



NATIONAL LGBT HEALTH
EDUCATION CENTER

A PROGRAM OF THE FENWAY INSTITUTE



Caring for Intersex Patients at Health Centers

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interACT

Our Roots

Fenway Health

- Independent 501(c)(3) FQHC
- Founded 1971
- Mission: To enhance the wellbeing of the LGBTQIA+ community as well as people in our neighborhoods and beyond through access to the highest quality health care, education, research, and advocacy
- Integrated primary care model, including HIV and transgender health services

The Fenway Institute

- Research, Education, Policy





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Today's Faculty

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Disclosure

Neither presenter has financial conflicts of interest.

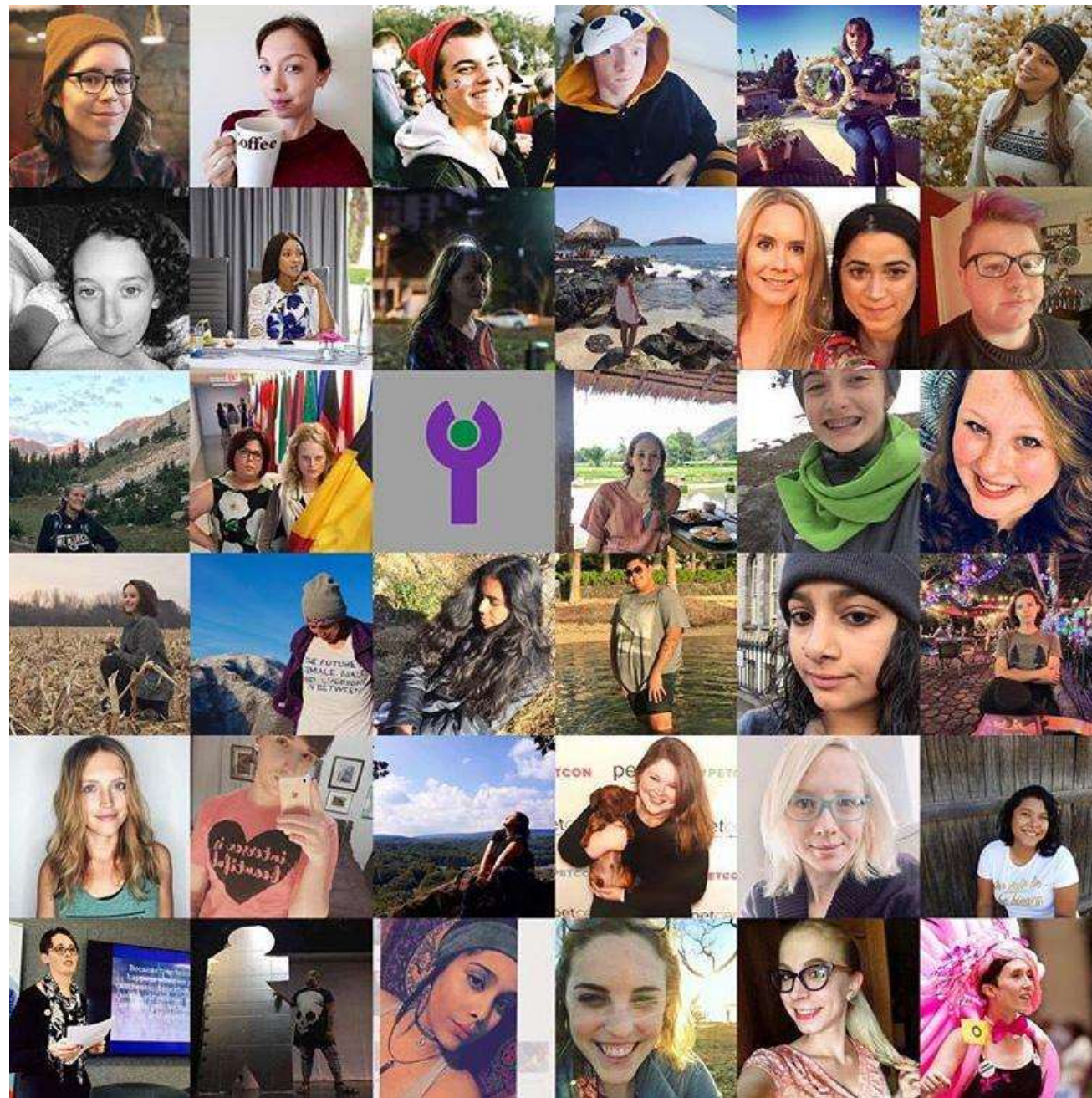


Who We Are





interACT is the largest organization in the world advocating to protect the rights of intersex kids. We do legal and legislative advocacy, media consulting and content creation, as well as intersex youth leadership development.





What is Intersex?



Defining Intersex

