

think it shows how important this advocacy work is. I knew how important it was when I was twelve, how important it was that just a few people stand up and remove this invisibility. That knowledge has only been solidified since my coming out. I have had so many people reach out to me in the last few months and it shows me how important it is that people know our stories. Intersex people are not rare; they're just invisible. If more people start removing the shroud of secrecy, then more intersex people will get the care that they truly need.



It's a Human Rights Issue!

Daniela Truffer

I was born in 1965 in Switzerland with a severe heart defect and ambiguous genitalia. The doctors couldn't tell if I was a girl or a boy. First they diagnosed me with CAH and an enlarged clitoris, and cut me between my legs looking for a vagina.

Because of my heart condition, the doctors assumed I would die soon. After an emergency baptism, I stayed in the hospital for three months. My mother would travel to the city as often as possible, though she was only allowed to see me through a glass window.

When I was two months old, and still in the hospital, doctors opened my abdomen and found healthy testes, which they threw in the garbage bin. According to my medical records, my parents had not provided consent. Further tests showed I am chromosomally male.

Later the "castration" was declared a "mistake": one doctor said I was a boy with hypospadias. As they had already removed the testes, however, they would have "to continue this way and the small patient must be made a girl."

After three months, my parents were finally allowed to take me home.

During my childhood, I spent a lot of time in doctor's offices and hospitals, suffering countless

examinations of my genitals and urethral opening. When I was two, our family doctor stuck his finger into my urethral opening; I was screaming very loud, my father says. My mother had to put me into warm water because every time I had to pee I screamed in pain. Later I was hurried to the hospital with a bad infection. Still today my urethra often hurts after going to the toilet.

I knew early in my life that I was different.

I learned fragments of the truth only after decades of ignorance and denial. I was lucky to obtain my medical records. The hospital initially told me they no longer existed. When I insisted, they eventually sent me some recent files pertaining only to care I received after I was an adult. I kept calling. Once I was put through directly to the archive, where I was told that indeed there were "lots of files on microfilm." However, it was only when I threatened to return with a lawyer that the hospital sent me a large pile of printouts.

Finally I had it in black and white: The doctors had systematically lied to my parents, instructing them to "raise me as a girl" and never talk to me or to anyone else about "the gender issue." Asked if I could have children, the doctors told them it was "doubtful." At seven, the doctors still claimed it had been necessary to "remove the ovaries," and at fourteen told me that I didn't menstruate because my "uterus was very small."

Because of the castration, my bone growth was reduced. To this day, I have to deal with health problems like a ruined metabolism, recurring fatigue and vertigo, and osteopenia.

I would eventually grow older than doctors had originally predicted. At seven, they decided to operate on my heart septum and valve. I went to the hospital for preparatory cardiac catheterization. However, because of an infection, doctors put off the procedure. Since I had already been admitted, they decided to "use the opportunity to conduct the genital correction already planned in 1965," and shortened my micropenis to the size of a "very small clitoris," allegedly with my consent.

Fortunately they didn't amputate the glans, and I still have sexual feelings left. But I remember the pain and unease, and how I often ran home from

school crying. Today I have a lot of scar tissue, which often hurts and itches.

After a few days I was brought back to the cardiologist for the catheterization, and a few months later heart surgery. The doctors saved my life and destroyed it in the same year.

I spent my childhood in fear, isolation, and shame. When I had to see a doctor, I was always scared stiff, but I never cried, and endured everything without any protest. I felt sick days in advance, and in front of the doctors I was like the mouse facing the snake—completely paralyzed.

I learned early to dissociate: I wasn't there, it didn't happen to me. Seeing the despair in my mother's eyes, my father's helplessness, and their embarrassment, I suppressed my feelings. I tried to be strong for my parents. My mantra was: it will be over soon! I remember how my mother always used to buy me candy or a little something afterwards, and how happy and relieved we both were.

When I asked questions, I was fobbed off with lies or half-truths. It was all very embarrassing to try and get answers others refused to give, so I stopped asking.

At fourteen, I got my first lead. My mother had tasked me once again to ask the family doctor why they had removed my ovaries. She was concerned that I couldn't bear children, and she never got any explanation for why that was the case. He became infuriated when I asked, and yelled, "There were no ovaries, these were testes!", and left the room. I threw a glance at the medical record on the table and read: "pseudohermaphroditismus masculinus." I wasn't really shocked; it somehow made sense. The doctor eventually returned, acting as if nothing had happened. I never told anyone, but started looking up books in the library, which left me confused and with the fear a penis might grow overnight.

