evolved. She now receives and solicits speaking engagements from groups of all kinds. She addresses nurses’ associations, doctors, medical students, anybody who will listen.

Among the Intersex Society's primary goals is ending the shame and secrecy surrounding being intersex, and toward that end, upon founding the society in 1996, Chase organized an intersex retreat. She wanted to help people, herself included, become more comfortable speaking openly about their condition. So she invited the 62 intersex people she had made contact with for a weekend at her farm in Sonoma. Eleven came. Chase made a raw and moving documentary of their time together, titled "Hermaphrodites Speak!" Ten people directly address the camera. Nine tell stories of surgery and lives nearly wrecked. One man refers to himself as a monster. Another says she's "damaged goods." One person, however, did not have an operation, and she alone looks fit and confident, sitting with great posture and seeming at home in her body. She grew up in a Catholic family, and when she first saw another naked woman up close, at age 12, her initial thought was, What's wrong with her? She modeled her sexuality on Grace Jones and David Bowie. Her story, though just one account, is consistent with the findings of Sarah Creighton and Catherine Minto, two London gynecologists. The two have reported, albeit with small samples, that genital surgery is likely to have a negative impact on sexual function and quality of life.

In the last several years, the Intersex Society has formed an active speakers' bureau, and at Cook County Hospital in Chicago, after Chase addressed the genetic counsellors, a young woman stood up to speak. A 20-year-old DePaul student, she was very pretty, in a chunky necklace, floral shirt and hip hugger jeans. "I found out last year I was intersex; I was in my freshman women's studies class," the young woman, who asked not to be identified in this article, said. Her professor was lecturing about various intersex conditions and started describing the symptoms — "No periods, can't have children, ambiguous genitals. I called my mom, and I said: 'What's it called? What do I have?' " It turned out she has partial-androgen-insensitivity syndrome, a phenomenon in which fetuses with male chromosomes (XY) can't properly metabolize male hormones and are born looking mostly like girls. "When she said the name I threw the phone across the room and started crying. I cried for like a week."

A few weeks after hearing this news, at the urging of Lynnell Stephani Long, a member of society's speakers' bureau who happened to be giving a talk around that time to the women's studies class, the young woman retrieved her medical records from Chicago Children's Hospital. "They photocopied them for me and I got them hot," she told the group of counsellors. "The first page said 'pseudo male hermaphrodite.' Just the words 'male' and 'hermaphrodite' made me want to throw up." Chase has since lobbied doctors to stop using the word "hermaphrodite." Intersex, she contends, is a medical condition, not an identity, and the consensus suggests using the term "disorders of sex development."

The young woman continued speaking, her story raw and captivating. "I grew up a girl. I was always a tomboy, I wrestled, I played softball. I had bladder problems when I was a kid, and when I went in to have my urethra fixed" — at age 3 — "they decided to give me a vaginoplasty and also a clitoridectomy," that is, surgically reshape the vagina and reduce the size of her clitoris. "When I finally learned all this, I spent a lot of time staring in the mirror" — she pressed her hands flat against her cheeks and stretched her skin of her face back toward her ears — "going: 'Do I look like a boy? Do I look like a boy?' Now I think being intersex is pretty weird but kind of sweet. I just wish someone had given me the tools to be able to talk about it."

Chase's position — that cosmetic genital operations on intersex children should be stopped and that children should be made to feel loved and accepted in their unusual bodies — is still considered radical. Most people believe, reflexively, that irregular-looking genitals would be extremely difficult to live with — for a child on a sports team, for an adult seeking love and sex — so why not try to make them look more normal? Katrina Karkazis, a medical anthropologist at the Center for Biomedical Ethics at Stanford, interviewed 19 clinicians and researchers of various specialties who treat intersex individuals, 15 intersex adults and 15 parents of intersex children, and she found that a majority of the doctors and parents felt surgery was a good idea. "We chose surgery for my daughter mainly because we did not want her to grow up questioning her sexual identity," one mother explained about her baby, who was born with congenital adrenal hyperplasia, a genetic defect of the adrenal glands that causes girls' genitals to appear masculinized at birth. "We felt that she should look like a female, so we chose the clitoroplasty and the vaginoplasty. We felt that she would have a better self-image if she did not have a 'phallic structure' and 'scrotum.' "

