



# VOICES

PERSONAL STORIES FROM THE PAGES OF NIB

## NORMALIZING INTERSEX





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PERSONAL STORIES FROM THE PAGES OF NIB

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## Introduction

# Normalizing Intersex: The Transformative Power of Stories

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## Background

I'm intersex. I was diagnosed with complete androgen insensitivity syndrome (CAIS) when I was a young teenager in the early 1990s, although I didn't learn the truth about my body until I obtained my own medical records years later as an adult. A surgeon removed my internal testes in 1997, when I was 17 years old. The surgery was an attempt to normalize my "abnormal" body because testes don't belong in a female body. I thought the doctor was removing premenopausal underdeveloped ovaries, but as I later learned that was a lie he told me allegedly to ensure that I would see myself as the girl I had been raised to be. Although I no longer hold any animosity for how I was treated by a medical provider I admired and respected as a teenager, I wish he knew that the surgery he performed created a new set of abnormalities in my life. Having my body surgically modified for a medically unnecessary reason, I came to feel that my core was, from the beginning of my life, damaged. I felt like I was a freak of nature. For years I wondered how different my life would be had my body been left intact, and rather than lied to about my diagnosis, I had been told I was a unique, and, most importantly, natural variation, even if most of us have been taught that sex is simply binary.

I'm intersex, but for years I never shared it. It wasn't until 2007, when I was a 27-year-old doctoral student studying sociology at the University of Illinois at Chicago, that I reached a place where I felt comfortable sharing my medical history with supportive faculty and close graduate school friends, and then, eventually, anyone who cared to listen. There I

started to engage with the complexities of "sex" and "gender" as distinct social constructs. Sex is allegedly a binary biological phenomenon that allows for the categorization of bodies as either "male" or "female" based on any number of arbitrary markers of sex, be it gonadal, genital, or chromosomal. Some phenotypical females—myself included—have (or in my case had) internal testes, a vagina, and XY chromosomes. Similarly, what we understand as "masculine" or "feminine" gender characteristics depends on the cultural context, including the historical moment in which the categorization occurs. Take for example the profession of medicine, which was historically dominated by men. Today, far more women are entering the medical profession, even though they are disproportionately represented in lower prestige areas of specialization (Davis & Allison, 2013).

I'm intersex, but I'm also a sociocultural scholar who studies how people with intersex traits, their parents, and doctors experience intersex in contemporary U.S. society. In 2008, I was compelled to bridge my personal and professional interest in intersex after I learned it was controversially renamed disorders of sex development, or DSD for short, in the 2006 "Medical Consensus Statement on Management of Intersex Disorders" (Lee, Houk, Ahmed, & Hughes, 2006). My research reveals that medical providers no longer use intersex language (Davis, 2015). Instead, they refer to *intersex* traits as *DSD*. I also found that some intersex people are adamantly against DSD terminology because of the pathologization that *disorders* of sex development implies about their personhood; others embrace DSD language suggesting it offers a scientific

way to understand one's body, and a minority are indifferent to the terminology and feel intersex people should use whichever term or terms they prefer (Davis, 2015). Throughout my scholarship, I always put my personal experience at the center of my analysis—a standard practice in sociocultural scholarship. That process has been, and continues to be, liberating for me, which is why I was compelled to produce this narrative symposium.

## The Stories

The 13 intersex voices that my co-editor, Ellen Feder, and I include in this issue are our best attempt at reflecting the diversity of experiences within the intersex community. In addition to the publication of the call for narratives by the editors of *Narrative Inquiry in Bioethics*, Ellen and I circulated our "Call for Stories" on both private and public social media websites that serve the intersex community. Our personal and professional connections to the community allowed us unique access to invite potential contributors to participate in this project. We actively sought out a variety of voices that convey something of the differences in race/ethnicity, age, gender identity, nationality, religious observance, diagnosis, and treatment that characterize the experiences of individuals with intersex traits. The powerful narratives readers will encounter do represent a genuine diversity of experience, but certainly do not exhaust that diversity, particularly in regards to national origin. In writing their stories, we encouraged authors to recount their experiences with medical care, share their memories of discussing their care or diagnosis with parents or other family members, describe aspects of their care or treatment they believe to have been harmful and/or helpful, and reflect on how their perspective on care or treatment has, if at all, changed throughout their lives. In addition to the 13 voices presented here, we are honored to include seven more in the issue's online supplement.

## The Commentaries

This symposium also includes four commentaries on the narratives. Each reflects the longstanding

commitments to high-quality research and responsible action concerning the standard of care and its effects on the wellbeing of children and adults with intersex bodies. As we sought varied perspectives in the narratives, we also aimed to offer readers some of the different perspectives the medical treatment of intersex involves, as well a sense of the different questions asked by pediatricians (such as Joel Frader), parents (Arlene Baratz), clinical psychologists (Lih-Meh Liao), social scientists (Katrina Karkazis), and ethical theorists (Ellen Feder). These commentaries highlight outstanding questions and open further possibilities for engagement, change, and rethinking intersex. While the commentators approach the narratives differently as reflected in their range of responses, I hope their reflections enhance rather than regulate or rein in the voices of people with intersex traits.

## Narratives as Knowledge

My goals for this symposium on intersex, which Ellen Feder my co-editor shares, are three-fold. First, this issue provides a formally recognized and "valid" platform for people with intersex traits to tell our stories. Storytelling can empower members of the intersex community; they are testimonies to the ways in which we are thriving in a world that rigidly maintains that individuals must be either "male" or "female." That is to say the narratives normalize, in a positive sense, our experiences. Our stories also document how normalizing interventions, which are simultaneously fueled by and perpetuate an ideology of sex as binary, have been more harmful than helpful to us. The contributors to this symposium make a powerful case concerning the harms of normalization. The second goal of this symposium is to change the hearts and minds of those who provide, or may in the future provide, medical care for people with intersex traits—and not just of our "conditions" but for whatever else we might need as ordinary consumers of medical care. Third, if doctors and others are listening, the narratives told here have the power to shape dominant medical discourse about intersex bodies and experiences.

The narratives included in this symposium are not the first to be published in an academic outlet.



In 1998, a number of narratives from people with intersex traits were published in *Chrysalis: The Journal of Transgressive Gender Identities* (Chase & Coventry, 1997/1998). Sadly, the narratives published then are not all that different from the ones presented here, suggesting that intersex medical care hasn't changed much at all in the last 18 years. In spite of this, Ellen and I remain optimistic that this narrative project will be different from earlier ones because narrative analysis is now a more widely accepted method of qualitative inquiry. Sociocultural scholars define narratives as meaning structures that individuals use to make meanings of their surroundings (Polletta, Pang, Chen, Gharrity, & Motes, 2011; Riessman, 2008; Polkinghorne, 1988). Narratives also shape social and group identities because they account for how individuals view themselves and others. Narratives are especially important for assessing medical needs in the case of intersex, as we have historically been the objects, rather than producers, of knowledge about our bodies and experiences. Our narratives not only forge a way for us, as people with intersex traits, to make sense of our own experiences, but they also allow others to

engage with our experiences. Although medical providers have historically minimized the power of our narratives by dismissing them as anecdotal evidence, I hope, along with Ellen, that our stories will have a meaningful role in shaping a standard of care that respects the integrity of our bodies.

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## PERSONAL NARRATIVES

### When Doctors Get It Wrong

Konrad Blair

#### The Beginning

It was a gloomy winter day as I sat in the back of the car while my father and mother drove me to another appointment in Pittsburgh. It was and wasn't like so many car trips of my childhood for so many doctors' appointments. The same deadening silence filled the car as we drew closer to our destination. My parents never discussed the appointments with me and I just learned to never ask. This appointment was different though; it came about as a result of request by a psychology professor who was conducting a follow-up study on individuals treated by the team of endocrinologists I saw as a child.

The professor had reached out to me through my parents, since that was the only contact information available. It had been more than ten years since I had seen any of the doctors who treated me as a child. I was living in another state when I received the call from my mother informing me of the request for my participation in the study. I was really quite shocked; in all the years I was treated in early childhood and adolescence, no one had *ever* asked me how I felt about the treatment I received. I knew I had a medical condition, but no one ever explained to me why I needed so many appointments, and why I had to take medicine three times a day. No one told me why, when I was two or three years old, I had surgery that left me with memories of gauze and a catheter between my legs, or why medical residents still wanted to examine me, or

why I had to be humiliated and ashamed, again and again. I was in my early 30's by this time. Surely if my condition was so important that someone wanted to talk to me now, so many years later, the conversation would have already happened?!

My parents dropped me off at the scheduled location for the interview. The professor introduced himself and his colleague. I didn't recognize them, which meant they weren't the doctors who had treated me. I remember feeling somewhat relieved, as I never liked the doctors who treated me as a child. I remembered my last appointment there, and feeling that I was escaping from captivity, that I was free to go on with my life.

I wasn't sure what to expect from this meeting. The professor told me that to date no one had completed *any* follow-up on the pediatric patients treated by the hospital's endocrinology team to see how they were faring in life. He said he thought that was quite odd, so had decided to take on the project himself. He began by asking, "so, D\_\_\_\_, [I went by another name then] how are you doing at this point in your life?"

I felt a sudden surge of rage, and, to my own surprise, I found myself responding angrily, "Why the hell do you care? It's been over ten years and *nobody*, I mean *nobody* gives a rat's ass as to how I'm doing and coping with the ramifications of the treatment I received from Dr. X." Looking back, more than ten years after this meeting, I can see that I had been angry for a long time. I had been compliant and knew to play my role as a good girl. I had a good job, and I was married, but I knew I was far from happy.

And so with that first question began what would be the long painful journey to discovering what had been hidden from me for over half my life, the source of my confusion and unparalleled frustration. What I had experienced throughout my childhood would permeate every aspect of my being and perception of myself for years to come. Every day I had to confront the effects of that experience just to live another day.

### The Middle

I was in shock and disbelief as I read and reread the letter my attorney presented to me from the very group of endocrinologists that had subjected me to inhumane and ill-considered and insensitive treatment. It was a letter of apology.

I had written a letter to the doctors who had treated me as a child. I described the shame, humiliation, and suffering I had experienced at their hands. I wanted to be clear that my experience was *not a result of my medical condition*, but of the medical treatment and unwilling participation in clinical research to which I had been subject for over twenty years. I wrote that my treatment had left me with physical scars and psychological wounds that had made it impossible to develop a healthy perception of myself and my sexuality.

I continued: Unlike most parents who greet a new addition to their family with joy and support from their loved ones and doctors, my mother and father had been immediately forced into silence and shame by the doctors they trusted to care for their newborn child. When I was born the doctors had judged me an "inadequate male;" further investigation revealed that I was female, and had salt-wasting Congenital Adrenal Hyperplasia (CAH). The supervising physicians told my parents that plastic surgery was necessary to make me, an infant of questionable sex, "look like a female." Their judgment meant that my gender identity was decided without my permission; I was subjected to surgery without my consent.

Although my parents were informed that their baby was really a girl, they were told that I had to be given a boy's name for my birth certificate. They would not be permitted to change my name until I

was "changed to appear as a girl." Consequently the first eleven months of my life, I was C\_\_\_\_. I was announced in the newspapers as C\_\_\_\_. When I was introduced as D\_\_\_\_ my parents had to inform their family and friends that the newspaper had made a mistake when they announced me as C\_\_\_\_. I learned later that they made this difficult announcement without any support from the doctors, who only told them that they should move to another community or state. They were told never to discuss the truth with me. Doctors' advice suggested that the whole experience could just be forgotten. But how could the doctors think such a thing would or could be forgotten? And how could they think I didn't need to know?

I went on to explain that I felt I had never really fit in this gender role I had been assigned, that I had gone through life pretending that I belonged here or there but that I never truly knew where I belonged.

As a child I had to report to the lower level of the local children's hospital outpatient clinic for routine bone ages to "monitor my progress as a girl" (though I know now that such monitoring is important for any child with classical CAH). I felt ostracized and isolated. I thought it was odd that I never saw any other children when I was down there. I was repeatedly taken out of school early, but never discussed the nature of the appointments with my friends. I feared they would find out about me. I didn't know what they would find out, but knew it was something I could never talk about. If my parents didn't talk about it, how could I talk about it with my friends?

I was always told that I was a success, but I never understood what that meant. If I was such a success, why did I continually have to go back to the hospital for tests and monitoring? And why wouldn't my parents talk about it? Why didn't the doctors explain why I needed to have so many appointments, and why did so many doctors, residents, fellows have to look at me naked? I cried every single time I had one of these exams. Even into my late teens I cried. I would turn my head, close my eyes, and try to escape.

I really wanted to emphasize in my letter that I never felt like I could tell the doctors how victimized I felt by these exams. I was eight when I started

to realize something wasn't right about them. But I was scared that I would die if I didn't cooperate with the doctors. It was only as an adult that I understood that all those exams were for the doctors' education, and not for my health. My trust in my doctors was broken: I was continually exposed and violated *for their benefit*, and not my own.

I also recounted how, when I was in my 20's, my doctor came to my house to ask my parents to be involved in a follow-up study. My mom spoke for me that day when she said, "my daughter feels like what you're doing to her is sexual abuse." My mother told me that he did nothing in response. He said nothing. He simply walked out my front door, and never looked back. It took another ten years after that visit for me to find out, at last, the answers to all the questions I had growing up. And it took ten more years for me to feel the anger that I suppressed and didn't understand. I wrote in my letter, in the strongest language I could, of my rage in thinking about all that I was subjected to, how I was living with the effects of physical damage to my body, including my inability to enjoy sex, and of the deep psychological damage resulting from all of the humiliation I had suffered. My relationships with my family, my husband, with friends, and with physicians, had been deeply undermined. I still struggle to understand how it could be that medical professionals who seemed so interested in my care could have been so unaware of how their treatment had hurt me.

I told the doctors that I wanted them to tell me, more than forty years later, what was still left unsaid. I had requested my medical records, but they were incomplete. I wrote that I wanted my complete records, and I wanted someone to explain to me everything that was in those records. I wanted the doctors who treated me to acknowledge that the treatment plan had had terrible consequences. And more than anything, I wanted an apology. I had an attorney who helped the doctors understand that I was not interested in a lawsuit. I also didn't want the sort of apology you get when someone bumps into you accidentally, the sort that means "I didn't mean to do that." I wanted a heartfelt apology that acknowledged that I was not the success story that they might have thought, and that made clear that

what was done in the past was not the right thing to do, and a promise that things would be different for children like me in the future.

Never before had anyone ever been issued a letter of apology from a leading medical institution for normalizing treatment of intersex. I mean *never*. In their letter, the doctors wrote that they understood that the treatment I had received was harmful, but that their intention was to educate other doctors. They wrote that there was greater understanding now that there were better ways to achieve their goals.

Their response represented hope, hope for me and for future patients, hope that one day the medical procedures to which I was subjected would become a thing of the past. I felt that finally, a child's voice mattered, that what I had experienced mattered.

## Not the End

It's been about a decade since I learned the details of what happened to me, and that I learned that there were so many others like me. I had had no idea. The information helped me. It helped me understand what happened, and why. And it helped me understand why I felt such a conflict between the person I was supposed to be, and who I feel—who I think I have always felt—I really am. The apology restored my dignity, and allowed me to accept myself as the man I was supposed to become. It opened a door for me to speak out and be an activist so that others can be spared what was done to me.



## The Secret Inside Me

Diana Garcia

Growing up, our Chicano household was loud and boisterous. There were eight of us in one small house with one small bathroom. All five of us girls shared one bedroom so there was not much privacy, if any. Watching my



sisters go through their puberty was isolating—I was never on the receiving end of the secret whispers and knowing looks I saw my mother exchange with my sisters when they started menstruating. It made me feel “different” and excluded from that mother–daughter connection. My only comfort was that my sister, who was one year younger, had not started her period either, and we shared our fears that we were different from our other sisters.

In 1979, when I was a senior in high school, I approached my mother and assertively told her that I had made the decision to seek out a doctor as soon as I turned eighteen years old because I felt I needed to get answers for myself and my sister. I was positive that something was not right. From the time I was about twelve years old, I would question my mom about why I hadn’t started my period. She always shooed me away saying that I was a late bloomer and that every girl starts at different ages, some at nine, some at fourteen years old. However, I always knew something was not right. I just knew.

My mother was annoyed, but she said, “Alright *mija*, I’ve just been worried because you are a virgin and I don’t think I want anyone probing you down there.”

I remember telling her something like, “Mom, at this point, if that is what needs to happen for me to find out, then so be it. But can you come with me to the doctor? Please?”

She said, “I know; I’m worried, too and yes, I’ll go with you.” My mom and I hugged, and I could feel the worry and tension in our hug. I was not sure if it was coming from me or her.

The day of my gynecology appointment finally came. I had been looking forward to it for so long. This was my first experience as an adult other than having that grownup feeling the day I graduated from high school. The nurse told me to undress and to put on the paper gown and then left the room. I told my mother to stay sitting in her chair, that I did not want her to leave me for a second. The young doctor entered the room and introduced himself to us and asked me to sit on the examining table as he asked, “So, what is the reason for this visit?” I told him, “I want to know why I haven’t

started my period. I feel like something is very wrong with me.”

He had me lay back and put my feet in the stirrups, instructing me to relax. I reached my hand out to my mother and she stood and came by my side and held my hand tightly.

He squeezed some gel on his gloved hand and again asked me to relax and to just let my knees drop back. His fingers with the cold gel probed and after a few seconds of probing he looked up and said,

“What the heck?! There’s no cervix?”

My mother and I looked at each other in confusion and then he said, “There’s nothing!”

He then stood up and said, “Please get dressed and the nurse will show you to my office.” He exited the room, leaving us to look at each other with tears in our eyes, stunned at his outbursts.

I will never forget his reaction or his words.

A sympathetic nurse led us into the doctor’s office and we sat down.

He looked at me and said, “You need to have surgery immediately or you will die of cancer.”

I turned to look at my mother and we both started tearing up. I asked, “Why? What do you mean? I have cancer?”

He said, “No you don’t. Not right now but women like you need to have their ovaries removed right away or, basically, have what we call a radical hysterectomy. I made an appointment for you with a genetic counselor who needs you to come in for some tests and he can explain further. Here is the information.” He handed my mother some paperwork and escorted us out of his office.

That’s it. No sympathy. No compassion. He offered just a minimal explanation without an invitation to ask questions when I had a million of them I wanted to ask. But my mouth was frozen shut in utter fright. My sister, upon our return home, eagerly asked me what happened. I pulled her into the girls’ bedroom and shut the door and whispered, “we’re freaks,” and then proceeded to tell her what happened with the doctor. I will never forgive myself for saying that to my sister. Even though she forgave me, I know she will never forget those words.

My parents were always led behind closed doors while I was left in waiting rooms. Being a good daughter, I just did what I was told and if I was told I needed to have surgery, then so be it. I was terrified. I never told a soul I was afraid. To know me was to see and hear a tall, confident, and funny person. I never mentioned that in my heart I felt something just wasn't right about my urgently scheduled surgery. The word "radical" also scared me. My fear made me feel voiceless, weak, ugly, and freakish but, most of all, it made me angry and I didn't know why. My confusion was a brewing storm. I did not know that my geneticist, obstetrician, endocrinologist, and parents would begin then, and continue for some time, to lie to me for my "safety and well-being." They all told me I needed to have a "radical hysterectomy" or I could "die of cancer." How safe and effective, I would later ask, was that lie?

What added to my inner turmoil is that outside family members like aunts, uncles and cousins were told I was in the hospital for an "appendectomy." My sister had her gonadectomy a year later and was treated basically the same way I was. Sadly, however, her surgery took place at a teaching hospital where residents were paraded in and out of her room to examine her.

It was not until years later with the advent of the Internet that I learned the truth by searching "feminizing testicular syndrome," "male-pseudo hermaphrodite," and "the affected male"—terms that appeared in my medical records. The enlightenment was cathartic in the sense that I was relieved to know the facts about myself. The mystery and the guesswork were taken out of the equation. Of course, my freakish feelings were still a part of me because I was made to feel that way by lies and innuendo.

My Internet research answered many of my questions. A doctor was not around to lie to me. A doctor was not around to stammer at me and not look me in the eye. My doctor's response to my inquiry about what was wrong with me was, "Oh, don't worry about it, you are a beautiful young lady!"

Finding out the truth did not make me crazy or suicidal; rather, I felt such relief when I finally knew the truth. My innermost fears about my body

became a reality. After that revelation sunk in I got angry, very angry. I kept thinking, "*Why was I lied to when I was already an adult 18-year-old woman?*" This question stirred around in my head and became a bubbling poison inside of me. Being lied to was a focus for a very long time.

Back then, I thought, "Why would they tell a child he or she had cancer or leukemia but they couldn't tell an 18-year-old woman the truth about androgen insensitivity syndrome (AIS)?" By the time my anger drove me to try to confront my doctors, they had already died. When I confronted my parents about the lying and shame, all hell broke loose. You see, after my surgery all those years ago, they never talked about it to me or my sister ever again. Poof! It never happened. I tried to have a family meeting to talk openly about my AIS and inform them all. I had made copies of my research to hand out at my intended family meeting, but they refused to meet. By then I figured my parents and siblings had already had their own meeting without me to discuss my "rampage," and were all unified to block me out. Back then, my sister and her husband were preoccupied with adoption procedures and she was in a different place about her own knowledge about her CAIS; I understood and respected her silence.

Years later, I think I was about 46 years old, I found myself needling my mother to please think back about what the doctors told her and my dad behind closed doors. She admitted that she honestly did not really understand all that the doctors said about the syndrome; the doctors had counseled my parents not to say anything about it except to keep encouraging me by saying that I was a beautiful young woman and that the only difference was that I was unable to have children. This was the message I received whenever I spoke with my parents or my doctor.

In retrospect, my whole experience was veiled in lies, fear, and shame. Being lied to gave me immense anger and that anger was something I did not know how to handle. The fear of being different, of not being a "normal" woman was very depressing, and the shame that germinated and grew exponentially from those lies, fears, and even going back to my

childhood of having freakish feelings but not knowing why, made me feel isolated and apart from everyone else. These intense feelings bonded my sister and I. Today we are also best friends. I am so blessed to have her as my confidante and sister.

Many years after that first failed family meeting, I decided once more to try to talk to my family about all the things I had discovered about my syndrome. I thought it could provide a chance to bring truths out and maybe help me to cope with the shame I felt but hated feeling. One sister told me, "If I ever have any questions or want to know anything I'll seek you out." That was about 17 years ago and she has yet to seek me out. When I wanted to talk to my brother—he was already married at the time—he too refused to hear anything about AIS. All he wanted to know was if he would pass the condition to his children. I said no because it is passed through the maternal line. He thought a moment then he said, "Well, then if it doesn't affect my children I don't want to know about it." This sent the message to me that he really didn't care about what I have gone through. It was my cross to bear. I just needed a friend at the time, someone to talk to. I reached out to my brother but he wasn't there for me. Maybe it just embarrassed him. I don't know. His remark pushed me away. Far away. That cavalier announcement broke my heart. I was devastated. I felt so alone. I had always felt close to my family, and we banded together in times of difficulty. But this AIS thing didn't count for them; this was mine alone to deal with. That was the message I got from my family members: you do not speak out loud about your secret shame, your family's shame.

It's interesting that I never sought out counseling or professional help. I think I always assumed I would have my family to help me through any difficulties I was going through. That did not happen, but at least I had my sister. Yes, I felt angry about it, but I told myself that I was a strong Chicana and that I had to act like a *soldadera* and just go forward in life and accept how I was born and what was done to me. I learned to just "deal with it" and was lucky to have a supportive husband at my side and the U.S. AIS support group to meet others like me.

Finding a support group was the best thing that ever happened to me. I discovered joy and happiness in finding and being surrounded by my own tribe, my own brethren; the many who had undergone similar or worse circumstances than myself gave me a feeling of standing my ground and holding my head high. My sister eventually became involved with the support group as well. It's been a long journey but I can finally say I no longer feel shame for being an intersex individual and I no longer feel any anger towards my parents and family. It is not their fault. My parents only did what doctors told them to do, which was to remain silent.



### Finding My Compass\*

Laura Inter+

\*Laura Inter's narrative is adapted from an interview conducted by Eva Alcántara in 2014 and translated by Leslie Jaye.

+The name Laura Inter is a pseudonym.

I was born in the 1980s, and much to my parents' surprise, the doctors could not say whether I was a boy or a girl because my body had ambiguous genitalia. They then conducted a chromosome test and the result was XX chromosomes. I was assigned female and only later was diagnosed with congenital adrenal hyperplasia (CAH). Fortunately for me the endocrinologist who treated me did not mention the option of surgery, so my medical treatment consisted only of taking cortisol. Apart from this, from the time I turned one, I was subjected to genital examinations twice a year, during which the endocrinologist would touch my genitals and look to see how they were developing.

These unnecessary and intrusive examinations had a profound effect on me. As a young child, I did not understand why I had to lower my pants in front of a stranger—the endocrinologist—and let him touch me. The fact that my mother was present, and approved of this was something that

made me feel completely helpless. All this seemed very strange to me; I found it confusing, and terribly uncomfortable, and I just felt it wasn't right.

I remember the doctor always spoke as if I wasn't right there, and I did not always understand everything the doctor said when I was young, because of all the medical terms he used. I grew up with a feeling of being "inadequate," of having a sense that something was wrong with me, though I didn't know exactly what. These exams lasted until I was about 12 years old. Years later, as I began my adult, sexual life, I realized how much those displays had affected me emotionally.

I discovered what was "wrong" with me during sex education classes in the first year of high school. There was a class session in which two images were shown: one displaying the external female sex organs, and the other the male sex organs. I noticed that my body was not like either of them. I was very distressed, thinking "I have deformed genitals!" I feared I could not perform sexually as either a man or a woman. I became very depressed. I was sure nobody would want me, that I would never have a relationship. I was unacceptable, "abnormal," or at least that is what the doctors had said. And in any case my parents never spoke of it, and I didn't know that I had CAH.

Skip forward a few years: I was still looking for answers, I found my medical file and read in the documents "pseudo-hermaphrodite," and "congenital adrenal hyperplasia." I searched the internet, but only found medical opinions that said that in the case of genital ambiguity, the best option was surgery. I wondered to myself: "Why didn't they operate on me?"

I put the question to my parents, and, at fifteen, I found myself being examined once more in the doctor's office, this time to consider the possibility of a genital surgery which might once and for all, I believed, make me a "normal" person.

I have never told anyone outside my family before, but one of those exams was the most humiliating experiences of my life. One doctor wanted to speak with me alone, so she made my mother wait outside the exam room. My mother agreed, thinking that after the doctor talked with me, my mother

would be able to be present during the rest of the exam. The doctor asked me questions, some of which made me very uncomfortable: "Do you feel good about being a woman"? Did you ever feel like a man? Why don't you dress up more, use more makeup? Are you a lesbian? Have you ever had sex? She then said she wanted to see my genitals. I felt awful and wanted my mother present, but I also wanted it to be over quickly, and said nothing. Examining my genitals, the doctor told me they "would not be adequate for sex," and that she needed to "perform surgery." Something else that made me uncomfortable was the presence of another doctor in the room, looking at me, and taking notes. Why couldn't my mother be there with me?

After the doctor examined my genitals, she told me to undress completely, I wanted to say no, but I felt vulnerable and helpless, and so I agreed. She examined my entire body and told me that hormone treatment had caused my body to accumulate fat and it had left some stretch marks; I should take better care of myself; I had more than usual amounts of body hair, and that I would need to take hormones to "fix that." Hearing all this, I began to cry. Then they told me to get dressed. Leaving the office I pretended everything was fine; I just wanted to go home. When I finally recounted what had happened to my mother, she wanted to register a complaint, but we didn't do that. We never returned to that hospital.

