

# Intersex Resources

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## **Introduction**

The term intersex refers to a biological sex outside the typical “male” and “female” categories. Sex is a complex constellation of characteristics including chromosomes, hormone levels, reproductive organs, external genitals, and secondary sex characteristics. By way of example, a “typical” female-sexed adult person has XX chromosomes; an abundance of estrogens and progesterones; a uterus, fallopian tubes, ovaries, and vagina; a vulva; and breasts. When an infant is born, a sex assignment is determined by assessing the external genitals. In some cases, a child will present with “ambiguous genitalia” and will be identified as intersex; in other cases, an intersex person will not be identified until puberty or later, or not at all.

Many intersex adults were given unnecessary genital surgeries as infants. Some of them did not discover their intersex status until well into adulthood, when fertility or other health issues necessitated testing. The stigmatization and concealment of intersex identities has created a situation wherein the general public is unaware of the spectrum of intersex identities, yet offensive slurs like “hermaphrodite” or “he-she” are readily used by bullies to shame gender nonconforming people. To be clear, intersex is not the same thing as transgender, though some intersex people do not identify with the gender they were assigned.

Because of rampant misinformation, the concealment of medical records, stigma and shame, and because accurate information is difficult to locate; libraries should take care to develop collections on this topic and librarians should be prepared to field reference inquiries. This resource was created in order to assist libraries with collection development, as well as to directly assist intersex people and allies wanting to locate information and media. Resources include fiction and nonfiction books, articles,

multimedia, and internet sources. No science fiction was selected in order to keep the focus on accurate depictions of intersex identities.

This resource was created by Charlie McNabb and approved by the GLBT Roundtable Resources Committee in June 2016. Please contact the Committee to report broken links or to suggest new resources.

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## Glossary

[Thanks to ISNA for most of these definitions.]

### 5-Alpha Reductase Deficiency

5-Alpha Reductase is an enzyme that converts testosterone to dihydrotestosterone. A baby deficient in this enzyme develops as a girl until puberty, when testosterone production increases and causes virilization. This condition is due to a defect on an autosome (not a sex chromosome) and requires two mutated genes, one from each parent.

### Ambiguous Genitalia

Genitals that don't appear typically masculine or feminine. Intersex activists often use quotation marks to indicate that the term is problematic.

### Androgen Insensitivity Syndrome (AIS)

An inherited genetic condition in which an XY person's body does not respond to androgen and the fetus develops testes, a vulva, and a partial vagina, but no uterus, fallopian tubes, or cervix.

### Aphallia

A condition where an XY baby with otherwise typical male anatomy is born without a penis.

### Chromosomes

A structure found in cells that carries genetic information.

### Clitoromegaly

A descriptive term meaning a larger than typical clitoris.

### Concealment-Centered Model

A model of patient care in which parents were urged to quickly decide on a gender assignment for their intersex baby. The notion was that a child would identify with whatever gender the parents were raising them as. In practice, this often meant unnecessary genital surgery, hormones treatment, and concealing the child's medical history from them. Also called the Hopkins model.

### Congenital Adrenal Hyperplasia (CAH)

A genetic condition in which an XX person is unable to manufacture cortisone. The adrenal glands instead synthesize an androgen precursor that is virilizing, both in-utero and after birth. A baby with CAH may be born with a larger than typical clitoris and/or labia that look like a scrotum, and may develop dense body hair, a deep voice, and other masculine-typical features. This is the only intersex condition that constitutes a medical emergency, as the serum sodium balance may be upset.

### Gender Assignment

Labelling a baby as a boy or girl. Does not require surgery.

### Gender Identity

An individual's personal feelings about their gender. A person may have a different gender identity than the gender assigned to them at birth.

### Gonadal Dysgenesis

A condition in which a person is born with gonadal streaks rather than functional gonads. A child born with this condition will look like a typical female, but will not develop secondary sex characteristics because streak gonads do not produce sex hormones. Also known as Swyer Syndrome.

### Gonadal Streaks

Minimally developed gonad tissue present in place of testes or in place of ovaries.

### Hermaphrodite

A mythological being that is both fully female and fully male. This is physiologically impossible, and also considered a stigmatizing term. Note: Although some intersex people have reclaimed this term, it should never be used by sex-typical people.

### Hopkins Model

A model of patient care in which parents were urged to quickly decide on a gender assignment for their intersex baby. The notion was that a child would identify with whatever gender the parents were raising them as. In practice, this often meant unnecessary genital surgery, hormones treatment, and concealing the child's medical history from them. Also called the concealment-centered model.

