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Courtesy Ali von Klan; Courtesy Axel Keating

THIS IS WHAT IT'S LIKE TO DISCOVER YOU'RE INTERSEX AS A TEEN

TWO INTERSEX 20-SOMETHINGS SHARED THEIR STORIES WITH MTV NEWS IN HONOR OF INTERSEX AWARENESS DAY.

by [KRISTINA MARUSIC](http://www.mtv.com/news/author/marusick/) ([HTTP://WWW.MTV.COM/NEWS/AUTHOR/MARUSICK/](http://www.mtv.com/news/author/marusick/))

10/26/2015



Last year when Lauren, everyone's favorite bossy-blond-mean-girl character on MTV's "[Faking It](http://www.mtv.com/shows/faking-it/)," revealed that she was intersex, a lot of people were confused. Luckily, Bailey De Young, the actress who plays Lauren, [teamed up](http://www.mtv.com/news/1974481/intersex-awareness-day/) with the amazing Emily Quinn — who is Intersex IRL and consulted on Lauren's character for the show — to clear things up in a PSA.



“Being born with an intersex condition is almost as common as being born a redhead,” Quinn revealed in the video. The pair went on to explain other facts about being intersex — like that there are more than 30 (<http://www.isna.org/faq/conditions>) different intersex variations (“intersex” is an umbrella term), that sometimes doctors can tell when someone is intersex and sometimes they can’t, and that people can find out they have an intersex variation at any age.

Today (Oct. 26) is Intersex Awareness Day (<http://intersexday.org/en/category/events/awareness/>), and to celebrate, MTV News caught up with 22 year-old Axel Keating and 26-year-old Ali von Klan, two super badass intersex awareness activists who both learned that they were intersex as teenagers. Now, they’re both proud to work with the youth-run intersex awareness organization Inter/Act (<http://interactyouth.org/>). These are their stories.



Axel Keating

MTV: When did you first learn that you were intersex?

Keating: I found out I’m intersex at 19 years old, which is a little bit later than most people find out that they’re intersex.

I also identify as trans, so I was having blood work done in order to start hormone therapy. One of the findings was that my hormone levels weren't in the typical "female" range. They kept doing more tests and it took about two years for them to figure out that I have Congenital Adrenal Hyperplasia ([CAH](http://www.mayoclinic.org/diseases-conditions/congenital-adrenal-hyperplasia/basics/definition/con-20030910) (<http://www.mayoclinic.org/diseases-conditions/congenital-adrenal-hyperplasia/basics/definition/con-20030910>)). CAH affects the way the adrenal gland creates cortisol, which can be potentially life threatening for some variations of CAH if not monitored, and can affect the size and appearance of the genitals. They told me what that was about and what that meant in terms of my body and my hormones.

I went to a few gynecologists and eventually learned that there had probably been a medical procedure done against my genitals as a child without my knowledge.



