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Raising
Awareness
Intersex

*Koomah, an artist, advocates for education and awareness
regarding the intersex community.*



By Shea Connelly | October 3, 2017



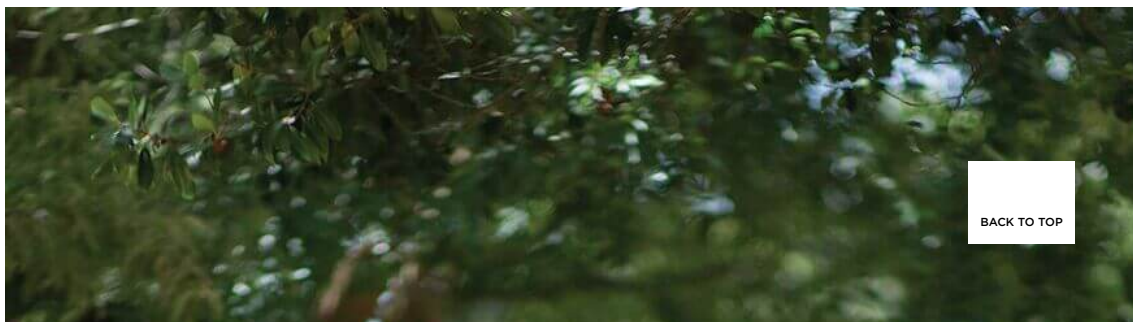
Raising Awareness of Intersex Issues

7 MINUTE READ

Every Friday night, for years, Mo Cortez and Koomah attended the same youth group. They sat in a room together for hours, neither knowing they each harbored the same secret intersex.

"We both didn't talk about it, because there was a lot of shame and stigma," said Koor one name. "We sat next to each other for years feeling like the only person on the face

It wasn't until 2012, about a decade after they had met, that they discovered a kinship existed. Koomah, an artist, had written a performance piece that was related to being heard of the performance through a friend, which led to the two reconnecting.



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Koomah, left, who goes by one name, and Mo Cortez first met as teenagers, not knowing both [BACK TO TOP](#) *reconnected a decade later and founded the Houston Intersex Society.*

“That day, we decided nobody else should ever feel like we had,” Koomah said. June 17 was the founding of their organization, the Houston Intersex Society.

The term “intersex,” also known as “differences of sex development,” or DSD, refers to conditions in which development of chromosomal, gonadal or anatomic sex is atypical (American Medical Association (AMA)). While DSD conditions are not common, they are particularly rare—some estimates indicate between 0.05 and 1.7 percent of the population have intersex traits, according to the Office of the United Nations High Commissioner for Human Rights (OHCHR). The upper limit of that range is similar to the number of people who are born with

For decades, intersex conditions were seen as issues that needed to be corrected as often via surgery on infants or young children. “It used to be believed that a lot of sex was socially determined,” said Janet Malek, Ph.D., an associate professor in the Center for Gender and Health Policy at Baylor College of Medicine. “The practice was to make a decision as early as possible, and then raise the child with that gender the parents or doctors agreed was best, often depending on physical features.”

Cortez, 33, a contractor at a military vendor, recalled the first time he realized his body was different when he woke up in the hospital at age 5, post-surgery.

“Medically I was considered ‘corrected,’ but that was the first time I had a vague inkling that I was different,” Cortez said. Born with ambiguous sexual organs, Cortez said doctors told his mother to raise him as a girl. When he was 5 years old, his “mother was turned in to child welfare because someone was raising a boy as a girl,” according to personal medical records provided by Cortez.

“They went ahead and performed normalization surgery” to make him appear more female, Cortez said. “For the rest of my life, I will have to take synthetic hormones.”

Cortez’s experiences are not uncommon among intersex adults. But in recent years, more people are advocating for a change in the way the medical community approaches intersex conditions. One such moment, Koomah said, was a public demonstration held by intersex organizations at the American Academy of Pediatrics conference in Boston.

“That was a springboard moment of this community coming together and not being afraid to speak up anymore,” Koomah said. That day—Oct. 26—has since been declared Intersex Awareness Day. In 2017, Houston’s City Hall was illuminated in yellow and purple to mark the occasion. This year’s celebration will take place on Oct. 25.