“**Intersex**” refers to bodies that express a wide range of physiological variations of sex characteristics and development that may not fit traditional conceptions about female or male bodies.

- Internal and/or External Reproductive Organs
- Chromosomal Differences
- Hormone Production and Effect





**Intersex people
represent
0.5% to 2%*
of the population.**

* More Common than Identical Twins



Being **Intersex** is Different from Being **Transgender**

Transgender means having a gender that is different than what adults presumed based on visible anatomy at birth.

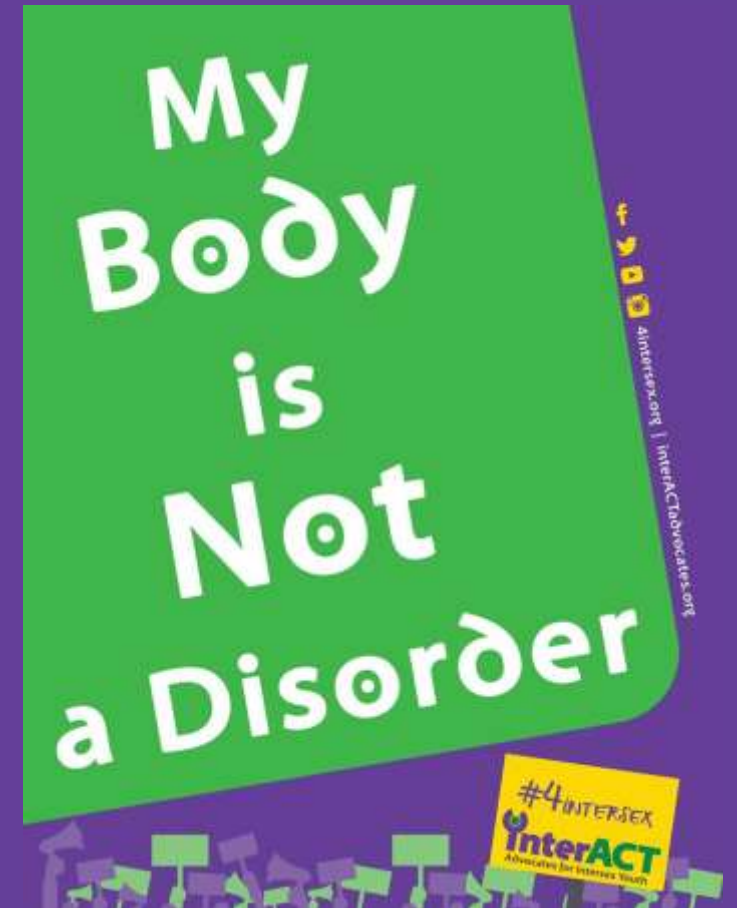
Cisgender means an individual's gender is the same as what was presumed at birth.

Intersex is an umbrella term for many different variations in sex characteristics that can cause an individual not to fit the two usual paths of human sex development.



Misconceptions

- Most people think biological sex is either “female” or “male,” but it can actually be more complicated than that.
- This “binary bias” results in intersex people feeling alone and unnecessarily ashamed of their bodies.