Within the medical community, Chase has been successful in tempering the explicitness with which people publicly make this argument. As Chase has explained innumerable times, intersex babies are not having difficulty with sexual identity or self-image. The parents are, and parental anxiety about the appearance of a child's genitals should be treated with counselling, not with surgery to the child. When I met Melvin Grumbach, one of the doctors who cared for Chase as an infant and who went on to become one of the most respected pediatric endocrinologists in the country, he'd clearly heard Chase's line of reasoning many times. He participated in forming the consensus, and he also signed it. He knew what he was supposed to say. "We say, 'Don't do surgery unless it's necessary, unless it's important,' " he told me in early summer in his office at the University of California in San Francisco, where he's now an emeritus professor. "But I think if the external genitals are really masculinized, you work it out with the family. I mean, good grief. What about the parents? The parents are raising the child. Don't they have some say?"

A debate has emerged in recent years concerning if and when parents and doctors should medically shape children. Should very short children be treated with growth hormone and surgery? Should children have multiple cosmetic operations to try to erase all traces of a cleft lip? In these instances, no studies have shown that these medical interventions improve children's quality of life. The same is true for operations on intersex children, though in truth, few well-controlled studies exist that prove much of anything, in part because the success of these treatments cannot be meaningfully assessed for at least 20 years, and by then most patients are lost to follow-up.

Among the arguments against genital surgery is the fact that sexual identity does not derive solely, or perhaps even primarily, from a person's genitals. As Eric Vilain, professor of human genetics, pediatrics and urology at U.C.L.A., has shown, many genetic markers go into making a person male or female, and those markers affect many parts of the body. In studies of mice, he has found 54 genes that work differently in male and female brains just 10 days after conception. In humans, we've all been taught, and we'd like to believe, that being male or female is as simple as having XY or XX chromosomes, but it is not. Even the International Olympic Committee acknowledged this when it suspended its practice of mandatory chromosomal testing for female athletes in 2000, reflecting current medical

understanding that a female who tests positive for a Y chromosome can still be a woman. (Chase is XX, and the reason for her intersex condition has never been fully understood.)

Vilain has a clinic devoted to treating disorders of sex development, where he sees 40 to 50 new intersex patients a year. When he first left the lab and started seeing patients, he said he couldn't believe that surgeons were performing genital reconstructions with so little data. "To me it was shocking, because where I come from, molecular genetics, we're under extreme scrutiny," Vilain told me on the phone in July. "If you want to show that a molecule causes something, you have to show it with a bunch of excruciatingly painful controls. And here I was looking at a lot of surgeons who were saying, 'We think it's good to do genital surgery early on because the children are doing better.' So each time I would ask, 'What's the evidence that they're doing better?' And in fact the answer is there's no real evidence. Then I'd ask: 'What does it mean doing better? How do you measure it? Are you talking quality of life, or quality of sex life?' And there was never any convincing answer."

Other surgeons contend that not intervening presents its own risks. "There haven't been any studies that would support doing nothing," says Larry Baskin, Grumbach's protégé and current chief of pediatric urology at the University of California, San Francisco. "That would be an experiment: don't do anything and see what happens when the kid's a teenager. That could be good, and that could also be worse than trying some intervention." In Baskin's view, being intersex is a congenital anomaly that deserves to be corrected like any other. "If you have a child born with a cleft lip or cleft palate or an extra digit or a webbed neck, I don't know any family that wouldn't want that repaired," he told me. "Who would say, 'You know what, let's wait until Johnny is 20 years old and let him decide'? You probably get those fund-raising postcards from the Smile Train all the time. I can't send those out, because you can't put pictures of penises on postcards. But if you could, I think I'd be able to raise a lot of money."

