



ADVANCING EXCELLENCE IN SEXUAL
AND GENDER MINORITY HEALTH

Affirming Care for People with Intersex Traits:

Everything You Ever Wanted to Know, But Were Afraid to Ask

Katharine Baratz Dalke, MD MBE

She/Her/Hers

Director of the Office for Culturally Responsive Health Care Education

Assistant Professor of Psychiatry and Behavioral Health

Penn State College of Medicine

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NATIONAL LGBT HEALTH
EDUCATION CENTER



A PROGRAM OF THE FENWAY INSTITUTE
AND GENDER MINORITY HEALTH



HARVARD
MEDICAL SCHOOL

Goals

By the end of this hour, you will be able to:

- Appreciate the diversity of intersex traits, and the conditions associated with them
- Describe the traditional approach to people with intersex traits and its impact on health
- Implement an affirming approach to physical and behavioral health care for people with intersex traits



What are intersex traits?

Group of *congenital* variations relative to endosex traits

- Sex chromosomes, hormones, and/or internal or external genitalia
- May also see variations in secondary sex traits
- Included among sexual and gender diverse/minority populations
- Present at any time across the lifespan



About Language...

That  is complicated

- Hermaphroditism
- Intersex/uality
- Differences/Disorders of Sex Development
- Intersex (traits/conditions), DSD
- Endosex



Why Learn About Intersex?

People with intersex traits...

- Are common (1 in 100 - 2000)
- Benefit from quality medical care
- May receive care in SGM health settings
- Are rarely intentionally included in SGM health