### Hormones

Chemicals created in the endocrine glands that regulate physiology and behavior. Sex hormones include androgens, estrogens, and progestogens.

### Hypospadias

A common condition in which an XY person's urethral meatus is located along the underside of the penis, rather than at the tip.

### Informed Consent

The practice of weighing all options, considering evidence, alternatives, and potential risks in order to make a truly informed medical decision.

### John Money

A psychologist in the 1950s who theorized that gender was completely dependent on "nurture." He advocated for genital surgery on intersex infants and raising them as girls.

### Karyotype

A microscopic photograph of the chromosomes in a cell. The number and type of chromosomes indicates the sex of the person. For example, a typical male has karyotype 46 XY and a typical female has karyotype 46 XX.

### Klinefelter Syndrome

A common condition in which an XY person inherits an extra X chromosome, making their karyotype 47 XXY. People with this condition have smaller than typical testes and produce no sperm. Some do not virilize strongly and may develop breasts.

### Micropenis

A descriptive term for a penis with typical development (differentiated, with urethral meatus at tip) but with a stretched length at or below 2.5 standard deviations for age and stage of development.

### Mosaicism

A condition in which a person has one karyotype in some cells and a different karyotype in other cells. This can occur due to incorrect cell division during the embryo stage.

### Mayer-Rokitansky-Küster-Hauser (MRKH) Syndrome

A Mullerian duct anomaly in which an XX person has normal ovaries and fallopian tubes, but the uterus and upper vagina are absent or abnormal. Also called Mullerian agenesis. Some people also have vertebral or renal anomalies.

### Ovotestes

A condition in which one or both gonads contain both ovarian and testicular tissue. People with this condition may appear typically male or female or have “ambiguous genitalia.” The testicular tissue in ovotestes present a higher risk of gonadal cancer.

### Partial Androgen Insensitivity Syndrome (PAIS)

An inherited genetic condition in which an XY person does not completely respond to androgen. Infants are typically born with “ambiguous genitalia” and testes.

### Patient-Centered Model

A model of patient care in which an intersex person has access to factual information about their diagnosis and makes decisions based on informed consent. When an infant is born with an intersex condition that constitutes a real medical emergency (such as an absence of a urethral opening or an endocrine imbalance), medical procedures are performed. Genital “normalizing” surgeries, however, are only performed when a child is mature enough to desire and consent to them.

### Phall-O-Meter

A satirical measuring device developed by intersex activist Kiira Tria to assess whether a newborn’s phallus is an acceptable size.

### Progestin Induced Virilization

A condition caused by prenatal exposure to progestin (a drug that was used to prevent miscarriage in the 1950s and 1960s). An XX baby will have ovaries and a uterus, but the clitoris may be enlarged, the labia may be fused, and the vagina may be absent. Due to functional ovaries, puberty will cause feminization (breast development, etc.).

### Swyer Syndrome

A condition in which a person is born with gonadal streaks rather than functional gonads. A child born with this condition will look like a typical female, but will not develop secondary sex characteristics because streak gonads do not produce sex hormones. Also known as gonadal dysgenesis.

### Turner Syndrome

A karyotype of 45 X (only one X chromosome is present). A person with this condition generally has female sex characteristics, but they may be underdeveloped.

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## Resources

### **Books-Nonfiction**

Callahan, Gerald N. 2009. *Between XX and XY: Intersexuality and the Myth of Two Sexes*. Chicago: Chicago Review Press.

Argues that the concept of binary sex is a social construct and that intersex people should be accepted.

Colapinto, John. 2000. *As Nature Made Him: The Boy Who Was Raised as a Girl*. New York: HarperCollins.

The true story of David Reimer, whose parents tried to raise him as a girl after a botched circumcision. Includes discussion of intersex children born with ambiguous genitalia.

Connella, Katherine. 2000. *Sugar and Spice and Puppy Dog Tails: Growing up Intersexed: An Intimate Memoir*. Hollywood: Self published.

Actress/author Katherine Connella's autobiography of her childhood and adolescence.

Dreger, Alice. 2015. *Galileo's Middle Finger: Heretics, Activists, and the Search for Justice in Science*. New York: Penguin Press.

In this scientific but highly readable narrative, Dreger investigates scientific ethics through historical data and interviews with contemporary scientists. Topics include surgical "correction" of intersex babies, prenatal drug regimens, and intersex activism.

Dreger, Alice (Editor). 1999. *Intersex in the Age of Ethics*. Hagerstown, MD: University Publishing Group.