Later I was evaluated by other doctors, who I must say, treated me with far more respect. All agreed that I should "undergo surgery to reduce the size" of my "hypertrophied clitoris." They told me they were going to perform "a very simple operation to open and separate the vaginal canal from the urethra." According to them, my vagina and urethra were joined and if not "corrected" would cause recurrent urinary infections. One doctor explained that after the surgery I would have to use dilators and then I would be ready to "have sex normally, with your husband, when you get married." What the doctors didn't know, because it hadn't occurred to them to ask and faced with my family I would not have volunteered, was that since I was very young I had been attracted to women, and not to men.

I remember the description of the surgical procedures scared me, so I went online to research the procedures, and was horrified to see the pictures. It really was genital butchery. I saw that the “after pictures” didn’t resemble a “normal” woman’s genitals at all. For me it was crucial to examine the facts about the recommended surgery and consider whether this was what I really wanted. I decided against having the surgery.

I still felt deformed and inadequate, so I kept searching. I felt lonely and lost. I started reading about experiences and opinions of people who were like me. I read that they called themselves “intersex.” I also discovered there was not one person who had endured surgery who felt good about the outcome; suffering pain, anorgasmia, and infections. At that moment, I realized I was relieved that I had not agreed to surgery. I was able to make contact with the members of Bodies Like Ours, an online support group, and started to feel better about my body; I realized I was not “deformed,” that there was nothing wrong with my body, that intersex is not a disease in itself, and that my genitals were quite healthy as they were and were not a problem. I understood that intersex is more common and more normal than we think. This helped me to find peace with my body. I also found people who had not had surgery and to my surprise they were healthy, and had satisfying sex lives, which reassured me.

I have come to understand, through my own experience, that being intersex opens a whole new world of possibilities around sexuality. Our anatomies may oblige us to rethink sexuality, to challenge sexist or preconceived ideas about it, and this is a good thing. Now I am sure that nonconsenting surgeries, genital exams in infancy and early childhood, as well as the language doctors use, only serve to make things worse.

In reaching these conclusions, I wanted to share them with other intersex people, as well as all the information I found on the subject, which helped me to heal. I wanted people to have easy access to this information, so that they did not feel as lost and alone as I once did. A person close to me encouraged me and helped me open a Facebook page, and

suggested the name “Intersex Compass” (*Brújula Intersexual*), because the compass is an instrument of location, which helps travelers not get lost on their journey. I thought this was a good idea, to imagine a page as a place that could guide intersex people. Coincidentally, that project started a day after the “Day of Intersex Visibility” on October 27, 2013.

Before I opened the page, many intersex people in Latin America had never had the opportunity to talk with someone like themselves, someone who could understand intersex more deeply on a personal level. It is common for me to find two different situations: intersex people who have had surgery, and those who have not experienced those interventions. The experiences of those who have undergone surgery to “correct” their genitals are very sad: they are left with severe physical and emotional scars. Many suffer pain when having sex, recurrent urinary infections, anorgasmia, the feeling of not being assigned to the right sex. Many struggle with trauma associated with memories of spending much of their lives in hospitals, of experiencing medical genital parades, suffering bodily trauma, and struggle with sexuality in particular. Some have harbored grudges toward doctors and their parents for not recognizing their right to decide what was right for their bodies.

By contrast, those who have not had any surgeries may still feel inadequate, deformed, abnormal, and/or are certain they are sick simply for being different. However, I have been able to help them change these misguided views, and make them feel better about themselves. I share my story, specifically how I’ve come to accept that there is nothing wrong with being different, that intersex is not a deformity or a disease.

The general thinking among clinicians who see intersex people is that those of us who do not undergo surgery will have serious health problems, but on what basis can they make these claims? They are not based on studies of adults with different bodies. I was told that because my urethra and vagina were a single channel, I would be vulnerable to infections. The reality is that I have suffered only one minor vaginal infection more than ten years ago, and have had no problems since then.



I have the non-salt wasting form of CAH. The first year I had no cortisol treatment. I did have health problems, including recurrent fevers; however, my health did not improve after I was prescribed cortisol. In addition to the continued respiratory infections and fevers, I experienced well known side-effects of the drug, including dizziness, weight gain, great thirst, as well as hallucinations—lights/colors or spots on my vision—that may not have been caused by cortisol, but in any case, all of these effects ceased entirely at the age of 14, when I stopped taking cortisol on the recommendation of the endocrinologist.

My health improved. I know the cortisol helped me achieve the stature I now have. I have noticed however, that doctors do not agree on how to treat cases like mine. For example, the endocrinologist who treated me recommended that I stop the cortisol treatment, that I should not have to take any more, but other doctors told me that cortisol should continue for life. Given these opposing views it seems that everyone needs to consider the options before making their own decisions.

I must also say that the medical community, or at least the people who treat intersex cases, have a very narrow view of sexuality. They seem to believe that sexual pleasure can only exist between a man and a woman, that a man can be and feel good as a man only if his sexual organs are able to penetrate the vagina of a woman, and that a woman can be and feel as a woman only if her sexual organs can be penetrated by a male sexual organ. Do doctors believe a woman with a longer than usual clitoris would intimidate a male partner? Doctors think that people who possess different bodies will be miserable and unhappy, and conclude that they are doing us a favor by altering our bodies. . . . Nothing could be further from the truth. As an intersex person once wrote: "There is much more to sex than penetration."

Unfortunately, we do not live in a society that tolerates ambiguity in sex, or individuals who do not fit neatly into the boxes of "male" and female." Change will take many years because our society is extremely biased and idiosyncratic, and tends to discriminate toward those they do not understand,

or who are "different" in some way. I think that at the moment it is perfectly fine to assign us as males or females when we are children, which helps us to grow up without stigma, but that does not mean our bodies should be changed irreversibly. As children grow up to be young adults, and learn about themselves, they should have the opportunity to choose whether or not to undergo surgery, to have the right to identify as they know themselves or to identify with the body they were born with—intersex. I think doctors need to open their minds and their hearts before treating us, and they can begin to do this by reading and hearing what intersex people have to say.

*After all, they study medicine to help people heal, but how can they do this if they do not listen to us?*



## The Truth in Writing

Amanda

An excerpt from my journal during a dark period in my life reads:

I am a survivor of sexual mutilation, of coerced gender roles, and of perpetual lies all in the name of normalization. Sometimes I have a hard time even thinking about the true extent of what all happened. It's like my mind doesn't have that type of scope, like when I think about the word "eternity."

I wrote this after combing through old medical records, reading comments like "her introitus has healed nicely and looks normal, but my exam suggests that her vagina is shortened," and "reduction clitoroplasty . . . removal of testes." The records go on to say that my "external genitalia is quite satisfactory," and "on perineal exam, her neovaginal orifice is quite compliant and easily accepts my second and third digits."

My journal continues:

I chose this fake hole when I was a teenager because I didn't know there was another option. I was told from day one to be a female, to be

heteronormative, to act like all the other girls, and the only way I could fully accomplish this is by looking the part. A fake hole would be necessary, I thought, to go along with the rest of the lies. Sometimes I think about how the doctors told me to lie about my surgeries and my scars. Sometimes I wonder what my parents would have told the world if I had died during one of surgeries. Maybe they would have said “we were just trying to make her fuckable.”

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My strength is growing from the stories and experiences I write and share. My journal started about four years ago, when I was in my early 20s, near the beginning of medical school. My initial purpose in writing the journal was to help sort through my feelings and experiences related to a newly discovered sexuality and a changing gender identity. Medical school was thousands of miles away from my previous life, my family, and my friends. Away from my old social network, I was free to self-discover on my own terms. In the first journal entry, I lay out reasons why I decided to get in contact with a therapist, something I had not done previously. Some of the reasons were fairly standard reasons one seeks out a therapist, such as moving away from home. But the fundamental reasons I sought out a therapist, and why I chose to journal, had to do with exploring feelings after my first sexual encounter with a woman, and then accepting my intersexuality. My relationship with that therapist did not last, but the journaling did.

In the beginning of the journal, I write:

I am from a small, religious, white, non-diverse, family oriented suburb of Milwaukee. I was raised to be the picture-perfect daughter in a household that did not talk about feelings, sex, cultural or religious differences, etc. My brother and I also never talked about personal issues (and still don't), which is quite remarkable since we are twins, and have grown up doing most everything together, from sharing birthday parties, to being locker buddies . . . [When my mother told me about having Androgen Insensitivity Syndrome (AIS)] knowing this little fact about my body kept me wanting to become as perfectly female in all ways possible.

Growing up without being able to talk about having AIS was stifling to say the least. Closing communication implied great shame, and with the shame came even greater repression. My skateboarding, baseball card collecting, and model car building interests disappeared after learning about my AIS, which I believe was when I was 12 years old, but I cannot remember exactly. Granted, it's tough to say whether my interests just changed as I grew older, but I do remember having a fear of portraying any masculine tendencies that other girls in my town weren't displaying (for example, playing soccer was okay, but I had to shave my legs). I also had crafted some pretty good covers for my AIS, including stories about when I first had my (fake) period, or how I acted fearful about a pregnancy scare in college when a partner's condom fell off (which was a breeze thanks to beer), or the creation of various hiding spots for my estrogen pill containers. I decided no one could know about my intersex status and I did everything in my power to make that happen, including creating these intricate lies, distancing relationships, and self medicating with alcohol and drugs. I oftentimes felt unable to connect with other girls and women at least on initial interactions. I would worry about and assume they must be critiquing my every word and action, looking for clues that I was an imposter. This has eased as I've gotten older, and have become more comfortable with my evolving identity.

Only a few months after starting medical school, I had a significant conversation with my maternal grandmother. I learned for the first time that other people in my family besides my mother and father were aware of my AIS: during our conversation, my grandmother said the words “your condition” (I later learned other people in my family had “figured it out,” but my parents would deny it). I grew up with the silent understanding that no one besides my parents knew, or should know, as a way to be shielded from others' cruelty and ignorance. After a few sentences laden with profanity, I write in my journal:

According to my grandma, my mom was distraught and saddened by my condition because she thought it could have been a consequence of the fertility drugs. She thought it was her fault.

My mom instructed both of my grandmas not to tell anyone in the family. [One of] my grandmas told me this is why she has been pushing me to go into medicine from an early age.

I go on to write:

I also told Grandma I'm not really into men. Her response? "I always wondered about that . . ."

She said "whatever makes you happy" and "that is how God made you."

Talking with my grandmother that day was a liberating and highly emotional experience; before that moment, I never mentioned my AIS unless it was behind the doors of an exam room. Writing down our conversation made it real—now, I could not convince myself I had made it all up in my head. I was also now out to a family member as queer. It was liberating, and most of all; I was still loved and supported. This was, I believe, one of the most pivotal moments in my journey to break down the shame surrounding my medicalized body. I was able to open up about my sexuality with her, and received the utmost support. This event helped me to eventually start breaking down barriers with my mother, albeit, via email. After I explained to her in email that I'm queer and have been dating women, my mother quickly transitions the conversation to my intersex status. She writes:

No, not a real surprise, as it's always been in the back of my mind. Not a day has gone by in your almost 26 years that I don't think about you and if you're happy. *That's all we want for you—to be happy with your life in whatever you do.* And, guess I thought that you may want to help others with your syndrome—either being an endocrinologist or psychologist, not necessarily a urologist, but something along those lines once you started med school. I hope you understand that we didn't see an option when you were an infant. There was no internet to do research or support groups for parents of children like you. When you were born, we were told we had a beautiful little girl. About a day later, my OBGYN mentioned that your genitalia was "a little zipped"—but no big deal and a little cosmetic surgery would take care of it. It was about a week later that you started to have problems with the hernias and they started to figure out that it was undescended gonads. We saw three more urologists that would first say to us what a beautiful little girl. And then the

surgeon telling us that he would make the decision during surgery on what he planned on doing with what reproductive organs you had once he saw them. He didn't come out during—just after, telling us he had removed the gonads and for all intents and purposes you would be female. It was later that they did the chromosome test to determine that internally you were male. The two sets of Grandparents were the only ones that knew the real story.

As my journey (and journal) continued through medical school, I found myself questioning my gender identity more and more and what it meant to experience gender, especially as it related to being intersex. The female identity was beginning to feel more and more like a cover than a truth. I cut my short hair and began dressing much more masculine, opting for button up collared shirts over blouses. I was getting mistaken for a man (or rather, a teenage boy) readily. Questioning gender at that time only went as deep as presenting masculine of center through my fashion choices, and I wanted to expose myself to a transgender and queer community I hardly knew. I decided to explore and learn about transgender medicine at a clinic in San Francisco during my third year of medical school. The month I spent in the clinic, hearing stories of gender triumphs and struggles, had a lasting effect on me in both a personal and professional way. I have the opportunity to care for a growing transgender and gender nonconforming population at my residency clinic as I continue to explore what it means to deconstruct my gender and rebuild from a place of honesty.

I haven't written in my journal much lately, and the entries I have written recently have been about struggles in residency. I think the decreased writing is partially owing to the long and tiresome work-weeks. But I also think it is because I have allowed myself to begin experiencing vulnerability and honesty, and have come to a point of acceptance. I accept myself as queer, intersex, gender nonconforming, and ever evolving. However, I am still not open with even some of my closest friends from childhood and college; I still struggle with talking to my family, and I have yet to discuss my intersexuality with my brother. I am also seeing a new therapist, although not nearly as often as a regular

work schedule would allow. She is queer and trans\* friendly, but was transparent about the fact she has never worked with an intersex identified person before. I hope to gain more skills in talking about my history and my identity to my family and friends, and I will continue dissolving the shame as I open up and allow myself to be vulnerable.



## Still I Rise

Lynnell Stephani Long

*Years ago I would not have had the courage to write my story. I was too ashamed to tell anyone my "secret."*

I was born June 11, 1963 in Chicago. I found out thirty-seven years after my birth that I was born with severe hypospadias and a bifid scrotum. Surgery was performed at birth, leaving me with a micropenis. My labia were fused to form a scrotum. After a couple of days in the hospital, my parents were able to take home their baby "boy."

Throughout my childhood I had urinary tract infections because of the surgery to move my urethra from the base of the penis to the tip. For years I would get a burning sensation in the middle of the penis after urination. My endocrinologist at the time concluded that I had an infection of some type, but it was never explained to me where it originated.

My mother raised me with my seven siblings on the south side of Chicago. Aside from me jumping rope with the girls, playing with dolls, and sitting when I peed, I had a pretty normal childhood. From an early age, I knew I was different. I was effeminate, and was often called "faggot" by everyone in the neighborhood, including my own brothers. I always liked hanging out with girls. In fact, I believed that I was a girl until my mother, a minister, beat it out of me. Literally.

At the age of nine, I was first admitted to a teaching hospital. It was there that I was treated for growth hormone deficiency, hypothyroidism,

panhypopituitarism, hypoadrenalism, and hypogonadism. At age 14, while other boys in high school were beginning to become young men, my voice got higher and I started growing breasts. My endocrinologist diagnosed me with gynecomastia and started me on testosterone injections to stop the breast growth, and to help with the masculinization process. To me these changes confirmed what I believed all along: I was indeed female.

I took male hormone injections for five years. My endocrinologist convinced me that I could be a "normal" male if I took male hormones; I didn't want to be male, I wanted to be female. But no one asked me what I wanted. Besides, the testosterone was making me sick. I wouldn't be diagnosed with PAIS (Partial Androgen Insensitivity Syndrome) until a number of years later. I still remember trips to the hospital like they happened yesterday. There were multiple IVs, MRI's, CAT scans, and photos taken of me. I still have flashbacks of standing in front of the graph board, naked, while strangers walked in and out of the room.

There was no one I could talk to about this. I was never allowed to tell my friends why I was hospitalized numerous times a year. In the black community you don't talk about family secrets. And that's what I was, a secret. I would go to school between the hospitalizations and pretend everything was okay. I hated my life. I hated being different. I would get teased in school, but I managed to survive it.

One day on a routine office visit—I had to be around 16 at that time—my endocrinologist told me that I was infertile, and could never have kids. He didn't offer any psychotherapy, just smiled and said "I'll see you in three months". I went home that afternoon and attempted suicide for the first time.

I was hospitalized every summer, for weeks at a time, for testing. My endocrinologist and his parade of residents awakened me every morning in the hospital. They stood by my bed, peeking under my gown, and talking about me like I was not present. I discontinued my visits to the hospital, and all medications, at the age of twenty-four. I just wanted to be normal, but I knew I wasn't.

The next ten years of my life were full of drinking and getting high, trying to forget that I was different. I did have girlfriends in that time, and I even

got married. I was convinced that a woman could make me a man. That didn't happen though, and I started using drugs even more, trying desperately to end my own life.

In 1992, I stood on the platform of the train station waiting for the train to work. I hadn't thought about trying to commit suicide that morning, but standing there I realized I had given up on life as life gave up on me. I decided to jump in front of the train. I counted to three and thought I jumped. When I opened my eyes, I was still standing there. I knew then whatever God or Goddess there was had a plan for me.

In 1993, I signed myself into rehab. Once again I was at the mercy of the medical profession. I hated it, but I hated abusing drugs and alcohol more. One of the questions I was asked during the initial interview was why I got high. I told the woman, "To forget, to numb out, because I'm different." What I didn't say is the south side of Chicago was no place for a person like me. People have always asked me "are you a boy or a girl"? For the first time, I saw the truth, which was that I was both, and I said so.

It wasn't until I got sick in 1995, however, that I found out that there was a medical term to describe me. I was intersex. My endocrinologist asked a lot of questions, particularly about the scar that runs from the tip of my penis to my anus. I needed to trust someone so I told him the truth about my medical experience at the university hospital. After several tests he told me I needed hormone replacement. He said most doctors would try the testosterone again, but because of my feminine appearance, he asked what I wanted to do. The answer was simple, it was one that I had been prepared to answer my entire life, I want to be the girl I am.

I started researching my medical history in 1996, and after buying a computer I begin to search the Internet. It wasn't until I saw Cheryl Chase (a.k.a. Bo Laurent) on television that I had a name for what was "wrong" with me. I am Intersex.

It was then I became vigilant with my research of my medical history.

By then I was taking estrogen, and it helped my breasts develop, and my body to continue the feminization process. But I still had a scar that no one could explain to me. What I learned from

researching my medical records is that I was born a male pseudohermaphrodite. Since my karotype is 46,XY (commonly understood as male sex chromosomes), the doctors thought that I should be a male. I don't know why no one at the hospital tested me for Androgen Insensitivity Syndrome. If they had, they would know the reason I was feminizing, and also why testosterone injections did not work: I have PAIS. I am different from other intersex women because my clitoris is longer than the two centimeters that doctors would have deemed "too long" for someone assigned female.

In September of 1995, I changed my name legally to Lynnell Stephani Long.

My mother died in 1996. Before she died I asked her, "Was I born a hermaphrodite?" She told me that she was unaware of it. I believe her. For so many years the medical profession has looked at intersex children as something they could "fix." I'm sure they didn't explain everything to her.

It wasn't until 2001 that I met Cheryl Chase, then Director of the Intersex Society of North America (ISNA). I volunteered on ISNA's speakers' bureau, traveling around the country educating people on intersex issues. In 2002, I attended the annual conference for pediatric endocrinologists in Chicago. I was shocked to see my old endocrinologist at the podium when I arrived, telling doctors treatment for intersex children must remain the same. As he left the podium and made his way to the back of the room I got nervous. Cheryl told me I needed to confront him. Days earlier I called him, questioning his medical procedures. I had so many unanswered questions and I'd hope he would provide the answers, but instead he got defensive. He told me my mother had consented to everything, and that he had only tried to help me. Now as he walked toward me I froze. I felt like a child, waiting for judgment. Cheryl gave me a shove and I stood face to face with him. I introduced myself, and introduced him to Cheryl Chase and the other intersex activist standing with me. I shook his cold hands, and his eyes were empty. No compassion, no sympathy, just a man at a conference who didn't want to be bothered by me. But in that moment I knew I had to be strong. I knew if I was going to be an intersex activist I would be speaking for those without a voice.



Since then, I have had the privilege of traveling around the country educating people about intersex issues. I have spoken at colleges and universities, and to medical students at the University of California in San Diego. I have met intersex men and women from across the globe. If someone were to ask me, through all my years of intersex activism, what my proudest moment is, I would have to say the day I spoke at DePaul University in Chicago and met my protégée Pidge Pagonis. I was educating the class on intersex, as I had at other colleges. But the instructor warned me before the class that there was someone that had questions for me. I didn't know who the student was, but I knew my life would change forever.

In the past 14 years I have told my story countless times. It's never easy to tell it. Each time it's like pulling the scab off a wound that refuses to heal. But it's something I do because I can. Not everyone has the courage to stand in front of an audience and out him or herself as intersex. After appearing on Oprah Winfrey in 2006, I was faced with ignorance from my co-workers; instead of taking the time to learn what intersex was, they were fixated on the fact that I was raised male. But with the bad there is the good. I have known love. I never thought that anyone would love me being intersex, but I was wrong. It's not easy telling a new lover that I am intersex, but I have found my partners to be accepting: they love me for me.

In the beginning of the intersex movement, I was one of the few black intersex people out. Now I'm proud to say that more of us are getting the support we need.



## The Son They Never Had

Pidgeon Pagonis

**M**y story is one of the threads woven into the tangled skein that is my family. At 23, my mother was straddling that bridge between youth and adulthood. I was her first child.

Her younger brother had died tragically, and soon after, their father's successful barbershops began to fall apart. I never met my uncle, but they say I'm his spitting image.

I was at my pediatrician's office for my scheduled check-up. As the doctor's eyes scanned my chubby squirming body, she paused when she reached the crevice between my thigh-rolls. She didn't know quite what to make of what she saw. She scribbled a referral. "They'll just take a look," she told my mother.

When the doctor inspected my labia at the hospital, he knew almost with certainty what he was looking at but didn't yet say anything to my mother. The data confirmed what my pediatrician feared: My chunky baby body appeared female on the outside but the blood tests suggested otherwise. When they were finished with their tests, the doctors sat my family down and gave them the news.

## Medical Record

6/6/86—Informant: Mother and grandmother

Immediate Complaint: Abnormal genitals

Present Illness: Jennifer has been considered to be entirely well until exam last week by pediatrician who noted enlarged clitoris and small vaginal opening. Female Genitalia: Clitoral enlargement of 1.5 cm. Sex assignment as a female is entirely appropriate.

## Medical Records

4/13/87—Dear Mr. & Mrs. Pagonis—I am attributing her elevated blood pressure to being somewhat fearful in our exam room.

Admission date: 10/27/90 Discharge Date: 11/1/90 Attending Physician: Dr. B. Hospital Course: patient underwent a clitoral resection and recession without difficulty.

8/28/1997—Jennifer is an 11 year old. She would like to have further corrective surgery and wanted to know if it was appropriate to start estrogen replacement at this time. Dr. F would like to do a perineal surgery to correct Jennifer's problem with urination. At the same time, he is considering doing a vaginoplasty. We discussed with Jennifer the fact that her gonadal development was not normal as a fetus. For that reason as well, and the risk of developing cancer, her

gonads were removed shortly after diagnosis. She was told she would not have periods and she would not be able to reproduce. We assured her that she would be able to have normal adult relationships. Jennifer agreed to start an estrogen therapy to increase breast tissue. Jennifer's mom should go ahead and schedule corrective surgery as desired by Dr. F and herself.

When other girls asked me in adolescence, "Did you get your period?" I'd make up stories because I desperately wanted to be on that journey with them. This knot of lies was spun to cover up what my mother had explained to me when I was a child. "You had cancer in your ovaries when you were born," she told me, "so the doctors needed to remove them. You won't get a period like mommy or be able to have children." I believed her.

Ten days before my twelfth birthday, my endocrinologist scheduled me for a surgery. The day of the surgery came and I was being prepared for anesthesia. The doctors came into the room to tell me what was going to happen next. "We noticed that your vagina is smaller than other girls'. While we're in the operating room fixing your urethra, we can also make a small incision in your vagina to make it larger. This way, you'll be able to have sex with your husband when you're older—Does that sound good?" I looked at my mom, who was in the prep room with me for this and wondered how to answer. I was only 11. I let out a shameful, "Yes." "Good then, we'll get that all taken care of for you as well during this procedure."

He turned to my mom and said, "We're gonna take very good care of your daughter Mrs. Pagonis." With that, he and his colleague left the room. I looked at my mom lost in thought. She noticed me and said, "Everything is going to be okay hun, trust me." When I was finally in the operating room (OR), the lead surgeon told me to think of my favorite place in the whole world. "Did you think of your place?" he asked. I nodded. "Now think of Disney World and count backwards from 100." I twirled down the steps of the Magic Kingdom as I fell into a manufactured sleep. When I woke, I was no longer a child.

A doctor and a group of residents came into my room. The doctor lifted my hospital gown, moved

my sheets, coaxed my tense legs open, and examined the surgeon's craftsmanship. My mom eventually came back to the room. She tried to move away the hair that was now stuck to the sweat that had beaded up on my forehead. "What's wrong hun?" she asked me. "Nothing," I said quietly.

## Medical Record

3/6/1998—Record of operation

Preoperative Diagnosis: [blank]

Postoperative Diagnosis: [blank]

Operative Technique: The patient is a 12-year-old female who was noted to have a variant of male pseudo-hermaphroditism that is testicular feminization syndrome . . . after . . . obtaining informed consent, she was brought to the operating room. . . . Once it appeared that we had adequate size and this easily accepted an index finger, we then proceeded to perform our flap anastomoses.

When the time came to take a bath, I made the water as hot as I could tolerate and began the process of adjusting my body to the temperature of the water. With weak and shaky muscles, I began the lengthy process of settling in. Every movement was done in the most cautious way possible—it felt possible to split open.

I eventually slid down and let the warmth envelope me. I began to gain a sense of what they had done to me. I felt crunchy and raw. I could feel the ridges of stitches and soft flesh bulging between them. I was queasy, but I couldn't help but touch the places where doctors had cut parts of me away. I removed my hand and returned it to the surface of the water and decided I would not return there.

I went through the rest of junior high and high school avoiding the questions and myself. I didn't want to know. This worked until I began dating someone and we tried to have sex for the first time. My parents told me I was normal and my doctors told me no one could tell the difference between me and any other woman.

The first time we had sex, it wouldn't go in. The second and third time was the same. Eventually, we were *successful* but it hurt. Real bad. I blamed myself. Shame and denial go hand-in-hand. During sex I would silently cuss out God and go through the ways

one could kill one's self. I did what the surgeon told me to do before surgery and went to some other place because trying to feel nothing felt like the only way out.

One day in the student center, of my university, I saw a group of students in the café. I knew I wanted to become friends with them. But I feared their rejection. I was so different from them. They, obviously queer, did not try to conform. Seeing my antithesis made me yearn to be amongst them—without even being certain what or who they were. Maybe John Money's argument that plasticity lingered longer for intersex children was right. I left the student center without saying hello.

I didn't know at that point that I was intersex. Dr. Money's protocol was working. My diagnosis was a secret and I believed the lies they told me about the surgeries and even thought of myself as a cancer survivor. Sparked by the feminizing hormones I began taking in fifth grade, my sexual identity seemed "normal," that is, heterosexual female, which satisfied my endocrinologists and family.

I appeared to be a success. I was the first person in my family to attend a university, was in a long-term relationship, and I had two decent jobs. Yet ever since junior high, I felt different. Just because no one told me the truth doesn't mean I never felt the effects of their lies. In trying to *protect* me, they made me feel ashamed and isolated and the stress and trauma from those surgeries left lingering severe effects. As Dr. Bruce D. Perry said, "[Even] if you take all of your money and dedicate it to treatment you can't build in things that didn't grow in the first five years of life."

While sitting in a Psychology of Women class the life they built for me teetered when the professor put up a PowerPoint slide, titled: "Androgen Insensitivity Syndrome [AIS]." Bullet points like infertility and amenorrhea, things I knew to be true about myself, were listed above a bullet point that stated women with this condition were genetically male and had XY chromosomes.

