



# INTERSEX 101

Show Up #4intersex – material courtesy of  
interACT: Advocates for Intersex Youth

Don't forget to introduce yourself! Explain how you learned about intersex, why it's important to you, and why the audience should care (whether it's your biology class, an LGBT group, your pet turtle...).



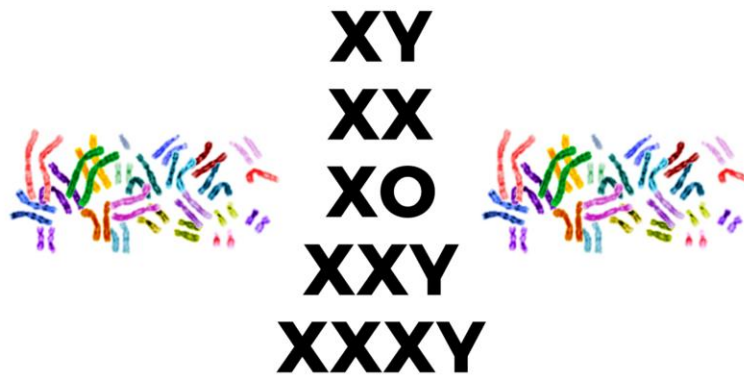
## What do you know about intersex?

Ask what people already know! That can get the audience engaged and set the tone. They might have some misinformation, so flag those points to come back to and correct as they come up in the slides.