When Intersex Variations Might Be Noted

- Prenatal ultrasound
- Birth of an infant with genital variation
- Inguinal mass/hernia in a girl
- Failure to proceed through puberty
- Unexpected physical changes at puberty
(e.g., rapid virilization of a child assigned to female sex)
- Incidental finding during laparoscopy for another concern
- Evaluation of an adult for infertility





Features of Common Intersex Conditions	CAIS (Complete Androgen Insensitivity Syndrome)	Gonadal Dysgenesis	CAH (Congenital Adrenal Hyperplasia)	Klinefelter's (47 XXY or variants)
Karyotype	XY	XX or XY	XX	XXY
Gonad Type	Internal testes	Streak	Ovaries	External testes (smaller than average)
Sex Hormones Naturally Produced at Puberty	Testosterone from testes	None	Estrogen and above average testosterone	Below average testosterone (may have breast development, infertility)
Androgen Response	Convert to estrogen	Virilize	Virilize	Virilize
External Genital Appearance	“Typical” labia, may have vagina that is short	“Typical” labia	At birth, may have a range of genital ambiguity	Often “typical” penis, smaller than average testes
Frequency	1 : 100,000	1 : 80,000	1 : 15,000	1 : 1000



Issues Faced By The Intersex Community: Infants and Children

- Medically unnecessary cosmetic surgeries, including multiple procedures to revise an initial surgery
- Initial sex assignment may not fit the individual as they mature
- Providers uneducated in intersex issues; truth withheld
- Repeated genital exams
- Parental distress
- Lack of peer support





Issues Faced By The Intersex Community: Adults

- Gender transition, if initial sex assignment incorrect
- Providers uneducated in intersex issues
- Access to health insurance
- Dependence on hormone therapy for many
- PTSD and other mental health issues
- Scarring/loss of sensation due to prior genital surgery
- Fear of intimacy
- Lack of peer support





Areas of Medical Care Common to Various Categories of Intersex Individuals

- Psychological health, including interpersonal distress and PTSD
- Gynecologic care
- Hormone replacement therapy
- Bone health: prevention and treatment of osteoporosis
- Surveillance for cancer



Example of Medical Standard of Care: Breast Cancer Surveillance in Klinefelter Syndrome

- Breast tissue development at puberty is common in KS
- Breast cancer rate commensurate with their cis-sisters.
- Men with Klinefelter should:
 - be taught breast self-examination technique.
 - have mammograms at the age and frequency of cis-women.
- Consider genetic testing for breast cancer risk genes, particularly if there is a strong family history of breast or ovarian cancer.





Lived Intersex Experiences





Importance of Compassionate Care

- 82% of intersex patients who report having a negative experience with a provider, do not return for a second or follow-up clinical visit.



“It is totally fine if you as a medical provider don't know much about my condition when we first meet. Not many people do and you can learn. On my return visit, I expect you to have researched the basics. If this is going to be too outside your purview or what you want to learn about, please use your contacts and refer me to someone who does know or is interested in learning.” -*Affected adult*

*Johnson, Emilie K., et al. “Attitudes towards ‘Disorders of Sex Development’ Nomenclature among Affected Individuals.” *Journal of Pediatric Urology*, vol. 13, no. 6, 2017, doi:10.1016/j.jpuro.2017.03.035.



What Intersex Youth Said About Past Surgeries

- I had surgery when I was just three. I still wish my parents were given more options. I regret that I have a huge scar and no say about what happened to my own body!
- Unconsented surgery on my genitals wrecked my sense of self, and my confidence as a partner and lover.
- Do not tell a child that surgery is the only way for them to have "normal sex."



Raising Resilient Intersex Adults

“WHAT I WANTED AND NEEDED MOST from my providers was guidance to learn how to *live with* my condition. My medical care was focused on *disappearing it*.

Surgical intervention was the only option I was offered, which in turned robbed me of the opportunity to get to know who I really am. It’s too late now. I had ‘corrective’ surgery when I was 15 years old.

I was asked what I wanted for the first time when I was 47.”



What Intersex Youth Said About Past Surgeries

- My parents weren't told they had a choice. Always offer a nonsurgical option. Surgery is a last resort for everyone else. Why should it be different for us?
- If doctors had been more honest about potential surgical success, my parents would have made different decisions on my behalf.
- Do not tell us that only a medical eye could tell the difference between a "normal" body and a surgically altered intersex body. It's devastating to hear and it's completely untrue.