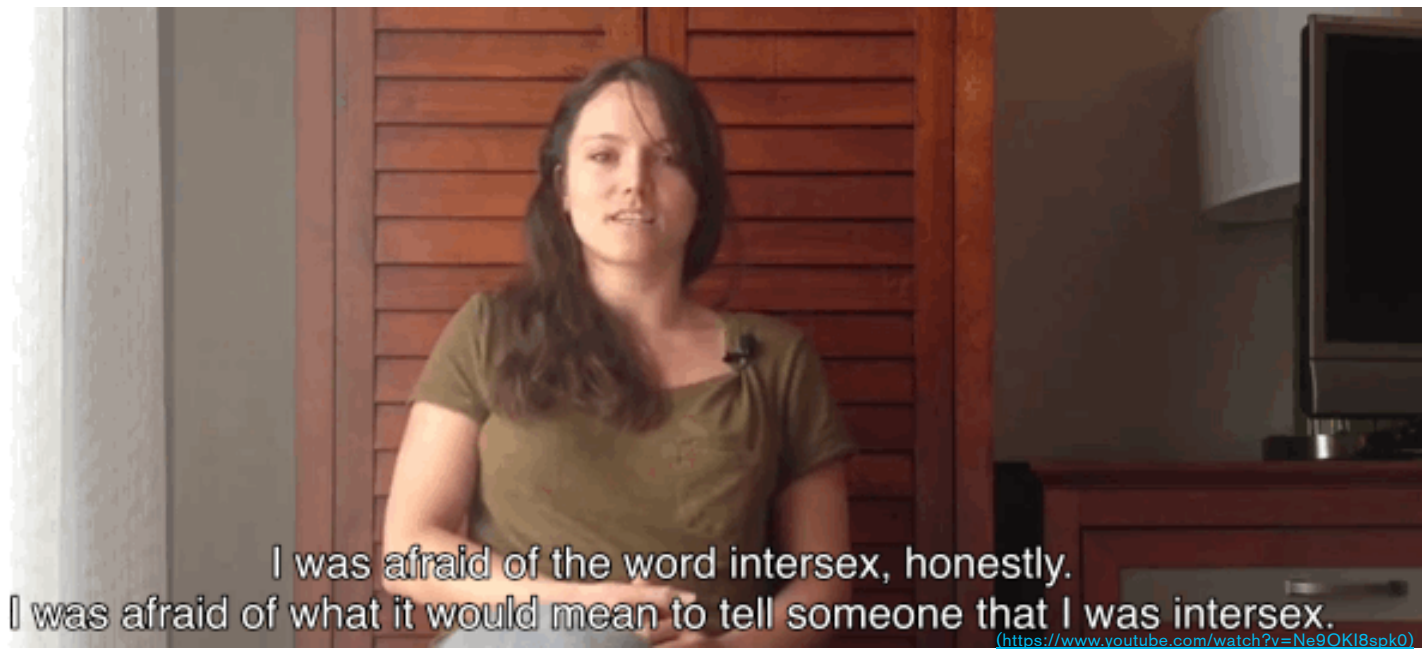
Ali Von Klan

Von Klan: I didn't see a physician about my difference in sex development until I was 16, when my main reason for going to the doctor was due to the absence of a period. I exhibited some secondary sex characteristics of a typical female. I had body hair and I had acne. But I had very little to no breast tissue development whatsoever. I was also really athletic... so I looked at myself at the mirror and I didn't see a very feminine form, and all of that combined gave me a lot of anxiety about what the doctor was going to say when I went in.

I had blood drawn and an MRI of my pelvic region. And then a week later, my father received a perplexing phone call. Either a doctor or a nurse spoke to him over the phone and he remembers them saying that there must be something wrong with the results because they revealed that I was chromosomally male.

I went to a second appointment with an endocrinologist where I was told the truth about my body — I learned that I have [Swyer Syndrome](http://www.webmd.com/a-to-z-guides/swyer-syndrome) (<http://www.webmd.com/a-to-z-guides/swyer-syndrome>). I learned that I have XY chromosomes, and that although my body developed phenotypically female — I have a uterus, a fallopian tube, vaginal canal, and vulva — I had developed no [ovaries], so no egg development whatsoever.

What I really took out of this appointment, as a 16-year-old, was feeling really upset thinking that I was never going to get a period and might never be able to have kids — which ultimately turned out not to be true, since with hormone modulation I can menstruate, and could potentially carry a child one day — but at the time, I felt a lot of grief and sadness over that loss of typical femininity.



Ali von Klan/*Interface Project* (<https://www.youtube.com/watch?v=Ne9OKI8spk0>)

MTV: What was the response from your family like?

Keating: I had never heard about this growing up — no one had ever talked about this. So that summer I went back home and talked to my mom about it. I asked her, “Have you ever heard of this thing? Have you ever heard of intersex people? Have you ever heard of this intersex variation?” And she said she had never heard of it before.

But then I started using more vague language like, ‘Have you ever heard of things like ‘Have you ever heard of sex that isn’t strictly considered “male” or “female?”’ And finally after talking about it for a little while, she remembered that when I was born, the doctors weren’t really sure of my sex. And she started connecting the dots.

She remembered that the doctors had suggested a surgery in order to “fix” what they called a “disorder” that the doctors said occurred in the womb in regards to my sex, and she thought it was just a correction for something that might have gone a little bit “wrong.” She was in her late 40’s when she had me, so she had always been worried that that something was going to go wrong with me. She just wanted the doctors to make sure I was OK. But the doctors used inaccurate language such as “difference” or “disorder” to convince her to consent to this surgery.

However, nothing was wrong with me. I have a natural variation of sex. They just used that language in order to fit me into an imagined sex binary, thinking that it would be better for me. But it actually has created a lot of harm for me, and for many other people.

Keating: And then everything made sense — all the things that had seemed a little bit off about my body, especially in terms of the pain around the places where they performed surgery on me — on my genitals; it made sense why there was a lot of pain and sensation around there and why I had a lot of body hair and a precocious puberty.

It took me a while to deal with the anger and frustration of not being told about this by any of my doctors ever in my entire life. I also felt anger at my parents for a little while. Eventually, I was able to forgive my mom and understand this was something she wasn’t told either, and the doctors had kept this from her as well. They were never really honest with her about her child.

Von Klan: My parents were divorced when I was 2. I was living with my dad at the time, so my dad was there with me, and he was really great. He asked all the right questions.

My doctors told my parents everything they needed to know. What I lacked and maybe what my parents lacked were directions to peer support groups that would perhaps better explain ways to support a 16-year-old with Swyer Syndrome. My dad had really good intentions asking about how I was feeling, but my automatic response was always just, "Fine," as most teenagers do. It took me a long time to really find a community and the support system I needed.

MTV: Did you come out to any of your friends as intersex when you found out?

Keating: I came out as bisexual when I was in sixth grade and I came out as trans when I was 14, and then came out as queer sometime later in high school. So I already had a lot of experience coming out to friends and family members, and I was very much already a part of queer and trans communities.

So when I found out that I was intersex, I was like, "Okay, this is just another identity I hold then." And I personally incorporated it as very much an identity for me from the beginning. Intersex is my sex identity.