Review of Sex Development



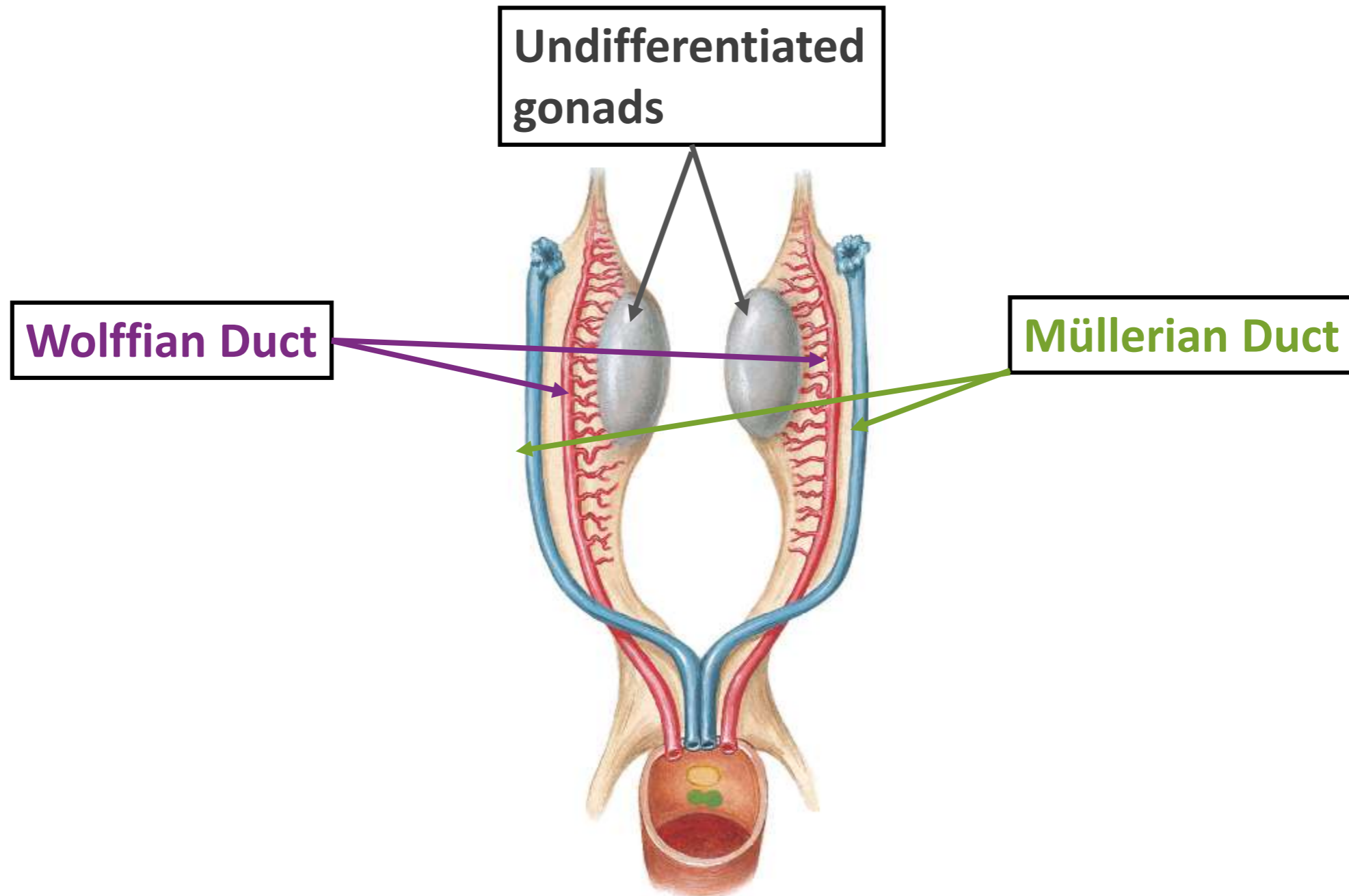


Sex Chromosomes

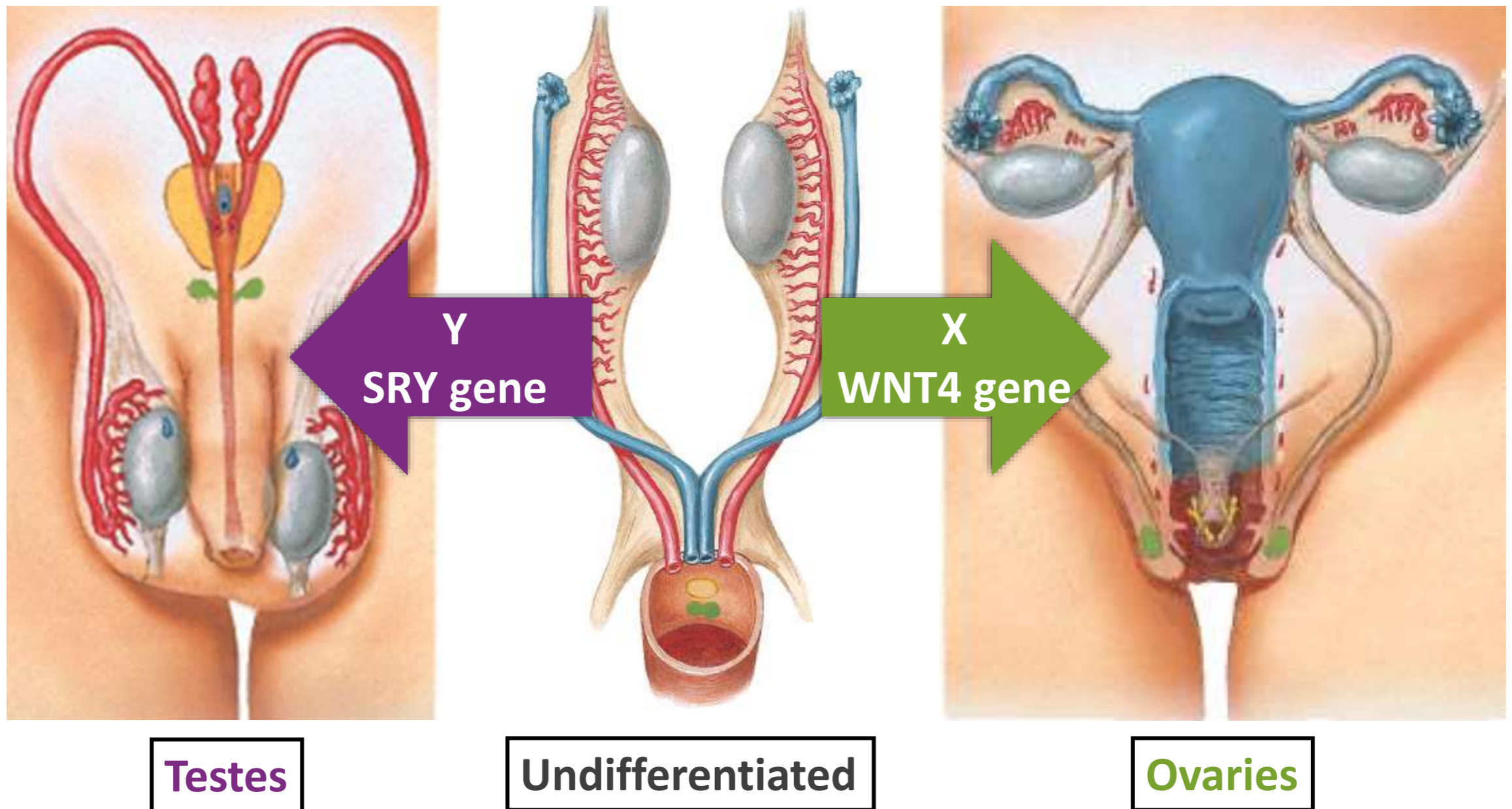
- Eggs: X, XX XO
- Sperm: X, Y, O, XX, YY
- Sex chromosomes initiate gonad development
- Gonads produce hormones and gametes