From Intersex Youth



**INTERSEX SURGERY
INCLUDES:**

“Repositioning” or “reducing” a naturally large clitoris for aesthetic reasons, based on what some doctors think is “normal.”

Clitoral surgeries have many nicknames, but are usually recommended to parents and done before intersex kids turn 2.

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**INTERSEX SURGERY
INCLUDES:**

Removing gonads (ovaries, testes, or ovotestes) that do not “match up” with the external genitals, but would have been a person’s natural lifelong source of hormones.

Parents and intersex adults are often talked into removing intersex gonads for “cancer risk,” but the data isn’t there.

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**INTERSEX SURGERY
INCLUDES:**

Creating or deepening a vagina for an intersex child before puberty, based on outdated ideas that “girls are supposed to be able to receive their future husband.”

This type of surgery may require manual dilation, performed by parents or doctors on children, who often grow up scarred.

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**INTERSEX SURGERY
INCLUDES:**

Moving an already working urethra so a child will someday pee standing up, because that is “what normal boys are supposed to do.”

“My first surgery was at 4 months old, and since then I’ve had more than I can remember because of complications.” – Anick, 24

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interACT Youth

is a group of intersex advocates in their teens and twenties working to raise intersex awareness.

We decided it's **time we told our own stories** and spoke our truths. In 2012, we started a conversation about **what we wish our doctors knew.**

We're sharing that with you now, and we hope you'll pass it on.

Disclosure

- Be honest. I have a right to know about my own body. Secrets make me feel like I should be ashamed.
- I'll end up doing my own research online, and would so much rather hear it from you.
- I wish that I had known about everything at age thirteen, when my parents knew.
- Please don't lie to my parents, or advise them not to tell me about my own body.
- I'm not as fragile as you may think I am. I can handle the truth!

"For most of my life, my doctors knew more about my body than I did. None of them ever took the time to explain my condition to me in depth. I felt confused and alone."
-Ali, age 23



Medical Exams

- Brief the nurses and medical assistants who are going to work with me.
- Don't patronize us by speaking to our guardians instead of us.
- Ask the patient how they would like the exam to go. It's okay to give us some control.
- Engage with patients as experts on their own experiences.
- It's ridiculous to think genital exams wouldn't bother a child! Even adults hate them!
- Give us the option of who we want in the room with us. This includes both family members and other medical professionals.
- Don't stick your fingers up a child's vagina if it's not absolutely necessary.
- Don't give a genital exam if it is simply for your own curiosity.
- Don't ask young kids if they have questions right after they've been shell-shocked from the genital exam you just gave them. Give them time to process.
- Help a child to understand the difference between a standard genital exam and molestation.
- Have a pediatric speculum nearby.
- Don't take pictures of my genitals!



Communication

- Don't assume I am comfortable with the medical term "DSD" versus intersex. Ask me what I prefer.
- Being intersex doesn't mean I'll have a certain sexual orientation or identity. Don't assume you know how I identify, and don't assume I'm confused about it. Just tell me the facts about my body.
- Don't speak in absolutes, i.e. "This vagina will never be sufficient for marital relations."
- Don't ask me things that wouldn't pertain to my body. For instance, if you know I don't get my period, don't ask me when I had my last period.
- Please know what you're talking about. We shouldn't have to educate our doctors.
- If we DO have to educate you ... *listen.*
- Don't emphasize how rare this may be. That just makes me feel more alone.
- My doctors told me I'd never meet anyone else like me - it turns out I've met many!
- Do not treat me like I'm a once-in-a-lifetime opportunity for you. This isn't about you.
- Please don't forget to remind me of the *positive aspects* of my variation.
- Encourage us to email or call you if we have questions or concerns. And mean it.

"After many years of complications, I was referred to a doctor who was one of the finest people I've ever met. She cared for me. She would sit with me for an hour and just talk ... What was I feeling? What did I want? What worked and what didn't? Because she took the time to get to know me, it made all the difference in the world."
- Monica, age 26





How to Help Intersex Patients?