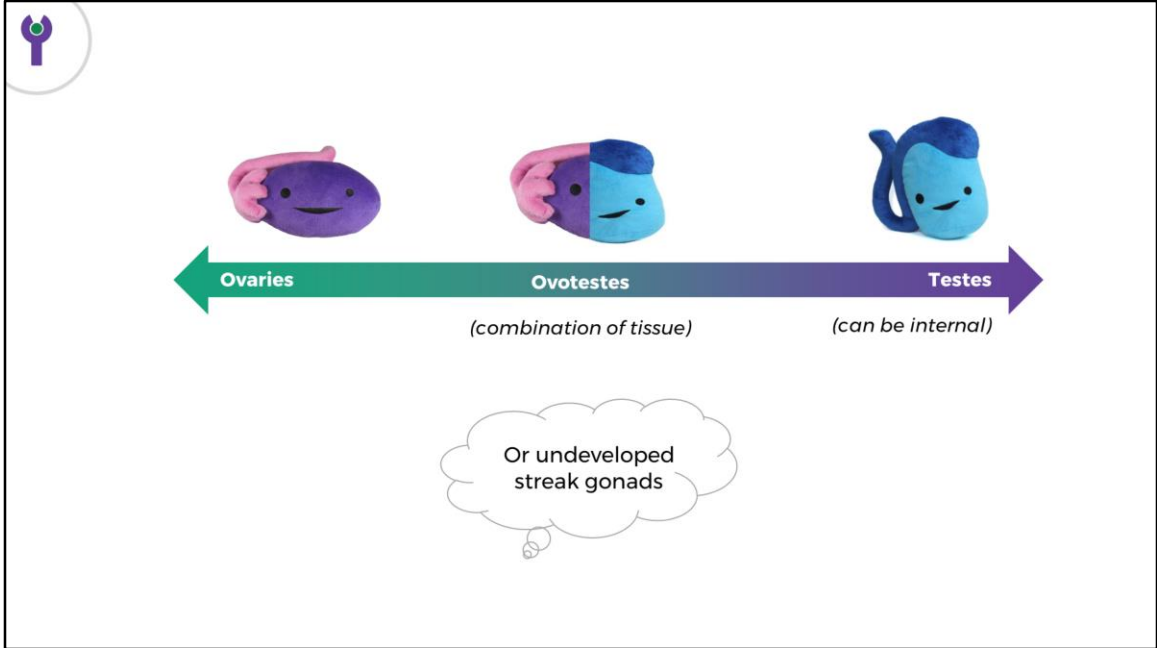


## There are lots of ways to be intersex.

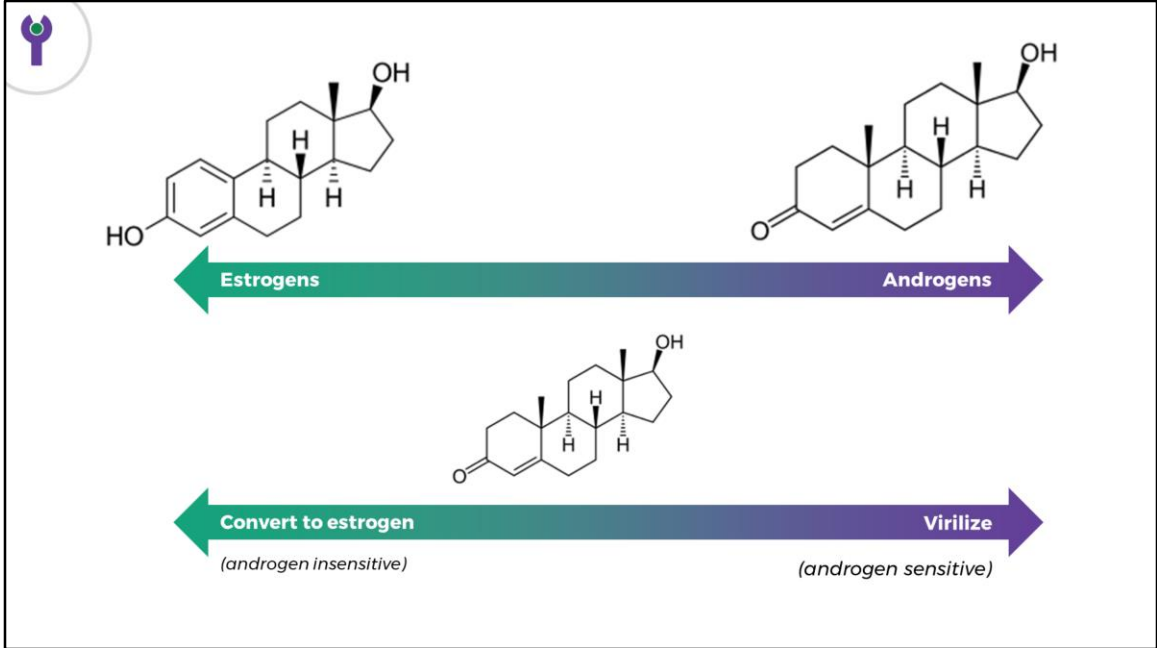
Just like there's no one way to be "male" or "female," there is no one way to be intersex, either! There are lots of different kinds of traits that can cause someone to have a variation in their sex characteristics, but what intersex people have in common is that their differences are either present at birth or manifest spontaneously at puberty. Intersex refers to physical sex characteristics that are different from what we usually think of as a typical male or typical female body – it is not the same thing as being transgender, but an intersex person can be transgender, cisgender, LGB, straight, or asexual – just like anyone else. Let's take a look at the specifics of how someone can be intersex so we can be clear about what we're talking about.



Intersex traits can be chromosomal, meaning that your chromosomes are something other than XX or XY – like XO, XXY, or XXXY – or that they are different from what is “expected” for your body, so you might have XY chromosomes with a typically female phenotype (physical appearance), or XX chromosomes with a typically male phenotype.



Intersex traits can be gonadal. Gonads are organs like ovaries or testes, but the tissue starts out with the potential to become either type and can also become a combination of tissue types (ovotestes). Sometimes the tissue becomes a type of gonad that isn't expected based on your external phenotype at birth, for instance someone with a vulva who later discovers that they have internal testes instead of ovaries. You can also have tissue that does not develop into either type – called “streak” gonads – that do not produce any hormones.



Intersex traits can be hormonal. This is where we get into issues like controversy in athletic testing. What is a “normal” range for estrogen and testosterone? What does your body produce? And whatever levels of hormones you produce, how does your body respond? In some intersex variations, your body produces testosterone, but you are completely insensitive to its effects, so you do not develop the typical secondary sex characteristics associated with testosterone, and your body instead converts it into estrogen.



Genital tissue also develops along a spectrum, too. The same tissue can become either labia or a scrotum. The same tissue can become either a clitoris or a phallus, but if the size falls somewhere in the middle of what is considered typical for either one, historically it has been up to individual surgeons to determine what is considered “normal” versus “in need of surgical correction.” In intersex infants we can see different combinations along these spectrums, and almost none of them carry medical consequences. The only urgency is if a child is unable to urinate. Outside of that case, any genital surgery on intersex children is enforcing arbitrary notions of “normalcy,” when we see that there can be a lot of natural variation.



