



## **Genital surgery**

# **Surgeons claim: "things are different now"**

There was never any reason to suspect anything strange. I appeared female when I was born in 1972, and I was assigned and raised as a girl.

When I was twelve, I started to notice that my clitoris had grown more prominent. At least, that's how I perceived it. I can't remember whether I thought anything about it; I just remember that I began to notice it. I'm sure that it was at least three months after I had taken note that my mother caught a glimpse of me as I bathed one day after returning from the dance studio. She tried very hard not to let on how alarmed she was, but of course a twelve year old girl-child just senses such a thing. When the pediatrician examined me the next day she was also obviously alarmed. She referred me to a female pediatric endocrinologist at the University of Illinois Medical School.

Within ten days I was admitted to Children's Memorial Hospital in Chicago for surgery. They told me a little bit about the part where they were going to "remove my ovaries" because they suspected cancer or something like that. They didn't mention the part where they were going to slice off my clit. All of it. I guess the doctors assumed I was as horrified by my out-sized clit as they were, and that there was no need to discuss it with me. After a week's recovery in the hospital, we all went home and barely ever spoke of it again.

Four months ago, I finally got some of my medical records from Children's Memorial Hospital, in Chicago. They are shocking. The surgeon who removed my clitoris summarized the outcome as "tolerated well."

Now 23, I've spent the last ten years in a haze of disordered eating and occasional depression.

ISNA charges that medical specialists treat ambiguous genitalia with aggressive surgery, often profoundly damaging sexual response and emotional well-being, and ignoring emotional support.

When they bother to respond to these charges, specialists assert that "things are different now." The surgery is improved, they say. They are careful to provide counseling, they say. Because many women who have not had surgery are inorgasmic, they insist that we cannot blame our damaged sexual sensation and response on surgery that occurred before we were sexually active; we have no standard against which to compare our current level of function.

Ana's story (left) is recent enough to demonstrate that girls can still lose their clitorises, emotional well-being, and sexual response to "clitoral recession" at major U.S. hospitals without even a hint of counseling. Ana and several other ISNA members were subjected to this damaging surgery during adolescence—after they had become sexually active—and thus can reliably attest to the damage to their sexual function. Surgeons have no reliable evidence to support their claim that sexual sensation and orgasmic function are undamaged by clitoral surgery.

My struggle with bulimia has been an all-consuming although mostly secret part of my life, and I now believe it represents my attempts to express the fear, shame, rage, and intense body-hatred that I have felt as a result of the—until now—unspeakable assault that I experienced under the guise of medical treatment.

I do have some clitoral sensation. I sometimes masturbate and I do have an experience which I call orgasm—some faint muscular contractions. But the response is unreliable, and nothing like the tremendous sensitivity and wonderful juicy orgasms I had before the clitoral surgery. I would say that the clitoral recession and vaginoplasty decreased my responsiveness by a factor of five or ten.

I hadn't made much sense of my medical records until a recent visit to my gynecologist, at Barnes Hospital in St. Louis. I was referred to her three years ago, by the University of Illinois pediatric endocrinologist, to determine whether I would "need" the vaginoplasty. This was all news to me as I had never been informed that I would ever need more surgery. As it turned out, my gynecologist concluded that I had a sufficient vagina and she recommended only pressure dilation.

Anyway, just about a month ago I visited the gynecologist for my routine annual physical—she's the only doctor I ever see. This time, when she asked what kinds of questions I had, I pulled out my records. "Get dressed and meet me in my office," she said. Then she actually spent over an hour with me explaining some of my records to me. One phrase that stuck in my head was "Androgen Insensitivity Syndrome." I left that day still in a fog, but a little more confident that at least someone had taken my questions seriously. She brought me closer to the truth than I had ever been, but I was still confused.

Then, just under a week ago, I received a package by mail from a friend in whom I had confided some very sketchy details about my surgery. Natalie Angier's article about ISNA ("Intersexual Healing," New York Times Week in Review Section, page 14, Sunday, February 4, 1996) and the Winter 95-96 issue of ISNA's newsletter Hermaphrodites with Attitude had crossed her desk, and she realized that this might be related to my situation. In fact she was absolutely right. I couldn't believe it as I sat there reading stories that I could have written.

After reading these articles and others that I located at the ISNA website, I now suspect that I have Partial Androgen Insensitivity Syndrome. The medical team lied to me about removing my ovaries; they actually removed my testes. I do know that I have a 46 XY karyotype. I have lived openly as a lesbian for almost three years, what I consider one of my greatest life accomplishments.

As for sophisticated counseling—what a hoot! First of all, they made a traumatizing hospitalization even more traumatizing by putting me on show for parades of earnest young residents with you're-a-freak-but-we're-compassionate grins on their faces. This, all without nurses or my parents anywhere around. Second, I know now from my parents that the pediatric endocrinologists repeatedly advised them that I didn't need to know the truth. They told my parents some horror story about a girl like me who had peeked at her file once while the doctor was out of the room and then killed herself. My mother asked the doctors specifically if they thought I would benefit from any type of counseling. They discouraged her from pursuing it. That's what passed for emotional support among the Children's Memorial Hospital intersex specialist team in Chicago in 1984.

I am horrified by what has been done to me and by the conspiracy of silence and lies. I am filled with grief and rage, but also relief finally to believe that maybe I

am not the only one. My doctor told me more than once that I wasn't the only one, but I never got to meet any of them. I'm full of anticipation, fear, and craziness at the thought that, through ISNA, I may finally be able to speak with and meet others who share these experiences. ■

## Medical ethics and truth-telling

### Special rules apply to intersex diagnoses?

The Canadian Medical Association Journal, in its Feb 15 1996 issue, carries an article titled "Medical ethics and truth telling in the case of androgen insensitivity syndrome." *Medical ethics and truth-telling* seem ordinary enough. But why should author Anita Natarajan qualify them by *in the case of?*

Natarajan opines that, since the physician can provide no services other than surgical reconstruction of the vagina and counseling on adoption, and because she believes that after surgery patients will lead "the same lifestyle as a heterosexual, infertile, genetic female," the best course is for the physician to deceive the patient about the nature and medical label of her condition. So long as the physician merely deceives, and does not lie, she reasons, his actions are ethical. This article won the \$750 second prize in the Dr. William Logie Medical Ethics Essay Contest.

"Truly autonomous people can deliberate effectively only if they have the abilities required for effective reasoning and the disposition to exercise them," notes Natarajan. Does not the physician's deceit undermine the patient's autonomy? No, the author concludes, because "the AIS patient who is told she is genetically male is likely to experience confusion or strong emotions that could diminish her sense of rationality, her ability to deliberate effectively and, in effect, her future autonomy." In other words, doctor knows best, and for heaven's sake let's not have any tears in the office.

Few ISNA members were told all, or even much, of the truth of their diagnoses and treatment history. In practice this means that many are left with a feeling of monstrousness. It is all too obvious that doctors and parents are hiding something, which implies that the secret must be unspeakably awful. Many of us have learned our diagnoses as children, by overhearing it or by stealing a glance at our medical records while the doctor's back was turned, or as adults, by researching in medical libraries, or obtaining our records. We were thus left absolutely alone, with no help in interpreting the information and no emotional support or company in digesting it.

Many of us have felt so betrayed by these deceptions that we have avoided all contact with medical providers, and more than a few of us are estranged from our families. Most of those with a history of gonadectomy who write to ISNA are not aware of the risk of extreme osteoporosis that attends failure to replace hormones. Some have already suffered severe loss of bone density. ■

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