Intersex Newborns and Their Families

- Discuss in a warm and matter-of-fact manner that intersex is more common than people think.
- Assist and support families in their dealings with specialized/tertiary care centers.
- Prioritize communication and community support
- Avoid heteronormative standards
 - Gendered behavior / Sexual orientation
- Clarify desired outcomes:
 - Decisions should not be determined by parental comfort
 - Prioritize mental health and psychosocial support
- Gender assignment should be *Provisional*





Intersex Adolescents and Their Families

- Present information in a way that is accessible to patients and their families. Staged discussion with very young children.
- Find out what the patient already knows about their body.
- Ensure that patients and parents understand what is happening by suggesting they explain it to you in their own words.
- Ensure that communication is two-way, authentic, and active.
- Encourage youth to ask questions and be curious about their bodies.





When Body Changes at Puberty Are Not as Anticipated

- Discuss in a warm and matter-of-fact manner that this circumstance is more common than people think.
- Prioritize communication and community support.
 - Ensure that communication is two-way, authentic, and active.
 - Encourage youth to ask questions and be curious about their bodies.
 - Anticipate strong emotional reactions.
 - Screen for anxiety, depression, substance use, suicidal ideation/intent.
 - Provide links to peer support resources.
- Facilitate referral to trustworthy tertiary care center for medical evaluation.



Intersex Adults

- Ask what pronouns and terminology they prefer
- Don't assume gender identity or sexual orientation - ask !
- Don't assume patient has menstrual periods. ("Q: Date of Last Period?!")
- Understand the right to refuse to be examined, observed, or treated by trainees when the primary purpose is educational or informational rather than therapeutic, without jeopardizing the patient's access to medical care, including psychiatric and psychological care.





Experience of Intersex Adults

- Understand that your adult intersex patient has likely experienced medical trauma and may have a high level of anxiety when visiting a clinician/health center.

“Often an intersex diagnosis is treated either as the biggest deal in the world and a huge social emergency or else it is brushed off as hardly relevant, not interesting, and unknown. Somewhere in the middle would be great – it’s not the end of the world but it’s an important aspect of my health and I need you to take it seriously.” - *Affected adult.*



For Persons of All Ages and Their Families

Facilitate connection with support groups, for example:

- AISDSD.org (All conditions, becoming “InterConnect”)
- HEAInfo.org (Hypospadias and Epispadias)
- BeautifulYouMRKH.org (MRKH)





Potentially Challenging Health-Care Encounters for Intersex Individuals

- First visit without parent(s).
- Academic health care center where learners may be present.
- Interacting with the office of a health care provider where binary sexual anatomy and function is presumed, e.g., OB-GYN care
- Seeking care for a medical condition where gender and genital appearance are entirely irrelevant, e.g., asthma, ankle sprain.
- Male dealing with insurance re: coverage for Pap test



Update Health Center Policies to be Intersex- Affirming

- **Anti-Discrimination Policy**
 - Ensure that the hospital does not discriminate against any person on the basis of intersex status, intersex traits, differences of sex development, or atypical sex characteristics.
- **Patients Bill of Rights**
 - Empower intersex patients to make autonomous decisions around their care
 - Right to Privacy, Compassionate and Informed Care
 - Right to refuse being examined, treated by, or observed by medical students when the primary purpose is education or informational and not therapeutic, without their right to care being jeopardized.



Update Health Center Policies

- **Review Treatment of Intersex Youth**
 - Care provided at multidisciplinary center with full psychosocial capability
 - Provisional gender assignment *without surgery*
 - Consideration of the effects of anesthesia on developing brains
- **Protocols for Interaction with Intersex Patients and their Families**
 - Respecting gender identity
 - Developing and understanding of the relationship between the child and their parent(s)

As is true for any individual, intersex persons have the right to access their medical records and to be told the truth about their intersex status, intersex traits, and any related medical information, including any history of medical intervention.