My endocrinologist always told me I couldn't have a boyfriend without a proper vagina. I wanted to be normal, and insurance wouldn't pay after I turned twenty, so at eighteen I decided to have a vaginoplasty. They cut a hole next to my urethral opening, and lined it with a skin graft from my backside. After surgery, I was bleeding and in pain, but I had to dilate my vaginal opening to prevent

stenosis. It was humiliating. The doctors said I "best get a boyfriend soon."

Soon after, I went abroad to learn English, with the intention to "use" my artificial vagina. I told myself: I have to try, and if it's a disaster, never mind; I am far away and nobody knows me. In the end I was too afraid. Sex was for me a technical matter from the beginning—zero romance or acting out of genuine desire.

During the final appointment my endocrinologist told me I had male chromosomes, but it would be better not to tell my boyfriend, because "he might not understand." The doctor didn't explain further, and when I asked if there are others like me, he said there were very few.

I left home when I was twenty, and tried to live a normal life. My first boyfriend knew I couldn't have children, was born without a vagina, and had male chromosomes. We had "normal" sex, but it was always mechanical. I wasn't able to relax, and I was ashamed of my body. Although penetration wasn't always pleasant, I mostly insisted, because I was obsessed with the idea that my vagina would shrink and more surgery would be necessary.

I worked and took evening high school courses. After graduating I went to university to study literature. Although I was "abnormal," I was intelligent, the first in the family at the university. To all external appearances, I had my normal life, boyfriend, work, and university, but I always felt numb inside. I often had to pretend to be like everyone else, for example, when a friend asked me if I'd like to have children or how to deal with menstrual pains. I smoked a lot and started drinking. I didn't want to think about my childhood, but felt always ashamed of being a fake. I had little contact with my family.

An obsessive-compulsive disorder controlled my everyday life for decades: I had "bad thoughts," which I had to "neutralize" with absurd actions. In the end, I couldn't open a book, because there was always a "bad" word on its pages. I couldn't study anymore; I was always exhausted and desperate, and I couldn't talk to anybody, for who would understand? Later I realized I had already shown signs of OCD as a child, when I used to beat my forehead with a knuckle till it hurt.

At thirty-five, I had to pull the emergency brake. I started psychoanalytic therapy, which lasted ten years. Three times a week, I faced the despair, the anger, the self-hate, and the obsessive-compulsive behaviour. A third of the costs I had to pay myself. I worked only part-time, and interrupted my studies. My boyfriend and I were still together, but we led two different lives.

I started trawling the Internet for answers, which was a blessing: I discovered that I am not alone and that there are self-help groups. I still remember the first meeting: For thirty-five years I had been completely alone and isolated. And now I was sitting together with people who had lived the same experiences. It felt like finally coming home.

In 2007, with the aid of my current partner, I started a weblog and we founded the human rights NGO Zwischengeschlecht.org / StopIGM.org. That same year, Christiane Völling succeeded in suing her former surgeon in Germany, eventually winning 100,000 Euro in damages. I organized a nonviolent protest for the first day of the trial, which changed my life considerably. After a lifetime in hiding, I spoke out openly before the international media covering the trial. I just wanted to testify in order to prevent future intersex children from suffering like I did. Family and friends I had known for decades saw me on television and were shocked, though supportive.

With our NGO and international supporters, we protest in front of children's clinics and medical congresses, write open letters, initiate and support parliamentary initiatives, are consulted by ethics and human rights bodies, write reports for the United Nations, and testify in the media on the injustice of the ongoing intersex genital mutilations (IGM). As a result of our efforts, in 2012 the Swiss National Advisory Commission on Biomedical Ethics was the first national body to recommend a legal review including liability, limitation periods, and criminal law. The Swiss recommendations were soon followed by statements by the UN Special Rapporteur on Torture and the Council of Europe (2013), and several more UN bodies including WHO, OHCHR and UNICEF (2014). In early 2015, the Committee on the Rights of the Child declared

"medically unnecessary surgical and other procedures on intersex children" a "harmful practice."

In my experience, when informed of the actual medical practices in plain language (and without appropriation of IGM for the purpose of advocating on behalf of LGBT rights, or gender issues), people on the street immediately grasp the issues at hand, often beating us to the punch: "They should be allowed to decide for themselves later." Also surprisingly many doctors give us a thumbs-up or say, "I'm on your side."