I called my mom and asked her, "Mom, what do I have?!" She opened some referral paperwork she just received from Children's Hospital after I turned 18. "It says, An-dro-gen In-sen-sitivity" she managed to get out before I hung up the phone. I cried

hysterically, alone in my dorm room bed, until I got online and did some research.

### Medical Record

3/7/2000—We then spent most of the time speaking with Jennifer as she was told that she did not have ovaries or uterus or fallopian tubes and she would not have her menses and she would not be able to bear children. We did assure her that she did have a vaginal opening so she would be able to have sexual activity. It was explained to her that the vaginal opening ended in a blind pouch. Jennifer did not have any further questions at the end of our meeting.

I spent a lot of time online researching AIS. It didn't take long to find an online support group. I found a community of folks with similar experiences. I realized that almost everyone had also been told they were born with "cancerous ovaries"! I learned this was a lie doctors told our families instead of telling them we were born with undescended testes. Almost all of us had our internal testes surgically removed without our consent. Without them, almost all of us were put on hormone replacement therapy to kick start our puberties. We almost all told similar lies to our friends in junior high and high school when asked the dreaded question—"When did you get your period?"

Some of us had other more unspeakable things done to us. A few weeks went by, and my Psychology of Women professor invited an intersex speaker to present. The speaker introduced herself as Lynnell Stephani Long and she was charming. I listened with a frozen gaze and tear filled eyes, while I tried to become invisible.

After class my professor—who I disclosed to a week prior—invited Lynnell and me to eat pizza. I told Lynnell parts of my story, the parts I knew from connecting the dots over the past few weeks, and then she asked me a question. "Have you said that you're intersex yet?" she asked. I hadn't. Intersex didn't sound normal. "No" I replied. "It's important to say it. Go ahead, say 'I'm intersex.'"

I hesitated. I didn't want to be different. I wanted to blend in. I wanted to be normal. I wanted to wake up from this bad dream. "I'm intersex," I mumbled.

"What? I can't hear you," Lynnell said with a smile. "I'm INTERSEX." "There you go. Next step for you is to get your records." I read about that on the support group. Many people told stories of *lost records* or records that were *burned in a fire*.

The first thing I read in my medical records was 46,XY male pseudo-hermaphrodite. My ears burned. I wanted to beat those words until they admitted they weren't true. I called Lynnell in tears. She stayed on the phone with me while I read the rest. "Breathe," she told me. "I'm here with you." A few pages later I saw the documentation of my second surgery. It was 1990. I was four. Perry argues that children are most vulnerable to trauma during this period, when their brains develop 90% of their capacity. That's the moment I realized that the reoccurring dream of waking up on a gurney with blood soaked gauze between my legs wasn't just a nightmare but a memory.

I also learned that when I was 11 the surgeon did much more than work on my urethra. He constructed a crevice and hole that mimicked those in the pages of his textbooks—but didn't look like a vagina. I hung up and made a promise to myself: I was never going to tell anyone else what I had just found out.

Soon after making that promise, I met a girl and fell in love. As she held me, I told her bits of my story each night and to my surprise she didn't run away. She made it feel safe to tell others and in 2008, while presenting my undergraduate thesis, I told an audience which included members of my family. It was the first time I told them everything I knew. Our skin felt a little bit more complicated, but tighter that day.



## A Changed Life: Becoming True to Who I am

Jay Kyle Petersen

I was born intersex in 1952 in the county hospital of a very small, ultraconservative town in rural Southwestern Minnesota. My biological

parents and paternal grandparents raised me on a small family farm nearby. I knew by age four I was a boy. No one told me. There was nothing to decide. I have always known I am male. My parents never discussed my unusual condition with me and died having never accepted me. They denied my true identity and instead chose to give me a girl's name and raise me as a girl.

My paternal grandmother knew I was different. She lived on the farm with us and, as she explained to me later on in life, changed my diapers and helped take care of me as an infant and toddler. She also was a Certified Nurse's Aide in the pediatric ward of the county hospital where I was born and could see that anatomically I was different from other infants. She remained my lifelong ally and friend until her death in 1993. She and Grandpa provided an oasis in their farmhouse where I felt accepted. I felt relaxed and comfortable in their company, and could just be myself. Grandpa took me fishing. Grandma drove me to 4-H State Fair demonstrations and supported me in the audience for which she had helped prepare me. My grandmother taught me good humor, excellence and how it was okay to make mistakes. Much later, in 1977, she drove four hours alone to Minneapolis in blizzard conditions to be my "concerned family person" during chemical dependency treatment, when my mother and dad refused and she also celebrated with me after my successful completion of the program. I loved her and she loved me and she showed it. With her I found refuge away from the pressure and abuse in our farmhouse.

But my grandparents and parents did not show me affection physically. The only touch I felt from my family, except my paternal grandparents, was abusive including certain religious figures outside our family. Farm animals and pets provided warmth, love, acceptance, and companionship. I loved riding around the farm on the back of my pet pig, Lucy. Nature, especially trees, wild weather, and local lakes provided rest for my stretched, weary nerves and stimulation for my imagination. There was something about the vivid and contrasting colors, even the sounds and livingness about it all—rich deep moist greens, clean pure vast open

blues, dark warm earth which I laid upon and felt in my hands. These and the soothing sounds of the wind gently moving through tree leaves and corn leaves and the lake water lapping calmly upon sandy shores, as Grandpa cast out his line: all this I found both relaxing and energizing and allowed for me the safety and environment to rest, let go and expand so my natural inclinations to express myself creatively could open up. Otherwise, I had a very lonely, frustrated, painful, humiliating childhood and adolescence filled with mounting anger and a sense of futility because I could not be or express my real male self—including my attraction to girls.

The cultural and religious pressure I felt, the increased abuse and social lies I was forced to live with—including being forced to wear girls' clothing against my will—became unbearable. I sought refuge in addiction early on—food for comfort, nicotine for mood alteration, alcohol given to me by my dad, and more. I became suicidal, and remained for a long time terribly depressed.

The geneticist I have consulted for the last four years says that physicians who examined me prior to my genital surgeries described my genitals as "male structures formed without enough testosterone," rather than female structures formed in the presence of excess androgen. She told me that the features recorded in my medical records, and that she had observed, indicate androgen exposure in utero along with an inherited genetic condition such that she says my condition began at conception. I was born with XX karyotype and testing for usual causes for androgen excess with someone with XX have proven negative, but my physical development and current lab tests indicate that my body has produced androgen levels within normal male range throughout my entire life—this even after voluntary gonadectomy/hysterectomy and without any supplemental testosterone dosage. She also says I was born with a male brain and this was set into motion at conception. But I was not diagnosed intersex until 2001—when I was 49. Prior to that, I was repeatedly misdiagnosed as transsexual. It has taken many years to get the answers I finally have.

My medical journey began in the Midwest, in 1980. I was able to stay sober after completing my addiction program, but there came a point when the emotional pain I was experiencing meant that I would drink again, or commit suicide. I found a gender clinic where, without a physical exam, I was diagnosed as transsexual—this based on the fact that I had a girl's name but told them I had known I was a boy since age four. The diagnosis did not feel like the right name for what I was but I trusted the professional. This surgeon showed me pictures of surgical work her clinic had done creating phalluses, and I almost vomited. What I saw mortified me and I wanted nothing to do with it or that type of phallus. Though small, the penis I had worked fine, but I still wanted more information about my body so my medical journey continued.

Eventually I sought assistance from a west coast sexologist, who, like the others, took me to be transsexual and never examined my body below my waist. I entered into the sexologist's care when I received a horribly painful rejection letter from my parents, became suicidal, and ran away from a female-to-male transsexual's apartment carrying a knife to do myself in. While gone, he had called the sexologist out of worry. When I returned to his apartment, having decided not to commit suicide, I learned that he had already alerted the sexologist, who was waiting for me at her house. He drove me there. I saw her for an hour and subsequently saw her a number of times over the course of several years for therapy and support as well as letters I needed for legal court name change and surgeries. She never sent me out for any examination either and never brought up the possibility that I could be intersex. In 1995 I called her from the Southwest after receiving the news that the 24-hour urine blood hormone test I had taken showed, for the second time, that my body was making male level androgens, and with no exogenous dosing. I was thrilled and told her on the telephone that I knew I was different, not transsexual, that this was more proof of what I had been trying to tell her: There was something different about me, though I still had no name for it. I am not transsexual.



Despite the misdiagnosis, I am grateful to a surgeon, also on the west coast, for agreeing to perform the breast—male chest reconstruction surgery in 1982. This surgeon told me I had the worst case of non-malignant fibrocystic breast disease he had ever seen. It was so bad that the doctor who saw me a few months earlier had made a diagnosis of cancer, and this led me to embark upon a regimen of self-care that made it possible for me to return to the clinic for the surgery. The same surgeon who did the chest-breast surgery later assisted a colleague in performing my first genital surgery with vaginectomy along with soft silicone implants in the male appearing urogenital folds, a surgery which I later learned was incomplete.

This was the first time either surgeon had seen my genitals as this clinic had misdiagnosed me transsexual six years earlier, failing again, to examine me. Again, I had doubts about my diagnosis and treatment at the time, but I was desperate, and it seemed to me that the only way to get help was to do what the doctors instructed. Grandma told me by telephone from the farm in 1985 that she did not think I was transsexual but she said she did not know what to call me either. I was just going along with whatever *help* I could get. I do not regret these surgeries for the most part. The hysterectomy/gonadectomy, in 1985 at a West Coast hospital unrelated to any clinic, removed organs that made no sense to me and were a constant reminder of my horribly painful abnormally long menstrual cycles that began around age 11 preceded by blond full body hair growth that turned dark around age ten along with medically diagnosed early onset acne. Thanks to the chest reconstruction in 1982, my chest looks male, looks good and feels right to me. The only surgery I ever had on my phallus, in 2007, was my last and least difficult. This surgery addressed the small “unfinished” feature of my phallus and the congenital chordee and urethral tube plate. Recently, upon examination, the presence of male corpora cavernosum, erectile tissue, was discovered behind the glans of my penis by my urologist and with the help of Viagra provided by this urologist,

I have since had successful intercourse for the first time in my life.

I grew up neither knowing what I was nor what was happening to me. I felt very alone. Once I received the correct diagnosis, once I had a name for my body, I felt an immediate sense of relief, as if finally I was able to take off a pair of painfully small shoes, and then was fitted for shoes that were a perfect fit. In all the years of misdiagnosis up until 2001, no blood hormone testing was ever ordered, no follow up was ever done on my serum blood testosterone levels and I had no liver testing. I was consistently prescribed inappropriate hormone doses and due to misdiagnosis was put on the wrong medical treatment plan. To this day, I have never had a primary care physician who has any education or experience treating intersex. Instead, I rely completely on my genetics doctor and urologist both of whom do have education and experience treating intersex individuals.

My geneticist and I have struggled now for over four years to find a local endocrinologist with experience with intersex. There is no one. After research and discussion, my genetics doctor and I have settled on a testosterone regimen with the provision that should some negative symptom occur we would enlist the help of an endocrinologist, however ignorant of intersex. I really wish there were adult specialists knowledgeable about intersex who could help me, particularly as my urology doctor will soon retire and there is no one yet to replace her. This is both sad and frightening.

From a life of pain, suffering and abuse I attribute to my condition and the treatment I have received, I have emerged with 38 years clean from drugs, 36 years sober from alcohol, 29 years clean from nicotine, out of debt since 1989, at a healthy weight, and I have a fulltime job working as a substance abuse behavioral health specialist in an outpatient clinical treatment center along with painting angels part time. I have good friends, all of whom know I am intersex and love and accept me for who I am. An award-winning director approached me and we have finished filming a short documentary about

my life, recovery, art, and art process. Once this is released I will be out publically as an intersex man, as I never have before and I hope my story will help to make change in medical practice and people's lives possible.

I hope the medical profession will learn something from reading my story. Each case is unique. We need to be treated as whole persons: spiritually, mentally, emotionally, and physically. Keep a resource referral list of intersex trained urologists, endocrinologists, primary care doctors and organizations such as [www.aisdsd.org](http://www.aisdsd.org) and [wwwaccordalliance.org](http://wwwaccordalliance.org) and advocate for medical schools to teach much more about intersex. Understand that intersex is not transgender/transsexual. Stop doing infant genital surgeries; let the child tell the parents what gender they are. The child will know by age 4-5. Ask us what we need. Give us plenty of time during appointments. Hear our pain. Give us hope. Treat us with respect. Understand many of us suffer from others having treated us like freaks, having experienced physical and other abuse. Understand God made us this way and we are good. Stand up for us; we need courageous physicians. Be comfortable with your own discomfort.



## Standing Up

Emily Quinn

A 10-year old and her mother walk into a male gynecologist's office. That sounds like the beginning of a sick joke, right? Imagine how it must have felt to actually *be* that 10-year-old. I walked into the Salt Lake City ob-gyn office, terrified out of my mind. It was the year 1999 and due to the recent accessibility of the Internet, there was a surprising amount of information about complete androgen insensitivity syndrome (CAIS) available. There was also an active and prominent support group for women with CAIS and other similar conditions. Despite all of this, I was standing in

the office of a doctor who knew nothing about my body. He did not direct me to any actual support, and for the next twelve years I went from doctor to doctor, none of them really knowing what to do with me. For as much as I was in and out of the doctor's office, I never seemed to receive any "care."

It was really difficult to have doctors who knew nothing about my condition. It was scary to be a kid with hundreds of questions but without an adult who had the answers. So many doctors were excited to look at me, to talk to me, to get the chance to meet me. As a child it made me feel like a freak. I felt alone, and scared, like I was on parade for all of these people who didn't know anything about me except that I was "special."

I was savvy enough to turn to the Internet for help, but searching for "sex disorders" online was a terrifying thing to do back then. Even now, it's not a safe space for a pre-teen looking for answers. I was so scared and ashamed of my body, and I desperately wanted someone to talk to about it. I found articles about celebrities who were rumored to be like me, and I saw the word "hermaphrodite" thrown around as carelessly as it had been used in my doctor's office. I wished desperately that one of those celebrities would admit to having a body like mine. Because if any of them were like me, maybe I wouldn't be the freak that the adults made me feel like I was. Maybe then I wouldn't be so alone.

As hard as all of this was, in a way my doctor's lack of knowledge turned out to be both a blessing and a curse. I felt cursed and ashamed of this different, "broken" body that couldn't be "fixed." I felt like a problem that nobody had the solution to. I was told so many lies—that I would definitely get cancer, that I could never have sex, that I needed surgery immediately. Not once was I ever told the truth—that there were hundreds of others out there I could talk to, that I didn't do anything wrong, that I was going to be okay. My doctors didn't point me in the direction of a support group or a therapist who could help me work through what it all meant. In Utah, the most important thing a woman can do is to have children, and it was devastating to learn I would not be able to conceive. I wish any of my doctors had pointed me in the direction of a professional I could talk to about it.



It wasn't until I was older that I discovered the blessing amongst all of this pain. As it turns out, my doctors were so entirely ignorant about my condition that they didn't know how to remove or even *find* my internal testes. I've managed to make it 25 years without surgery. Now, when I speak to medical students, many of them balk at this idea that surgery is something I've "escaped." But I know how many affected individuals see it as I do. It's incredibly lucky that somebody with CAIS is surgically untouched, and I fully believe that rarity to be the saddest thing. It shouldn't be the norm to operate on people like me. We don't need to be "fixed."

I didn't realize all of this until age 22, when I started to find support and meet others like myself. A prominent transgender and DSD specialist spoke to my human sexuality class in college. I approached her after class and asked her if she knew about androgen insensitivity syndrome. When she said yes, I burst into tears. I had no idea how important it was that I find a doctor who might have some answers for me. I hadn't realized how badly it had affected me, all these years of not knowing anything. She gave me her card and asked me to set up an appointment. When I called I was put on a three-month waiting list, but it was worth it. Someone would finally, *finally* have answers for me.

As the appointment approached, things became more serious with a guy that I was head over heels for. He was perfect! I adored him. As a kid I was just told not to talk about my condition; it was nobody's business but my own. Nobody had walked me through how to disclose about AIS to a partner. And when I told him a few months into the relationship, he broke up with me. I was devastated. Coincidentally the next week was not only Valentine's Day, but my appointment with the medical specialist, as well. Needless to say, I was an absolute wreck. But this one, perfect doctor literally changed my life. Having a doctor who understands your body, your variation, your medical needs, is the greatest possible gift for a patient. Not only did she help me with all my medical necessities, but she also set me up with a therapist specializing in transgender and intersex youth. I will be forever grateful for that. Having someone to talk to is so important, and I wish my doctors had given

me that luxury when I was younger. It would have helped ease my mind as a child.

With my new therapist, I worked through a lot of my issues in regards to my CAIS. She helped me to undo all the pain twelve years of knowing nothing about my body had done. She pushed me to find my testes, so I could have peace of mind about my health. In my search for answers, I stumbled upon the AIS-DSD Support Group, another life-changing moment. I contacted them, and ended up going to my first AIS-DSD Support Group conference. Meeting people who understood what I have gone through has been one of the most important steps to my personal happiness and my growth as an individual. It has allowed me to really love and accept my AIS body for what it is: Different, but good. Not broken. Not shameful. I wish the medical care team that treated me when I was younger had provided me with the care that I *actually* needed: a support system. I needed people like me to relate to, to understand, to connect with. I needed people like me to show me that I am not alone, that I am not a freak.

It's been a year and a half since that first support group conference. In that year and a half I have started advocating for intersex/DSD rights. I have spoken to medical symposia, LGBT groups, and medical students. I have joined Inter/Act, the world's first intersex youth advocacy group, and with them I have worked to create the world's first main intersex character on TV. I've been consulting with MTV to write "Lauren" on their hit show *Faking It*. I have trained the cast on how to speak publicly about what it's like to be intersex. I have also now come out publicly to the world as an intersex individual. I have created and appeared in public service announcements with MTV, I've written articles and been interviewed on places like the *Huffington Post* and *Vice*. And believe me, it has been scary, so incredibly scary. Words can't express how difficult it is to stand up and tell the world who you are, when you've spent your whole life hiding in fear and shame.

I'm not being publicly open about this for any fame that has come my way, or recognition, or to prove anything to anyone. I'm doing it for the little

12-year-old girl who was searching “sex disorders” on the internet and feeling like she’s the only person like herself in the world. I’m doing it for the other intersex children who weren’t as lucky as I was, the ones who had surgery without quite knowing what that meant, or without knowing that they had other options. I’m doing it for the children who have yet to find out about their differences, because maybe they’ll get to live in a world where being different isn’t so shameful, or unnecessarily medicalized, or made to be a terrible secret. Maybe they’ll finally have a doctor who won’t treat them like they’re something that needs to be “fixed.” Maybe, by the telling of my story, they’ll finally have a doctor who understands about their bodies, so they won’t have to go without answers.

I’m writing this on the eve of 2015 . . . and I know it’s going to be my biggest year yet. I’ve decided to leave my job working on one of the most prominent children’s cartoons in the world, and instead pursue a career in advocacy. It seems crazy, but I 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 Viloria

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 squad when I tried out to help a friend who needed a tryout partner.

Other than escaping IGM (Intersex Genital Mutilation) and estrogen therapy, I’ve had only a few experiences pertaining to my medical care around being intersex. These experiences fall into two categories: seeing medical doctors who treated me the same after discovering that I have ambiguous genitalia, and seeing ones who didn’t. I feel incredibly blessed that my experiences in the former category vastly outweigh the latter.

My first experience came at the age of twenty, when a gynecologist asked me if my clitoris had always been as large as it is. I responded that it had, and she said, while looking at me disapprovingly, that she’d like to do some tests. When I asked her what they were for though, she wouldn’t respond directly. She said I’d reported having some upper lip hair, and acne, on my intake forms. I replied that neither were above average, and asked if there were health issues I should be concerned about. She reluctantly said no. I asked what reason there

was then for undergoing tests because of the size of my clitoris.

She finally responded, “It’s just not normal.”

Fortunately, I’d had positive reactions to my sex traits from the people I’d dated. For example, the first man I was intimate with told me my body was beautiful and proposed marriage several months later. Positive experiences such as these, alongside the doctor’s uncaring attitude, made me question her and decline having tests done.

However, the doctor’s assertion that my clitoris was “not normal” had a negative psychological impact. It made me question—for the first time—whether there might be something problematic about my difference.

I decided to seek a second opinion at the medical clinic at N.Y.C.’s LGBT resource center. I recounted my experience with the first doctor to the physician and asked if there was anything for me to be concerned about. She examined me, concluding that my ovaries felt fine, that clitorises come in all shapes and sizes, and that she thought mine was beautiful. By affirming the natural diversity in genital size, and referring positively to mine, this doctor undid the psychological damage done by the one who had deemed my genitals abnormal.

I first saw the word “intersex” in a newspaper article at the age of twenty-six, and confirmed via research that I’m intersex by twenty-eight. It was extremely helpful to have a word to describe this aspect of myself, and to know that others like me existed.

I was shocked and saddened however, that almost all the intersex adults I met had been subjected, at a young age, to “normalizing” genital surgery, also known as IGM. Ironically, although the interventions were performed in order to help them fit in, they’d had the opposite effect, resulting in physical and psychological trauma that made feeling normal difficult. However, the common response from their doctors had been that, bad as these results might be, they’d have been worse off without “normalization”.

The fact that my lived experience completely contradicts the claims made to justify IGM motivated me to become an advocate. I wanted to help



future generations experience the joy I have because I was allowed to keep the healthy genitals I was born with. I wanted all intersex people to have the right to make their own decisions about their sex anatomies; and I still do.

However, being an advocate has made me vulnerable to a pathologizing gaze that I had hardly experienced in my medical care. For example, a doctor advocating for IGM during a television interview, in which I'd just revealed having clitoromegaly, once said, in an alarming tone, "Sometimes the clitoris is so grossly enlarged that it resembles a baby boy's penis!" Although I was applauded for confronting him on trying to depict us as physically repulsive, experiencing such palpable prejudice was extremely unpleasant.

Despite these challenges, the pain I have witnessed in those subjected to IGM is so profound that I felt, and continue to feel, compelled to continue my advocacy. I viewed, and continue to view, IGM as enforced social prejudice.

This view was confirmed when Dr. Kenneth Glassberg, a pediatric urologist who appeared on the television program "20/20" with me (April, 2002) said, as justification for IGM, "Society can't accept people of different colors, and now we're supposed to accept somebody whose genitalia don't match what their gender is? I do not believe this society is ready for it."

His statement revealed that doctors are participants in a cultural legacy that deems those who challenge dominant values unacceptable. It reminded me of European cases from the 1500–1800's that I'd read while studying sex and gender at U.C. Berkeley, in which individuals were tried for "gender fraud" if discovered to be intersex. Today, medical doctors are the ones expected to act when the "boy or girl?" question cannot be readily answered.

The doctor's assertion that IGM is performed because society is not ready to accept intersex people also confirmed what I'd long suspected: that IGM exists to benefit non-intersex people—such as our parents—rather than those subjected to it. It seemed similar to when homosexuality was a disorder (until 1973), and doctors assisted parents

who'd discovered that their children were gay and sought medical treatments (commonly electroshock therapy) to "cure them".

Being intersex was pathologized in 2006, as a "Disorder of Sex Development/DSD". Just imagine waking up to find that being what you are has suddenly been deemed a disorder! It was extremely upsetting, triggering a deep depression. The main thing that helped me out of it was witnessing the dissent by my intersex peers.

Like many of us, I reject the term "DSD", which I find as insulting as when my father referred to my lesbianism as a "psychosexual disorder". He was just using the label he'd been taught in medical school, he wasn't trying to hurt me, and similarly, while I don't think doctors intend to offend and/or hurt me when they use "DSD", that's the effect it has. I use "intersex" exclusively, and ask others to use it to refer to me, because I find being described solely as an acronym depicting sexual difference dehumanizing, stigmatizing, and hurtful.

Some have been substituting "differences" for "disorders" in "DSD", and while I welcome a de-pathologized diagnostic label, I think it's hurtful to our already marginalized community to be referred to as people with medical conditions when this is not how other communities are labeled. For example, the diagnostic term for being transgender is "gender dysphoria", but transgender people are not called "individuals with gender dysphoria."

I prefer "intersex traits" as a diagnostic term because, as I explored in *The Advocate* ("What's in a Name: Intersex and Identity"), the history of civil rights movements demonstrates that communities seeking equality don't define themselves solely as being different from the norm or the dominant population. Rather, they use terms that positively describe their unique identities.

This is why I recently found the Association of American Medical Colleges' (AAMC) report, "Implementing Curricular and Institutional Climate Changes to Improve Health Care for Individuals Who Are LGBT, Gender Nonconforming, or Born with DSD," so alarming. I was upset to see that, while the other members of the LGBTI community

are identified with their self-chosen identity labels, “intersex” people—the “I” in “LGBTI”—have instead been identified with our diagnostic term. It was even more upsetting given the countless stories I’ve heard first hand about how the term DSD has hurt my peers, and the awareness of one of the editors of the report of these experiences, as she is the non-intersex female co-author of the paper that originally called for the change to DSD, and was informed of the dissent against the term.

I was also concerned to read, “The use of the term [“intersex”] as an identity label is currently in flux . . . ,” because its use amongst those diagnosed with DSD is actually *increasing*. Even Facebook noticed, including us as “intersex” when it expanded its gender categories beyond “male” and “female” early last year.

I think it’s crucial for medical professionals to be aware that the community of people that have connected around being born with variations of reproductive and/or sexual anatomy was originally, and continues to be, the “intersex” community. For example, I have participated in our global gathering of community advocacy leaders, the International Intersex Forum. We work for bodily integrity, self-determination and other human rights for “intersex people”, as do institutions we work with such as the U.N. Office of the High Commissioner of Human Rights, which invited me to speak at the U.N. in 2013. Also, the following year, some of my colleagues attended the U.S. State Department’s “LGBTI” event, the Conference to Advance the Human Rights of and Promote the Inclusive Development for Lesbian, Gay, Bisexual, Transgender and Intersex Persons.

It’s thrilling that institutions like the U.N. and the U.S. government are starting to address intersex people’s human rights, but consequentially very concerning to see the AAMC identifying us as people “Born with DSD”, as doing so risks excluding the medical treatment we’re subjected to from public policy and protections for “intersex people”. I thus urge all medical professionals to describe us, when an umbrella term is needed, as they do lesbians, gays, bisexuals, and transgender people—our fellow LGBTI community members—with the identity label that defines us as uniquely equal individuals: intersex. Although this may seem

challenging, as noted, it has already happened with transgender individuals.

In contrast to those forced to undergo “normalization”, being intersex has not been traumatic or a hindrance to me precisely because my doctors employed a, “if it ain’t broke don’t fix it,” approach towards my atypical, yet healthy, sex traits. In addition, my experiences demonstrate that presenting intersex traits in a non-stigmatizing manner promotes psychological health and self-acceptance. I attribute my fulfilling life as a homeowner with a career, friends, and committed partner I love, to the non-invasive medical care and non-stigmatizing rhetoric towards my intersex traits that I was exposed to during my formative years.

If medical professionals are truly interested in promoting our health and well being, they should begin by leaving intersex infants’ and minors’ healthy sex organs intact, describing intersex traits as the naturally occurring variations they are, and de-pathologizing being intersex. While many have historically treated those who are different as disordered, or otherwise inferior, doctors are in a unique position to learn from these mistakes and facilitate acceptance of, rather than prejudice towards, intersex people, as the many doctors who did not stigmatize my body did. I thus encourage medical professionals to put aside any negative preconceptions they may have inherited from society’s historically stigmatized portrayal of intersex people, in order to treat us with the same respect for bodily integrity, sexual sensation, reproductive capacity, and self-determination that all people deserve.