An edited volume with contributions by intersex scholars and scholars who are intersex. Topics include intersex as a social phenomenon, life as an intersex person, shifting clinical perspectives, and guidelines for parents and providers.

Dreger, Alice. 1998. *Hermaphrodites and the Medical Invention of Sex*. Cambridge: Harvard University Press.

A history of the biomedical treatment of then-termed hermaphrodites in France and Britain in the late nineteenth and early twentieth centuries.

Fausto-Sterling, Anne. 2012. *Sex/Gender: Biology in a Social World*. New York: Routledge.

An accessible treatment of sex and gender from a biological standpoint, with discussion of the historical and social contexts. Chapters are pithy and include excellent Further Reading references.

Fausto-Sterling, Anne. 2000. *Sexing the Body: Gender Politics and the Construction of Sexuality*. New York: Basic Books.

In this book, Fausto-Sterling argues for biological and cultural theories that allow for human variation. Accessible for a general audience, with detailed endnotes to satisfy the scholarly audience.

Fausto-Sterling, Anne. 1985. *Myths of Gender: Biological Theories about Women and Men*. New York: Basic Books.

A passionate argument for scholars to engage with the personal and political components of their scientific theories.

Foucault, Michel. 1980. *Herculine Barbin: Being the Recently Discovered Memoirs of a Nineteenth-Century French Hermaphrodite*. New York: Vintage Books.

Herculine Barbin was a schoolgirl in a Catholic orphanage who was suddenly discovered to be intersex and reclassified as a man when she was 22. Foucault brings together her memoirs, medical and press documents, and a thoughtful introduction, followed by a short story based on her life, written by Oscar Panizza in 1893.

Harper, Catherine. 2007. *Intersex*. Oxford: Berg Publishers.

Harper provides details of various intersex conditions, woven with personal testimony from intersex people.

Hillman, Thea. 2008. *Intersex (For Lack of a Better Word)*. San Francisco: Manic D Press.

In this series of essays, Thea Hillman reflects on sex, gender, and community.

Holder, Taylor J. 2007. *All Points in Between: Shifting on the Scale of Sex and Gender*. New York: iUniverse.

Discusses the social construction of both sex and gender, and argues for a more nuanced view of sex and gender as spectra.

Holmes, Morgan. 2008. *Intersex: A Perilous Difference*. Selinsgrove: Susquehanna University Press.

In this autoethnographic and theoretical text, Holmes situates intersex medical/surgical interventions in a historical context and highlights individual intersex voices. This book is relevant to both clinical practice and intersex activism.

Karkazis, Katrina. 2008. *Fixing Sex: Intersex, Medical Authority, and Lived Experience*. Durham: Duke University Press.

Through interviews with intersex adults, parents of intersex children, and clinicians working with intersex patients, Karkazis deftly explores the medical treatment of intersex conditions. While the primary focus is intersex lived experiences, the complicated decision-making of parents and clinicians is also sensitively portrayed.

Kessler, Suzanne J. 1998. *Lessons from the Intersexed*. New Brunswick: Rutgers University Press.

This book provides an introduction to the medical literature on intersexuality geared toward cultural theorists. Kessler contextualizes the cultural factors of genital surgeries, analyzing clinical criteria and ideas of normalcy and deviance.

Parens, Erik (Editor). 2006. *Surgically Shaping Children: Technology, Ethics, and the Pursuit of Normality*. Baltimore: Johns Hopkins University Press.

A unique mix of intersex people, parents, theorists, and clinicians examine intersex treatment.

Parker, James N. and Philip M. Parker. 2007. *Klinefelter Syndrome: A Bibliography and Dictionary for Physicians, Patients, and Genome Researchers*. San Diego: ICON Health Publications.

A 3-in-1 reference book, including a comprehensive medical dictionary, bibliographic citations, and annotated internet resources. Intended for physicians and medical students, but also highly useful for people with Klinefelter syndrome.

Parker, James N. and Philip M. Parker. 2007. *Turner Syndrome: A Bibliography and Dictionary for Physicians, Patients, and Genome Researchers*. San Diego: ICON Health Publications.

A 3-in-1 reference book, including a comprehensive medical dictionary, bibliographic citations, and annotated internet resources. Intended for physicians and medical students, but also highly useful for people with Turner syndrome.

Preves, Sharon E. 2003. *Intersex and Identity: The Contested Self*. New Brunswick: Rutgers University Press.

Preves conducted in-depth life history interviews with more than three dozen intersex people, providing rich data on personal experiences with medical interventions, identity and coming out, and activism.