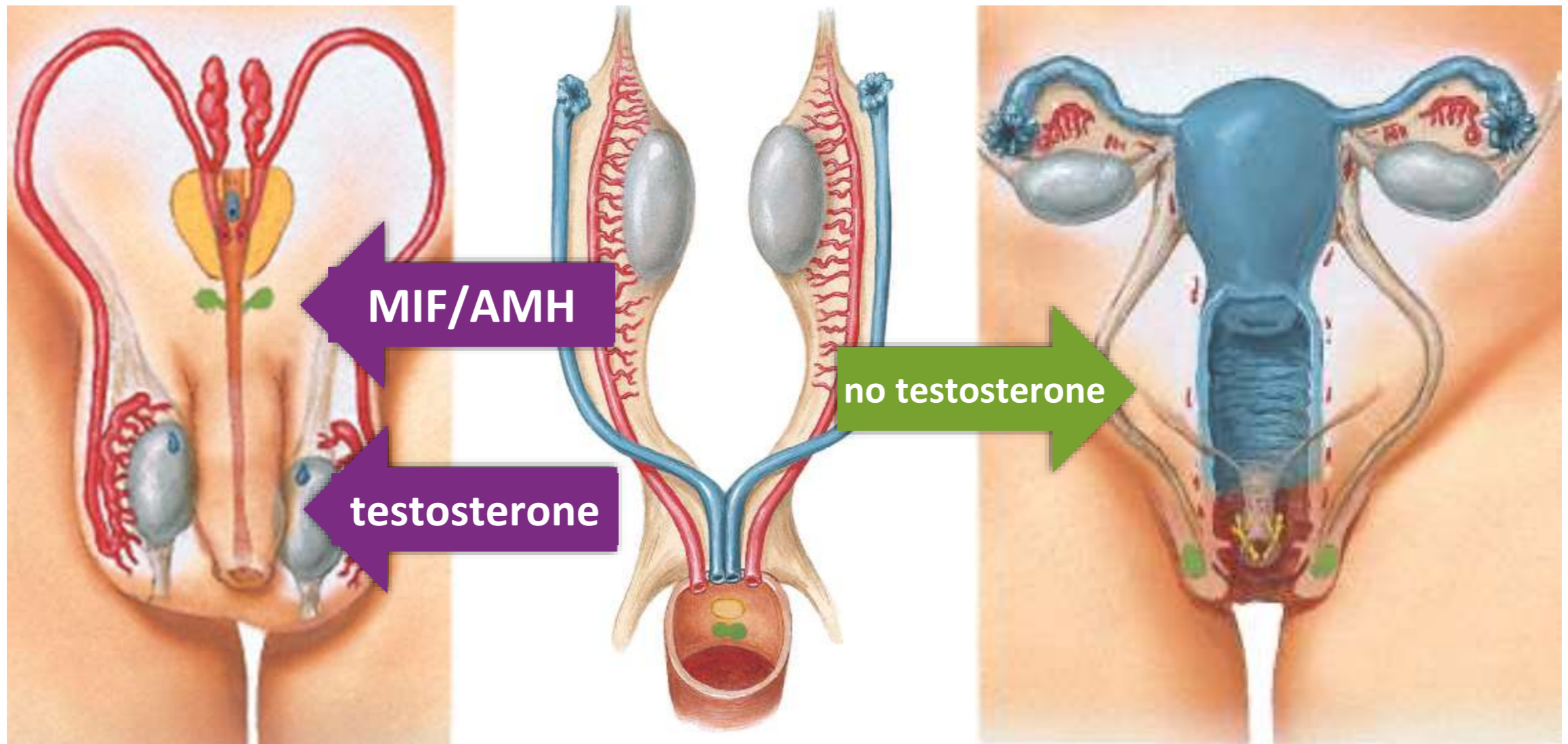
Prenatal Development



Prenatal Development: Gonads



Prenatal Development: Internal Genitalia

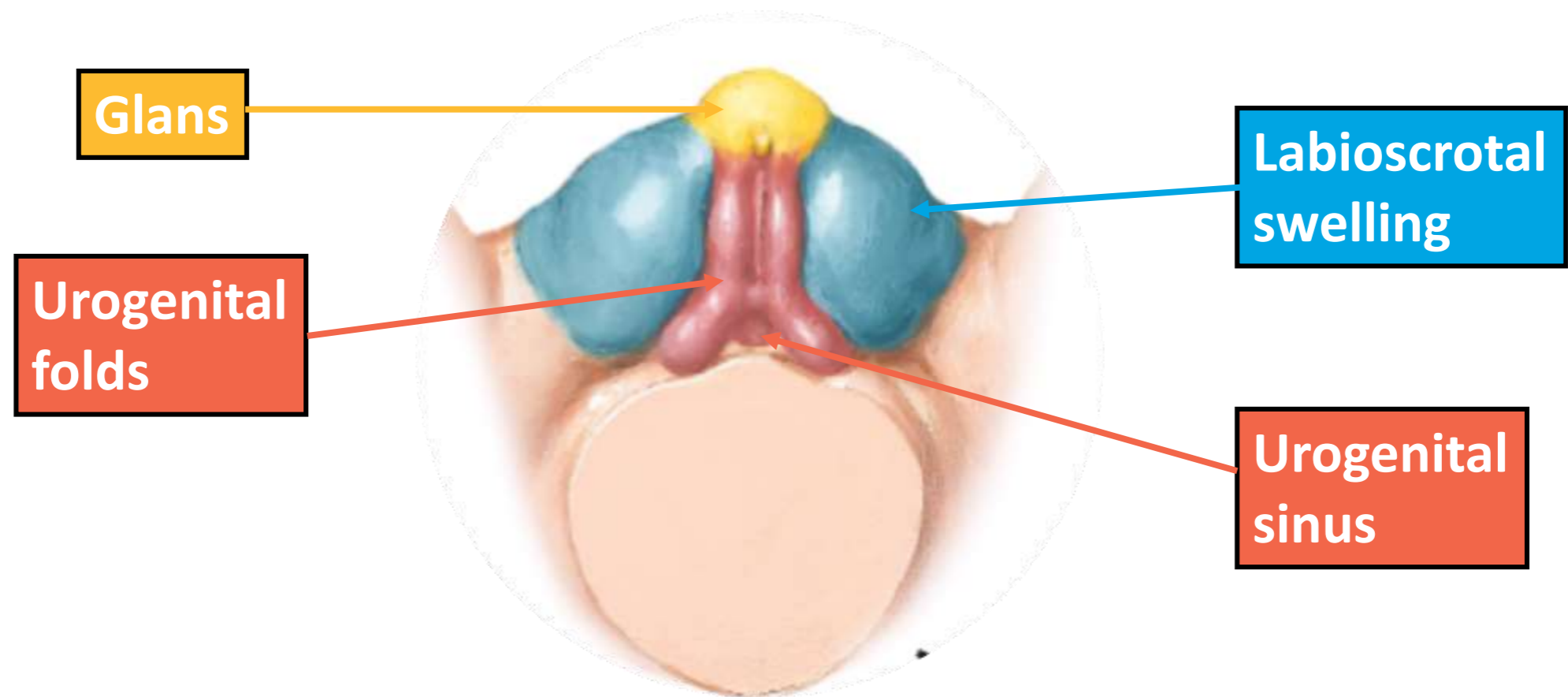


Wolffian duct

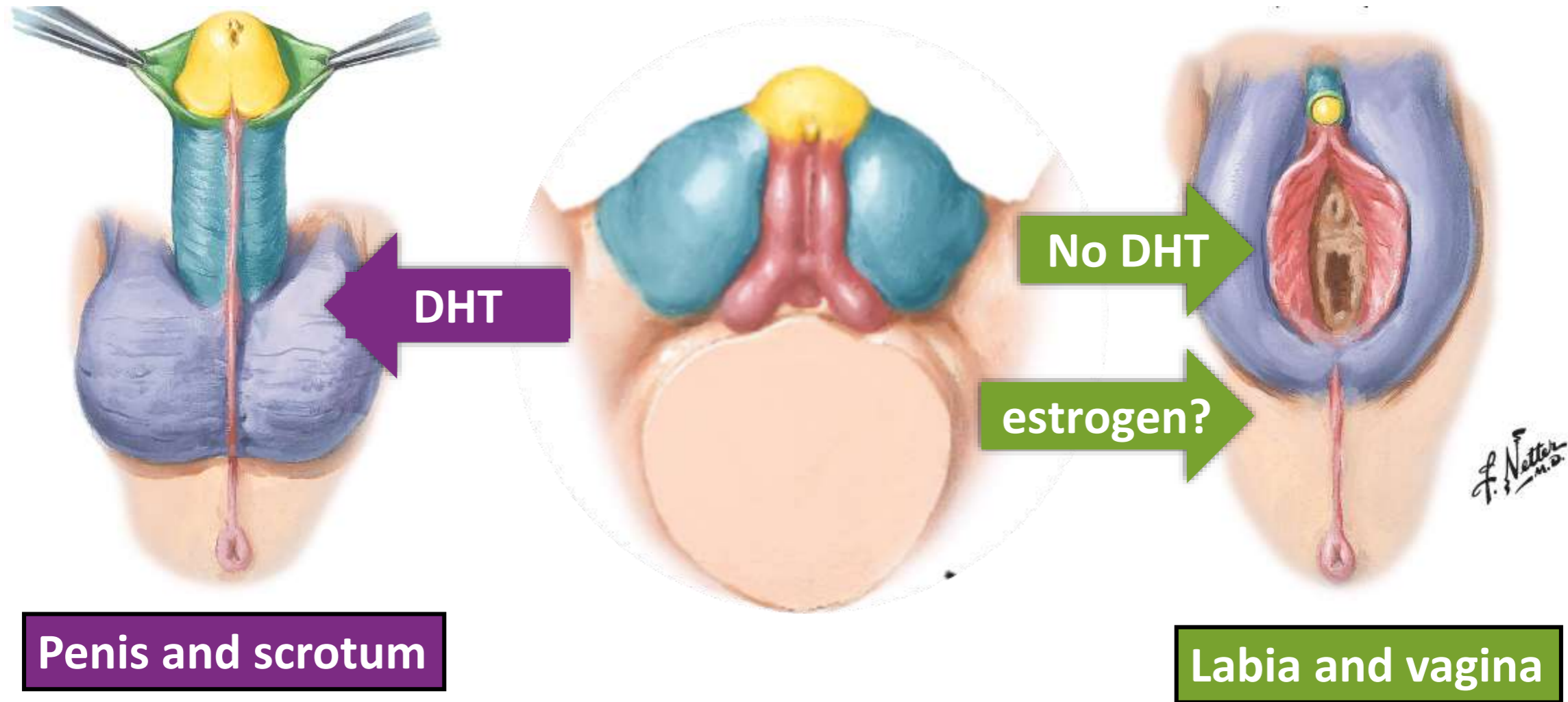
Müllerian duct



Prenatal Development: External Genitalia




Prenatal Development: External Genitalia



	Endosex female	Endosex male
Karyotype	XX	XY
Hormones	Estrogens	Androgens
Internal genitalia (Gonads, urogenital sinus, Wolffian & Mullerian ducts)	Ovaries Fallopian tubes Uterus & cervix Vagina	Testes Epididymis Ductus deferens Seminal vesicle Ejaculatory duct Prostate
External genitalia	Clitoris Vulva, Labia	Penis Scrotum
Brain	Girl	Boy

	Endosex female	Endosex male
Karyotype	XX	XY
Hormones	Estrogens	Androgens
Internal genitalia	Ovaries Fallopian tubes Uterus & cervix Upper vagina	Testes Epididymis ductus deferens seminal vesicle ejaculatory duct Prostate
External genitalia	Clitoris Vulva, Labia	Penis Scrotum
Secondary sex traits	Breast development Menstruation Pubic & axillary hair	Voice change Genital enlargement Pubic, axillary, facial hair
Brain	Girl	Boy