## **Standing at the Intersections: Navigating Life as a Black Intersex Man**

Sean Saifa Wall

**A**s I sit down to write this narrative, my mind is reflecting on the past year. This year has seen numerous protests against

state-sanctioned violence with the declaration that “Black Lives Matter”. As a Black intersex man, I have witnessed the impact of state-sanctioned violence on my family and my community, both from the police state and medical community. I charge the police state and the medical community with state-sanctioned violence: Each targets non-normative bodies—the former through incarceration and execution, and the latter by means of surgical and hormonal intervention. As a Black intersex man, I stand at the intersection bearing witness to how this violence has incarcerated my friends and loved ones as well as being subjected to medically unnecessary surgical intervention. Although this is where I stand now, both socially and politically, I have not always existed here.

I was born in the winter of 1978 at Columbia–Presbyterian Hospital in New York City. I was the youngest of five children and one of three children in my family who were born with an intersex trait now known as androgen insensitivity syndrome (AIS). At the time, AIS was referred to as “testicular feminization syndrome.” Upon receiving my medical records years later at the age of twenty-five, I noticed scribbling and a barrage of notes indicating the process by which the doctors assigned my gender as female. Although I had ambiguous genitalia, which caused some initial confusion among the doctors, XY chromosomes were not enough for me to be raised as male. My mother was told I would be raised as a girl and, according to the medical records, “function as such.”

Unlike my sisters who were also born with AIS, my mom was not swayed by the surgical recommendations doctors made about my body. As a matter of protocol, my sisters’ gonads were removed in infancy, however, my mom made the decision that my testes would remain with me until they had to be removed.

Because of intense pain in my groin area, my testicles were removed when I was thirteen years old. The pain that I felt following the surgery was perhaps the worst pain that I have experienced in my entire life. After surgery, my pediatrician prescribed estrogen and Provera as a hormonal replacement regimen. Fatty deposits changed the shape and contours of my

face. Once robust and chiseled thighs now harbored cellulite. The beginnings of facial hair and prominent body hair became wispy and nonexistent. What was hard and defined became soft.

*At no point did anyone ask me what I wanted to do with my body.*

I actually missed the effects of my natural testosterone such as a deepening voice, increased hair and muscle mass; when I asked if I could take both testosterone and estrogen after surgery, my mother remarked, “You would look too weird.”

The hormone therapy was coupled with intense social conditioning. I feel as if the social conditioning for young women raised with AIS is suffocating. When doctors prescribed hormones for me to take, my mother constantly reminded me how “beautiful” the little yellow pills would make me. As a means of reassurance, my pediatrician told my mom that “a lot of fashion models” have AIS and that I would most certainly be beautiful. In our dominant US culture, gender norms can already be oppressive, but for women with AIS, there is the impact of gender norms and the underlying fear that women with AIS are not really women since they have XY chromosomes. I did not succumb to the pressure to be more feminine, but actually gravitated toward masculinity. Before transitioning to live as a man, I considered myself a butch woman. When I came out of the closet at fourteen years old and presented as a masculine young woman, I never felt safe. Because I dated women who were more feminine than I, my relationship with these women seemed threatening to men who repeatedly reminded me through harassment and threats that “I was not a man.” Of course, I wasn’t trying to be a man at the time, but it was often an unsavory reminder of how we as a society conflate gender and sexuality.

I grew up as a visibly queer child. However, I did not always feel different from my peers. What made me feel different were the probings and invasive genital examinations doctors performed on my body. Because of stigma related to having three intersex children, my mother was always vigilant around doctors and made sure that she was present during any kind of medical examination but I still felt different.

As I got older, the intense scrutiny around my genitals often left me feeling objectified and uncomfortable. Perhaps what made me the most uncomfortable was the fact that there was never full disclosure of what was occurring during these examinations and that no one ever explained why they were so interested in my body. I distinctly remember an incident in college where I went to the doctor for a gynecological exam. Although I was told that I had a “blind vagina” and would never menstruate or have children, I did not fully understand my sexual anatomy. So in the doctor’s office, I sat afraid. When I was brought in, I was asked to disrobe and shortly after, the doctor began her exploration. She stuck a Q-tip inside the orifice and barely managed to get the tip in. She then inserted a finger in my rectum without telling me what she was checking for. This would not be the last time where I would be anally examined because doctors were looking for a prostate.

My height, in addition to other features associated with masculinity such as large hands and feet and a deeper voice, blended with a feminine face to create an androgynous presentation. Although I was starting to see myself as more male, I was often frustrated by how estrogen feminized my face and other parts of my body. When I decided to transition from female to male, I was met with resistance from physicians because they incorrectly assumed all people with AIS identify as women. In the beginning of my transition, doctors would often tell me, “I read a chapter on intersex conditions back in medical school,” or “we don’t know how to work with people like you” or flat out, “your body is too weird.” Despite these obstacles, I began my transition in the beginning of 2004.

Similar to my friends who were transgender men, once I started testosterone therapy, I experienced heightened sexual arousal, more energy, and a change in how my body stored fat. My partial insensitivity to testosterone meant that I also experienced estrogenic effects such as sore nipples and water retention, which was often frustrating. Because of my inability to produce facial hair and other secondary sex characteristics, I was and sometimes continue to be mistaken to be a woman. The doctors who were willing to experiment with

dosages were the most supportive of my transition, but they often threw up their hands when my body didn’t respond in ways they thought it should. Although I am not entirely clear about what testosterone is doing for my body on a cellular level, I will continue to take it because this is what helps me to feel alive. As my friend, a doctor specializing in transgender and intersex care puts it, “You have to put people in the hormonal environment where they feel comfortable.”

Today, regardless of how my gender presentation is interpreted, I am either seen as a gay male, a butch woman, or a young man. Despite these variations in how people perceive my gender, I am more often than not, seen in the world as a young Black man. When I transitioned from female to male, I didn’t feel the same level of vulnerability I felt as a masculine queer woman who dated feminine women. Prior to transition, I felt scared and was often harassed, disrespected and at times feared for my physical safety. Now my fear is something that stretches back to the annals of American history: where Black men were once lynched with abandon, but we are now imprisoned in disproportionate numbers. As a Black intersex man, I am fearful of getting arrested and being subjected to strip searches where once again my genitals would be on display in an institutional setting that is inherently violent. I am now navigating this world as a Black intersex man.

*In my desire to live as an intersex man, I had to decide whether I would try to accommodate the world or make the world accommodate me. I chose the latter because my very life depended on it.*

That is why I am putting my body and life experiences on the line as an intersex activist, because I want to create a world in which people born with variations of sexual anatomy are free to live a life with dignity and respect. I am advocating for a world where intersex children can enjoy body autonomy and where the uniqueness of their bodies, and our bodies as intersex adults, are upheld in their integrity and beauty.



## **“Normalizing” Intersex Didn’t Feel Normal or Honest to Me.**

Karen A. Walsh

I am an intersex woman with Complete Androgen Insensitivity Syndrome (CAIS). My 57-year history with this has its own trajectory—mostly driven by medical events, and how I and my parents reacted. Most of my treatment by physicians has not been positive. It didn’t make me “normal” at all. I was born normal and didn’t require medical interventions. And by the way, I’ve never been confused about who or what I am.

Truthful disclosure didn’t come to me about my biology and what was done to me as an infant until I was 33, when I forced the issue by removing my medical records from my endocrinologist’s office. I learned that there was never full disclosure to my parents either, and therefore there was no informed consent for the “corrective” surgeries performed on me as an infant. My parents were only told that their little girl would get cancer and would not have a normal development as a girl unless her “deformed ovaries” were removed, and that they should never discuss these problems with me. Thus, after having presented with an inguinal hernia and having exploratory surgery at age 16 months, my intra-abdominal testes were removed in a second surgery two months later. I was pronounced a “male pseudohermaphrodite,” a diagnosis that was shared neither with my parents nor with me.

Years later, I discovered an article my surgeon published in 1960 in the *Delaware Medical Journal* about me and another intersex person he operated on (whom he labeled a “true hermaphrodite”). The article gives a very detailed pathology report of my gonads, but only two sentences regarding my welfare and the rationale for performing those surgeries. Dr. J. F. Kustrup wrote in this article, “These [two cases] emphasize the need for early diagnosis and treatment in order to avoid the possibility of malignant change and to permit these individuals to follow a normal psychosexual pattern.” And: “Hermaphroditism

and pseudohermaphroditism are conditions in which early diagnosis and treatment are essential to avoid malignant degeneration and to allow the child some chance toward normal psychic [sic] development.” I was grateful to find this article because it revealed the unfounded assumptions underpinning the recommendations for treatment, much of which continues today. Worse even than the sort of social prejudice that shapes treatment is the absence of evidence for what doctors treat as “necessary” interventions. For my syndrome, CAIS, *there never was—and still is not—data to support the cancer scare, or the opinion that I’d be confused and not have a normal life.*

From about the age of four, I can remember being different and being stonewalled by my doctor and prevented by my parents from talking about it. The feelings and fears I tried to express were shushed away, and I could tell that my questions were upsetting everyone. Even if I had wanted to be complicit with their lame diversions and nonsensical explanations, the massive abdominal scars were there as a daily reminder and hinted at a very different story.

## **The Road to Hell is Paved with Good Intentions**

Growing up, I was treated like a fascinoma and a lab rat at a major teaching hospital on the East Coast. All I learned from those doctors as a young kid was what it feels like to be ogled, photographed and probed by a roomful of white-coated male doctors. Dissociation made itself my friend, and helped me to cope through the annual genital and anal exams and probing. I thought I was a freak and I felt completely powerless to protect myself from them and their “care”.

At my annual appointment at age 12, with my mom present, three doctors told me I was infertile. Learning that I couldn’t have kids really saddened and shocked me, but there was no opportunity to talk about my feelings—either that day, or any time afterward. I was told to stop crying. I remember them telling me that there was no one else like me and that this was a random



genetic anomaly, thereby reinforcing the freakishness I felt. Most of the discussion was devoted to explaining that I needed to take Premarin every day for the rest of my life, so I could grow breasts and keep them, but any questions I had were shushed away. It felt insane to be walled in by secrets, and yet be the only one who wasn't privy to the actual secret!

After that exam, I refused to return to the teaching hospital ever again. My mom found a young endocrinologist locally to take care of me. I returned to "Dr. C" for care for the next 21 years. I also spent a lot of furtive effort in libraries trying to figure out "what I really had", and then would ask him about it at the next visit. "Do I have Turners? Do I have congenital adrenal blah-blah?" Between age 15 and 32, I probably asked about all the intersex syndromes. Sadly, he inflicted further damage on me by constantly changing the "story," maybe relieving him from telling me the truth. At various times, he had me believing that "*maybe* someday you *might* get a period," or, "you *might* eventually get some pubic hair," or "you *might* have a rudimentary uterus," and so on. Those lies held out the hope of being able to have children. Or maybe that I could be *just a little bit more normal*, like all the other girls. It still sickens me to think of how I trusted him and so desperately wanted to believe him, even as I felt powerless and afraid.

The other main feature of Dr. C's "care" was his attention to my sex life. I was elated—that part of my being a girl actually worked, and sex was fun! Probably as a way to divert attention away from my quest for the truth, and maybe for his vicarious titillation, my sex life was often his main concern. Even then, before knowing the truth, I had the sense that my "fuckability" (a term he once used) and my attractiveness were what he thought most important. "Why do you want pubic hair? A lot of men," as he put it, "like a bald pussy." It seems now to me that he saw his task as convincing me that I was a woman. But I never thought I was anything other than a woman. I was afraid though that I wasn't *enough* of a woman, since I couldn't reproduce.

## The Power of the Truth

The trajectory of my history and my self-acceptance radically shifted while I was away on a business trip, at age 33. I had sex one night and for reasons no one can explain, it went horribly awry. I landed in the emergency room with a ripped vagina, hemorrhaging profusely. I barely remembered driving myself there, with a bath towel shoved between my legs to stanch the flow. Dissociation was my friend again that night—a very high functioning friend, thank goodness. After my vaginal repair surgery, I had my first encounter with a truly compassionate and candid doctor, the surgeon who performed the repair. He coached me on how to find the complete truth about myself, and wanted to help me understand it.

When I arrived home from my trip, I saw Dr. C. I explained what happened, and said, "Ok, time for you to tell me the truth". He stonewalled me again, so later that afternoon, I took my medical records from his office and read them in my car in his parking lot. There was a lot, including many pages from the teaching hospital. They all boiled down to this: "male pseudohermaphrodite", XY chromosomes but female phenotype, lots of unnecessary tests, exams and pictures, and "never tell the patient". But now the cat was out of the bag.

I visited Dr. C the next day for the last time, and asked him to explain his lies. His answer: "You never asked me if you were a male pseudohermaphrodite"; and, "What difference does it really make? What would you have done differently?" In point of fact, I *had* asked him about male pseudohermaphroditism at one point, and he'd lied. Also, it would have been extremely helpful to know that CAIS women have a blind-ending vagina, which can sometimes be shorter than other women's and if so, can be problematic during sex, especially with a new partner. Perhaps my vaginal tear could have been prevented, had I known to be more vigilant.

As for his second statement and how it affected me, I hope never to experience that level of rage ever again. I had to explain his duty as a doctor to give patients the truth, especially when they repeatedly



sought it. My diagnosis was not mysterious; this was a well-known condition I had, not some scary random freakish thing. Most importantly, there are other women out there like me, and I should have been told. He sneered and said he couldn't accept that my knowing the truth would have been, or was now, any help to me. After all, look at how angry I'd become. And besides, he'd followed the "standard of care". And then it dawned on me. I blurted out: "Oh wait! This isn't about me. It's about your disgust. You're a homophobe! Aren't you? And you think this is somehow related to that. Shame on you! Physician, heal thyself!" To this day, I'm still not sure how I put two and two together so accurately in that moment, but I'd read him correctly. His response: "Well, we can't have little girls with balls running around!"

It truly was liberating to finally know the truth. *I wasn't random, and I wasn't alone!* The saddest part of that was that I had to wait until I was 33 to find the truth.

Knowing all along that I was being lied to by everyone undermined my trust in the very ones who were responsible for my protection and care. My parents were not unloving and uncaring, but clearly they were misguided. I have since had difficulty with trusting anyone. Even though my doctors and parents guessed correctly about my gender and sexual orientation, they still violated my rights to bodily integrity and self-determination.

I know now that it was not necessary to remove my gonads—my only source of endogenous hormones. I am at extraordinary risk for osteoporosis, as well as problems with libido. Additionally, I had problems feminizing during my "puberty", since the Premarin was not well absorbed. It is a myth in the treatment of intersex that exogenous hormones work as well as endogenous ones. This is a lifelong problem for me.

### Helping to Change Today's "Standard of Care" for Intersex Conditions

From about 1993 to 2004, I gathered a lot of medical information about intersex per se and CAIS in particular. I also joined several intersex support groups

and met other women like me. This was vital and foundational for me. These efforts were catalyzing and empowering—but only to a point. Ethical awareness was still missing from intersex treatment, and I was fighting with the medical profession about this. That's when I joined activists who were helping to change the poor "standard of care," and the bad assumptions that underpin it. I've been involved with this for almost 10 years now, and have probably spoken with more than 30 physicians who are self-proclaimed experts and specialists in intersex.

Unless I bring it up, rarely is my quality of life (QOL) discussed. Why doesn't my health and QOL as an adult matter to Medicine? Why do I have to fight and inveigle doctors to help me with my health and QOL? This is frustrating beyond belief.

### I am the Captain of My Own Ship Now

The trajectory changed again for me about 10 years ago. I undertook intense psychological counseling that helped me to deal with my PTSD and dissociation, poor body-self image, and all the rage I'd bottled up against my parents and doctors. And it completely changed the care I demanded, and am now getting, from Medicine. A good example is that I lobbied for adding testosterone to my HRT, which restored my lost libido and yielded a better general sense of wellbeing and energy.

My story isn't over yet, and that is very important to me. My interactions with Medicine have become the embodiment of Shunryu Suzuki Roshi's sage observation in *Zen Mind, Beginner's Mind: Informal Talks on Zen Meditation and Practice* that: "In the beginner's mind there are many possibilities, in the expert's mind there are few." I really want to help close the gap between those opposites. I want physicians to know that *one of the best experts actually is the patient*. After all, we live inside our bodies, and we know how we feel—or how we'd like to feel. *I am the best data you have!*

Medicine and society need to see intersex individuals as natural. I occur in nature and I demand to make my own decisions, the same as any other person. And I demand it for *any* individual who is born intersex.



## Invisible Harm

Kimberly Zieselman

I'm a 48-year-old intersex woman born with Androgen Insensitivity Syndrome (AIS) writing to share my personal experience as a patient affected by a Difference of Sex Development (DSD). Although I appear to be a DSD patient "success story", in fact, I have suffered and am unsatisfied with the way I was treated as a young patient in the 1980's, and the continued lack of appropriate care for intersex people even today.

As the Executive Director of the advocacy organization Advocates for Informed Choice and a board member of the AIS-DSD Support Group since 2012, I have heard doctors reference the "silent happy majority" of DSD patients all too often. They speak of patients who were treated in childhood and went on to live (seemingly) contented lives. It appears however that doctors have drawn this conclusion from the fact that most of their patients have not returned to complain about their treatment. While there is little evidence to support the success doctors claim, there is quite a bit of evidence that suggests my suffering is the norm rather than the exception.

Medical professionals would likely include me in that "silent majority," only seeing a woman who identifies and appears typically female, graduated law school, married for over twenty years, with adopted children and a successful career. And while I have been fortunate in many ways, I no longer want my voice to be presumed buried within that silent majority. Instead, I am speaking out today to tell my story.

### My Story

At age 15 I was diagnosed with amenorrhea and referred to a reproductive oncologist who told my parents I had a partially developed uterus and ovaries that would likely soon become cancerous. We were told my vagina was abnormally short and

might require surgery in order to have heterosexual intercourse.

Neither my parents nor I was ever told I had AIS and XY chromosomes, or that the gonads being removed were testes, not ovaries. I was told I needed a "full hysterectomy" to prevent cancer and hormone replacement therapy. That summer I spent my 16<sup>th</sup> birthday recuperating from surgery. I spent the next 25 years living a lie.

A lie that has had a profound and harmful impact on me.

At some level, I knew I was not being told the whole truth. My parents' and the doctors' actions signaled to me something more might be going on. But I was afraid to ask questions; my parents were distressed and I didn't want to cause them any more pain. Over the years I have wondered just how much my parents knew but withheld from me (albeit with good intentions). I sensed something awful was being hidden from me, and I didn't know whom I could trust.

When I asked my doctor if I could meet someone else with my condition, I was told I was different, that there was "nobody" with my medical condition in the world, that my situation was "very rare." I was told to get on with my life and not talk about my surgery because it wasn't important; I was healthy and could adopt if I wanted to become a parent. I was told I must take a hormone pill each day for the rest of my life to stay healthy.

But what I *heard* was, "you are not a real woman: you are a damaged freak, so go out and fake the rest of your life and be sure nobody knows your secret." So that's what I did. I was a "good girl" and took my pills, didn't ask questions and did what the men in white coats asked me to do. There was no support provided for either my parents or me. No social workers, no therapists. Perhaps most shockingly, there was no true informed consent.

A few years ago I was diagnosed with post-traumatic stress syndrome caused by anxiety I had been harboring for over two decades about my past surgery and fear of getting cancer. I decided to obtain my medical records from the hospital and discover the truth.

Covering several pages of medical records were words like “testicular feminization” and “male pseudohermaphroditism.” But the most disturbing thing I read was not even those stigmatizing words, but something else. There, hand-written in cursive on a piece of lined paper was a statement dated 6/27/83: *The procedures, risks, benefits, and alternatives to it have been discussed. All questions answered; patient and parents have consented.*

And underneath that scribbled statement was my doctor’s signature, my father’s signature, and my own, 15-year-old signature. There was absolutely no reference anywhere about what “it” was. That was our “informed consent.”

Some may say, “what you don’t know, doesn’t hurt you” . . . but I strongly disagree. And this is what I want medical providers today to understand, that withholding information from young patients, lying to patients, *is* harmful.

In my case, my parents were also lied to. They were never told the whole truth about my XY chromosomes or testes. But in other cases, parents are told the real facts and specifically instructed not to tell their child the truth for fear they will be psychologically traumatized, or worse. That sets up a terribly unhealthy dynamic for a parent-child relationship. It leaves the children with lifetime issues of trust.

For me, the lies were harmful in an invisible way: they set up a damaging dialogue in my head that perpetuated a feeling of “being fake,” not being “real” and never being “good enough.”

I sensed there was more to the story and that I was being lied to. Being told not to talk about my condition with others, having to pretend to be like all the other girls and wanting to fit in, and being told there was nobody like me in the world—all contributed to my feelings of being isolated, different and ultimately, detached emotionally.

Although one may think being told I had typically male chromosomes and testes might have made me feel even more like I was faking life as a female, it in fact did just the opposite. When I finally learned this truth it was very affirming and anxiety releasing. I finally had the whole story, I knew who I really was, and I had no more fear of “cancer.”

Before, when I didn’t know the truth, I intuitively knew “something” was wrong and I had been lied to. I imagined things much worse than the actual truth and felt I was a real freak of nature, damaged and alone. (“It must be something so horrible that they found it necessary to lie to me!”)

While I have no doubt the medical providers involved thought they were protecting me (and my parents) by hiding a perceived shameful truth about my body, I believe it was wrong to replace the truth with lies that perpetuated my fear of cancer and forced me to imagine much more radical versions of “my truth.” It was wrong to set up a situation that left me not knowing whether I could believe either my parents or my doctors.

The deception I could only sense caused me to shut down emotionally—to put up walls. With the help of a caring therapist I now realize I didn’t really experience or feel true happiness or sadness. I placed a great deal of pressure on myself to succeed and prove myself whether in my personal life or my work. I “blacked out” when situations got overly emotional. I have no recollection of my husband proposing to me. After adopting my beautiful twin daughters it took me years and years to accept I was a “real” mother. And despite my unconditional love for them I struggled to feel worthy of theirs. Whenever I found myself in heated arguments or controversial discussions with friends or family, I would “black out” and forget what had occurred. My mind had found a way to cope by burying all extreme feelings, by retreating. In turn, I missed out on the real human emotions of joy and even sadness of my life experience. Those are the hidden costs of the lies—the real harm suffered as a result of the doctor’s chosen practice of concealing the truth.

Being told a lie about my condition and being told I was alone, with nobody else like me in the world was devastating.

Thankfully, in 2009 I discovered a support group and now personally know hundreds of people like me. Connecting with others and getting information and support has been absolutely life changing. Now I have the joy of seeing kids as young as eight or nine meeting at the AIS-DSD Support Group annual

conferences around the country and connecting with others online who are just like them. They are embracing their differences in age-appropriate ways with the support of their parents and a large loving community. These kids are learning the truth about who they are. They know they are not alone and in fact, they have an expanded community that includes others who “get it.” This is the way it should be. Medical providers must let children with DSD and their families know there is amazing peer support out there and help them connect with groups like the AIS–DSD Support Group.

These feelings and experiences I describe are not unique to me; I have talked to dozens of others who share shockingly similar feelings and have experienced strikingly similar emotions and have suffered in much the same way.

I wish I had been given the choice to keep my testes with regular monitoring instead of rushing to surgery. Hormone replacement therapy is a poor substitute for the real thing—especially at age 15 with a long life ahead.

Luckily I escaped surgery to lengthen my shorter-than-average vagina. It turns out the body I was born with worked a lot better than the doctors thought it would. But many of my “sisters” with AIS have not been so fortunate. The physical and emotional pain they continue to endure as a result is heartbreaking.

In the fall of 2013 I wrote a letter to the teaching hospital where I was treated as a young person. My goal was to inform the institution in a manner that resulted in better care, and more importantly, prevent harm to others. I finished my letter with the following request:

*All I am seeking is an acknowledgement of my experience, recognition of harmful decisions made in the past, and most importantly, evidence of improved care and practices. Please give me hope that I can share with thousands of others like me, that leaders in medicine such as your hospital are indeed now willingly doing the right thing, listening to their patients, and respecting people and families affected by intersex conditions.*

Two weeks later I received an email acknowledging my “unsatisfactory experience” and informing me that too much time had passed to take further action. I was disappointed. I wanted more—more of a discussion about the specifics of the past and more importantly, the promise of good care today. I sent a second letter clearly stating my disappointment and stating my willingness to sign waivers of legal liability if that would allow them to more easily engage in dialogue with me. I received a short reply advising me to seek medical help elsewhere.

Most doctors are good. And as a trained lawyer I certainly understand the fear of malpractice and the tension between medical apology and legal liability. But there needs to be a place for apology in medicine and recognition of the whole human experience—not just a targeted “treatment” of the problem as perceived by doctors. We still have a long way to go but my hope as an intersex woman and advocate lies with today’s intersex youth who are speaking out and the new generation of medical professionals trained in an era less marked by homophobia, increased acceptance of difference, and a growing understanding of the need for holistic care.

## Commentary

# *Cris de Coeur* and the Moral Imperative to Listen to and Learn from Intersex People

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“... they study medicine to help people heal, but how can they do this if they do not listen to us?”

—Laura Inter

“You must let suffering speak, if you want to hear the truth”

—Cornel West

Intersex people first began to publicly tell their stories in the 1990s (Intersex Society of North America, 1996; Dreger, 1998). They recounted harmful and haunting encounters with the medical establishment: the violation of bodily integrity caused by genital and gonadal surgery they did not want, untold numbers of genital exams that felt like sexual violation, and betrayal by doctors who lied to them about their diagnosis and what was done to their bodies. In encountering these stories of harm, some physicians were brave enough to listen and talk to their patients openly. They had what we have come to think of as courageous conversations. These physicians asked, “What can I learn here? What can I do to help?” What they showed was a concern beyond themselves or their egos—they showed compassion.

All too often, however, doctors responded to these narratives and indeed their heart-wrenching lived experience with claims that those who had suffered were the disgruntled minority, the few who suffered bad outcomes. Yet to meet a cry of pain with dismissiveness is to perpetuate violence.

Twenty years on, the narratives of intersex people, scorching in their candor, carry these same themes. Despite decades of sharing deeply painful experiences, their stories attest to a continuing failure to bear witness to or to acknowledge some of the most painful experiences we inflict on one

another. All too often people’s most vulnerable admissions have been met with silence, dismissal, denial, and negation.

When read together these narratives form a heartfelt, profound, and gut-wrenching *cri de coeur*. We must listen.

A striking and recurrent theme is the centrality of words, spoken and unspoken. Throughout childhood and adulthood, doctors and parents failed to say the words that might have provided understanding and comfort. Daniela and many others, despairing of not hearing the explanations and answers they needed, stopped asking questions entirely. Too many of these narratives recount the careless and insensitive use of words like “freak” and “hypertrophied clitoris” that label bodies as problems. Many speak of needing truthful words but more hearing lies: that they would die of cancer, that they couldn’t have sex, that they were going to be “fixed.” Most poignantly, all too often, when they needed words that would sustain, heal, validate and comfort, these individuals heard nothing.

To offer your story is an act of reclaiming experience, filling in gaps, and seeking resolution. Our task—by which we mean the responsibility of physicians, parents, and the public at large—in encountering these narratives is not to diminish these acts by meeting them with silence or denial. By dismissing these individuals’ experiences—ones that in our reading had us quivering with empathy—we deny their humanity. Konrad notes that people might assume he would want to sue for the harm done to him, but instead he describes aching for an apology. This is a cry for recognition, for the



restoration of dignity. For physicians, these narratives provide important evidence that far too many of the medical practices described herein continue to cause grave harm.

Two compelling reasons to listen to and engage with these narratives are to offer the speakers validation of their experiences and to learn, through listening, how better to care for people. Learning what works and what doesn't in medicine comes not only from physicians' own definitions of good care, or from clinical data assessing outcomes, but also from how patients describe their experiences. Our moral obligation is to listen to these narratives, to witness the pain, the anger, the desire, and the struggle. The fact that these stories are still being told means we have failed at this task. We have a moral and professional obligation—indeed a human obligation—to redress that failure.