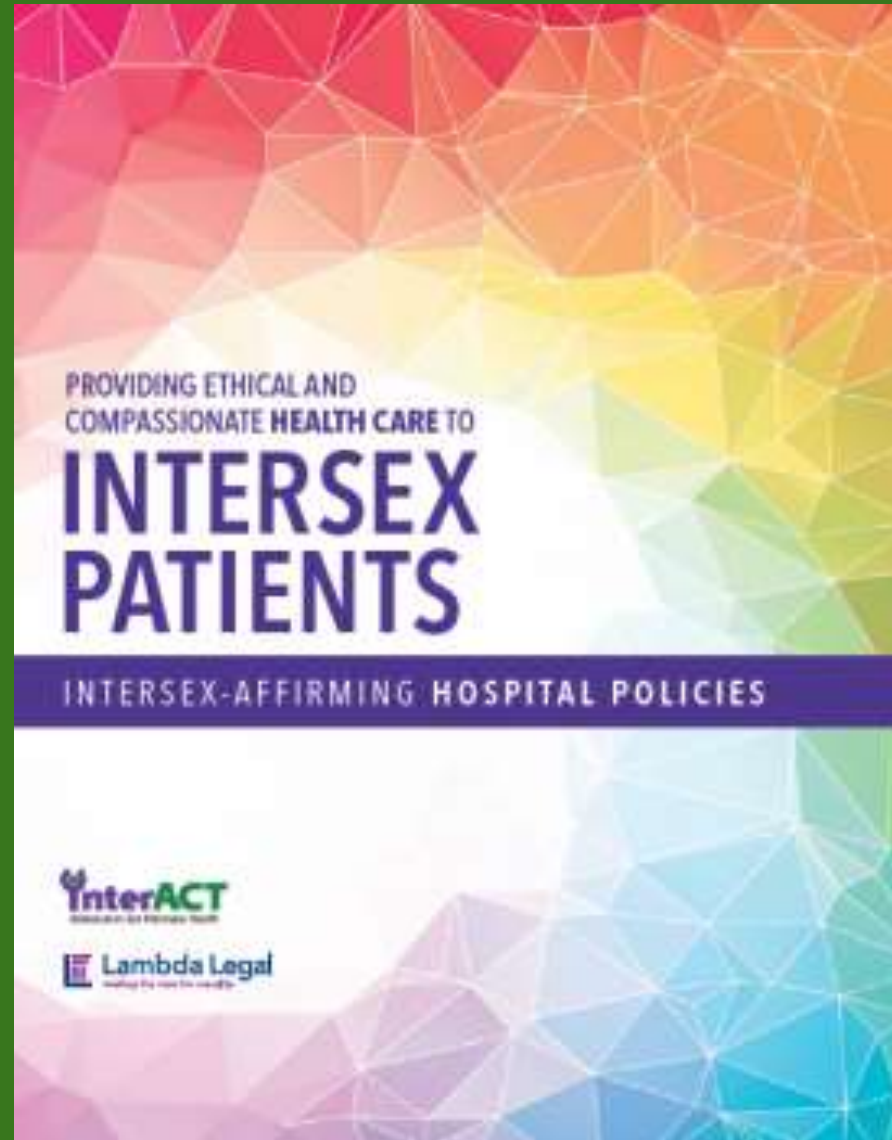
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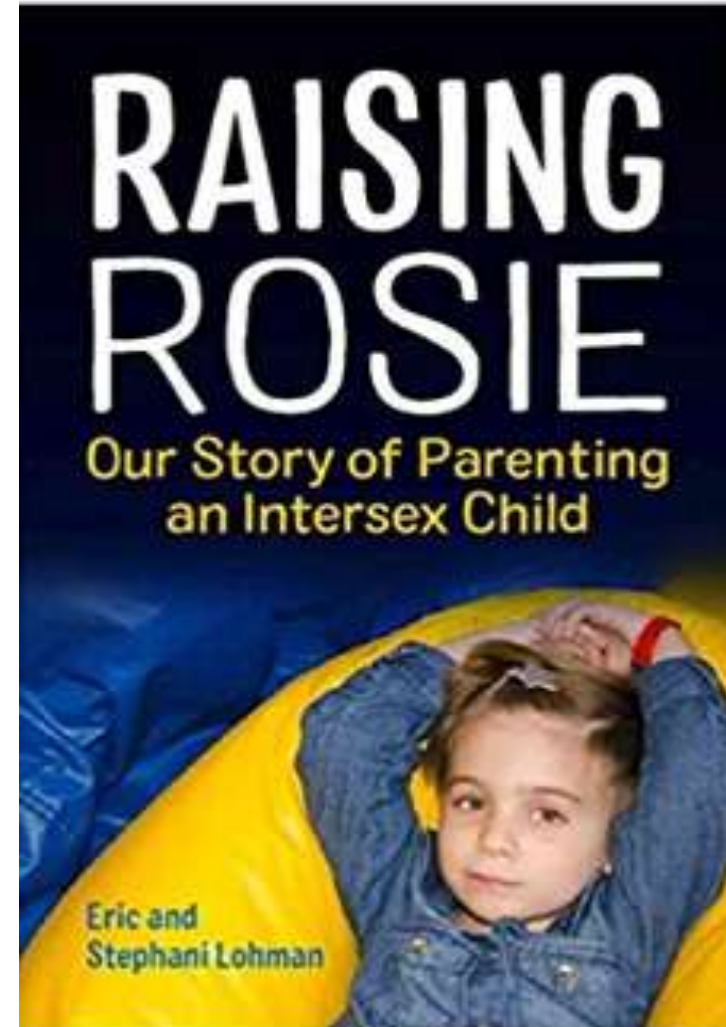
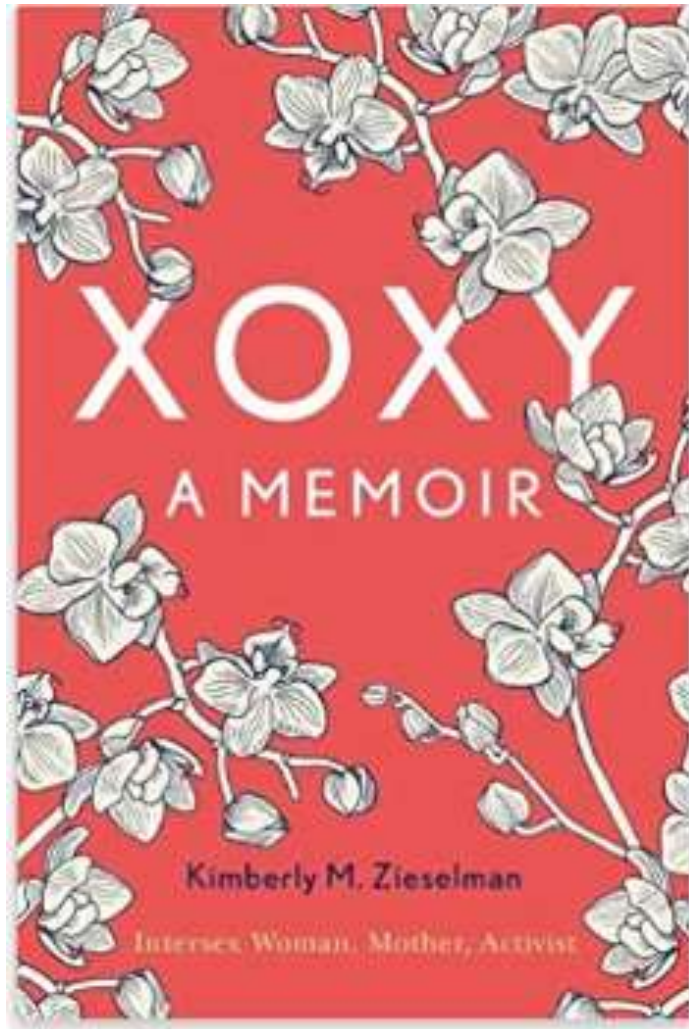
Resources



interactadvocates.org



interactadvocates.org





Video Resources

[Raising an intersex child: 'This is your body. ... There's nothing to be ashamed of'](#)

[The Fight To Stop Genital Surgeries on Intersex Infants](#)

[The way we think about biological sex is wrong | Emily Quinn](#)

[US: Harmful Surgery on Intersex Children](#)

See additional resources [here at interactadvocates.org](https://interactadvocates.org)

Questions?

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