	Endosex female		Endosex male
Karyotype	XX	XXY XO XY/XX	XY
Hormones	Estrogens	Quantity or function variance	Androgens
Internal genitalia	Ovaries Fallopian tubes Uterus & cervix Upper vagina	Gonadal dysgenesis Ovotestes Mullerian variations	Testes Epididymis ductus deferens seminal vesicle ejaculatory duct Prostate
External genitalia	Clitoris Vulva/Labia	Glans length variations Labioscrotal variations Urethral variations	Penis Scrotum
Secondary sex traits	Breast development Menstruation Pubic & axillary hair	Gynecomastia Primary amenorrhea Hair variations	Voice change Genital enlargement Pubic, axillary, facial hair
Brain	Girl	Any/all genders	Boy

Overview of Intersex Traits by Developmental Process



Classification of Intersex Variations

- Karyotype
- Gonads
- Hormonal milieu
- Genitalia



Classification of Intersex Variations

- Karyotype
 - Klinefelter Syndrome (XXY)
 - Turner Syndrome (XO)
 - Mosaicism (XX/XY)
- Gonads
- Hormonal milieu
- Genitalia



Classification of Intersex Variations

- Karyotype
- Gonads
 - Gonadal Dysgenesis (Swyer's Syndrome)
 - Ovotesticular Syndrome
- Hormonal milieu
- Genitalia



Classification of Intersex Variations

- Karyotype
- Gonads
- Hormonal milieu
- Genitalia
 - Müllerian agenesis (MRKH)
 - Hypospadias
 - Penile agenesis or microphallus



Classification of Intersex Variations


- Karyotype
- Gonads
- Hormonal milieu
 - Androgen Insensitivity Syndrome (AIS)
 - Congenital Adrenal Hyperplasia (CAH)
 - 5-alpha Reductase Deficiency (5-ARD)
- Genitalia



Classification of Intersex Variations

- Karyotype
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	Endosex female		Endosex male
Karyotype	XX	XXY XO XY/XX	XY
Hormones	Estrogens	Absolute or functional variance	Androgens
Internal genitalia	Ovaries Fallopian tubes Uterus & cervix Upper vagina	Gonadal dysgenesis Ovotestes Uterine variations	Tetes Epididymis ductus deferens seminal vesicle ejaculatory duct Prostate
External genitalia	Clitoris Vulva/Labia	Glans length variations Labioscrotal variations Urethral variations	Penis Scrotum
Secondary sex traits	Breast development Menstruation Pubic & axillary hair	Gynecomastia Primary amenorrhea Hair variations	Voice change Genital enlargement Pubic, axillary, facial hair
Brain	Girl	Any/all genders	Boy

	Endosex female	Androgen Insensitivity	Endosex male
Karyotype	XX	XY	XY
Hormones	Estrogens	Androgens -> Estrogens	Androgens
Internal genitalia	Ovaries Fallopian tubes Uterus & cervix Upper vagina	Testes No/limited seminal structures Shorter vagina No uterus or cervix	Testes Epididymis ductus deferens seminal vesicle ejaculatory duct Prostate
External genitalia	Clitoris Vulva/Labia	Endosex vulva Glans and labioscrotal variations Urethral variations	Penis Scrotum
Secondary sex traits	Breast development Menstruation Pubic & axillary hair	Breast development Variable pubic, facial axillary hair	Voice change Genital enlargement Pubic, axillary, facial hair
Brain	Girl	Varies (often girl)	Boy

Traditional Medical Approaches to Intersex Traits



History of Intersex

- Before the 1960s
- From the 1960s to the 1990s
- From the 1990s to the Present



History of Intersex

- Prior to the 1960s
 - Limited diagnostic tools
 - Limited surgical options
- From the 1960s to the 1990s
 - Developments in genital surgery
 - Gender theory
 - “Concealment” model of care



Gender Theory

- Biological sex is not the same as social gender
- Biological sex informs social gender
- "Normal" gender aligns genitals, role, sexuality
- Nurture can override nature
 - Before the "window" closes at 4 years old
 - No ambivalence in rearing



Gender Theory

In practice:

- Gender assignment influenced by surgical technique and capacity for heterosexual intercourse
- Diagnostic and surgical information withheld from patients, and many parents