I remember going to the bathroom and calling up my partner who I was dating at the time and telling him that they told me I'm intersex and I wasn't really sure what that meant for me. He was really great about that. ... I started dating a new person about a year ago, and I told him right when we started dating that I am intersex, and this is what it means for my identity and my body, and it's very liberating that we can talk about everything.

Embedded from [www.youtube.com \(https://www.youtube.com/embed/dPspfgOjvs0?feature=oembed\)](https://www.youtube.com/embed/dPspfgOjvs0?feature=oembed).

...I've also been really lucky to have a supportive community. I work at an LGBTQ student center, so everyone around me is queer or trans or an ally, and is very accepting of me being intersex. There might be some questions of what does intersex mean, or what does it mean to you? But everyone has been very open and willing to be educated on intersex identities and issues.

Von Klan: Right after I was diagnosed, I had a panic attack in the middle of a basketball game that crippled my ability to play. It was four days after I had found out. It was an intense game and I was the star defensive player. And in the middle of the basketball game, I just broke down and started sobbing.

My coach was so great — he was a really nice, supportive, father-figure of a guy, and he was very supportive — I didn't actually tell him what was wrong, but him being understanding still made me feel better.

I did tell a few close friends about my XY chromosomes and shared that I didn't get a period and I thought I could never have kids because of that, but I didn't know that intersex was an identity at that point.

<https://www.youtube.com/watch?v=Ne9OKI8spk0>

MTV: What can people do to be a good friend to someone who comes out as intersex?

Keating: You can do more research on your own into intersex identities to better understand what that means, and then you can help raise awareness about that by starting conversations about it when it comes up in places like school.

Being inclusive is really important, and because I work in a lot of queer spaces, I want my intersex identity to also be included and welcome by using acronyms like LGBTQI or LGBTQIA. I know that not everyone wants that, but for me, that is really important.

Everyone is different, and has different preferences around terminology, so it's also really important to talk with an intersex friend about how they view themselves — whether they view it as an identity, or however they might contextualize their intersex variation to be — and what terminology they would prefer to use, like intersex man, intersex woman, non-binary intersex person, person who happens to be intersex. It's important not to assume how being intersex affects any other aspects of their life or identities.

Embedded from [www.youtube.com \(https://www.youtube.com/embed/Ne9OKI8spk0?feature=oembed\)](https://www.youtube.com/embed/Ne9OKI8spk0?feature=oembed).

Von Klan: I think it's important to know that not every person who has an intersex variation identifies as intersex. They could identify as male or female as well — just ask questions, and try not to put people into a box or make assumptions about someone's sexuality or gender identity just because they reveal that their biological sex is intersex. Appreciate that there's a wide range of human experiences and human bodies.

You can always be there for a friend by asking how they're doing, and if they have an upcoming doctors appointment, maybe send them a message asking whether they'd like to talk about it, or about anything going on at home or in relationships. Just show that you care and have empathy.

You may not know what it's like to be given an intersex variation diagnosis, but you probably do know what it's like to have a secret that's hard to share.

For more stories and information about intersex youth, head to [InterActYouth.org \(http://interactyouth.org/\)](http://interactyouth.org/)

[KRISTINA MARUSIC \(HTTP://WWW.MTV.COM/NEWS/AUTHOR/MARUSICK/\)](http://www.mtv.com/news/author/marusick/)

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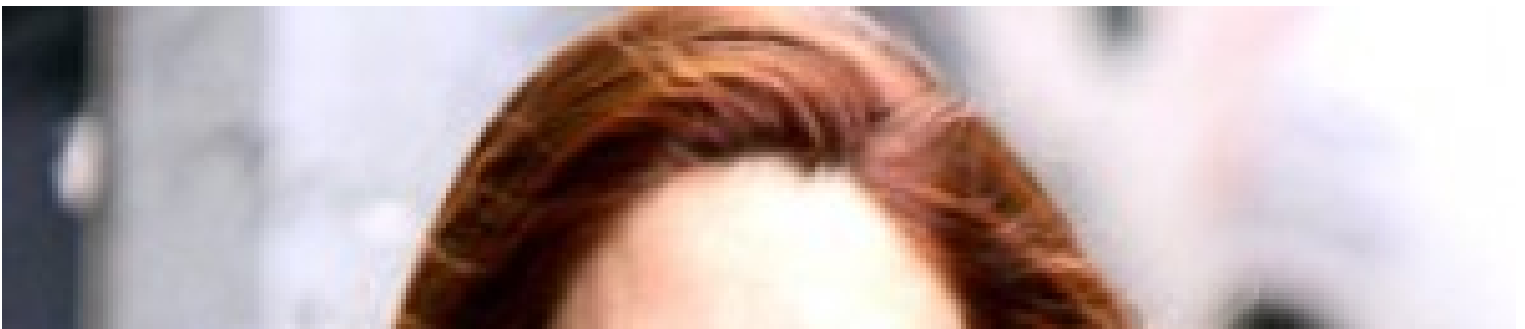
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