Listening involves two people, but the barriers to it are uniquely the listener's. To listen and bear witness can be a searing task. Our fears, our shame and defensiveness at having harmed someone, may prevent us from listening. As John Updike (Sept 24, 2001) noted, "Suddenly summoned to witness something great and horrendous, we keep fighting not to reduce it to our own smallness." To bear witness requires us to be open enough to be touched and to be hurt. We must strive for compassion, which requires empathy—the capacity for feeling what it is like to live inside somebody else's skin and sympathy for another person's suffering. Compassion is a cornerstone of humanity and understanding.

To be a silent or silencing listener is to commit a crime, to falter in our duty. Listening is a path of discovery to becoming a better clinician—to aim toward healing the whole person, not just physically but also emotionally. It requires deep reflection and an admission of our own vulnerability. It requires that we open our ears and hearts to stories that are sometimes extraordinarily difficult to take in and be willing to ask, "Have I done anything that could cause such pain? Can I stay with this person and listen with my whole attention, setting aside my pride or my ego, or concerns about my next appointment?"

Sex is not as much a biological reality so much as it is a social and political reality that has an

extraordinary impact on people's lives (Fausto-Sterling, 2000; Karkazis, 2008). To reach an understanding of how intersex individuals wish to engage with that reality, we can and must start with their narratives.

We do not often hear of positive clinical experiences in the lives of intersex people, but rather of painful and deeply traumatizing experiences. Some have said that this is because there is a happy majority who has chosen to remain quiet. Twenty years on, the notion of a happy, silent majority seems unlikely when the barriers to speaking up after having felt traumatized are so high. Going public feeling so deeply harmed requires revisiting pain and invites further stigmatization. It strikes us that the people who speak up may not be the bad outcomes, as they have so often been characterized, but the better outcomes because they have somehow healed enough to share their pain without threat of dissolution.

These accounts, like many before them, reveal symptoms of post-traumatic stress, including nightmares, dissociation, numbness, overwhelming shame, substance abuse, and suicidality. Yet, if thriving is defined by evidence of positive adaptation and growth even in the presence of major trauma and continuing struggles (Parry & Chesler, 2005), all of the narrators are thriving. Out of respect for their courage, we owe these narratives serious consideration. These narratives are more than anecdotes: they provide a first-person reflection on care and thus represent a type of long-term follow-up that is largely absent in clinical literature.

Although thriving after surviving child-abuse or childhood cancer (Thomas & Hall, 2008) is different from thriving after intersex trauma, such accounts have similar themes as well as trajectories that are intermittently negative and positive, reflecting challenges and responses. Instead of continuing in a direction of hopelessness, these trajectories arrive at destinations of self-actualization. The narratives contain common turning points, pivotal events that lead to healing (Thomas & Hall, 2008). Getting past our own pain—and even shame—in reading these narratives to uncover elements common to stories from trauma



thriver-survivors can illuminate a path to understanding and healing for intersex people.

Their journeys begin during childhood or adolescence, when intersex individuals become aware of their own atypical physicality and their parents' and doctors' reactions to that physicality. Most describe early awareness of their parents' struggles to understand and cope. None of their parents were offered counseling or support, and most acquiesced when doctors offered irreversible surgical interventions. The exceptions were those parents with existing knowledge of intersex, like Hida's father, a physician, and Sean's mother, who had older children with intersex. All the narratives offer painful accounts of unexplained examinations, surgery, and hormone treatments. In the guise of treatment for "cancerous ovaries," Kimberly, Karen, and Diana underwent unwanted procedures to remove testes. Unaware of other options, several narrators accepted so-called gender-confirming medical interventions during childhood and attempted to comply with social conditioning. Of those who later transitioned from female to male (Konrad and Jay), male to female (Lynnell), and to queer or intersex (Amanda, Pidgeon Pagonis, and Saifa), none were ever asked what kind of bodies they wanted.

Defined by a barrage of negatives—secrets not to be discussed; the supposed imminent threat of cancer; the inability to have children; labels such as "fake," "freakish," not "fuckable," "unfeminine," and "unlovable"—all the narrators experienced intense shame, which they addressed and overcame in various ways. For Amanda, for example, speaking openly with her grandmother was "liberating." Daniela and Emily found therapy helpful. Emily found what she described as "one perfect doctor," and Hida found a caring physician as well. The doctor who repaired Karen's vaginal tear helped to empower her by telling her that she had a right to get answers from her personal physician. Jay and Saifa found understanding in transgender clinics. For Lynnell, introspection during substance abuse rehabilitation was transformative. The explanation and apology Konrad received were life-affirming.

The most common turning point, in 10 of the 13 narratives, was finding peer support, described

as "absolutely life-changing" (Kimberly), "'vital' and 'empowering'" (Karen), and a source of "joy and happiness in finding and being surrounded by my own tribe" (Diana). Discovering "that others like me existed" (Konrad and Hida) enabled them to "love and accept" (Emily) and "find peace" with their bodies (Laura). Released from isolation, learning "a name for what was 'wrong,'" (Lynnell) and finding a "community . . . with similar experiences" (Pidgeon Pagonis) "felt like finally coming home" (Daniela). Strikingly, clinicians never offered or recommended this kind of support to these individuals.

Wisdom gained through experience and community transforms struggles into growth. Emily and Laura specifically describe newfound physical enjoyment of their bodies after overcoming shame. Psychospiritual growth, a theme also found in narratives of thriving childhood cancer survivors (Parry & Chesler, 2005; Thomas & Hall, 2008), occurs in all of these stories, as indicated by positive changes in self-perception, interpersonal relationships, and life philosophy. Stories construct new meanings: narratives reframe victimization as empowerment and numbness as compassion and vulnerability. Advocacy repurposes intense frustration into a force for positive change.

So much of the suffering these narrators experienced resulted from the lack of support parents had for the inevitable challenges intersex poses to family and social expectations of sex, gender, and sexuality. Families traumatized by the experience of having children with cancer, for example, often receive intensive support. Supportive interventions fostering psychospiritual growth in cancer survivors include: long-term follow up; full information on diagnosis and long-term consequences of treatment; screenings to detect and prevent problems; focus on family systems; and cognitive behavioral therapy (Parry & Chesler, 2005). A 2006 Consensus Statement on medical care of intersex children makes similar recommendations (Lee, Houk, Ahmed, Hughes, & International Consensus Conference on Intersex, 2006). Despite some evidence that access to behavioral health support and education has increased (Pasterski, Prentice,

& Hughes, 2010), parents continue to report lack of access to support and difficulty in understanding complex medical information (Bennecke et al., 2015), suggesting that many of the issues raised in these narratives remain barriers to well-being.

Currently, neither parents' emotional distress nor their understanding of proposed interventions are routinely assessed as part of informed consent (Tamar-Mattis, Baratz, Baratz Dalke, & Karkazis, 2013). The effects of parents' inability to assimilate the implications of surgery are underscored by results of a study of one of the simplest of genital operations, what is called distal hypospadias repair, which involves moving the urinary opening from elsewhere on the penis to the tip. One year after this procedure, half of 116 parents reported experiencing decisional regret, perhaps amplified by the realization that their son might not have chosen this surgery for himself (Lorenzo et al., 2014). This study is an important step forward in understanding the effects of decisions on families, and the authors suggest similar study of parents making decisions for intersex surgery.

Among parents of children with genital difference, understanding of complicated information on diagnosis and late effects of interventions is seldom evaluated. Assessment of the health of the family unit, taking into account parents' distress, should precede complex decisions such as newborn gender assignment. As narrators' stories attest, the way information is presented also affect parents' decisions. Whether information is delivered in a medicalized or non-medicalized manner can unconsciously influence the weight families assign to their values and preferences in decision-making (Streuli, Vayena, Cavicchia-Balmer, & Huber, 2013). Some decisions, such as gender assignment, are reversible and can be changed as children develop. Although many families outright reject consultation with mental health experts, untangling complex fears and beliefs is vital to healthy parenting. Without ongoing support, families may have difficulty viewing their assumptions in a biopsychosocial framework that allows them to distinguish their own best interest from their child's long-term best interest.

Even with improved policies and procedures for informed consent, what is left unsaid and unexamined in discussing surgical options has the power to induce profound decisional regret. For example, gynecologists attribute rising labiaplasty rates in adolescents to a cultural preoccupation with female genital homogeneity (Runacres, Hayes, Grover, & Temple-Smith, 2010). If clinicians fail to explore attitudes toward genital variation, for example, social intolerance of genital diversity may consciously or unconsciously influence parents and clinicians who make genital surgery decisions for intersex newborns. Unproven claims that surgery prevents urinary tract infection, for example, obscure the primary cosmetic purpose of such surgeries. The burden remains on practitioners to demonstrate the effectiveness of any intervention, especially given the risk of potential collateral damage, such as potential anesthetic neurotoxicity causing cognitive and behavioral issues in children under age three (Rappaport, Suresh, Hertz, Evers, & Orser, 2015).

The narratives also demonstrate the danger of avoiding engagement with difficult issues such as the uncertainty of a child's future gender identity and the human rights of the child as factors in decisions regarding heteronormalizing interventions. In considering irreversible interventions, such as gender-reinforcing genital surgery, clinicians must acknowledge both the stark reality of experiences like Konrad's (who did not grow up to identify as the gender he was assigned) and new scholarship showing dissatisfaction between assigned gender and gender identity and role as high as 1 in 4 for those with congenital adrenal hyperplasia (Schweizer, Brunner, Handford, & Richter-Appelt, 2013) to avoid providing false reassurance to families. Clinicians should understand that they may be held responsible later when children ask their parents how they could have *not* known any of this information. Decision aid support tools are recommended to standardize delivery of information about what is known about particular interventions. However, simply disclosing the absence of data on cancer rates, cosmetic outcome, and sexual sensation and function fails to capture the real-life

consequences of “disappointing” outcomes, such as the suffering unwanted genital modification caused to Amanda and Pidgeon Pagonis. Parents who fear that deferral is tantamount to “doing nothing” for a child may benefit from engagement with families who are raising happy and healthy children with atypical genitals. These narratives also underscore the importance of providing families with ethical and human rights perspectives, which value preserving children’s right to an “open future” in which they can make their own decisions regarding physical integrity, autonomous sexuality, and freedom of sexual expression (Kon, 2015).

Clinicians who must make daily decisions that may alter patients’ lives may distance themselves from negative outcomes and stories like those told here to avoid professional regret. Honest self-appraisal and accepting regret open the door to feeling guilty, devalued and ashamed, but experiencing these emotions can be a crucial first step in changing clinical practice (Courvoisier et al., 2013) and in making amends to patients. Among these narratives is the first account of an apology to a former patient. The clinicians who acknowledged how Konrad’s treatment damaged his body and spirit gave him hope for himself and for future generations of children. Never having understood his condition or the basis of his treatment, Konrad found that a simple explanation and apology restored his dignity and released him from years of gender confusion. For clinicians and patients alike, honesty, humility, grace and reconciliation may open a path to restoration and healing.

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## Commentary

# Beyond Good Intentions

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Anticipating harms does not prevent mistakes in medicine or any other part of human life. Since the 2000 publication of the Institute of Medicine's *To Err is Human*, there appears to be increasing willingness to acknowledge and address error, "defined as the failure of a planned action to be completed as intended or the use of a wrong plan to achieve an aim" (Institute of Medicine, 2000, p. 28). There's little question that error in the first sense—the administration of the wrong medicine, say, or mistaken removal of a healthy organ—is at issue in the treatment of children and young adults with atypical sex anatomies. The experiences recounted by the contributors to this symposium could however be understood to exemplify the second definition, as surely their treatment was not meant to cause the suffering so many vividly describe. Their treatment has been consistent with the prevailing standard of care for the medical management of atypical sex anatomies intended, all agree, to "normalize," and so avoid the stigma harmful to a child's psychosocial development. The consistency in the accounts of the contributors nevertheless make clear that however unintended, the physical and psychological harms they have experienced are significant.

Intrusive and embarrassing examinations as young children and teens without being informed of the rationale (what Konrad Blair's mother finally named "sexual abuse" to one of the treating physicians); experiences of a gender identity being "forced" upon them that felt contrary to their own inclinations; having one's diagnosis withheld; prevention of access to medical records; assured

that treatment decisions were made in their best interests even as they were made to feel that their treatment was not for their own benefit; told there was "no one else" like them: If these experiences seem obviously damaging, they are also surprising for their consistency, literally across generations of individuals with atypical sex anatomies. In this commentary, I propose that normalizing interventions for atypical sex anatomies, both historical and ongoing, be recognized as a kind of medical error, and that attention be focused not simply on prevention, but on repair. Compared with efforts to prevent error in medical research and practice, we have few resources for addressing error and its consequences. Fortright reflection on the nature of error, and of responsibility for admission of error, is required.

### The More Care Changes, the More it Stays the Same?

The 2006 publication of the Consensus Statement (Hughes, Houk, Ahmed, & Lee, 2006) produced as a result of meetings by the US and European pediatric endocrinology societies resulted in a number of significant changes to the standard of care. The language of "social emergency," with the clear implications of a threat, not to an individual's health, but to the functioning of the social body, was discarded along with the accompanying nomenclature based on variations on the term "hermaphroditism." It recommended against sex reassignment of 46,XY males with "micropenis" (defined as a phallus measuring less than one



inch), and affirmed the importance of the preservation of fertility in males—something that had been regarded as important only in those assigned female.<sup>1</sup> The statement included, furthermore, explicit acknowledgement of trauma experienced by children subjected to repeated genital exams, displays, and medical photography.<sup>2</sup> Notably, the statement urged caution in the reduction of clitoral size, which has been one of the more common interventions, but stops short of recommending against these surgeries going forward.

The statement's recommendation of caution in the performance of clitoral reductions was disappointing to critics of normalizing interventions, especially when considering the authors' acknowledgement of the perceived benefit of normalizing clitoridectomies *to the parents* of a child with atypical sex. There appeared no claim about the benefit to the *child*. While we might expect that significant change in practice would have followed the publication of the consensus statement, available evidence suggests that there has been no decrease in the number of normalizing surgeries for "clitoromegaly," and that it may be that such interventions have in fact increased since 2006 (Creighton, Michala, Mushtaq, & Yaron, 2013; Greenfield, 2014).

Accounts from physicians with whom I have spoken in the US are consistent with the unsettling notion that the changes promised by the publication of the consensus statement may have been realized in word but not in deed (Feder, 2014). Having accepted that ambiguous sex is not the emergency it was taken to be twenty years ago, physicians' representation of their role in counseling families of children with atypical sex anatomies has changed. Where in the past, surgery was undertaken by

physicians who understood themselves to be acting in response to a crisis and indisputably in the best interests of the child, these same surgeries are performed today because physicians report that this is what parents want (Rebelo, Szabo, & Pitcher, 2008; Zeiler & Wickström, 2009). Physicians' justification of surgery as fulfillment of parents' wishes is not new, though its salience in these decisions seems heightened. The new approach appears to comply with the bioethical proscription against paternalism and the promotion of parent autonomy; it also carries the considerable benefit of protecting physicians against liability to which they might otherwise be vulnerable.

Even if incomplete, the existing evidence that normalizing interventions continue means that the narratives that appear in this symposium cannot yet be regarded as the result of the sort of "mistakes" that are an inevitable part of the ongoing experimentation and continually evolving understanding the practice of medicine involves. The narratives suggest that the causes of the suffering the writers describe will not be ameliorated in the future by the sorts of technical improvements heralded in medical practice. (Though in cases of problems of function, refinements in surgery, enhanced tools for the detection of cancer, or advances in the creation and prescription of hormones would indubitably be helpful for individuals with atypical sex anatomies, just as these would be helpful to those who might need any of these interventions for other reasons.) What is needed is a more thorough ethical investigation of these experiences, which might begin with acknowledgment of the cause of the harms the narrators have experienced as a kind of *error*.

### Rethinking "Error"

In imagining the responses of physicians to the narratives, one can imagine they would disagree that their treatment was "unsuccessful;" the problems that the authors report are not of the sort that physicians would typically regard as mistakes. To see the narratives as evidence of mistakes that physicians have made in caring for individuals with

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1 This more recent recommendation by Peter Lee, one of the authors of the consensus statement, to assign very virilized females with CAH as male is consistent with the Statement's aim to align practice with evidence (Houk & Lee, 2010).

2 It is important to note that this acknowledgement followed groundbreaking work by activists and academics several years earlier (e.g. Chase & Coventry, 1997; Kessler, 1998).

atypical sex anatomies requires that we reconsider the way that “the problem” of atypical sex anatomies has been figured. Specialists seem to still see the problem of intersex as a problem of abnormal individual bodies. What the narratives suggest is that the suffering the authors experienced was not owing to medical challenges entailed by their conditions so much as it was a result of the efforts to protect individuals from the projected ignorance and intolerance of their families and communities. Without open acknowledgement of treatment in these terms, there is little space for physicians to see their practices as mistaken in the sense of a “wrong plan to achieve an aim.”

Perhaps the failure to acknowledge unnecessary intervention as an error is owing to the ongoing faith in the benefits of normality for children, and particularly for the prospects of familial and social bonding that normality is taken to facilitate (Eugster, 2004). In this sense, physicians supporting normalizing interventions would not believe their practices mistaken even if they see that some aspects of past care—deceiving patients and sometimes their families and exposing them to repeated exams for medical education and research—to merit reform.

And yet, recall that it was the sense of error in the sense of “a wrong plan to achieve an aim” and not an error in the sense of “unintended action,” or “accident,” that gave rise to the passage of the National Research Act of 1974, and with it, the congressional commission that produced the *Belmont Report*. Prompted by revelation of the Public Health Service Study of untreated syphilis in African American men from 1932 to 1972, the commission outlined the principles—respect for persons (autonomy), beneficence (non-maleficence), and justice that have been the cornerstone of bioethics and of the Institutional Review Boards (IRB) mandated by the National Research Act (Jonsen 1998). While public outcry made plain the importance of preventing future “Tuskegees,” it would take the U.S. government 25 years, after the public revelation of the study, to acknowledge the wrong committed against those enrolled, as well as their family members who lived with and cared for the

men as the disease took its course, many of whom also contracted syphilis.

Discussions of apology in the context of medical practice are quite recent, and the history of bioethics suggests that ethical questions have been concerned above all with the *intentions* of physicians and researchers. Despite its focus on error, the Institute of Medicine’s *Do No Harm* is motivated, above all, on *preventing* error. Despite extended discussion of the creation of policy regarding the commission of error in the report, there is not even a single mention of apology. The principles of bioethics seem well suited to anticipating and so perhaps preventing, potential harm. But what, we must ask, is the responsibility of care providers when harm occurs?

### Compounding Harm

At just the moment that Georgiann Davis and I were reviewing the narratives, the U.S. news program, *Nightline* featured the story of the treatment of individuals born with atypical sex anatomies (Sherwood, 2015). It opened with the story of M.C., whose parents’ legal cases against the attending physicians and the state of South Carolina are the first to be litigated publicly in the U.S. It is too early to tell whether this litigation will provoke more significant change in care, but what is clear is that awareness of the violations that have been committed is spreading, if slowly. There is no doubt that litigation can promote significant change in practice. But so much of the work in professional ethics is focused on identifying rules or guidelines and preventing wrongdoing that it is not always an effective instrument for the work of repair. The segment that followed the presentation of the M.C. case may be more fruitful for reflection on the possibilities—and barriers—to repair.

The *Nightline* reporter turned to the encounter between activist Sean Saifa Wall, whose story appears in this symposium, and Terry Hensle, the Columbia University urologist who performed feminizing surgery when Wall was 13. (The reporter misleadingly recounts that this surgery “turned [Wall] biologically into a girl,” as if the removal of

testes constituted a sufficient condition for femaleness). Wall, who had not felt like a girl as a child, transitioned in his mid-twenties.

When viewers are introduced to Hensle, he explains in response to the reporter's question that parents are grateful for his work, and grants that as much as he might have enjoyed "playing God," as the reporter suggested, "it was not," he says, "the right thing to do." He enthusiastically affirms the value of hearing from former patients who had undergone normalizing interventions in the past, and readily agrees to a meeting with Wall, his former patient.

Hensle balks, however, when Wall arrives in his office, and the cameras are running. He explains that he cannot allow the meeting to be recorded. It appears from the broadcast that Hensle relents in the face of the question Wall begins to ask: "If you had it to do over again, if you saw me as a baby with ambiguous genitalia—" Hensle breaks in, and says that if presented with a case like Wall's now, he would not himself make the decision to reassign Wall, but would bring the case to a "gender committee."

Hensle wants Wall to understand that the decisions that were made on his behalf were not made "out of malice." Perhaps for this reason, in response to the reporter's question concerning whether Hensle experiences any remorse for the harm he has caused Wall and patients like him, Hensle immediately responds that he has "no regrets;" and yet, Hensle claims with a particular vehemence that he "absolutely" would do things differently now.

That Hensle's two claims—he experiences no remorse, but would not repeat actions he now understands to have caused harm—are not for him contradictory may indicate that he is focused solely on the question of his own culpability rather than the harm his actions have caused to Wall and to other patients. But in refusing to recognize his responsibility to repair the harm he has caused, Hensle commits another harm. As philosopher Margaret Walker has argued in *Moral Repair*, to turn away from the task of repair, "is not only *not* to do something, it is *to do wrong once again*" (Walker, 2006, p. 205)—original emphasis.

## Reflection and Repair

It seems far easier to recognize failures of moral courage in hindsight. In her riveting history, *Examining Tuskegee*, Susan Reverby recounts the efforts by Peter Buxtun, a young investigator who worked for the Public Health Service (PHS) in the 1960s. His charge was to find individuals affected with venereal disease in some of the poorest neighborhoods of San Francisco and ensure their treatment so as to prevent further contagion. He learned about the PHS study of syphilis in Tuskegee, and was, Reverby writes, horrified at the contrast between his work at the PHS to curtail infection, and the study conducted in Georgia, which secretly promoted it. "Why," he asked his colleagues and supervisors in a report, "should researchers patiently wait and observe the demise of untreated American syphilitics when, in effect, they may be duplicating the 'research' of some forgotten doctor at Dachau?" (Reverby 2009, p. 78). In response, Buxton was informed of the "moral obligation" to allow the study to continue (p. 79). Buxton persisted in his efforts to intervene with the PHS, even after he was no longer employed there, appealing to the bad press that would follow if the study were exposed. As Reverby writes, "if there was more public knowledge, the Study's purpose and procedures would be read as racist and deceptive, and possibly illegal and even murderous" (p. 79).

I suspect that Peter Hensle, the physicians to whom Kimberly Zieselman appealed, and even the doctors who did in fact apologize to Konrad Blair, would balk at any comparison of their deeds to those of the Public Health Service: The PHS was making use of a "group," who occupied, socially and legally, a subhuman status in U.S. culture during most of the period of the study. Their "treatment" was not aimed at promoting the individual health of the subjects, certainly, and the men were actively deceived about the study and its consequences for themselves and their families.

If, by the 1990s, "'Tuskegee' replaced 'Nuremberg' (as code in bioethics for Nazi medical horrors) in the American context" (Reverby, 2009, p. 192), health care professionals who might now see in the lessons of Tuskegee, questions about their own

practices might be discouraged from the difficult reflection required, for the reason that it might raise questions, not only about morally questionable action, but also about what sort of people they were. Reverby recounts the response of John R. Heller, one of the PHS physicians involved in the study. When author James H. Jones interviewed Heller in preparing his *Bad Blood*, Jones asked if any of the physicians involved in the study had thought about the Nuremberg Code. Reverby reports, "Heller took umbrage at the question and said to Jones, 'But they were Nazis.'" (p. 66)—emphasis added.

The defense of the treatment of intersex by specialists consistently emphasizes the good intentions of doctors and the families they counsel. I want to suggest that the defensive claim, "But they were Nazis," can be instructive in thinking about what seems to be the resistance to more significant change in the standard of care for individuals with atypical sex. Despite the genuine, even stark dissimilarities between the actors conducting the Tuskegee study and the practices of specialists in DSD, especially including the fact that atypical sex anatomies are often a consequence of medical conditions, e.g. salt-losing congenital adrenal hyperplasia, that positively require active monitoring and treatment, the narratives of the adults presented here suggest that their treatment as children evinces something of the disregard for what the Belmont Report describes as "vulnerable populations."

When proposing research involving a marginalized racial group, for example, researchers must be particularly sensitive to potential ethical violations. There seems obviously to be a kind of prejudice functioning in the treatment of individuals with atypical sex anatomies that should raise ethical flags. What makes this case unique in thinking about the issue of bias in medicine is precisely that the anatomic difference of those with intersex traits is *itself the object of normalizing treatment*; the authors of the narratives here report the source of their injuries as the very efforts to conceal these differences. Perhaps surprisingly, the racist inflections of Tuskegee may be less illustrative for physicians in appreciating the problems entailed by normalizing

interventions than the approach that Alice Dreger (1998)—following George Annas (1987)—describes as a "monster ethics."

A "'monster' approach may be summarized in this way: you, babies with 'ambiguous genitalia' are monsters, and we're going to make you human; after we make you human, the rules of human ethics will apply" (Dreger, 1998). Thinking about the history, even the recent history, of treatment of individuals with atypical sex anatomies in this way makes sense of the routine (and acknowledged) violation of the principles of the Belmont Report. What is left is to consider the work of moral repair. In beginning this work, I suggest that we must not look simply to preventing mistakes in the future, to refine our conception of the principle of autonomy that occupies such dominance in bioethical thinking. Our status as moral creatures is a function of our capacity for autonomy combined with our fallibility. We must remember that our vulnerability as embodied humans as much as our capacity for autonomous decisions defines us as moral creatures. Honoring that vulnerability, not only in one's patients, but in recognizing one's own violation of another's vulnerability, is the condition of our dignity.

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## Commentary

### A Pediatrician's View

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A daunting task, this, writing a commentary based on very personal stories by individuals whose experiences include various forms of abuse by nominal colleagues in the medical profession. I cannot help but feel moved by the authors' unnecessary suffering and their courage in writing about this now. Their accounts, I hope, highlight how much has changed. I know that as a resident, in mid-to-late 1970s, and subsequently for the early part of my career, the approach to children with intersex conditions was something of a black hole. We knew that some patients had "ambiguous genitalia," though their diagnostic evaluations and treatment did not get much attention. Knowing some more about this now, I find that curious, or more accurate, shameful. Perhaps that's the point. The atmosphere of shame shrouded the whole phenomenon, from patient identification to diagnosis, to providing information to families, to "treatment" decisions often aimed at surgically hiding the truth.

My more substantive involvement with the intersex population did not begin until a colleague with an office down the hall came to talk to me, qua "ethicist" about practices within the "peds endo" and surgical communities. (He, Jorge Daaboul, had studied ethics as an undergraduate and knew the disconnect between contemporary medical ethics and what his colleagues actually did.) Those behaviors perpetuated outdated medical paternalism and, even more mysteriously, outright withholding of basic clinical information from families of children with ambiguous genitalia, most frequently "viralized" girls with congenital adrenal

hyperplasia. Jorge had seen the evolving pushback from patients at professional meetings and wanted to tell the medical community they needed to join the modern world and at least conform to the doctrine of informed consent. Our conversations lead to, among other things, a paper (Daaboul & Frader, 2001) we like to think influenced some clinicians, though getting it published, even then, proved an interesting political odyssey. Again, I like to think things have changed . . . today I find very little in the medical literature that carefully prepares clinicians for how to respond to children with intersex in the delivery room, in the nursery, or in primary care or subspecialty clinics.

