The Son They Never Had

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Introduction
Normalizing Intersex: The Transformative Power of Stories

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Abstract. The voices of 13 people with intersex traits are shared in this symposium to shape dominant medical discourse about intersex bodies and experiences. Four commentaries on these narratives by experts from various disciplines are included in this issue, with each raising questions that hopefully enhance rather than regulate the voices of people with intersex traits.

Key Words. Disorders of Sex Development, Intersex, Medical Apology, Normalization and Normalizing Interventions, Shame

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 premalignant 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 that 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. Coincidentially, 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."

**

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 workweeks. 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

My 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 stiches 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 skein 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 corposa 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 and www.accordalliance.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 to 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

As 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 pyschic [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 16th 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.