On the other hand, medical specialists directly involved in the practice of IGM inevitably exhibit symptoms of professional tunnel vision, especially regarding human rights issues, and almost universally refuse to enter into a real dialogue.

Here is a sample of the sorts of things I have been told by IGM doctors I have confronted since becoming an activist:

"But you are still standing here." (Yes, still, unlike my best intersex friend and all my other peers who took their own lives.)

"Since CAIS patients live as women, what do they need their abdominal testes for?" (Hint: How about vital daily hormone supply?)

"Only bad surgeons have patients with diminished sensation after clitoral surgery. My patients are all happy; they marry and have children." (Sure, not unlike the women "of a number of African tribes" invoked for decades by IGM doctors as a proof for "normal sexual function" after clitoridectomy.)

"As long as there are parents, we'll continue to operate." (Obviously, children have no rights.)

"They'll never know what they're missing." (A popular urologist's joke responding to the risk of loss of sexual sensation.)

"And what about my human rights?" (Doctors resenting they can't legally prohibit us from calling them mutilators.)

I doubt most of them will realize the blatant contradiction between their idea of helping intersex children "to have a normal life" by performing genital surgeries, and the consequences most of us actually have to live with: lifelong trauma, loss of sexual sensation, and scars.

There are individual doctors who have changed their practices, who refuse to prescribe or perform some or most surgeries, but they're a drop in the ocean. I know of only four progressive paediatric surgeons throughout the world. All of them still have colleagues in-house or nearby who gladly take any "patient" of the dissenting surgeons refusing to operate themselves. At least one "objector" would be in trouble if he'd refuse all cosmetic surgeries.

The only thing that will make them stop is a legal ban of IGM practices—or, as one surgeon recently put it, "It's a pity that, because of a lack of ethical clarity in the medical profession, we have to get legislators involved, but in my opinion it's the only solution."

It would mean a lot to me if in the future children like me were no longer mutilated and told lies. Personally, I live a better life than before, when I was trying to be normal. But I will always be the little child, sitting on the edge of the bed in the hospital with its little suitcase, terrified—but quickly putting on a smile again, when mother's desperate face appears in the door to say goodbye for the third time.



Promoting Health and Social Progress by Accepting and Depathologizing Benign Intersex Traits

Hida Vioria

I was born with ambiguous genitalia and it was a doctor who, by honoring my bodily integrity and not "fixing" me, gave me the greatest gift I've ever received. Because my body and its sexual traits are a positive, fundamental part of my experience and identity as a human being, I know that having my genitals removed or altered according to someone else's vision would have deeply damaged me, both physically and psychologically.

The doctor who protected my autonomy was, unsurprisingly, my father. I say "unsurprisingly"

because in my experience parents are typically more protective of their children than doctors are of their patients. Also, doctors do not discuss cases with other doctors in the same way they do with laypeople, as doctors know more about medical issues such as the risks involved in infant genital surgery.

Other than having clitoromegaly (a large clitoris), my reproductive anatomy is typically female, and so I was assigned female and raised as such without incident. My parents didn't discuss my intersex traits with me, and I grew up thinking of myself and being accepted as, a girl.

When I began menstruating, my father told me I'd need to take pills to "grow taller." I thought this unusual, as I wasn't short, and later overheard my mother arguing with him, saying that the pills were "experimental". I was reminded of this discussion years later, when she told me that the pills had actually been hormones to make my breasts grow. I never took them though as she convinced my father not to make me.

Article 7 of The International Covenant on Civil and Political Rights states that, "No one shall be subjected without his free consent to medical or scientific experimentation," and I'm grateful to both my parents for protecting my civil rights as they protected my health.

Due to my Catholic upbringing and schooling, I had no opportunity to compare my genitals to other girls', and it wasn't until the age of twelve that I realized, while perusing magazines with friends, that I have atypical sex anatomy. Contrary to common speculation however, this awareness didn't make me question being female. I simply assumed there must be some genital variation in humans.

I feel my parents made the wisest decision possible by registering me as one of the two accepted, available genders but allowing me to live, physically and behaviorally, as who I am. Despite not having developed a stereotypically curvaceous female figure, I was popular and excelled in typically feminine social activities, as well as sports and academics. For example, I was one of four girls selected out of one hundred twenty-five that competed for a spot on my high school cheerleading