



# Intersex Awareness

Aliza Norwood, MD, FACP, AAHIVS

8/25/23

# Conflict of Interest Disclosure Statement

- Speaker has nothing to disclose

This program is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of an award totaling \$4,205,743 with 0% financed with non-governmental sources. The contents are those of the author(s) and do not necessarily represent the official views of, nor does mention of trade names, commercial practices, or organizations imply an endorsement by HRSA, HHS, or the U.S. Government. For more information, please visit [HRSA.gov](https://www.hrsa.gov). *Any trade/brand names for products mentioned during this presentation are for training and identification purposes only.*



# Use of Trade/Brand Names

This program is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of an award totaling \$4,205,743, with 0% financed with non-governmental sources.

The views expressed do not necessarily reflect the official policies of the Department of Health and Human Services, nor does mention of trade names, commercial practices, or organizations imply endorsement by the U.S. Government. *Any trade/brand names for products mentioned during this presentation are for training and identification purposes only.*

# Unconscious Bias Disclosure

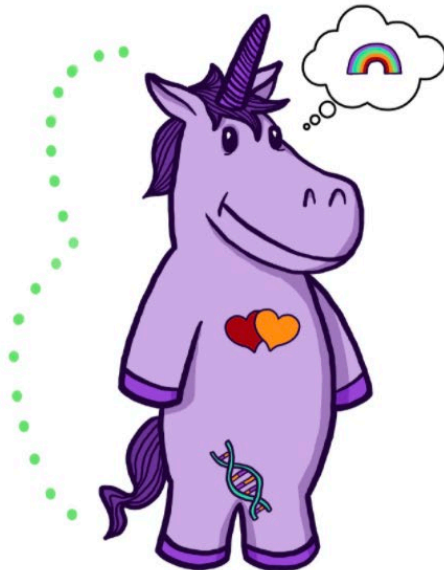
- SCAETC recognizes that language is constantly evolving, and while we make every effort to avoid bias and stigmatizing terms, we acknowledge that unintentional lapses may occur in our presentations.
- We value your feedback and encourage you to share any concerns related to language, images, or concepts that may be offensive or stigmatizing.
- Your input will help us refine and improve our presentations, ensuring they remain inclusive and respectful to participants.

# Learning Objectives

1. Understand what the I in LGBTQIA+ stands for and who it represents
2. Identify ways to reduce contributing to stigma & isolation for intersex people in your practice setting

# The Gender Unicorn

Graphic by:  
**TSER**  
Trans Student Educational Resources



To learn more, go to:  
[www.transstudent.org/gender](http://www.transstudent.org/gender)

Design by Landyn Pan and Anna Moore

# LGBTQIA+- Don't Forget the I

**L**esbian

**G**ay

**B**isexual

**T**ransgender

**Q**ueer

*I*ntersex

**A**sexual

**+** for all others

# Definitions



Austin Intersex Awareness Day  
October 26, 2019

- **Intersex:** Person born with a reproductive or sexual anatomy that doesn't fit the typical definitions of female or male sex. Socially constructed biologic category that reflects natural diversity of sexual anatomy. Distinct from gender identity.
- **REMEMBER:** terminology may not be universal, and that individual patients' needs & identity terminology may vary



# Harmful Intersex Terminology

## Avoid using:

- Disorders of Sex Development (DSD)
  - Introduced in medical community in 2005
  - Controversial and pathologizing
  - Some advocates replace “disorders” with “differences”, but most intersex community members prefer avoiding
- Hermaphrodite
  - Outdated, medically inaccurate term
  - Derogatory



**XY**

**XX**

**XO**

**XXY**

**XXXY**





**Ovarie**



**Ovotestes**

*(combination of tissue)*



**Testes**

*(can be internal)*

Or  
undeveloped  
streak gonads

# Examples of Intersex Variations

- 46, XX salt-wasting Congenital Adrenal Hyperplasia (SWCAH)
- Androgen Insensitivity Syndrome (AIS)
- 46, XY complete gonadal dysgenesis (Swyer Syndrome)
- 46, XY partial gonadal dysgenesis
- 5 alpha reductase-3 deficiency (5 ARD deficiency) and 17beta-hydroxysteroid dehydrogenase-3 deficiency (17 BHSD deficiency)
- Ovotesticular DSD
- Mayer-Rokitansky-Kuster-Hauser (MRKH)
- Hypospadias and Epispadias
- XO Turner Syndrome (TS)
- XXY Klinefelter syndrome