<b>Common Parts of Intersex Variations</b>	<b>CAIS</b> (Complete Androgen Insensitivity Syndrome)	<b>Swyer</b> or Gonadal Dysgenesis	<b>CAH</b> (Congenital Adrenal Hyperplasia)	<b>Klinefelter's</b> (47 XXY)
<b>Karyotype</b>	XY	XX or XY	XX	XXY
<b>Gonad Type</b>	Internal testes	Streak	Ovaries	External testes (smaller than average)
<b>Sex Hormones Naturally Produced at Puberty</b>	Testosterone from testes	None	Estrogen and above average testosterone	Below average testosterone (may have breast development, infertility)
<b>Androgen Response</b>	Convert to estrogen	Virilize	Virilize	Virilize
<b>External Genital Appearance</b>	"Typical" labia, may have vagina that is short	"Typical" labia	May be considered "ambiguous," e.g. large clitoris	Often "typical" penis, smaller than average testes
<b>Frequency</b>	1 : 20k to 100k	1 : 150,000	1 : 20k to 36k	1 : 1,100 to 1,500

This table illustrates some common intersex variations and their mixes of sex characteristics. For example, people with Complete Androgen Insensitivity Syndrome have XY chromosomes and internal testes, which produce testosterone. Because the body is not sensitive to androgens, the testosterone is converted to estrogen, and this causes the development of secondary sex characteristics like breasts. There are many more variations than the ones listed – and not everyone agrees on what qualifies as “intersex.” For instances, variations like hypospadias, where the urethra opens somewhere other than the tip of the penis, might be considered intersex, and some people with polycystic ovarian syndrome also identify as intersex.





How common is it  
**to be intersex?**

(Pause for guesses.)



**Intersex people are  
0.5% to 2%\*  
of the population.**

\* About as common as twins or natural-born redheads in the U.S.

These estimates have a wide range in part because of the disagreements over what “counts” as intersex, as just mentioned.



# **1 in 2,000**

are at risk of receiving surgery in infancy to  
“normalize” genital appearance.

1 in 2000 is the approximate number of babies who are born with bodies that look different enough from what is “typical” for a male or female infant that they are at risk for genital-“normalizing” surgery. Again, these surgeries are cosmetic and not necessary for any medical purpose.



Intersex kids still face  
nonconsensual, medically  
unnecessary genital surgeries.

Often because of  
**social discomfort.**



Gonadectomy\*  
Orchiectomy of internal testes  
Clitoroplasty / Clitorectomy  
Vaginoplasty  
Hypospadias repair\*\*

\* in cases where gonads were healthy and producing hormones at puberty  
\*\* very high complication rate

What are some of these unnecessary surgeries, specifically? Gonadectomy – the removal of gonads such as ovaries or testes, including when they are healthy and producing hormones. Taking out hormone-producing gonads means the child must be placed on hormone-replacement therapy for the rest of their lives, and can also be sterilizing. Gonadectomy is sometimes said to be necessary to prevent the development of cancer, but for most intersex people, the risk of gonadal malignancy is very low and would not be considered a high enough risk to prompt the organs to be removed in someone who was not intersex – at least not before the individual could weigh their options and give consent. Clitoral surgery is intended to reduce the size of the clitoris so that it looks more “feminine,” and doctors who publish about these surgeries admit that the purpose is cosmetic and to make the body conform more closely to what is expected for a female sex assignment. Clitorectomy, which is complete clitoral removal, is said not to be practiced anymore. Vaginoplasty is the creation or enlarging of a vaginal opening, which some individuals may desire later in life, but it is never necessary to perform this procedure on an infant or young child, and doing so will mean the opening must be dilated with solid objects to keep it from closing after surgery. This can be deeply traumatic for children, who may not have wanted a vagina constructed in the first place. Hypospadias “repair” involves surgery to move the urethral opening to the tip of the penis, and while this might sound

relatively benign, this surgery has a very high complication rate that can involve extensive damage to both urinary and sexual function. People who have these surgeries as children often need multiple follow-up procedures to address complications introduced by the first one.



**Physical risks:**

Scarring  
Chronic pain  
Loss of sexual sensation/function  
Urinary incontinence  
Sterilization  
Need for lifelong hormone replacement therapy  
Complications requiring multiple follow-up surgeries

**Psychological risks:**

Depression, PTSD, increased risk of suicide  
Feelings of shame, isolation, and inadequacy  
Sex assignment not matching eventual gender identity

These are just some of the risks associated with these procedures when they are performed in childhood without the individual's consent.