History of Intersex

- From the 1990s to the Present
 - Founding of activism and support groups
 - Surgical complications
 - Culture of shame, secrecy, and stigma
 - 2006 Consensus Statement
 - Multidisciplinary teams, more conservative surgical management
 - Disclosure of diagnoses



The Clinical Needs of People with Intersex Traits



Legacy of the Old Model

Disclosure of Diagnoses:

- Information routinely withheld from patients and families up through early 2000s
- Propagated shame, stigma, and isolation
- Patients continue to grapple with these



Legacy of the Old Model

Interventions Continue *Today*:

- Gonadectomy
- Clitoral reduction
- Vaginoplasty
- Hypospadias surgery
- Hormonal interventions



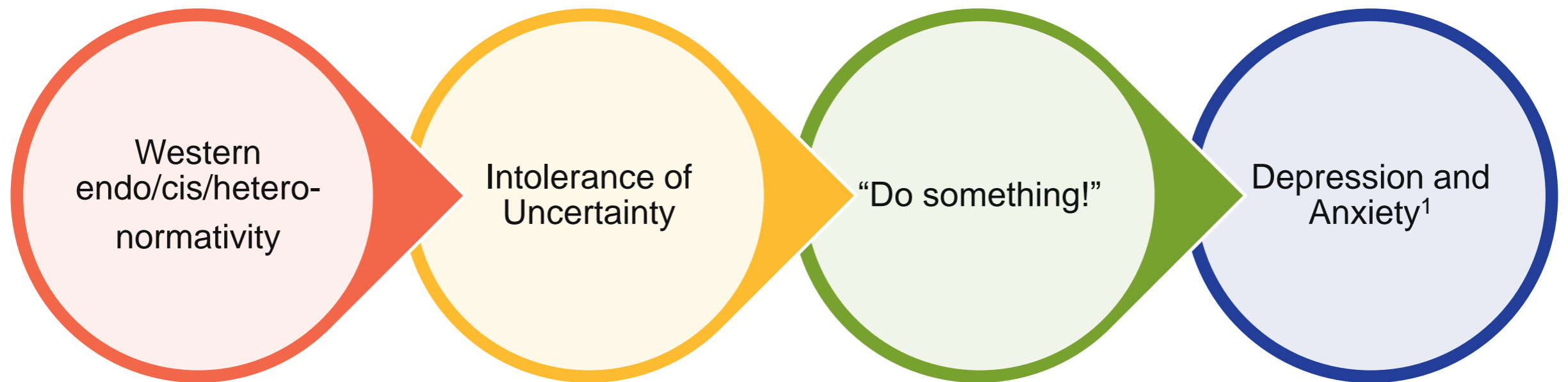
Legacy of the Old Model

Interventions Continue *Today*:

- In infancy
- Before ability to assent
- With insufficient psychosocial support
- To address distress



Parental Stress



Distress

- False dichotomy: “Do surgery or do nothing.”
- No compelling evidence that:
 - Distress is unmanageable for parents
 - Genital surgery reduces psychosocial distress relative to no surgery



Legacy of the Old Model

Physical risks:

- Scarring and chronic pain
- Urinary and sexual dysfunction
- Sterilization
- Lifelong hormone replacement therapy
- Complications requiring multiple follow-up surgeries

Psychological risks:

- Depression, PTSD, suicidal thoughts
- Shame, isolation, and inadequacy
- Gender incongruence

Population level risks:

- Negative health outcomes due to negative experiences accessing care



Groups Calling for Delay

- US Bureau of Public Affairs for State Dept
- State legislatures
- German and Swiss ethics councils
- Australia, Chile, Argentina, Malta governments
- World Health Organization
- Several UN organizations, Special Rapporteur on Torture
- Amnesty International, Human Rights Watch
- Physicians for Human Rights
- GLMA Health Professionals Advancing LGBT Equality
- American Medical Student Association
- American Academy of Family Physicians
- Indian, Colombian, Kenyan courts



What do Patients Need?

A different model of care, that:

- Affirms sexual and gender diversity
- Celebrates strength of patients and families
- Repairs trauma



Affirming Care

Traditional Model	Affirming Model
Sex defined by single factor	Sex defined by balance of factors
Sex is binary	Sex exists on a spectrum
Intersex is a disorder	Intersex is a natural human variation
Gender is binary & predictable	Gender is flexible & exploratory
Genitals must be “normal”	Genital diversity can be affirmed
Children will be ostracized and distressed	Children can be prepared and supported
Only heterosexual, penovaginal intercourse is normal	A wide range of sexual activity is normal and enjoyable



What Do Patients Need?