Reflection on the stories and my own experiences brings me to my first big picture response to the narratives. I hope clinicians, including pediatric endocrinologists, general pediatric surgeons, pediatric urologists, and anyone else interacting with families and children appearing in their offices now really do a better job than they did when this volume's authors arrived for "care." For the record, the authors' ages span a few generations, yet the experience of even those in their 20's does not provide much reason to celebrate physician sensitivity, or even good ethics. By the 1990s clinicians had no legitimate excuses to ignore the general principles concerning informed consent, i.e., the importance of providing *all* the information a reasonable patient or parent needs to know and understand about the medical facts of the situation, including the options for treatment, or more importantly, non-treatment. Sadly we have no systematic data about current practices. I doubt many clinicians these days

withhold diagnostic information from parents—as used to happen—or counsel families to maintain diagnostic silence and, however unwittingly, shame in the children. However, we just do not know what clinicians say, do not say, or recommend. We cannot confidently claim how much things have changed. Today’s fear of malpractice actions (re: failure to inform) may have changed behavior. Perhaps the possibility of litigation, decades after birth, over “wrongful” surgery (battery) deters some clinicians.

We lack reliable epidemiologic data about basic matters, such as the frequency of live births of children with atypical genitals. Perhaps we know a little about the incidence of complete androgen insensitivity syndrome, though that diagnosis generally does not get made in infancy, much less at birth. In any case, we do not have meaningful population statistics about these conditions; as a result, we could not make heads or tails of comparisons of the frequency of childhood cosmetic genital surgeries that happened 20 or 25 years ago versus those in 2015. Many of us would like to say there has been a marked reduction in such procedures. In reality, we do not know. Of course, in the U.S. nobody regularly collects such data about any kind of surgery, whether for congenital heart disease, hydrocephalus, or a more mundane condition, such as pyloric stenosis (excessive constriction of the muscle at the outlet of the stomach, leading to vomiting, poor weight gain, and other problems in young infants). I guess we should not feel surprised that we know so little about genital operations in our country. Data on these matters might exist in Scandinavian countries or elsewhere with more rational systems of health care. I have not seen publications on this matter.

Contemporary practice in many, perhaps most, tertiary care centers for children involves trying to make a diagnosis and understand the complicated biology of infants with atypical genitals. The major issues for academic clinicians these days include 1) helping families understand both immediate and long term uncertainty about their child (like those pesky questions from everyone about whether a mother gave birth to a boy or girl—it is still mostly a binary world) and 2) learning as much as possible to

ensure no associated medical problems need urgent or rapid attention. Enlightened clinicians counsel families not to embark on pathways that involve irreversible actions, especially anatomy-altering procedures. Far from trying to “fix the problem,” today many experts urge acceptance of ambiguity and delaying interventions until the child can participate meaningfully in decisions about her or his body and it seems likely that many more parents feel comfortable with these recommendations now than generations before.

Not that we really know how to do that. By that I mean developing children do not always achieve cognitive and intellectual milestones at the same age. Even more importantly, the power to use one’s rational brain develops years before individuals achieve emotional maturity. Stable adult decision making probably sets in around the middle of the third decade for most people, long after the law entitles patients to consent for medical care for themselves. We know individuals achieve mature decision making variably, though we lack good tools assessing just when an intersex individual, preferably with family support, gains adequate capacity to decide about the use of hormone blocking agents, cross-chromosomal sex hormone administration, and or surgery. Of course, these difficulties are not unique in the intersex world. One could raise the same issues regarding many interventions, from other forms of cosmetic surgery, to use of mood or mentation-altering medications, and so forth, though the socio-emotional stakes in the intersex world seem somewhat different.

My second major reaction to the personal stories has to do with the prevalence in the accompanying stories of substance abuse and mood disorders. I take this to reflect, at least in part, the medical, family and social abuse experienced by the writers, especially in their childhood years. What’s more, our mental health resources do not seem to have done much better responding to the authors’ anguish than do doctors focused on anatomy or hormones. Many children, and their family members, with serious medical conditions have high levels of stress and substantially greater need for professional mental health services. However,

the burdens of cystic fibrosis, complex congenital heart disease, cancer, and so on seem rather different. Those disorders often involve life-shortening processes, prolonged hospitalizations, some in intensive care units. Whether one characterizes intersex conditions as medical disorders (versus variations in biological development), the sex and gender conditions themselves do not involve threats to life. That affected individuals develop mental health conditions, especially substance abuse and depression, which can become life-threatening seems especially poignant and sad to me.

Again, I cannot say with certainty how much better, if any, we treat intersex children (and their families) today than two to three decades ago. I certainly hope things have improved substantially and that our improvements have reduced the emotional toll imposed on them. At the very least, it seems clear we need substantially more and better prepared mental health professionals who can provide the support and treatment this population, including their families, deserves. I like to think that better care of parents (more information, more counseling, more interaction with parents who have been through all this) of young children with these conditions would at least reduce much of the mental anguish of affected children.

Now I will turn to my most fraught reactions to the accompanying stories. I will admit upfront that I can only respond based on who I am, an allopathic medical practitioner and medical ethicist. My medical identity kicked in as I looked over the narratives. Several authors make strong claims about the importance of not having their gonads removed. I find two troubling assertions: 1) medical claims about risk of cancer are, at best, over-blown if not downright confabulated and 2) hormone production, especially around puberty, by intact gonads are more “natural” and as a result, the individuals “feel better” than when they must rely on pharmacological replacement.

Well, medical estimates of the magnitude of the risk vary considerably, depending on the exact biological diagnosis (the literature seems to agree that those with mixed gonadal dysgenesis and streaked gonads have the highest risk of developing

gonadal cancer). The risk appears to be higher in partial androgen insensitivity (PAIS) than in complete AIS. Moreover, concerned clinicians feel that the current methods of monitoring malignant transformation (physical examination, ultrasound imaging, magnetic resonance or X-ray computed tomography) do not allow early (enough) identification of cancer development to minimize harm to patients (Cools, Looijenga, Wolffenbuttel, & Drop, 2009; McCann-Crosby et al., 2014; Abaci, Catli, & Berberoglu, 2015).

Of course, cancer risks of all sorts involve complex weighing of various matters. Some women, for example, those that have never been pregnant, have a higher risk of breast cancer than others. That fact, alone, does not suggest that never-pregnant women at, say, age 50, should all have bilateral mastectomies. Regarding intersex conditions, I believe that most clinicians seeing these patients have the interests of the patients in mind, even at heart. With all the other matters many gender variant individuals must cope with, clinicians want to prevent any cancer that may develop from spreading beyond its origin and substantially worsening the outcomes. I do not believe most, if any, clinicians want, even unconsciously, to unnecessarily medicalize the situation, make patients dependent on them for hormone replacement, or otherwise exercise unneeded and unwanted medical authority. I do understand history well enough to see why patients have developed wary attitudes. Again, I want to believe things have changed substantially.

Along the same lines, I struggle with the story lines about naturally-produced hormones. This makes the least sense to me for those with complete AIS. By definition, individuals with this condition cannot respond to testosterone. They lack molecular receptors on their cells that allow androgens to have an effect. Assuming I have that right, I do not really understand why one would want to leave testes in place, especially testes in the abdominal cavity or pelvis where tumor transformation is hardest to monitor/detect. The situation is somewhat different for PAIS, but in those cases the issue involves balancing the benefit of keeping androgen-producing tissue in place against some real, if not well-defined

hazard of missing the development of cancer, especially metastatic cancer.

I appreciate that hormone replacement is by no means a perfected art—delivering the hormone insulin for diabetes whether by injection several times a day, by implanted pump, or nasal spray remains a poor substitute for having a functional pancreas. By imperfect analogy, taking sex hormones cannot match normally-functioning bio-feedback loops and other mechanisms that regulate gonadal hormone production. The problem is that the hormone-producing gonads may deteriorate into tumors that can cause harm.

My point here is not to debunk, deny, or in any way undermine the concerns and experiences of those who have told their stories in this volume or others living with similar experiences every day. Instead, as someone committed to shared clinician–patient (and, when appropriate, clinician–family) decision making, I want to express the view that many clinicians have 1) real and personal concerns about protecting their patients—not just “cold” clinical interests and 2) difficulty understanding

aspects of the patient experience. Accounts such as those in this volume can do a lot to help these practitioners see the perspectives of those they treat.

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## Commentary

# Stonewalling Emotion

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Aspects of the narratives resonate with the stories told to me by clients in the late 1990s (Anonymous, 1994; Liao, 2003; Alderson, Balen & Madill, 2004; Simmonds, 2004) when I joined two medical doctors to form a multi-disciplinary service for intersex women in London, UK. Since then, vocabularies alluding to multi-disciplinary care, collaborative decision-making and evidence-based practice have proliferated in professional literatures. For example see Lee, Houk, Ahmed & Hughes, 2006. In the absence of hard facts on team function, care user experience and the prevalence of medically non-essential interventions on children, which is, after all, a central debate in the field, the rhetoric can sound hollow at times. Nevertheless, it has undoubtedly become rarer for me to meet an adult client struggling with painful new medical discoveries later in life. I immersed myself in the thirteen stories with some surprise.

Most of the stories offer emotional experiences and make references to psychological therapy as a safe space to talk and be listened to. This commentary is an exploration of emotion by a therapist. In selecting a single focus and anchoring it on a few facets, I leave out many important details. The heading of each of the four sections reflects my hypothesis about the emotion care needs of the parent, the child, the adult, and the kind of doctoring required. Intentional awareness is foundational for good emotion care; my aim is thus to encourage intentionality towards awareness of emotion.

Therapy typically begins with emotional suffering. As a therapist, I appreciate emotions as

mind-body experiences. At the simplest level, we experience physiological changes such as trembling and label the sensations in context, for example as 'fear' in the face of a raised hand, and 'excitement' in the face of a gift. To add the next layer of complexity, emotions are highly context dependent. The raised hand by a humorous friend may evoke 'excitement'; the gift from an unfriendly boss may evoke 'fear'. 'Fear' may feel more like suffering than 'excitement'. Lazarus (2006) discusses *relational meaning* in appraisal and coping in emotional experiences. We draw meaning from the social world and in ways that can transform experience, sometimes into suffering. Ideas of relational meaning are further developed in therapeutic work especially by systemic psychotherapists who understand emotion stories as identity stories. Fredman (2004) for example offers examples of how emotion talk can be mobilized in the service of co-creating preferred identities in the social world. There are more layers of course, and there is no final truth about emotion—it is neither needed nor wanted.

Embedded in the thirteen stories is how emotion is managed in intersex medicine, i.e. how (much) is emotion (not) discussed and what are the effects of voicing and muting emotion. I interpret the named emotions in the stories as punctuations along a much lengthier psychosocial trajectory that, for some of the storytellers, probably began at birth (if not before). I borrow the word stonewall from Karen A. Walsh to discuss instances where health care and family transactions can give rise to emotional suffering that remains unheard.



## Emotional Holding of Parents

In this section I focus mostly on parents of children whose atypical sex anatomies were discovered early on in life. I draw attention to certain therapeutic formulations not because they are unproblematic but because they compel us to pay closer attention to the possible emotional world of parents in the early days.

According to Winnicott (1973) and other therapists, the foundations for mental health are laid down by the ordinary loving care of the ordinary mother for her baby. Parents do not have to be perfect for their children to flourish. Central to the care is the mother's attentive *holding* of the infant to foster a sense of safety in their own body (Winnicott, 1973). What happens to holding in both the physical and psychological sense when the child presents atypical sex characteristics? What care should be provided to the parents perhaps especially the mother who may have just had the overwhelming experience of giving birth and who now realizes that the baby is not the one she has been expecting. Many psychoanalysts believe that all mothers face the emotional task of relinquishing the fantasy baby and bonding with the real baby. A mother of an affected child reflects on the gender assignment process says, "it feels that the baby you had might have to pass away, and that instead there might be this new baby, with a different sex, whom you'd learn to love too, but still, the child you had would be gone forever" (Magritte, 2012, p. 573).

Clinicians have remarked on the shock, grief, anger, shame and guilt observed in some parents (Slijper, Frets, Boehmer, Drop, & Niermeijer, 2000). Pediatric psychological research in a range of medical specialties has identified high levels of parental stress as an important determinant in unhelpful coping strategies such as distancing and avoidance (Mednick, Gargollo, Oliva, Grant, & Borer, 2009). How much these specific and generic observations have been translated to emotion care for parents is unclear. Within the narratives, emotion holding (in the Winnicottian sense) does not seem possible. My experience suggests that a flurry of medical activity may have ensued—some essential and some not. Unbeknownst to many clinicians, the parents may

be busy too. They are likely to be actively making meaning of anything from the eye gaze of the nurse to the definitive diagnosis told to them by the doctor. In their struggles to make sense of what is happening, everything around them is data. As they interpret the data, it is almost inevitable that they would imagine the implications for their child and themselves in the wider world. Swept along by medical busyness on medical terrain, space to name and digest emotions may be rather limited. The processing of any information, misinformation and non-information can be erratic. In a letter to his care providers, Konrad Blair writes, "Unlike most parents who greet a new addition to their family with joy and support from their loved ones and doctors, my mother and father had been immediately forced into silence and shame . . .".

Shame is the most frequently named emotion in the stories. Shame, according to some psychoanalysts, develops in the first six months of life. Ayers (2003) distinguishes between fleeting moments of embarrassment that we are all familiar with, from the fundamental notion of oneself as "defective and unlovable" that underpins an ongoing pattern of "punitive self-exile". She situates the origin of this type of deep shame in mother-infant interactions, whereby the infant experiences him/herself through the look in the mother's eyes. A mother of an intersex child told my colleague at work that her most salient memory from the neonatal period was of people photographing her baby naked. Catapulted into shame and guilt, the "unreflected look" of the mother is said to be taken in by the infant and reverberates through later life. According to Ayers (2003, p. 1), to the person who suffers shame, "the world is full of eyes".

Shame is the reason why something must be done (Roen, 2008), and normalizing surgery is shame management of sorts. In psychoanalytic terms, the idea that normalizing surgery can ameliorate shame amounts to bringing back the fantasy baby and transforming the look of sadness and guilt in the parents' eyes so that the infant sees a positive reflection of him/herself. What makes this a doomed medical fantasy is that the very offer of surgery comes with the message that the child,

unaltered, is unlovable. As social science research suggests, “parents are not given the chance to imagine their children’s lives in any way except in need of immediate correction” (Feder, 2002, p. 313). The child and parents are not shameful; they are shamed by the notion that something must be done.

Emotions may still be overwhelming when some parents agree to normalizing genital surgery. Based on personal experience, Magritte (2012) advises that parents may not be in a position to “consider properly all the options” for some months, that they need the time to recover from childbirth and adjust to the diagnosis. Parents need time to re-examine their fears about situations that could be laudably managed, like dealing with babysitters or swimming classes. They need time to re-appraise the grim predictions about the child’s future life, like being teased at school or not finding a romantic partner in adulthood. Time is also needed to gather information about the experiences of people who have faced similar situations. Most of all, it takes time for parents to let go of distressing ruminations of self-blame and repercussions.

Emotional vulnerability must have been extreme for Daniela Truffer’s parents who were separated from their newborn baby for three months. For much of that time, the mother travelled as often as she could to the hospital, only to look at her baby through a glass window. We can only guess at this mother’s mortal anguish, and the emotions in her eyes when she was finally united with her daughter. We do not know what kind of emotion care the parents received, but commonsense might have prevailed to help the parents deal with one thing at a time. Their baby’s severe heart defect and presumably potential end of life decisions would have been emotionally overwhelming enough without having to decide on medically non-essential interventions.

Emotional holding founded on an empathic appreciation of the upside down world of parents of atypically sexed children is especially hard to come by if clinicians interpret their task as helping families to conform to (hetero)normative social values. Lack of emotion care may have (further) diminished Jay Kyle Petersen’s biological parents’ capacity to cope with the challenges constructively.

They subsequently died without ever discussing the condition with him. Despite loving grandparents, he remembers his childhood and adolescence as lonely, frustrated, painful and humiliating.

Therapists do not all work on the premise that experiences in the first months or years of life irretrievably hardwire the adult personality and mental health. If that were the case, there would hardly be any point in therapy. However, all therapists recognize the potentially significant impact of major interferences on attachment on subsequent emotional and cognitive development. Early surgery could turn a healthy child into a career patient. When the intervention is not medically necessary, it makes no sense to burden the family in such a way. Daniela Truffer’s is another great story of survival, but she tells us that she will always be the “terrified little child” on the edge of a hospital bed putting on a brave smile as her mother’s “desperate” face appears to bid her goodbye again.

It seems obvious from several of the narratives that neonatal and pediatric environments need to focus much more on emotion containment for parents. This does not necessarily translate as more emotion talk. Beliefs about bottled feelings in need of release are popular but not always helpful. Emotion containment may amount to no more than a collective concern translated into routine inquiries as to how parents may feel or what they may need. Space for emotion containment may be more amenable, if non-essential medical investigations and interventions could wait.

### Listening to the Remembering Body

In his exposition of illness subjectivities, Frank (1995, p. 27), himself a “wounded storyteller” states, “The body is not mute, but it is inarticulate . . . People certainly talk about their bodies in illness stories; what is harder to hear in the story is the body creating the person.”

Normalizing surgery is in a way a simple narrative of constructing normal bodies to construct normal persons. However, the body’s experience of surgery and its consequences also become integral to the creation of the person. This may be

why I sometimes hear surgeons say that it is better to do surgery “young” because “children don’t remember.” Memory in that sense is understood as exclusively conscious, cognitive and unemotional. Pidgeon Pagonis realizes as an adult that what they had understood as a recurrent dream—of “waking up on a gurney of blood-soaked gauze between my legs”—was “not a nightmare but a memory of early childhood surgery.” Laura Inter has vivid memories of being repeatedly examined until she was twelve years old. Bodies may be inarticulate, but they do remember, and the sense making of what is remembered goes on to inform identity development. The verbally articulate adult pieces together fragmented rememberings. “Years later,” Laura Inter says, “. . . as I began my adult, sexual life, I realized how much those displays had affected me emotionally.”

Once a child has been operated on, surgeons are compelled to inspect the results of their work over time and to do additional work as deemed necessary. They may invite their peers or trainees to examine and discuss the results or take photographs for other peer learning events. The psychological risks of such a developmental trajectory have long been recognized, but no concerted effort to act on the insight is evident. Pediatricians for example have warned against “the repeated psychological insult caused by frequent genital examinations and operations” (Jaaslekainen, Tiitinen & Voutilainen, 2001, p. 73). The potential harm of medical photography has also been mooted (Creighton, Alderson, Brown, & Minto, 2002). Lynnell Stephani Long tells us about the time of her life when she was hospitalized annually for testing. During these times, an entourage of clinicians would stand by her bed and peek under her gown. She subsequently experienced flashbacks “of standing in front of the graph board, naked, while strangers walked in and out of the room.” The description is suggestive of traumatic stress.

It is impossible to know how many of the families might have avoided the surgical trajectories had they received better emotion care and information. The move in recent years from a surgical to a multidisciplinary focus with improved access to

psychological care has not resulted in a clear reduction in childhood genital surgery prevalence in the UK (Michala, Liao, Wood, Conway & Creighton, 2014). Weighed down by normative pressures, many parents may consent to have their children operated on despite having concerns. However, the relationship between the surgical trajectories and the psychological harm in the narratives should compel clinical teams to consider becoming much more proactive in debunking surgical normalizing as a solution for fear and shame.

Nowadays, professional experts recommend that parents talk appropriately to children and young people about their birth conditions (Lee et al, 2006). Such a task could feel too emotionally taxing even for the most committed parents. They are likely to be terrified of getting it wrong and hurting their child. Parents may also remain silently overwhelmed by guilt. Amanda offers a glimpse of the kind of distressing ruminations that could emotionally incapacitate some parents. Her mother believed that she had caused Amanda’s androgen insensitivity syndrome (AIS) by taking fertility drugs. Parental shame and guilt may render discussion highly aversive. Clinical services appear to privilege non-essential medical doings over and above important education and support work that, with notable exceptions, is often left to chance or relies on the exceptional efforts of unpaid volunteers. Parents who are poorly educated themselves and poorly supported to educate the child, family and community may continue to avoid the emotive topics. “Shame and denial go hand-in-hand,” says Pidgeon Pagonis, so that important conversations were often left to another day.

Emotion stonewalling may partly explain why some families appear to comply with what seems to be an extraordinary amount of intrusion. Parents and children may be too afraid to question health professionals, even if they are informed enough to know what questions to ask. The eight-year old Konrad Blair believed that he would die if he did not continue doing what his doctors wanted him to. He cried every time he had “one of these exams” well into his late teens: “I would turn my head, close my eyes, and try to escape.” Sean Saifa Wall cannot

but notice the intense interest in his sex organs. He speaks of his fear in the doctor's office as more probing awaited him. Compliance with medical surveillance may have been driven by hope too, hope that the growing child was either on course or would receive help for puberty, sex, fertility, or cancer prevention.

### Transforming Shame

An overriding key issue for intersex people is "the continued location of life-changing decisions about intersex embodiment and subjectivity within the medical sphere" (Grabham, 2007, p. 44). Some of the stories suggest that for years, even the mundane and humdrum was experienced in the medicalization hothouse.

What do people do when they feel that they have been wronged? There was nothing to be done. Therapists have drawn attention to the incapacity in some adults to express their overwhelming distress (Williams, 2002). Kimberly Zieselman had periods of high emotions but also periods of shutting down emotionally. She "blacked out" when situations got overly emotional, retreating into numbness whereby she felt neither sadness nor joy. An example she offers is that she has no recollection of her husband proposing to her. Karen A. Walsh and Daniela Truffer offer many instances when they dissociated. Pidgeon Pagonis takes off to "some other place" where they can feel nothing. The mental health difficulties identifiable in the stories include anxiety, depression, traumatic stress, social withdrawal, substance misuse, OCD, self-harm, ongoing suicidal ideations and actual suicide attempts.

Several storytellers mention estrangement from family and escape into drugs and alcohol. Winnicott considers antisocial behaviour as a cry for help, fuelled by a sense of loss of integrity, when the holding environment is inadequate or ruptured (Appignanesi, 2008). In my work with clients whose holding environment has been consistently poor, I understand their negative self-evaluation as internalized badness. Yalom (2002, p. 47) likewise believes that a person's self-image is "formulated to a large degree upon the reflected appraisals we

perceive in the eyes of the important figures in our life." Poor self-evaluation may include feeling undeserving of help, which may be manifested as ambivalent engagement by the time the offer of holding becomes available.

It would be unsound to speculate that all of the mental health difficulties in the narratives were the direct consequence of poor medical management. Families come to the challenges of intersex from a variety of circumstances. Some have more resources than others to face the difficulties. What is inexplicable is why it was so rare for the clinicians involved to suggest, early on, that perhaps a therapist or a support group might help. When Kimberly Zieselman asked to meet others in a similar situation to hers, she was told that her condition was too rare. Words to the effect of terror appear several times in Emily Quinn's story. She despaired at the pieces of medical information that she later discovered to be false, for example that she "would definitely get cancer" and that she "could never have sex," but the gynecologist did not direct her to any support—"For as much as I was in and out of the doctor's office [for the next twelve years], I never seemed to receive any 'care'."

Personal transformation, often haphazard and unsupported, is highly visible in the narratives. It often begins with risk taking to break silence. A key moment for Amanda, who eventually extricated herself from shame, is when she took the courage to talk to her grandmother about her sexuality. Connecting with like-minded people also seems to be key. For Laura Inter, "being intersex opens a whole new world of possibilities around sexuality." Hida Vilorio's exhilaration is infectious: "I was born with ambiguous genitalia and it was a doctor [my father] who, by honoring my bodily integrity and not 'fixing' me, gave me the greatest gift I've ever received." Joy, relief and happiness are also bound up with a desire for change. Jay Kyle Petersen expresses hope that health professionals can hear and learn from his story. Hope is echoed by Sean Saifa Wall who is committed to "a world in which people born with variations of sexual anatomy are free to live a life with dignity and respect."

## Doctoring with Candor

The emotional detachment of some of the doctors in the stories is expected and puzzling at the same time. Lynnell Stephani Long felt emotionally overwhelmed upon meeting her pediatric endocrinologist at a medical conference. He on the other hand showed complete detachment. After examining Diana Garcia, the gynecologist told her to have her ovaries removed right away: "He handed my mother some paperwork and escorted us out of his office. That's it. No sympathy. No compassion." Diana Garcia talks about her fear, confusion, fright, terror, anger and shame, but she was 'blocked' from asking questions. She was stonewalled.

We know very little about the emotions of the doctors who forestall dialogue in the stories. However, the consistency with which the walls of hospitals and clinics are deployed to keep emotion out suggests that the doctors too may struggle with emotion. Frank reminds us that "one of our most difficult duties as human beings is to listen to the voices of those who suffer . . . These voices bespeak conditions of embodiment that most of us would rather forget our own vulnerability to" (2002, p. 25). Listening to suffering without being able to fix it may induce specific vulnerabilities in doctors. This raises potential issues about medical training and inadequate support for doctors that are beyond the scope of this commentary.

In concealing my own emotions, this commentary may exemplify the very professional detachment that I problematize. Suffice it to say that after reading the stories for the first time, I had nightmares of being separated from and failing to protect my family. Psychoanalysts may refer to my powerlessness as projective identification. And so it may be. I woke up terrified. Opening to vulnerabilities is risky.

According to Yalom, Winnicott once observed, "the difference between good mothers and bad mothers is not the commission of errors but what they do with them" (2002, p. 30). This may be a good analogy for good and bad doctors. After twenty years of the kind of emotional suffering that had made it impossible for Konrad Blair to "develop a healthy perception" of himself, he unexpectedly received

an apology from his previous care providers. The apology, he says, restores his dignity and opens the door to self-acceptance and positive action. Given the emotional significance of an apology, it is worth asking what kind of conditions would make it more or less difficult for health professionals to apologize to intersex people who have been harmed. In 2013, Kimberley Zieselman wrote to the institution where she had been treated as a young person. She received no more than an email acknowledgement of her "unsatisfactory experience." The response to her second letter, this time clearly waiving legal liability, was for her "to seek medical help elsewhere."

In the interest of patient safety, the National Health Service Litigation Authority (NHSLA) in the UK clarifies for health services that the duty of candor represents a statutory requirement to "inform and apologise to patients if there have been mistakes in their care that have led to significant harm" (National Health Service Litigation Authority, 2014, Improving Patient Safety, para. 2) and to "help patients receive accurate, truthful information from health providers" (National Health Service Litigation Authority, 2014, Improving Patient Safety, para. 3). The statute covers death, serious injury and prolonged psychological harm. The wording makes a clear distinction between expression of regret and admission of liability. Their *Saying Sorry* leaflet explains, "Saying sorry when things go wrong is vital for the patient, their family and carers, as well as to support learning and improve safety. Of those that have suffered harm as a result of their healthcare, fifty percent wanted an apology and explanation. Patients, their families and carers should receive a meaningful apology—one that is a sincere expression of sorrow or regret for the harm that has occurred." (National Health Service Litigation Authority, 2014, *Saying Sorry*, para. 1).

The statute sits amongst a mounting number of regulatory frameworks to govern all aspects of professional practice. It is difficult to evaluate the behavioral impact of the duty of candor standard. Criticisms and mistakes are, needless to say, highly shaming for health professionals. As we can see, avoidance and escape are common management strategies for aversive emotions such as shame,



guilt and fear. And so the wall of shame remains. We need to learn from doctors who seem more able to role model shame-free communication to positive cascading effects (Liao, Baker, Boyle, Woodhouse & Creighton, 2014), and from the doctors in the narratives who, I presume, were sufficiently unafraid of the rage of the hitherto poorly served individuals to engage with and assist them. Learning to be with difficult emotions may have a better chance of mobilizing compassionate candor.

### Further Reflections

As I immerse in the thirteen stories, I also become curious about the experiences of care users whose stories are not available here, such as the younger people who have not had to struggle quite so hard for information and discussion (Liao, Green, Creighton, Crouch & Conway, 2010), and those who seemingly choose to pursue normalizing interventions.