Still, Baskin acknowledges that intersex is different: genital surgery has the potential to diminish sexual function, and how do parents weigh that risk? Doubtless, surgical techniques have improved since Chase's clitoridectomy — Baskin describes the old operations as being "like bloodletting," when doctors were only able to excise the clitoris, not try and reduce it. Now, he says, "We have a pretty good handle on where all the nerves are." But whom are these operations serving? Do parents have a right to take chances with a child's future sexual function? And are we more willing to risk the sexual futures of intersex kids? The vast majority of adults — parents and doctors included — find intersex bodies, especially sexualized intersex bodies, unsettling. Karkazis, the medical anthropologist, heard from clinicians she interviewed of numerous cases of parents who initially decided against surgery but changed their minds when their children started to explore their own sex organs, often around the age of 2. "Masturbation in little girls with clitoromegaly" — abnormal enlargement of the clitoris — "is a situation I've encountered quite a few times, and that's actually pushed many parents toward surgical intervention," one doctor told Karkazis. "The little girl was masturbating, and the parents just fell apart and were back in the office the next week for surgery."

Chase says that her own mother's discomfort with and ignorance about sexuality contributed to the decision to have Chase's clitoris amputated. When Chase flew from Japan to Florida to discuss her childhood with her mother, she also quizzed her

mother about sex. "No, I don't know what human genitals look like, exactly," Chase's mother told her. "I have never looked at myself, and I never looked closely at my children. The doctor said your clitoris had to go. Mine never meant anything to me, so I didn't think it was wrong to remove yours."

Chase claims she wasn't even a social human being before age 35, when she started trying to recover from being "extremely pathologically shy and withdrawn." She has built her personality alongside her activism, both growing steadily more refined over the years. As we traveled from Chicago to New Jersey, where Chase was to address the New Jersey Psychological Association, she told me she was working very hard on presenting herself as "extremely moderate."

To do this, Chase has been honing her arguments about who has the right to do what to other people's bodies. Those arguments first took shape in 1998, when Chase wrote an amicus brief to the constitutional court of the country of Colombia. At the time, Colombia was considering the ethical and human rights implications of genital surgery, as it pertained to a case of a 6-year-old boy with a micropenis and the question of whether his penis should be reduced to the size of a clitoris, his testes removed and a vagina constructed out of a piece of his ileum. Medical convention has traditionally held that the phallic structure must be at least 2.5 centimeters long on baby boys and shorter than 1 centimeter for girls. And since it's easier to surgically construct a vagina than to make a penis, children with anatomies that fell in the middle were almost always raised as girls.

Building on work on the Colombia case, in 2004, Chase and the Intersex Society were involved in persuading the San Francisco Human Rights Commission to hold a hearing and address the question of medical procedures on intersex infants in the United States. Over the course of three hours, dozens of intersex people and parents of intersex people testified. When it came time to ratify the report, Chase addressed the commission. "What the Human Rights Commission has done. . . is to recognize me as a human being," she said. "You've stated. . . that just because I was born looking in a way that bothered other people doesn't mean that I should be excluded from human rights protections that are afforded to other people."

This is the one time Chase was seen crying in public. "She lost it crying, and I thought, What a perfect time to lose it," Chase's friend Alice Dreger, a bioethicist and medical historian at Northwestern University who writes about intersex and conjoined twins, told me. "I've never seen her cry in public since. She's damaged in a way that she doesn't get very emotional."