“If **one time in 20** you're cutting  
a little boy's penis off,  
is that a risk worth taking?”

Anne Tamar-Mattis, quoted in “The Spectrum of Sex Development,” *Nature* 533: 160-163 (2016).

Other studies have acknowledged rates of  
incorrect sex assignment up to **60%**.

Ieuan Hughes et al., *Consensus Statement on Management of Intersex Disorders*, 91 *ARCHIVES OF DISEASE IN CHILDHOOD* 554 (2006)

Although far from the only risk of these surgeries, there is a significant chance that any surgery performed to make the child’s body conform more closely to the sex assigned might end up enforcing a sex assignment the individual later rejects. Depending on the diagnosis, this risk may be relatively low, around 5 percent – but see the first quote. Is it worth it to not wait until the individual can decide for themselves? Even if the assignment ends up being “correct,” having tissue non-consensually removed or altered will change the way it looks, feels, and functions in ways the individual might not desire, and these changes cannot be undone.





Up to 40% of these surgeries have complications. Many require multiple follow-up surgeries.



Based on all these risks, why are these procedures not a last resort?

**How did we get here?**



## How is gender identity formed *An interview with Dr. John Money*

### Part I

BY NORA HARLOW

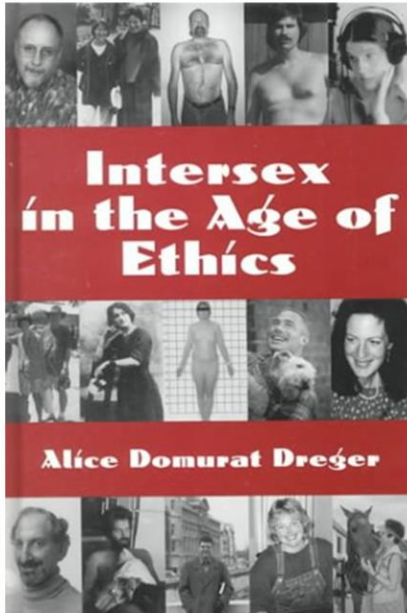
**The formation of gender identity**—one's essential maleness or femaleness—is, perhaps, the most important sexual happening in each person's life. Once thought to be absolute and irreversible from the origination of the first cell's designation as XX or XY, new findings in sexology suggest that not only are males and females strikingly similar in their prenatal development, but also that the newborn's mind is sexually undifferentiated as either male or female and must be instructed as to its proper sexual role.

To help the physician understand the far-reaching medical as well as cultural implications for these new insights concerning sexual differentiation, *Medical Tribune* consulted Dr. John Money, professor of medical psychology and associate professor of pediatrics at Johns Hopkins University and Hospital in Baltimore, Maryland and co-founder of the Gender Identity Clinic there. A pioneer in psychoendocrinology and director of Johns Hopkins' Psychohor-



Dr. Money's 25 years of work in psychoendocrinology at Johns Hopkins University and Hospital has led to new insights into the formation of gender identity—the way children differentiate as male or female. He is shown here at his home in Baltimore, MD., among his collection of African sculpture.

In the 1960s, the model of early genital surgery gained traction after a Johns Hopkins psychologist, John Money, popularized the theory that gender is malleable in early childhood, and that a child can be socialized in any gender if they undergo surgery so that their body “matches” that assignment. Importantly, for this to work, the child is not supposed to know that this ever happened, since this could introduce “gender uncertainty” and jeopardize their acceptance of the gender assignment. The case he is famous for – known as the “John/Joan case” – involved a patient, David Reimer, who had his penis badly burned in a circumcision accident as a baby. Dr. Money advised that the best course of action was to raise David as a girl, so he underwent feminizing genital surgery, and his parents renamed and raised him as “Brenda.” This case was widely reported as a success for many years, but it came to light later that David was never the happy patient Dr. Money reported. Once he learned the truth about what was done to him, he transitioned to live as a man, and eventually committed suicide. The theory, however, stuck. Intersex children are still operated on with the belief that it will make it easier for them to accept their gender assignment and psychosocially adjust, though there has never been any proof that this is the case.