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

\* About as common as having twin births (~3%)

\*\* Compared to the U.S. population of transgender adults, self-reporting at 0.6% in a 2016 study

# History of surgery to “fix” intersex kids

- Lore of “social emergency” of gender assignment
  - Parental fear of ambiguous genitalia
  - Often told (w/ certainty) that gonads will become cancerous
- Clitoral resection/recession
- Gonadectomy
- Vaginoplasty
- Hypospadias/epispadias repair
- “Normalization” of sex organs

# Corrective surgery for ambiguous genitalia

## PROS

- reduce parental embarrassment and anxiety?
- infant surgery may be less technically challenging (though doctors with experience with transgender surgery are changing this paradigm)
- possible benefits to intervening before memory of surgery persists

## CONS

- irreversible
- risks of pediatric anesthesia becoming more and more apparent
- discordant gender identification can be “catastrophic”
- potential for chronic pain and lasting adverse effects

Credit: Dr. Ilene Wong Gregorio

# The perils of our assumptions of gender- & hetero-normativity

- **12.8% of girls with CAH exhibited gender identity disorder**
  - n=39
  - Pastereski V et al. *Arch Sex Behav.* 2015; 44: 1363-1375
- **14% of adults with CAH identified with a gender opposite their assignment at infancy**
  - n=28 (24 virilizing, 4 salt wasting)
  - yet study authors state in their introduction: “for physicians it is obvious and unequivocal that a person with CAH and an XX karyotype has a female gender identity”
  - Binet et al. *J Ped Surg.* 2016; 51: 465-468
- **25% of adults with DSD were dissatisfied with gender allocation**
  - n=69
  - Schweizer K et al. *Psychology & Sexuality.* 2013; 5(1): 56-82
- **33% of girls with CAH developed gender dysphoria that reduced HRQoL**
  - n=33
  - Jürgensen M et al *Eur J Pediatr* 2014; 173: 893–903

Credit: Dr. Ilene Wong Gregorio





# What Intersex People Wished Their Providers Knew

- Offer peer support and therapy; let them know they're not alone
- Don't assume gender identity or sexual orientation
- Ask patient how they would like the medical exam to go
- Give patient the option of who they want in the room with them (family members, other med professionals)
- Don't give a genital exam if simply for curiosity
- Have a pediatric speculum nearby
- Don't take pictures of their genitals



"I am proud to be working with interACT.

I hope that by telling my story more people get outraged at the human rights abuses suffered by intersex children around the world.

-- Hanne Gaby Odiele  
Model & Intersex Advocate

**InterACT**  
Advocates for Intersex Youth

Learn more about Hanne's story and what it means to be intersex!  
[interactadvocates.org](http://interactadvocates.org)

SHOW UP  
#4INTERSEX  
RIGHTS



Support the work of intersex people

# Intersex Resources

- Bright Spaces (HEAL+NM)
  - [Recommended policies](#)
  - [Training](#)
- 4Intersex
  - [www.4intersex.org](http://www.4intersex.org)
- InterACT Advocates for Intersex Youth
  - [interactadvocates.org/](http://interactadvocates.org/)
- Community & Expert lectures: **UT PRIDE Pop-Up**
  - <https://guides.lib.utexas.edu/pridehealth/videos>

# Intersex Media, Books

- The documentary *Intersexion*
- *Contesting Intersex* by Georgiann Davis
- *Raising Rosie* by Eric, Stephani Lohman
- Video stories via [The Interface Project](#)
- New film projects such as *Ponyboi*
- [Rewire.News on the Intersex Movement](#)
- [Confronting Those Who Do Surgeries](#)
- On intersex isolation in queer spaces

# Intersex Media, Books

- Intersex in Washington Post Magazine



# HIV Resources

- National Clinician Consultation Center

<http://nccc.ucsf.edu/>

- HIV Management
- Perinatal HIV
- HIV PrEP
- HIV PEP line
- HCV Management
- Substance Use Management

- AETC National HIV Curriculum <https://aidsetc.org/nhc>

- AETC National Coordinating Resource Center

<https://targethiv.org/library/aetc-national-coordinating-resource-center-0>

# Follow us on Social Media!

 @UTHSA\_AETC

 @UTHealthSAECHO

# SCAETC Social Media

PLEASE FOLLOW THE SCAETC ON SOCIAL MEDIA

facebook



@SCAETC

Instagram



SCAETC

twitter



@SCAETCNM