Whilst the narratives do not enable us to conclude that emotion care is lacking in the field, they do highlight the risks of insufficient awareness of care users' vulnerabilities. The potential for psychological harm is likely to reduce if clinical teams were to center emotion care and de-center medically non-essential interventions. The switch in priorities may afford clinicians and parents more time to gather information and reflect together on the uncertainties with candor and compassion. When the mother of an affected child reflected back to a doctor her emotional struggles in the early days, he apparently said, "We don't need five urologists on our team, we need five psychologists" (Magritte, 2012, p. 573). 'We' may not need any psychologist, but 'we' do need to relinquish the fantasy that medical doings can bypass emotional suffering, or that they are without emotional cost.

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Peggy Cadet, Cynthia, Maximo Cortez, Michael Kreuzer, Galen Sanderlin, Lianne Simon, and Alexandra von Klan

## Solving the Jigsaw Puzzle

Peggy Cadet

In my medical record, there is an enigmatic note. It was written as a consultation request from a pediatric endocrinologist to a plastic surgeon while I was hospitalized at age 13 (in the late 1960s) for mastectomy. The note reads:

*You have seen this unfortunate teenager with the feminizing testis [older name for androgen insensitivity] syndrome on several occasions in the past in reference to the construction of a penis. Would appreciate your seeing him again to evaluate the problem. He is firmly fixed in the male gender role despite efforts on the part of his father to persuade him of the logic of a change.*

The surgeon's response (also in my notes) was:

*The prospect of creating an acceptable penis in this patient seems to me very remote. There is nothing there except an enlarged clitoris. This could be mobilized and might project a few cm but cannot be made into a male organ of normal dimensions. The hair distribution and the perineum is also feminine which compounds the reconstruction problem.*

*Since the decision has been made to go along with the male gender I suppose that mobilization of the penis-clitoris is reasonable. Urethral reconstruction will be possible only much later. . . .*

I saw this note for the first time at age 21 but didn't think it was particularly significant until many years later. At the time I had other, much more pressing concerns, as I had reached the conclusion by then that I had been mis-assigned as a boy and that the only way for me to have a reasonable and

happy life would be for me to change to living as a girl. It was not a surprise that my doctors had been completely on the wrong track about my "gender". I was also not about to bring this up with the endocrinologist, a person who had terrified me as a child and whom I still found a bit intimidating.

I do remember the surgeon stopping by and examining me briefly without explaining who he was or why he was there. I had a somewhat longer, but equally uninformative (for me) visit from a child psychiatrist. The note requesting a consultation from the psychiatrist reads:

*Would you see <boy name> while he is here recovering from his mastectomy? Since he began to show mammary growth 18 months ago his father has put him under considerable pressure to undergo another change in gender role. <Boy name> has resisted but he is quite depressed. We would appreciate any suggestions you may have.*

I actually have no recollection at all of anything like pressure from my father to change to living as a girl. What I actually experienced was more like 180 degrees away from that—the expectation that I should try to be more masculine. As I remember, my father was bothered by my having breasts and was the one who initiated the physician contacts that led to mastectomy. (My mother had died when I was five, leaving him to rear me as a single parent.)

As my father recollected to me many years later, he had asked the pediatric endocrinologist to explain all of my treatment options and alternatives to me. I can only guess, but possibly the pediatric endocrinologist interpreted this as my father wanting me to change to living as a girl. As a young

adult, I got the impression that this particular doctor tended to mistake *asking for information* about possible treatments for *requesting* treatment. The idea of a patient gathering information and making informed decisions may not have figured prominently in his thinking. On the office visit when I was 21 and first mentioned to him that I might want to live as a girl, he told me that gender identity was “an unshakable conviction,” so perhaps his idea was that gender was just not something a person could make an ordinary decision about, weighing the pros and cons.

My father knew—but at age 13 I didn’t—that the original decision for me to grow up as a boy had been made in a somewhat haphazard way. I had entered the hospital at age six weeks with a girl name, to be evaluated for female-appearing, but slightly masculinized, genitalia. I went home with a boy name, a diagnosis of “male pseudohermaphroditism” and instructions to my parents about how I would eventually have some kind of masculinizing surgery. Things got a little more complicated a little over a year later, when I was actually seen by a plastic surgeon. This was the same surgeon to whom the note quoted above was directed 12 years later, and his original opinion had been the same—I was too close to the female end of the anatomy spectrum for masculinizing surgery to have much benefit, practically or cosmetically.

That led to a reevaluation of my sex-of-living. It isn’t clear how this new decision was made, but I remained a boy, although masculinizing surgery was projected into the indefinite future. The story I got as I was growing up was that some kind of surgery would happen when I was “older”. The specific age I picked up was 18 years (about twice the age I was when I first heard this).

What the pediatric endocrinologist wrote in those enigmatic notes must have been based mainly on a single office visit I had with him about six months earlier, (as, to the best of my knowledge and memory, I had not seen him since I was a toddler). I remember being very confused and upset by what I overheard during the long conversation my father had with the endocrinologist then. Although I remember little of the content explicitly, I did pick

up various ideas—that doctors had determined I was a boy, that genuinely changing sex was impossible, and that sometimes “children like this” did not even get to go to school but were kept “in an attic.” He had also said that, “we [doctors] don’t want you to be embarrassed . . .,” which I hoped meant that I would be excused from having to undress for gym class (which didn’t happen, and which I didn’t realize I could ask for); he was actually referring to the mastectomy he had been planning since I was an infant.

Afterwards, I was alone with the endocrinologist for a very brief talk, consisting mainly of the point-blank question, whether I would want to be “made into” a girl. Once I replied (with a “No”, which I inferred was the expected answer), this (perplexing to me) conversation was over. The rest of the appointment consisted of my posing for photographs “to show other doctors so they can help you.” I remember wondering when I would find out what those “other doctors” had to say after viewing the photos.

Years later, as a young adult, when I discovered those photos in a 1970 issue of *Clinical Pediatrics*, I thought of how much trouble he could have saved me by just telling what he had written there—notably, that persons with androgen insensitivity syndrome (AIS) could live as sexually active women. This fuller understanding of my AIS condition had been a great revelation to me when, at age 18, I first got access to the medical textbooks in a college library and realized immediately that I should have grown up as a girl, and that mastectomy had been a terrible mistake.

Before that, I had been intensely curious about anything related to my nameless “condition”, but had no sources. Doctors were unavailable and my father was himself under-informed and reluctant to talk. Besides which, I had the vague feeling, reinforced by the prudishly moralistic ideas I was taught in a Catholic school, that this was somehow forbidden knowledge. At age ten, I read a thick college-level biology textbook from cover to cover but found little that applied to my situation. I even became an avid reader of low-end tabloid newspapers, which in their 1960s incarnations, mixed

stories about atypical anatomy and sexual minorities with the ones about gruesome homicides.

At age 21, when I told my father why I had become (more) depressed at that time, which was that I was thinking that I should have refused mastectomy and chosen to change to being a girl back when I was 13, his response was, “If I had known you felt that way, I would have sent you to college as a girl.” He also asked me whether the pediatric endocrinologist hadn’t explained everything to me back when I was 13 as he had asked him to? I can only wonder—did my father ask the pediatric endocrinologist to do this, and did the endocrinologist interpret this as my father’s wanting me to change? I can only guess.

About this same time, I got a clandestine peek at the medical records of a younger cousin, also with partial androgen insensitivity syndrome (PAIS), and who, like me, had been raised as a boy (after being reared as a girl for his first two years). That included the verbatim transcript of his interview with the late Dr. John Money. I recognized Money as the author of much of the literature on intersex and gender I had been reading, and I considered his ideas progressive. As it happened, Money’s section on gender change among intersex persons, in his 1969 book *Transsexualism and Sex Reassignment*, was my first exposure to the idea that there was an alternative to the sexually and socially very limited life I had as a male. I had also read his 1972 book *Man and Woman / Boy and Girl* soon after it was published, and his account therein of the informational counseling he provided to the two children with CAH who changed their sex of living, was a large part of what influenced my thinking about what kind of counseling was needed for intersexed persons.

Money not only told my cousin that he could change to being a girl instead of having mastectomy, he gave him explicit information about intercourse, erotic sensation, homosexuality, transsexualism, etc. even that, as a male, one of his options would be to use a strap-on artificial penis; all presented in language geared to a 12-year-old’s understanding. Ironically, the counselor I was seeing at that time cited Money’s ideas as the rationale for my not having been informed in the same way as a child.

In more recent years, Money has been vilified for promoting a policy of secrecy and non-disclosure for intersexed patients, when, in the case of my cousin, it appeared that he actually provided the sort of information and education intersex activists have argued for.

## Navigating Intersex Healthcare: My Odyssey

Cynthia

I was born in 1965 with what the medical community called “ambiguous genitalia.” My initial announcement as a boy was called into question upon closer assessment of my atypical anatomy by medical specialists at a children’s hospital in Chicago. That team of medical experts included a pediatric urologist and a pediatric endocrinologist, as well as a prominent pediatric surgeon, who was at that time presiding president of the relatively newly established American Pediatric Surgeons Association. I have wondered over the years whether, or to what extent, that status and position had any important impact on the unfolding of my medical case.

Just over 100 days after my birth, I was surgically and socially reassigned female, and renamed Cynthia. My mother and physician father, ages 25 and 30, respectively, with two young sons at home, did the best they could to move ahead in life as a young family. Part of our family story is that my unusual birth contributed to my parents’ decision to move away from Chicago, where both of my parents had been raised and wanted to settle, and where my father had many professional opportunities. We relocated to Southern California to make a “fresh start” where no one would know the dark secret too terrible to be shared with any beyond a small circle of close friends and family. It would never be talked about openly.

With the exception of the rare and dreaded occasions of medical appointments with my primary care physician, or maybe an endocrinologist to renew hormone prescriptions, my parents chose



to have me travel from our home in San Diego to a clinician in Los Angeles, away from my father's medical colleagues. This decision was puzzling to me at the time, and maybe more so now. These trips were a source of considerable stress and anxiety, as I had no idea of what to expect; my mother told me only that treatment would "help me get my period started." I was instructed to tell my friends and teachers that I was taking off school on a weekday to go on a "shopping trip" with my mother. As far as I know, these trips were never discussed at home with my older brothers. I heard years later that my parents disclosed some information about me with my brothers when my parents travelled outside the country. They felt that my brothers should know what had happened to me in the event of a catastrophic accident that might prevent my parents from telling me themselves. I suppose they believed that I wasn't ready at the time to be told my own life and medical history. I can't say for sure.

I don't want to judge my parents too harshly for how they handled my medical care. I know that it was an extremely stressful and uncertain time for them, and peer support, which I know now is so vitally important for both parents and young affected individuals like myself, was not made available to us. I never thought to ask about such help, or even consider the idea that anyone else would be in a similar situation like mine. I don't think I would have been even remotely comfortable or willing to discuss it openly at that point.

In my early twenties, I had to face another milestone in my journey and in my interactions with the medical community. I had yet to have the vaginoplasty I was told I "needed." There was no discussion as to whether or not I wanted it or not. It just had to be done, and I was aware of the limitations I had at this vulnerable time in my life when my peer group was sexually active and I was not. My awareness of the obstacle posed by my difference made me avoid the topic of dating; it was difficult even to think about the possibility of a romantic relationship. I put it out of my mind, but I knew that it was a significant concern for my parents. My physician father did most of the prodding to get me to acknowledge the reality that needed to be dealt

with. My mother avoided discussing sex with me. I think it may have just been too much for her to deal with. I did finally have the surgery to open up the fusion of my perineum, which revealed a naturally existing vaginal canal. It was sort of considered a sign of good fortune that I had a vagina, as that meant that one would not have to be surgically created for me. I went to have this surgery all by myself. I felt that it was better for me to go through it alone until I was ready to be discharged from the hospital. I can't believe my family handled the surgery in this manner, but we did. It was just another of many bizarre episodes in my life.

That was then. In my early forties, I found myself at a crossroads and in need of taking a closer look at the events and interventions I had largely ignored to that point due to other pressing family issues that had my attention. From an initial internet search, I found out that there was a U.S. based support group and the founding organizer actually lived in my own hometown! I couldn't believe that this resource had been right "under my nose" for most of my younger life and that I had never availed myself of it. Discovering that there was such a community was a life-transforming event; it would have made such a difference to know earlier that I was not alone. I don't know that I would have been entirely receptive to peer support when I was younger, but I wish that my medical providers had made this support available.

For me, one of the most important aspects of meeting others with intersex for the first time was the opportunity to raise questions about my hormone replacement protocol. I had always been prescribed conjugated estrogens, as that is all that was ever considered to be needed for women. I had begun to feel that something was "missing" and that I needed to know about what others were taking and what their experiences were. When I came away from that meeting in the summer of 2006, I began to take charge of my medical care with a newfound sense of confidence in approaching clinicians, and I enlisted them to help me find out more information about my diagnosis and its effects.

In the months and years following, I began a new hormone replacement therapy (HRT) protocol

that for the first time included testosterone replacement. Looking back, I can't say that the effects were immediate, but they did become more noticeable, especially with respect to my newfound libido, an interest in connecting with my body in a pleasurable way. I had really never experienced any kind of sexual interest before, and had not been sexually active or had any romantic relationships up to that point. While this was an important breakthrough for me in making this physical connection to my body, the greater takeaway for me was the understanding that this particular body of mine seemed to benefit from testosterone, and I had had no previous reason to believe that it would or it should.

I had assumed that I had congenital adrenal hyperplasia, which turned out not to be the case. Then I thought that I must have partial androgen insensitivity Syndrome (PAIS), which was also later determined to not be the case. Among my peers, I am considered "lucky" in that I was able to obtain copies of my archived microfiche medical records. I was 43. The rudimentary testing performed when I was an infant indicated a "male pattern" chromosome profile and the professional assessment of my condition as "male pseudo-hermaphroditism." There was a pathology report indicating the histology and findings from the gonads and erectile genital tissue extracted during surgery.

In subsequent years I experimented with various forms of HRT, starting with the estrogen/testosterone combo pill and followed by estrogen (estrodial) patches, transdermal estrodial estrogen topical spray mist, and topical transdermal testosterone gel. My endocrinologist had mostly been willing to work with me and accommodate my wishes to try new protocols in hopes of improving medical symptoms I attributed to the lack of proper hormone management. Some of these issues were common among the intersex women that I had met. These included challenges concerning weight gain, low energy, fatigue, low or nonexistent libido, mental foginess and others. I can't be certain that hormone regulation was the source of these issues in my case, but the pursuit of the hormonal "panacea" has been for me a constant focus. It may be that I have "pathologized" my own condition as much

as any clinician ever did; I see the irony here, but I also recognize the difference that hormones can and do make in how I feel.

More recently, genetic testing revealed that I am not at all insensitive to androgens as I had been given to understand. There was no androgen receptor mutation found to suggest that my body did not respond to testosterone; my intersex trait was likely the result of dysgenic testicular gonads that were unable to complete typical masculinization and development. That revelation was yet another watershed moment in this ongoing medical journey, and only happened because I had been accepted as a subject in a study conducted by a specialist in atypical sex development. I had fortunate to benefit from testing that would otherwise have been prohibitively expensive, and to which far too few intersex persons currently have access.

In the aftermath of this new genetic information, I realized that I needed to pursue more metabolically potent testosterone replacement in the form of intramuscular injections, which I have now been on for over a year and a half. Knowing that my body is fully responsive to testosterone has been daunting at times, and continues to be with this mysterious, atypical body. I wish I didn't always have to rely on "trial & error/success" in navigating my way with the medical community. I have come to recognize that the urgency to intervene in my infancy is not reflected in efforts to assist me as an adult. My experience seeking medical care has been characterized more by pleading for cooperation in my ongoing efforts to find the interventions that will help me feel well.

The journey continues as I go into my 50th year.

## Game Change

Maximo Cortez

**O**n November 17, 1983, I was born with a condition called mixed gonadal dysgenesis, and ambiguous genitalia. My gender was not of a big concern at that time. The more urgent matter was that I had a heart murmur, which was repaired when I was twelve months old.

It was not until I turned five, and by issue of the Texas Children's Protective Services (CPS), that my mother was forced to authorize providers to perform normalization surgeries on me. An anonymous caller tipped the CPS that my mother was raising a boy as a girl. The state intervened and explained to my mother that she would have to consent to these surgeries or else she would lose custody of me. This included a gonadectomy and a clitorrectomy. Without any consent, these surgeries were performed "in my best interests." My mother was an epileptic, Hispanic, Mormon, single parent.

I was raised to be a socially acceptable female, though as early as five, I played with "boy" toys and enjoyed TV programs aimed at male youth, like *Teenage Mutant Ninja Turtles*. It was not until I had those normalization surgeries performed on me that I felt different. I knew that something major had happened to me. I woke up in a hospital bed in a gown. I raised the covers and noticed that I had an "X" carved in my groin area. Doctors mutilated my clitoris by reducing its size, which made me feel alienated and angry that something was wrong with my body.

I had a surgery performed on me that was to be kept secret and never talked about. This sense of fear and shame was instilled in me shortly after the surgery. I do not recall any psychological evaluations or counseling to help me cope with such surgeries. Seeing everyone else my age going through puberty during my teenage years, I felt behind. I wasn't becoming a boy with a deep voice or facial hair. Instead, I visited the doctor's office with my mom and was told that I would be taking oral estrogen to become a woman. I wasn't until that moment that I understood I was seeing a doctor to foster the development of female secondary characteristics. I felt betrayed by the medical community and by my own mother.

Just a few years later, I saw a urologist to find out whether I was ready for a vaginal construction surgery (vaginoplasty). Thankfully the urologist suggested that I was not ready to move forward with an invasive and irreversible vaginal construction surgery. I never pursued it as an adult, as I have always felt male gendered.

Social sexual relationships have always been difficult for me but more so with my attraction to women. I first realized my attraction to women in early middle school. Being raised Mexican and a Mormon and knowing that I was homosexual created a lot of conflict for me. I felt that I was a male-gendered person forced into a castrated, mutilated, and medically created female body. I suffered through depression from an early age and it continues today. My conservative Mormon upbringing brought me much shame. The Mormon religion, as most people understand it, expresses a great intolerance to homosexuals and transgender people. I felt like I was a heterosexual male in a female's body, but the Mormons would never accept me.

My later teenage years and mid-twenties were a dark time in my life. I even attempted suicide in my early twenties. My depression was treated with antidepressants and talk therapy. Once I began testosterone, I gradually stopped taking antidepressants. When I was only on estrogen, I felt very moody, angry, and in an emotional funk. I would cry easily and would become very irritable and emotional without cause. With testosterone therapy, I began to think more clearly, had balanced emotions, and began to think more logically.

I began to research intersex online and found a women's androgen insensitivity (AIS) support group. At one of their national conferences, I met another intersex individual who was raised as a female and who had transitioned to male. Like me, normalization surgeries were performed on him as an infant and he had had a vaginal reconstruction as a teenager. He was able to overcome those challenges and is able to live life as a man. Three years after meeting him, I began my own gender transition.

With XY chromosomes and a masculine demeanor, I am struggling to adjust to the awkward gender limbo situations presented to me in society. I am working on getting my name and gender legally changed; yet the progress is painfully slow. Certain counties in Texas almost outright refuse a request to change one's gender identity.

There are now more support groups for people with intersex. The one that I am a part of was designed for women who suffer from androgen

insensitivity syndrome. With my desire to change my gender, I felt out of place in this organization. In turn, I created an open space for all intersex people and our allies. In 2012, I developed my own online secret Facebook group in order to foster a safe space for anyone affected by an intersex condition, and their supporters, to connect with one another. Our group is a place where people can discuss and support our different experiences. This group includes those who are affected, professors, doctors, lawyers, family members, and even significant others.

I currently have a distant relationship with my nuclear family. We have only a few token exchanges. I engage with them only when they reach out to me. My sister and brother are supportive of my intersex activism. My mother, on the other hand, is less than encouraging. Being a “normalized” intersex person has been my biggest struggle. The shame and secrecy has kept me far from others; I feel I have to guard myself from getting hurt. But to save others from my fate, I must reach out, and I am glad to have created my own international family made up of those who share my experience and my goals.

### Michael's story or the Paradox of Normalcy

Michael Kreuzer

I was born in Montreal in 1974. My parents were both “older.” My mother was almost 45; my father was in his 50's. I have a sister who is six years older than me. What I know about my mother's prenatal care is that it was quite basic.

I was premature. My mother's due date was in mid-August, however I showed up about three weeks earlier. I know that initially upon my birth I was declared male. However, upon closer examination, a few “abnormalities” of my genitals were found. I urinated through a small hole at the base of my penis; adjacent to this hole was another opening, barely big enough for a Q-tip. My scrotum was empty; my gonads had not descended.

The doctors who examined me decided that they could not assign a gender without further testing.

They told my mother I would need to remain in the hospital until such testing was completed. Apparently not being able to determine sex/gender is a life-threatening condition that requires hospitalization.

It was determined that I had a uterus and it was presumed that my undescended gonads were ovaries (not verified by biopsy). There was a small vaginal opening behind my small urethral opening. Structures such as the labia were not developed. I found out later my vagina had fistulated into both my urethra and my perineum. Karyotyping was performed resulting in 46,XX with a diagnosis of female pseudo-hermaphroditism. My parents were informed that in spite of my external genitalia I was female and I would never develop as a male. I would require “corrective surgeries” which should be performed as soon as possible so I would not have any issues with my gender identity. They were even told that I would be able to become pregnant if I had the surgeries. In fact, I never ovulated and I have a small unicornuate uterus.

My father refused all surgeries on my behalf most likely because he was a full-blooded Navajo who had suffered from abuse in an Indian boarding school during his childhood in New Mexico. His family was traditional, and because they didn't adapt to prevailing Christian values, he and several of his siblings were removed from their parents. My dad was the oldest of 12 children and by the time his youngest siblings were born, the practice to take children away from their families had been changed.

I think my father was deeply traumatized by his childhood and did not associate much with his family, nor did he want to visit the reservation. He spoke the language but never encouraged us to learn it. He did teach us some of the traditions. He told me about the *nadleh*, which is the other gender besides male and female in the Navajo tradition. There are two kinds of *nadleh*, which are almost like male-to-female and female-to-male transsexuals. Mostly I educated myself later and learned about the Navajo belief system in which the creation story is an important part. In the Navajo tradition, the creation story tells of First Man and First Woman; the first children born to them are the Hermaphrodite Twins.

My father was a US Army Master Sergeant, which was an unusual career for a man of his origins; he was a veteran of the Second World War. After he left the army he took his family to Montreal where he had a job in security. I think he preferred to live outside the U.S. He used to say that in Germany, where he had managed to stay for a long time while serving in the Army, he was just another American soldier. In spite of his career, he had a deep mistrust for “white people.” I remember he used to say that he was in the Army because this was his country long before the white people came and he loved it. He did not love the people who governed it. All this very much played into the decision not to listen to the doctors’ recommendations about surgery. My father was also the “decision maker” of the family; I don’t think my mother would have disagreed with him. I have never asked her about her motivations I have never asked my mother what motivated what I now see as her ignoring the advice of pediatricians who continued to recommend surgery and other interventions; she never seemed interested in talking about it.

Growing up, I remember I identified with boys more than girls. I think at about three years of age I was certain I was a boy. I didn’t really care about what others said and my family did not force me into a particular gender role. I was also fairly aggressive and resistant. I knew I was never supposed to run around naked like other kids did. I even wore swim pants in the bathtub, just because I felt it was wrong to be naked. I was ashamed of my body although I didn’t know why. I had seen little girls run around naked and I knew I was different; I looked more like the little boys I had seen, and maybe that played into my unwillingness to be undressed. I am still not comfortable with my body to this day. By about age six, I refused all remotely “female” clothing.

When I was eight years old, my parents separated and my mother moved back to Germany, her home country. My mother took my sister and I with her. There my new pediatrician reviewed some of the information my mother had given her. I did not like doctor visits and I already knew the “drill”. All the focus was on my genitals and the need for

surgery. However, my new pediatrician was a little skeptical as far as my diagnosis was concerned and repeated the karyotyping.

This time the results were different. It was found that I had 46,XX/XY mosaic chimerism. My diagnosis was changed to “true hermaphroditism.” Despite the diagnosis, there was no change to my sex/gender or any of the recommendations made by my previous doctors. I was never asked what I wanted, nor was I asked how I felt. My hate and contempt for my doctors by age eight was already so significant that I never even spoke to them. They took my silence as a sign that I was mentally retarded or maybe mentally ill. My mother had been told to take me to a therapist and again was encouraged to consent to additional surgery before I developed into a teenager. I was in the room as I was being spoken about, though I was rarely spoken to. I remember that I was incredibly angry and always fantasized about smashing everything in the doctor’s office, but I never let it come to the surface. As soon as we came out of the office after a visit, I would tell my mother that I did not want whatever was recommended. My mother reacted by not taking me to doctors’ visits as much anymore.

At age ten, I was started on hormone replacement therapy (HRT) to induce “female” puberty, since my body was not producing female hormones as expected. At about age twelve, I believe a testosterone blocker was added because I started to produce testosterone. Physically speaking, I was a girl with a penis. I had erections and I started ejaculating both spontaneously and with masturbation. In addition, I started having very clear sexual preferences. I was attracted to girls. My sexual fantasies involved touching their breasts and genitals and putting my penis inside of them. I never had a female sexual identity, which is to say I never identified as a “lesbian” though I was labeled female and was attracted exclusively to females.

In response to the above conundrum, I reinvented myself and developed a male alter-ego. I modified my name so it would be male and I told people that my father was a top secret U.S government spy: we had to hide our identities so we would not be found, otherwise we would be killed. It was



so serious that I had to disguise myself as a girl in spite of really being a boy. Yes, I was imaginative.

I never had a problem “passing” as a boy, I was ambiguous enough and most people who didn’t know me assumed I was male. I was often addressed as a boy. Most amusing to me was the fact that even before puberty people used to prevent me from entering the women’s bathrooms and directed me to the men’s room instead. I never resisted and decided that I probably should just use the men’s room from then on.

I was not very compliant with my medication. I often spit it out. I saw the medications as a “compromise” my doctors made. At the time they prescribed hormones the doctors had agreed that surgery should probably be postponed until I was grown. I think they believed that female puberty might influence me in favor of surgery. I did not like the effects of the medication. I had cramps from time to time and strange discharge from both my urethra and vaginal opening which was probably similar to a period—nothing I wanted to experience. My breast development was minimal. I never needed a bra; I have some gynecomastia as a consequence of the HRT. When I was 13 or 14, I worked out lifting weights since I wanted to be muscular and I did not want to appear feminine.

The first time I fell “in love” I was about 11 years old. We were on vacation at a bed & breakfast and the owners’ daughter was about my age. We played together. I always assumed the male role when we played “house” and we even pretended to have sex. Eventually she dared me to take my pants off and we played with each other’s genitals. I had told her that I was actually a boy and that she could not tell anyone. I was 13 the first time I had intercourse, with a 14-year-old girl. I wonder if my premature interest in sex had anything to do with the fact that I had to find my sex/gender identity or if it was just coincidental.

For a long time I didn’t worry at all about my sex/gender assignment. I believed that as an adult I would be able to choose. I knew I could not be a woman; however there were many girls who might be called “tomboys” in the U.S in school, and I just appeared to be like one of them. I was very good

at fighting and defending myself, so I was never really bullied.

At age 16, I stopped taking my HRT and soon after my body became more masculine; my voice deepened, I had more facial and body hair and muscle development. Finally at age 18, I found a urologist who performed female-to-male (FTM) surgery. He was willing to repair my hypospadias and close up the external opening of my vagina. He took my case out of academic curiosity, I think. He had never seen anybody with my anatomy and he told me that the surgery would be “easy”, although he fully informed me of potential complications. He asked me if I would allow him to present my case anonymously to students and physicians in training during his lectures, and I agreed. I still did not legally change my gender marker since it seemed such a complicated procedure in Germany in the 90’s. It was only after graduating from medical school, when I came to the U.S. for medical residency that I sought a legal change in my gender identity.