**"It's easier to dig a hole than to build a pole."**

*Intersex activist Cheryl Chase quoting a surgeon*

Sexist ideas about what it means to be a “real” man or woman are also at play here. In the past, it was common to raise intersex babies as girls even if signs pointed to more likely identification as boys in the future – solely on the basis that their phallus size was considered too small to be “adequate” for standing urination and penetrating a vagina. Similarly, surgeries on children being raised as girls often prioritized vaginal capacity – the ability of the vaginal opening to accommodate an average-sized penis – and ignored considerations of sexual pleasure by, for instance, removing clitoral tissue for subjective aesthetic reasons.



“We'll get you on hormones so you  
can develop for your future  
husband.”

As much as doctors who still do these surgeries claim they are for the good of the patient, here are a few quotes that illustrate the perspective from which these treatment decisions are actually made. These are all quotes said to intersex youth by their doctors, and they show how the priorities and assumptions at work might be very different from an individual's reality.



“You’re not really a boy.”



“You can have **real** sex one day. We'll just start you on dilation or do a vaginoplasty when you're ready to start dating boys, or when your parents are ready.”



## What can we do?

Luckily, there are activists, human rights organizations, and allies in all sorts of places working to make sure intersex people are allowed to maintain their bodily autonomy.





**interACT** uses innovative legal and other strategies, to advocate for the human rights of children born with intersex traits.



interACT is the first organization of its kind in North America, founded to protect the rights of intersex kids. They do legal and policy advocacy, media consulting, and operate a youth program of over 60 members to develop young intersex leaders and advocates.



World Health Organization  
Amnesty International  
Human Rights Watch

UN Office of the High Commissioner for Human Rights  
UN Special Rapporteur on Torture  
NYC Human Rights Commission  
San Francisco Human Rights Commission

These are some of the human rights organizations who have spoken out against non-consensual, medically unnecessary surgeries on intersex children.



“Those whose oath or conscience says ‘do no harm’ should heed the simple fact that, to date, research does not support the practice of cosmetic infant genitoplasty.”

Dr. Joycelyn Elders, Dr. David Satcher, and Dr. Richard Carmona, US Surgeons General 15, 16, 17

This statement from three former US Surgeons General was released in 2017, acknowledging that early surgery does not have data on its side. In other areas of medicine, data showing a treatment’s benefits and efficacy would be required BEFORE it became standard practice – not so here, where proponents of early surgery are demanding clearer evidence of harm before they will consider NOT performing early surgery.



# CALIFORNIA

JUST BECAME THE  
**FIRST STATE TO PASS  
LEGISLATION ON  
INTERSEX RIGHTS.**

SCR-110 calls on the medical profession to delay cosmetic genital surgeries on intersex children until individuals can participate in an informed decision, per international human rights guidelines.

**interACT**  
@INTERACT\_ADV

In the US, unfortunately, there is currently no ban addressing these surgeries. However, in August 2018, interACT and Senator Scott Wiener passed a historic resolution, SCR-110: the state of California is the first U.S. state to acknowledge the harms of non-consensual medical interventions on intersex kids, and encourages their delay.



1. Never assume.
2. Talk to intersex people.
3. Be aware of your language.

What can you do on a day-to-day basis to help improve the world for intersex people? First, let go of your assumptions. This includes assumptions about what it means to be “male” or “female,” such as assuming that all women have ovaries and get their period, or that no men do. It also includes things like assuming all people want to have heterosexual relationships and penetrative sex. These come out in doctors’ comments to intersex patients about their “future husbands,” and also in the surgical decisions that are made before children have any idea how they will want to express themselves in their relationships. Second, talk to intersex people to find out what they want, how they want to be treated and how to best support them. Third, be aware of the language you’re using. Outdated terms (like the “H” word) can be very harmful, and even hearing the label “DSD” for Disorders of Sex Development can be triggering for some. Be careful also not to unnecessarily gender body parts – phrases like “male chromosomes” can be replaced with “XY chromosomes” to be more accurate.



SHOW UP  
#4INTERSEX  
RIGHTS



Support the work of intersex people  
and intersex communities of color

Intersex people are so easily dismissed as a small minority or a group of “angry activists,” but this is not the case! Use any chance that comes up to show others that you are for intersex rights, whether it’s sharing a video on social media, contacting your legislators, joining a demonstration at a hospital...and make sure to follow the #4intersex hashtag on twitter so you can be in the know about allyship opportunities that are coming up.



**Questions? Contact:**

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