One of Chase's closest allies is William Reiner, a University of Oklahoma urologist who retrained as a child psychiatrist to better understand his intersex patients. Reiner, like Chase, says he thinks that a child transitioning from his or her initially assigned gender to the opposite gender should not necessarily be viewed as a medical failure. A baby who was born with a penis-size clitoris who had that penis removed and a vagina constructed out of a piece of her intestine but who ended up wanting to live as a man — that's a failure. Yet transitioning from one sex to another, says Reiner, is something a child can often handle. Transitioning, Reiner maintains, is much more difficult for parents than for children, because parents have large and complex psychological and social landscapes, while children have relatively small and simple ones. Reiner told me about a family he worked with in which a mother told her 7-year-old daughter that she was actually born a boy. "And within

an hour the child had chosen a boy name and announced he was a boy." Reiner continued: "The youngest child that I've had that spontaneously changed sexes was 4ð. This was one of the most assertive human beings I've met in my life. She cut off all of her hair one afternoon while Mom was at work." When asked to explain, the child said proudly, "Mom, I've been telling you: I'm a boy, and boys have short hair, so I cut off my hair."

Over the same period that the Intersex Society became effective, Chase's personal life bloomed. Chase married Robin Mathias, her partner of five years, in 2004, when gay marriage was legal in San Francisco, and the two live on a hobby farm in Sonoma. In recent years, Chase has also made some important professional connections, like David Sandberg, a psychologist at the University of Michigan whose work has been instrumental in raising questions about treating children with very short stature with growth hormone and who has now turned his attention to intersex. Sandberg joined Chase for her presentation to the New Jersey Psychological Association, and afterward they talked late into the night. Both Chase and Sandberg say that the first few days of an intersex child's life can set a tone within a family that persists for many years. Both say that medical professionals, right from the start, should behave as they would with any healthy baby and encourage parents to do the same — name the child, fall in love and bond. "If we don't care for the parents early on," Sandberg said as we all sat around Chase's hotel room, "we might lose the battles in terms of creating circumstances for a happy life for this child, and perhaps sacrifice the quality of life for siblings too."

The next morning, Chase came down to breakfast reading "On Becoming a Person," a book by the psychologist Carl Rogers. Her goal of appearing mainstream while publicly discussing fused labia and unusual gonads seems, at times, unattainable. Few would argue that her current message — that doctors and families should not rush into surgery — is nothing if not prudent. Nonetheless, her long-term goal remains the eradication of infant genital surgery for the sole purpose of altering appearance, and this continues to sound outlandish to many medical professionals and to most of the general public as well.

Over coffee, Sandberg told Chase that he, too, could not yet join her in taking the position that cosmetic genital surgery on infants is always wrong, and Chase was trying hard to understand why.

"But is there ever a good reason for reducing the size of a clitoris?" Chase pressed Sandberg.

"If the parent cannot tolerate it," Sandberg replied.

Chase paused, struggling to empathize with a mother unable to raise a child because of the size of that child's clitoris. Chase has spent her adult life explaining why such a position is unethical. The logic she has constructed is nearly unassailable. Yet for most of us, Chase's thinking is emotionally difficult to embrace. For starters, we tend not to be very rational when it comes to our children and to our genitals. Complicating matters, in treating intersex, as opposed to, say, a heart condition, what feels best for the parent in the short term may not turn out to be what is best for the child over time. Finally, parents feel entitled to make decisions based on the (sometimes false) sense that they know what's right for their families, and the reality is that in the case of intersex children, the right treatment for one child, or even the

majority of children, will not be the right treatment for all. Even Sarah Creighton, one of the London gynecologists who reported that intersex patients who have not had surgical procedures tend to fare better, has noted that no treatment is guaranteed or even likely to make the lives of those babies born intersex pain-free. "These are not all happy people, either," she has said. "Some of them have isolated, difficult lives. Some of the surgery patients are fine, and some of them are not, and it's very hard to separate all the things out."

Over time, the public may grow to accept Chase's idea that we, as families and neighbors, have an obligation to shed our own biases and accept bodies that are neither neatly male nor neatly female. Or maybe we will not get there, and our discomfort with ambiguity will never fade.