Physical Necessity:

- Cortisol replacement
- Relief of obstructions
- Address malignancies
- Sex hormone replacement for hypogonadism
- Evaluation for a specific DSD
- Education on anatomy, medical history, and medical records



What do Patients Need?

Physical Considerations:

- Gonadectomy for cancer risk
- Puberty blockers for discordant development
- Relocation of urethral meatus
- Vaginal dilation
- Genital surgery for appearance or sexual function
- Fertility preservation



What Do Patients Need?

Psychosocial Necessity:

- Professional *and* peer support
- Sex and Gender 101
- Flexible sex assignment
- Education on sexual health and wellbeing
- Discussions about family formation



Clinical Management

Psychosocial Themes

- Intersections with other identities
- Parents:
 - Adaptation and normalizing narratives
 - Decision-making in uncertainty
- Youth:
 - Navigating difference
 - Gender, sexuality, and global identity development



Clinical Management

Psychosocial Themes

- Adults: Shame, secrecy, isolation
 - Withholding of information
 - Trauma
 - Medical photography and exams
 - Nonconsensual surgery
 - Minority stress? Stigma?



Intersex Inclusion

- Consider documents and history-taking: not everyone assigned female at birth has a uterus, or produces estrogen
- Ask patients what they understand about their bodies
- Minimize intrusive examinations and questions
- Mirror language chosen by the patient, including names and pronouns
- Medical language may be associated with trauma



Intersex Inclusion

- Promote patient-driven goals regarding gender-affirming care
- Utilize multidisciplinary teams to optimize care, including mental health
- Careful, comprehensive informed consent
- Ongoing education of families and patients
- Refer to support groups



Case Discussion

- Natalia is a 16 year-old assigned female with partial androgen insensitivity syndrome who presents to discuss vaginoplasty
- At birth, Natalia had mid-range glans length, partial labioscrotal fusion, and bilateral inguinal testes
- Natalia's testes were removed at age 2 due to concern for malignancy risk, and laparoscopy confirmed lack of uterus
- Natalia reports considering surgery “so I can have sex.”
- What else do you want to know?



Natalia

- Mother and grandparents “want me to be normal”
- Understanding of surgery: “I have no idea”
- Sexuality: “No one will be interested in me.”
 - Romantically attracted to multiple genders
 - No fantasies, masturbation, or sexual partners
- Gender: “I guess female?” Androgynous, femme-leaning expression
- Physical exam: narrow vaginal opening, separate urethral opening
- How do you talk with Natalia about surgery? What else does Natalia need?



Natalia

Traditional model of intersex care:

- Surgeon-led
- Intolerant of uncertainty in decision-making
- Recommend “normalizing” vaginoplasty
- Discuss options for neovagina
- Obtain informed consent
- Schedule patient, often “before college”

Affirming model of intersex care:

- Psychosocial or medicine-led
- Understand and offer education on spectrum of sexual and gender identities and behaviors
- Understand context of decision
- Allow time for processing of information and consent
- Offer dilation as alternative



Natalia: 6 month f/u

Now Natalia has a clearer understanding of identity:

- Gender identity: “nonbinary/femme,” they/them/theirs or she/her/hers
 - “I don’t need a vagina to feel like myself.”
- Sexuality:
 - Panromantic, reluctant to label sexual orientation
 - Likely interested in peno-vaginal intercourse, “but there are other ways.”
- Researched different options for dilation, vaginoplasty, post-op dilation
- “All together, I probably want the surgery, but I’m still trying to figure out if it’s to make me feel good, or to make it easier for me to date. I think I’ll try dilation first.”



Resources

Peer support groups

- AIS-DSD Support Group (AISDSD.org)
- OII - USA, UK, Australia

Legal support and advocacy

- Inter/Act (interactadvocates.org)

Intersex stories

- Inter/Act Youth (interactyouth.org)
- "Born Both: An Intersex Life," Hida Vilorio
- "XOXY," Kimberly Zeiselman
- "Contesting Intersex: The Dubious Diagnosis," Georgiann Davis, PhD
- "Gender Revolution," Katie Couric and National Geographic

Medical Education Resources

- Diversity 3.0 Learning Series (www.aamc.org/initiatives/diversity)



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