Intersex individuals, along with the United Nations, human rights organizations and medical professionals, have also been questioning the practice of performing medically unnecessary surgeries on intersex infants or young children before they have the ability to understand and consent.

On 2016 Intersex Awareness Day, the U.S. Department of State released a report stating that intersex persons routinely face forced medical surgeries that are conducted at a young age without their

informed consent. These interventions jeopardize their physical integrity and ability to

And more recently, in June 2017, three former surgeons general—M. Joycelyn Elders, M.D., and Richard Carmona, M.D.—released a document entitled “Re-Thinking Genital Surgery for Intersex Infants.” They urge that “treatment should focus not on surgical intervention but on educational support for the family or child ... until children are old enough to voice the decision whether to undergo the surgery.” The question of informed consent is a key ethical consideration that comes to medically unnecessary surgery on children, Malek said.

“The idea here is that we should let the child be the one to make that decision. If the parents have the surgery very early on, they take that choice away from the child,” Malek said. “In the fact children will grow into adults who will need to make their own decisions, we want to give them that choice.”

The AMA does not currently have a specific policy for treating intersex patients, however the House of Delegates is expected to consider adopting an official policy at a future meeting. The organization does have established ethical opinions and policies that broadly address minors, including one that “encourages involving minor patients in decision making at an appropriate level.”

This past legislative session, Cortez and Koomah contributed to Texas Senate Bill 1342 which amended the Texas Family Code to prohibit “nonconsensual genital surgery” on intersex patients in state care. But the bill, introduced by Sen. Sylvia R. Garcia, D-Houston, died in the State Senate Committee at the end of the session.

Koomah and Cortez both emphasized that the bill was focused on surgeries that are “medically unnecessary.”

“There are things that do need surgical intervention right away, and we are not trying to ban all kinds of surgeries,” Koomah said. “But if it’s just cosmetic, it’s something that can wait until someone is older and can make their own decision.”

As part of that decision-making process, Marni Axelrad, Ph.D., a child and adolescent psychologist at Texas Children’s Hospital, counsels intersex children, as well as their parents.

“I talk a lot about gender identity, which is in some ways easier when it’s an older child whose gender identity is established,” Axelrad said. “With a baby, it’s tricky because we don’t know what the baby’s gender identity is going to be.” She added that typically children can reliably recognize their gender identity between ages two and four, “when it really becomes more established and clear.”

Additionally, Axelrad said, she discusses with parents the most developmentally appropriate ways to talk to their children about being intersex. Part of that includes initiating conversations when the child can understand that this is their body, and the importance of body autonomy. [BACK TO TOP](#)

“The ultimate treatment position for any child and any family is made on an individual about the overall wellbeing of the child,” Axelrad said. “Psychological wellbeing does p

Both Cortez and Koomah said their families did not have such open communication at or provide much psychological support.

“It was always a big secret. Part of that is I don’t think they fully understood it either. A own backgrounds and belief systems, they had their own perspective,” Koomah said. “ female enough for my parents, so there was this thought, ‘Well, if you’re not going to b going to be a boy.’ That didn’t really work either so I’m kind of in this great in between works and what makes me happy.”

Malek said society’s increased acceptance for ambiguity around gender, sex and sexual also be contributing to increased awareness and advocacy regarding intersex issues.

“People are more aware that it’s not necessarily black and white,” Malek said. “With inc understanding comes increased tolerance. Parents can say, ‘I’m OK with the idea that I whether my child is a boy or a girl.’ Obviously some still have a very hard time with it, I more accepting in today’s culture than it used to be.”

Acceptance, awareness, education—these are cornerstones of the advocacy work Cort doing. The pair, who live together as roommates, talk to medical students and give lec about being intersex. They attend conferences and participate in lobbying. Their goal visibility of intersex people in society so no other young people have to grow up with of isolation they both experienced.

“Our bodies are different,” Cortez said, “but embrace the diversity. Embrace the differ

“A lot of what is presented about our community is doom and gloom,” Koomah added of issues, but at the same time, there are a lot of happy, healthy, productive intersex p doing amaz-ing things. Our lives are not a tragedy. Whether a person has had surgery folks that are very happy with their bodies.”

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