

# An interview with Katie...

**Katie, our teen/young adult coordinator discovered at age 17 that she has an "intersex" condition – a rare genetic disorder that caused her to be born without internal female sex organs. How has it affected her and shaped her plans for life beyond medical school? How did it shape her feelings? Why did she go on the Oprah show? Below is an excerpt from a story written for her college alma mater and was presented in one of their alumni publications.**

**Interviewer:** What is intersex and how is it relevant to you personally?

**KATIE:** "Intersex" is a word used to describe a group of medical conditions (around 30 have been defined) that result in a child having sex characteristics that are somewhat unusual. It can range from a girl having a slightly enlarged clitoris to a child's genitals being so ambiguous that his or her sex is not apparent at first.

I have one of these conditions, androgen insensitivity syndrome (AIS). Instead of having two x chromosomes like most girls do, I have an x and a y chromosome, like most boys do. as a result, I never developed a uterus or fallopian tubes, and my gonads (the word used for either ovarian or testicular tissue) were undescended testes. However, when my testes began to produce testosterone like they're supposed to, my body couldn't respond to it. Accordingly, I developed as female from the end of the first trimester of gestation on, never forming any male internal or external organs--I didn't look any different than any other girl (and I still don't!) so no one knew what was up until I had a hernia operation and the doctors found my testes where they expected to find ovaries.

**INT:** How common is it?

**KATIE:** AIS is pretty uncommon--only about 1 in 20,000 babies are born with it, but intersex conditions (or disorders of sex development, dsds) are far more common--about 1 in 2,000 in total.

**INT:** You mentioned the lack of uterus & fallopian tubes, but what about eggs & ovaries? could you have a child via in vitro and a host mother?

**KATIE:** My gonads were testicular, so I never had ovaries or eggs. I'm totally infertile (and excited to adopt!).

**INT:** Can you tell us what intersex is not?

**KATIE:** Intersex, as the name disorders of sex development implies, is a medical condition. Intersex is NOT the same as transgenderism or gender dysphoria, and has very little correlation with sexual orientation.

**INT:** When and how did you find out that you had this condition?

**KATIE:** I was diagnosed with AIS when I was 6, when I had a hernia operation, but I never knew the name of my condition until I was 17. My parents had given me bits and pieces of the story as I grew up (no period, no pregnancy, etc.), but it wasn't until my sister found some information on AIS that sounded like me and confronted my parents with it that I learned about my diagnosis and my chromosomes.



**INT:** How has this condition influenced your life so far, and going forward?

**KATIE:** You might be surprised to hear that AIS has not had a huge influence on my life so far. I didn't learn about it until my identity was already well-formed--when my parents told me, I already knew that I was a happy, healthy female teenager. To be honest, it's biggest impact has been giving me something to be passionate about, going in front of students and health professionals and educating them about one of biology's best-kept secrets.

**INT:** How did college academics fit in? Were you able to pursue your interest in class and the lab?

**KATIE:** I actually wasn't a science major, but a classics major. I think that was actually really helpful, because I learned first to think about the theory of gender (as it applied to ancient lit), and accordingly had a pretty flexible concept of sex and gender when I began thinking about doing activism and education. I'm sure you would have been more than supportive of my desire to do some research (a little of which I did on my own), but I wasn't brave enough to ask for help.

**INT:** How did this affect your personal life here in college?

**KATIE:** Not all that much, honestly. AIS is just part of my life, not my whole life, so I was able to do lots of things that had nothing to with my gender identity. That said, I did get involved with SAGA (Sexuality and Gender Alliance) and found that the friends that I made there and through my music extracurriculars were super-supportive and encouraged me to take my story public.

**INT:** How did it figure into your med school application?

**KATIE:** I knew that I wanted to go to med school so that I could help people with DSDS where it matters most--in the doctor's office--so that's what I wrote about. I focused on the disconnect between biology and society, how biology loves variation but society can't tolerate it, and that's where the problem is--when doctors look to outdated and unrealistic social norms to justify unnecessary medical and surgical procedures to make people look more male or female.

**INT:** Why go on Oprah?

**KATIE:** I went on Oprah because I wanted to raise awareness. It's time that people with and without DSDS learn what I have--that intersex is nothing to be ashamed of. It's time to break the silence and drive away the shame.

**INT:** Were you concerned the producers would treat you like a novelty du jour?

**KATIE:** Of course I was concerned! But they were so sensitive and thoughtful, making me feel very comfortable. Even though the promo is a bit sensational, I'm feeling positive about the way the interview went, even if it focused on my story and not the wonderful advances that have been made in uniting doctors and patients towards improving medical care.

**INT:** How did the 'studio audience' compare with 'audiences' you've discussed this with in the past?

**KATIE:** You know, the Oprah audience was very different from my other audiences in that they were definitely less informed and had probably never thought about gender identity or intersex before (many groups to whom I've spoken have been gay/straight alliances or medical interest groups), but they were just as thoughtful and warm--in fact, I think some of those women "got it" more than the most intelligent groups I've spoken to (outside of you, of course!)