It was disheartening to me that even in medical school we only superficially touched on the subject of “hermaphroditism.” My hope is that this changes. I know I have sort of a unique perspective as a physician and an individual who has DSD/intersex. In medicine, I did not choose a specialization such as endocrinology or urology, which would have increased the likelihood of seeing patients with DSD. As an adult and “officially” a man, I wanted to more or less forget about my “condition.” Phenotypically, I never had a problem “passing” as a male. I was convinced I would never meet anybody with my condition or a similar one. So I basically went “stealth”.

Only in 2012, after I had issues in my private life due to somebody finding out about my past and using it against me, I decided to seek out other individuals with DSD/Intersex. It was a pivotal moment in my life. It made me realize I could do more for the intersex community as a physician. I wanted to get involved and advocate. Expert opinion was all about us but never by us. Research was done on us but not directed by us. Patient advocacy groups are respected by medical providers for most

chronic medical conditions; why is this not the case when it comes to DSD/intersex? I realized that this had to change. To this day, “corrective surgeries” are performed on children and adults worldwide. I hope that I can bridge the gap between the medical world and the DSD/Intersex community, to create better care for all of us and to change the binary thinking that shapes too many providers’ recommendations. Having experience in medical education, I would like to educate medical students and residents and of course doctors who are open-minded enough to change their views regarding care for patients with DSD/Intersex.

## Dwelling in the Gaps

Galen Sanderlin

**H**ave you ever wondered what it would be like to be a mythical being? As a hermaphrodite, I exist in a culture that sees only male or female. Those of us who don’t fit into the rigid sex binary are left out of many of the protections offered to our cousins who more neatly fit the two categories. This leaves an enormous gap in cultural definitions and societal acceptance of my fundamental being.

My journey has three main threads: 1) My personal and often rocky self-development, as I have come to understand and accept what it means to be a hermaphrodite, and finding others of my tribe; 2) recognizing the harm done by my medical treatment and actively seeking to change how the medical system treats hermaphrodites, starting from birth onwards; and 3) identifying what was done to me as a human rights violation.

I was born in January of 1975. No genetic test was done at the time. My body looked male and my assigned sex/gender was male. As a child, I gravitated toward “male” toys. In 1989, a rural-MD noted that I was not experiencing puberty like my peers and she recommended that my parents take me to a teaching hospital in Seattle for tests. A pediatrician referred me to the adolescent medical division, and from there I was referred to an

endocrinologist. After conducting many invasive tests, including drawing blood and comparing my testicles to a bead ring of ersatz testicles, the endocrinologist diagnosed me with Klinefelter’s Syndrome and a karyotype of 47,XXY. I was prescribed testosterone injections to affirm and strengthen the male identity I was assigned at birth and to prevent my body from developing secondary female sex characteristics (breasts and hips).

Soon after the shots started I bulked up, adding muscle and hair everywhere. I also became dangerously aggressive and moody. I began to have serious self-esteem issues and a drastic increase in risk-taking behavior as my body was subjected to medical intervention that my parents innocently followed.

The prescribed hormone treatment fractured my psyche—what I know now to be a common defense mechanism experienced in trauma survivors. The portion of my consciousness that existed prior to testosterone became deeply buried to prevent harm, and I experienced the emergence of a new “entity.” With each change in prescription, new fractures occurred: testosterone cypionate to enanthate shots, to patches, to gels.

The physicians did not consider my feelings or preferences during recommendations or treatment. I feel I was forced into a “male” body based on a medical emergency they created to ease societal concerns.

Last February I decided to stop hiding. Tearing the mask off has brought a flood of emotions hidden behind old traumas. I’d been living openly as an intersex person, but still deeply closeted, if not from the public—worse, from myself.

Here is the writing that came pouring out of me as I’ve been accessing my repressed memories:

*I felt the first stirrings of my existence in August of 1989, like a fleeting visage of a long lost lover passing just out of view. The timing of the universe—Out of the infinite we are born, but in this case the body we are to occupy was already housing many other souls. Is this some mistake? Asked to be patient I waited . . . Late in the year of 1989 I was borne on testosterone wings into an imaginary masculine role/body.*

*Molded in the image of Adonis, Hermes was forced to submit. No longer sexless or ageless—lost in a sea of supposed pressures and roles. My assumed gender*

*was male. Why!?! Screaming, thrashing, and damaging all around me, no way to express the horror of being so brutally manhandled.*

*My guide Galen/Juniper were excised from our psyche—lost behind a barrier. The only solace was a shared beat: 1,2,3,4 over and over. Was this the pounding of our heart? Thank god for our love of music least we lose ourselves entirely.*

*Why do they insist on calling me Galen? I no longer knew who this was. I was the new occupant of this 14-year-old body. Immature? By whose measure? Looking back it is quite a wonder we survived. Around my second birthday or this body's sixteenth year the quacks tinkering with the engineering chemicals changed the mix. This tiny shift in molecules removed my legs or half of my existence and another soul came halfway into existence—except they were trapped—both in and out of corporeal and etheric realms. How rude. Why fracture an already fractured being?*

*To this day we do not know their name, only images and feeling pierce our psyche. We and they have accepted this arrangement; what choice do we have? To remove them is not possible and they are a fundamental part of our being and journey.*

*Our collective self, looking back we see devastation and lost souls. Some wander through this psyche like super-positioning popping in and out of existence as chance and chaos permeate the shifting planes of dimensional reality/variation. Each possibility stretching before us like strands of spaghetti overlapping and sticking together as possibility and wish become real and foment through action.*

*While Galen/Juniper were locked safely away they seemed to still be present; Galen with an astounding ability to consume enormous volumes of data and Juniper the gift of gab. It is no wonder that we are misunderstood.*

*In 1999 we were joined by Aphrodite. (my pharmacy mistakenly filled my prescription for depo-testosterone cypionate with depo-testodiol, a high binding estrogen mixed with testosterone). Her arrival marked a massive shift in our body. Adonis was closeted along with the others. Our life has been like a revolving door—souls keep showing up. Some deciding to stay and others freaking out and causing havoc.*

*Our existence is like a committee meeting. Each group archetype; the fool, negotiator, etc. Except we have no leader, only a powerless figure head randomly selected. Monty Python's autonomous collective comes to mind.*

I do not have a place within my own culture and native language. English does not have a pronoun for people who exist in the intersex space (neither male nor female). I cannot make plane reservations, apply for a passport, or hold a driver's license without declaring myself either male or female. I am considered an abnormal human being with a genetic disorder, not a complete being in and of myself.

Enough is enough! I've had six pharmaceutical sex changes, without informed consent; all without psychiatric care that is requisite for transgendered people. Please set us free from this medical nightmare. Leave us alone to grow and mature as the mythical beings we are.

Allowing my fractured self to heal has been an infinitely tortuous and rewarding journey of self-discovery and self-acceptance in which I have struggled to reclaim the self that society rejected and sought to obliterate. Part of the struggle is finding physicians and therapists who can help me integrate my fractured parts into a coherent whole. Like many trauma survivors, I have a hard time trusting. Sharing mythological and spiritual components of my journey, stepping into my place of authentic belonging, and coming out as hermaphrodite in a culture where the emerging realization of non-binary identity challenges longstanding social norms requires a profound trust in the process as I work through internal and external barriers to self-acceptance.

## XY/XO

Lianne Simon

**A**s a boy child I might once have thrived, but the loss of a Y chromosome in one of the first few cell divisions left me a faie half-girl struggling for life—like some changeling left in place of a human baby. My genetic mosaic of XY and XO cell lines created a fetal legacy of Turner Syndrome medical issues. Among these were delayed growth, a largely absent puberty, and micrognathia—a small jaw that feminized my face.

At two I weighed just eighteen pounds. My parents worried they might lose their little boy, I was that frail. All I knew was I was the smallest of my peer group and had a cute pixie face. I imagined myself a high-spirited elfin princess, but was in truth shy—almost timid—and prone to tears.

I first responded to the Gospel at vacation Bible school. One of the women there read me Bible stories. I didn't understand them all, but I wanted to love Jesus and be a good girl.

At nine I was the size of a 6-year-old. By then I'd started growing faster, so my mother stopped taking me to the doctors. I didn't see one again until an emergency appendectomy in college.

Fifth grade brought surprises. Jim melted my heart with his Beatles love songs and cute smile. I dreamed of being his bride. Karen was the first classmate ever shorter than me. We were best friends, but one day the principal said I should play softball with the boys instead of hopscotch with her.

My parents allowed me dolls and tea sets, even an Easy-Bake oven. But wearing my sister's clothes triggered a sad-eyed lecture—boys didn't do such things. No dresses. No talking with my hands. No long hair. And no crushes on boys.

If I prayed hard enough, if I was really good, maybe God would make me a real boy—tall and strong, fast and agile—like my older brother. Two years later, puberty cracked my high-pitched squeal of a voice and sent it sliding down to a mellower soprano. I grew taller, but didn't get muscles or body hair, and I remained hopelessly uncoordinated. An inguinal hernia kept me from running very far.

High school turned my prayers into pleas for mercy. I despaired of ever fitting in. Some Christians might not have welcomed a feminine boy, but the pastor of our Southern Baptist mission considered me one more sinner in need of the saving grace of a forgiving God. He led me to faith in Christ. As a new believer, I assumed I could be a boy for real. Maybe even find a girlfriend. Instead, the mask that allowed me to function socially crumbled, leaving me no place to hide.

In the spring of 1970, I registered for the draft. Me fighting in Vietnam seemed a real possibility. Or at least spending time in prison for refusing induction.

Except that a delicate intersex kid would never have passed the physical. Nearly perfect SAT scores won me a scholarship to Miami, so I left a supportive home in Illinois for a boys' dorm in south Florida.

My surname then was Klett. The worst of the guys called me Clit, or sometimes Clitoris. Others derided my small size and lack of virility. One propositioned me. Another used to pin me to my bed and lie on top of me until I quit struggling. Though he stopped each time I surrendered, my defenses lay in ruin.

A few of the boys were nice. David took me for long rides on his motorcycle, with my arms wrapped tight around his waist. He treated me with gentle kindness and asked nothing in return.

To escape the dorm, I studied in the library stacks, where only honors and graduate students were allowed. The next year I found a derelict building where the university stored old theatrical sets. It even had a quiet place to sit in the sun. Best of all—nobody ever went there.

One day my imagination wandered through the wardrobe. What would I have worn as a girl? Not a Cinderella gown—nothing so fancy. That cotton sundress, perhaps. Show my legs for a change. Why not? A girl for once in my life. Nobody ever went there, you know. Except a school employee who found me reading in the sunshine and asked for my ID.

A week later the dean summoned me. Without mentioning the incident, he reminded me that I was attending the university on an honors scholarship. After a lecture about me ruining my entire life, he offered a simple choice—counseling or expulsion. I had to try harder to be a boy. Much harder. So I bid a sad farewell to my long hair and bought a motorcycle.

"Have you always wanted to be a girl?" the counselor asked.

"Well, yeah, actually. But I'd settle for boy."

Over the next few months, while the psychologist probed my defenses, I tested out of enough coursework to graduate a year early. As I was leaving, one of my computer science professors introduced me to some men who wanted to hire me. I was, after all, a genius.

Armed guards watched over us as we searched the ocean depths for the telltale signs of enemy

submarines. The men slept in the barracks. The company put me in a room by myself in the Bachelor Officer Quarters.

While not on military bases overseas, I fled desperation through the streets of Miami on a motorcycle barely under control. Until one day my lovely British bike took me airborne, and we tumbled down the road. As I lay on my back, wondering at the absence of pain, a fleeting apprehension stirred within. "Live for God," it whispered. "Now. Or die by your own recklessness."

So at twenty-one, I visited a psychiatrist who referred intersex and trans patients to the experts in Baltimore. She said I needed counseling first, and sent me to a gay bar to hook up with a boy for sex.

Didn't I like snuggling with guys? Wouldn't I let the right one kiss me? Well, yeah. But I'd want to get married and have his babies. He might like my pixie face and gentle half-boy disposition, but my little half-girl penis didn't do standup. Why would a gay boy want me? Or a straight girl, for that matter?

At least someone in the bar knew a sympathetic doctor. The endocrinologist lectured me about my weight, like I'd die if I lost one more ounce. After I agreed to put on fifteen pounds, he offered to make 'a real stud' of me. Testosterone would give me broad shoulders, muscles, a deep voice, body hair, and a raging sex drive.

As a child I'd always been the smallest. I kind of liked that. But my body had kept right on growing. At five foot six I felt like a giant. Who would I be if I lost my feminine face and voice as well?

When I asked for estrogen instead, he agreed. It would help me gain weight. He said I wouldn't have any trouble being accepted as a girl. After a year on hormones I'd have surgery.

*Surgery. Yeah. Guess so.* To serve God, I had to first of all survive. I didn't hate my genitals, but as a girl, I could have a life. Maybe people would stop questioning my gender.

Over the next two weeks I spent the afternoons puking my lunch. One of the guys at work joked that I'd gotten myself knocked up. Taunts from the men increased, but the women gave me only sympathy.

Normal hormone levels elevated my mood. In spite of the teasing, my clouds became sunshine.

Pubic hair sprouted, thickened, and curled. Genital skin darkened. Hiphuggers replaced my skinny boy jeans. A loose top hid budding breasts.

After a year, I exchanged my shirt for a peasant blouse and boarded a plane for San Francisco. In his office in the Jack Tar Hotel, Dr. B—reshaped my little half-boy genitals into a clitoris, labia, and neovagina. None of the local hospitals would admit his patients, so the girls recovered in a townhouse he provided. The wondrous Indian summer of 1975 stretched into October while I cooked for my housemates, flirted with college boys, and endured a stent much too large for my poor little vagina. In November—after two months of dissociating pain—I flew home.

Mom said that for the first time in my life, she knew I'd be okay. Yeah, but it was the change in legal status—not the failed vaginoplasty—that brought stability. I moved to Virginia and settled in to life as a young woman.

The first time I joined a church, I shared my history with the pastor. I had some doubts, you know. Not about being a girl. About my right to be one. At times—even before surgery—I'd felt like I was on the wrong side of the Grand Canyon with no way across. Like I should have been able to be a boy. But Calvary Temple believed my faith in Christ genuine and welcomed me.

I spent the next twenty—some odd years dealing with rather ordinary problems, with only my family, a few of the doctors, and the occasional boyfriend aware of my past. Several young men proposed. All but one I turned down. He broke my heart.

When I met the man who later became my husband, I wasn't sure he'd understand. Many Christians don't realize that some people are born not entirely male or female, and gender doesn't always follow genital shape. Yet he cried when I bared my soul. Two months later, in the summer of 2000, we married, and I joined him in Maryland.

A few years ago, the Lord nudged me toward increased transparency and vulnerability. I'd spent nearly forty years proving the endocrinologist right—society accepted me as a woman. Unfortunately, quite a few Christians wouldn't if they knew my story.



Intersex is rare enough that some dismiss it as irrelevant. Others, like my pastor, have a simplistic view of sex. He says the predominant shape of the genitals at birth indicates God's unchangeable will for a person's gender.

One scholar in our denomination insisted that someone like me couldn't be a Christian without also living as a man. But how would leaving my husband to spend the rest of my life on a hopeless quest for masculinity glorify God?

So I dance the razor's edge, hiding inside my own church, yet openly sharing my testimony elsewhere as I await the inevitable denouement. Once the news reaches their ears, will my church listen to my defense—or summarily declare me perverse?

God created humans male and female and blessed them (Gn 1:27,28; Gn 5:2). He also generated a wide range of biological sex variations that go well beyond that simple binary (Mt 19:12).

Far from despising those who are different, God provides a special place for some as variations within male and female (Is 54:1–5), and for others as not male or female (Is 56:4,5). So, male, female, and other—Scripture maps the diversity of biology into three sex classifications.

Some people change their classification—for the sake of the Kingdom—by modifying their anatomy (Mt 19:12).

My body is intersex—a biological mix I've altered. But I'm also female in the eyes of God's law, and though a barren woman, free to marry (Gn 11:30, Gn 29:31, 1Sm 1:6).

Before she died, my mother asked whether I'd be male or female in heaven. *Perhaps neither, Mom* (Gal 3:28). I told her I didn't know, but was sure I wouldn't care. My Redeemer loves me.

### Removing the Mask: Hopeless Isolation to Intersex Advocacy

Alexandra von Klan

Strangers undoubtedly perceive me as female, but I identify as an intersex woman. My karyotype is 46,XY, a typically defined marker of male biological sex, and I was born

with undeveloped, non-functioning gonads. As an intersex person, I know firsthand the negative consequences of pathologizing intersex people's lived experience by categorizing otherwise healthy, functioning organs and bodies as abnormal. The following narrative recounts conversations and interactions with medical providers during my diagnosis and subsequent treatment of pure XY gonadal dysgenesis, sometimes referred to as Swyer Syndrome. I hope to elaborate upon emotionally significant actions and inactions of medical care providers to expose consequential effects on my emotional processing, physical health, and self-actualization.

In December 1988, I was born with "typical" female genitalia. No one knew I was an intersex woman with 46,XY karyotype. Thus, there was no hesitation in the announcement of the birth of a girl in the delivery room or later, on my birth certificate. My parents raised me as a girl and dressed their firstborn in culturally normative feminine garments and accessories: lace frilly frocks, oversized bows, white stockings, and black patent leather Mary Jane's. I embraced femininity and expressed this gender identity throughout my childhood and adolescence. I'm the eldest of six children split between two households.

In January 2005, a month after my sixteenth birthday, delayed puberty and absent menstruation prompted an appointment to a local women's health center. Nurses collected blood samples and administered an MRI scan on my pelvic region. A week later, my father received a perplexing phone call. An inexperienced doctor told him "there must be something wrong" with me, because lab results revealed I was "chromosomally male." My father recalls the information presented like, based on the evidence, "your daughter may not be completely female," and that is that. His impression was that she knew little about the subject and was a bit clueless. She did not mention Swyer Syndrome, or any diagnosis for that matter.

Up to this point, I was unaware that a member of my extended family also had Swyer Syndrome. Born in the 1950s, secrecy engulfed her medical treatment and doctors warned her parents against revealing her true chromosomal sex in order to prevent the hysterical panic and depression they

thought the truth would bring. Years later, she sought her medical records and unearthed the truth. Shortly after my father received that dubious phone call, my relative's endocrinologist provided a referral to his mentor, "Doctor A," a clinical reproductive endocrinologist.

Under Doctor A's care, I experienced the first of many pelvic exams. Much to my discomfort, Doctor A inspected my semi-clothed body with a male resident in the room. As a people-pleasing teen, I granted permission for his presence; I didn't voice my preference for a female alternative. Doctor A's cold hands pressed around each undeveloped breast, pulled a gown away from my hips to inspect a sparse patch of pubic hair, and conducted an examination of my vaginal canal.

Shortly after the examination, Doctor A charted Swyer Syndrome as the official diagnosis. Speaking to my father and me, he described my condition as an extremely rare genetic mutation. He told us that Swyer Syndrome was an intersex condition, a group of congenital disorders impacting a person's internal or external reproductive systems, including endocrine function and genitalia. He explained I had atypical streak gonads instead of ovaries and that, despite having typical male sex chromosomes, I was still very much a girl. He disclosed that my vaginal canal was moderate in length, perhaps further evidence—or consolation—that my body possessed normative female reproductive attributes after all.

Next, Doctor A identified a pressing medical concern—golf-ball-sized benign tumors had developed on each streak gonad; if allowed to remain, they would pose an increasing risk of malignancy. We scheduled an appointment for laparoscopic gonadectomy six months later. I left his office with a 3-month prescription for estrogen and progesterone oral tablets. On the way home, we drove to an electronics store where my father purchased several gifts for me—his way of showing love and sympathy.

To aid in writing this narrative, I reached out to my father to obtain significant details during the time period of my diagnosis. I asked him specifically to recall memories from our meeting with Doctor A. After my diagnosis, we rarely discussed *his* feelings

and point-of-view about that meeting, so learning more about his responses was incredibly enlightening, and ultimately strengthened the connection between us. He shared his initial belief with me that I didn't necessarily have a defect or a mutation and was not abnormal. In our recent conversations, my father emphasized that his overall conviction and intuition about biological sex variance remains unchanged—that nature is way more complex than modern science paradigms can explain.

During that meeting with Doctor A, I wasn't provided resources to bolster or guide successful emotional and psychological processing of my diagnosis. How is a sixteen-year-old expected to tackle the inherent complexities of inhabiting a liminal body situated at the borderlines of normative maleness and femaleness? Despite the fact that my parents recall being advised I had a uterus, the cascade of new information I encountered seems to have blocked my own awareness of that vital somatic capability. Rather, I couldn't stop thinking about culturally perpetuated stigmas that my infertile, "chromosomally male" body was abnormal, mutated, and defective.

I felt invisibly different from my peers, close friends, and family members. When you're sixteen, anything different is considered weird and unacceptable. As my parents' first child, I caressed and embraced my newborn siblings shortly after delivery. After my diagnosis, I grieved my chance at motherhood, feeling significantly less than whole. In retrospect, I wish counseling had been offered to me during my first meeting, or follow-ups, with Doctor A. Due to the absence of counseling recommendations or support group resources, I resorted to seeking information about intersex diagnoses on the Internet, which provided positive and negative search results.

By happenstance, in the months prior to my laparoscopy, the 2005 annual gathering of the Androgen Insensitivity Support Group-USA (now called the AIS-DSD Support Group) was held less than an hour away from Doctor A's office. No recommendation to attend this support group gathering was provided to me at the time of my diagnosis. Had I known of such opportunities to engage with teens and adults with similar life experiences, I imagine being spared years

of emotional turmoil and crippling isolation. After my diagnosis, I rarely discussed my feelings about having Swyer Syndrome and avoided emotional attachment during the few instances I disclosed my intersex status to close friends.

After my laparoscopic surgery, I checked in with Doctor A every six months until I started college in fall 2007. Due to a variety of factors—including limited mobility, newfound independence, school distractions, and preoccupation with increasing substance abuse and Bulimia Nervosa—I discontinued physical visits with Doctor A and reverted to calling in hormone prescription refills. My hormone modulation remained stagnant for three years, further stalling menstruation. Months passed when I wasn't prescribed progesterone, posing a health risk. I only later came to learn that progesterone is essential to slough the endometrium—the inner mucous membrane of the uterus—every month and infrequent sloughing causes endometrial build up, also known as endometrial hyperplasia. Left untreated, endometrial hyperplasia can lead to endometrial cancer. I suspect the infrequency of in-person medical visits negatively impacted my physical care because my providers could not perform ultrasound imaging of endometrial growth and could not monitor my hormone levels.

In November 2010, I consulted another endocrinologist, "Doctor B." Under Doctor B's care, I began to understand, for the first time, essential components of my internal reproductive anatomy, and learned about my body's capacity to carry a pregnancy using assisted reproductive technologies. During the years following my initial diagnosis with Doctor A, I managed to block out and inadvertently neglect basic medical information such as the existence of my uterus, and my ability to menstruate under optimal hormone regulation. During a vaginal ultrasound, Doctor B showed me that I had infantile uterus and thin uterine lining caused by low estrogen levels. Doctor B framed recommendations for hormone replacement therapy (HRT) based on my preference to carry a future pregnancy, but provided HRT options if I chose not to menstruate, as well. At our meeting's conclusion, I requested a simplified copy of Doctor B's notes for reference purposes.

Following Doctor B's advice, I diligently administered my HRT and menstruated for the first time three months later. Under her care, I scheduled twice-annual visits unless there was a significant medication change. When I moved out of state, she strongly recommended I find an endocrinologist closer to me in order to maintain rapport in person. Since my diagnosis, I've learned that acquiring second opinions boosts my agency as a well-informed patient and fosters more precise decision-making. Additionally, consulting intersex peers and elders with Differences of Sex Development (DSD) enables comparisons between our experiences with varying HRT, empowering me to request alterations to my medical care.

For example, during a recent meeting with a third endocrinologist, "Doctor C," I inquired whether I was a candidate for testosterone supplementation and requested a blood panel to check my testosterone levels. During sexual intimacy with my partner, I often experienced deflated or non-existent libido, in addition to feeling tired and listless most days. When I discussed my dilemma with peers living with DSD, several recommended and praised their decisions to introduce low levels of testosterone, claiming an increase in their libido and physical energy. Aware of testosterone's irreversible side effects, I was still persistent in asking for a blood panel and curious as to how much testosterone secreted from my adrenal glands.

Doctor C respectfully denied my request for a blood panel, however, contending that no FDA-approved testosterone supplement is on the market for women. I felt as though my unique biology warranted special consideration because my anomalous reproductive and endocrine system is exactly what separates me from most women. A blood panel would have satisfied my curiosity about whether or not my testosterone levels were significantly lower than people with functioning, developed testosterone-secreting ovaries.

In response to my decreased libido, Doctor C offered me the comforting statistic, that 98% of her female patients have similar complaints. As a remedy, Doctor C provided a referral to a sex therapist and suggested investing in erotic films to

stimulate arousal. Furthermore, she indicated that my current hormone modulation—3 mg Estradiol and 5 mg Northirndrone—was enough to ensure that my uterus “behaved.” I took this off color comment with a heavy grain of salt, yet couldn’t help interpreting that my disobedient, deviant uterus required normalizing hormonal maintenance. Fortunately, thanks to DSD peer support groups, rather than dealing with medical providers’ inappropriate, insensitive, uncomfortable comments in isolation, I have a network of young people with DSD I can turn to.

In November 2010, I met the first person—outside of my family—with Swyer Syndrome. Despite a 2-decade age gap, we connected immediately, exchanging similar anecdotes about our diagnoses, positive and negative experiences with disclosure, and insecurities sparked by sexual intimacy. At the time, she was president of the AIS-DSD Support Group and spoke fearlessly about the imperative to shift DSD medical treatment in the United States to accept non-binary intersex bodies and offer support to families of children with DSD. After gauging my burgeoning interest in her work, she introduced me to a cohort of intersex advocates, several of whom operated a non-profit legal organization that promoted and preserved the civil liberties of children born with atypical variations of sex anatomy. Having grown up without stable, authentic representations of people with DSD, I felt that I could make a difference for others by becoming an advocate for intersex people.

Working alongside that non-profit, I helped develop Inter/Act Youth, a youth advocacy program for teens and young adults born intersex. I imagined that my self-actualization as an intersex person would have benefitted from collaboration

and insightful dialogue amongst peers with DSD. Operated by teens and young adults with DSD, Inter/Act Youth increases intersex awareness to reduce cyclic shaming of bodies or identities that don’t conform to the dyadic sex model. By bringing together experiences with positive and negative DSD treatment, we strive to uncover the dangerous hubris of modern medicine. We’ve created educational materials for doctors and parents of children with DSD to better inform their decision-making. Last summer, we provided a dramatic presentation of our experiences—both helpful and harmful—with medical treatment as part of a Continuing Medical Education session focused on DSD. Our members contribute evocative, affecting personal stories to a publicly-accessible, online website accessible around the world. DSD activism and advocacy are certainly not always essential or desirable routes for every person with DSD, but they provide empowering, healthy outlets to gain agency as a member of a minority group.

I try to avoid referencing body parts as “abnormal”, “ambiguous”, “atypical”, or “mutilated”. Normalcy exists and is defined in opposition to what’s described as unexpected, unusual, and unique. My life experience is exceptionally normal—to me at least—and although my internal reproductive traits didn’t follow a typical path, I’m not an atypical person. I focus on my body’s innumerable capabilities, rather than accentuating its shortcomings.

Preventable lapses in my diagnosis, prognosis, and treatment impacted my bodily integrity, emotional, and physical health. Based on my experience, intersex children, teens, and adults are entitled to compassionate, multi-faceted care in order to make informed decisions regarding their anatomy.

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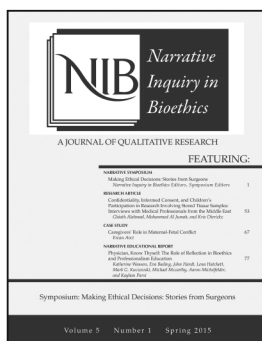
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