Reis, Elizabeth. 2009. *Bodies in Doubt: An American History of Intersex*. Baltimore: Johns Hopkins University Press.

Through an exhaustive review of medical case studies and popular literature, Reis demonstrates that medical treatment protocols for intersex patients is based upon shifting ideas of “normal” as well as a privileging of heterosexual reproductive activity. Covers the colonial period to the present.

Roughgarden, Joan. 2004. *Evolution's Rainbow: Diversity, Gender, and Sexuality in Nature and People*. Berkeley: University of California Press.

Roughgarden tackles medicine, social science, and evolutionary theory to argue that biological sex, gender, and sexual orientation all defy rigid binarism.

Sytsma, Sharon E. (Editor). 2010. *Ethics and Intersex*. Dordrecht: Springer.

An edited volume that addresses global ethical practice regarding intersex treatment.

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## **Books-Fiction**

Birdsall, Bridget. 2014. *Double Exposure*. New York: Sky Pony Press.

After moving to a new state and starting a new school, Alyx can finally be herself. But a bully threatens to disclose her intersex identity, which may disqualify her from playing.

Brugman, Alyssa. 2015. *Alex as Well*. New York: Henry Holt and Company.

Alex, who was raised as a boy, decides to stop taking hormones after she learns that she is intersex.

Duncker, Patricia. 1999. *The Doctor: A Novel*. New York: Ecco Press.

Historical fiction about Dr. James Miranda Barry, a girl raised as a boy, who was thought to be intersex.

Eugenides, Jeffrey. 2002. *Middlesex*. New York: Farrar, Straus, Giroux.

The story of Calliope, an intersex person raised as a girl; with the backstory of genetic twists and turns through several previous generations.

Gentle, Mary. 2006. *Ilario: The Stone Golem: A Story of the First History, Book Two*.

New York: HarperCollins.

The continuing adventure of would-be painter Ilario.

Gentle, Mary. 2002. *Ilario: The Lion's Eye: A Story of the First History, Book One*. New

York: HarperCollins.

An orphan grows up as the King's Freak, but escapes to a new world and new destiny.

Goyen, William. 1983. *Arcadio: A Novel*. New York: Clarkson N. Potter, Inc.

A former circus sideshow performer, "half man, half woman" Arcadio searches for his lost family and monologues to the reader about his life.

Gregorio, I.W. 2015. *None of the Above*. New York: Balzer + Bray.

A teenage girl discovers that she's intersex and must navigate challenging interpersonal relationships while she processes what it means to be intersex.

Tarttelin, Abigail. 2013. *Golden Boy: A Novel*. New York: Atria Books.

Max Walker is the beloved golden boy in his family and community: athletic, smart, kind, and handsome. He's also intersex, which has never been much of an issue until a childhood friend sexually abuses him.

Winter, Kathleen. 2010. *Annabel: A Novel*. New York: Black Cat.

When a rural Labrador woman gives birth to an intersex baby, she and her husband raise the baby as a boy, keeping the sex secret.

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## **Articles and Chapters**

Chase, Cheryl. 2002. "‘Cultural Practice’ or ‘Reconstructive Surgery’? U.S. Genital Cutting, the Intersex Movement, and Medical Double Standards." In *Genital Cutting and Transnational Sisterhood: Disputing U.S. Polemics*, edited by Stanlie M. James and Claire C. Robertson, pp. 126-151. Urbana: University of Illinois Press.

Intersex scholar-activist Cheryl Chase provides a brief history of intersex "reconstructive" surgeries and their impact on intersex individuals, including her own story from childhood surgeries to adult politicization. Then she moves into a discussion of the differing media portrayals of intersex surgical interventions in the U.S. versus clitoridectomy in Africa, identifying ethnocentrism in both journalistic and medical double standards.

Dreger, Alice and April Hernden. 2009. "Progress and Politics in the Intersex Rights Movement: Feminist Theory in Action." *GLQ: A Journal of Lesbian and Gay Studies* 15(2), 199-224.

The authors argue that some feminists' approaches to intersex has been problematic, and significant work remains to be done in order to prioritize intersex children's well-being over social norms.

Griffin, Pat. 2012. "‘Ain’t I a Woman?’ Transgender and Intersex Student Athletes in Women’s Collegiate Sports." In *Transfeminist Perspectives in and beyond Transgender and Gender Studies*, edited by Anne Enke, pp. 98-111.

Philadelphia: Temple University Press.

In this chapter, Griffin interrogates gender and sex binary assumptions in women’s sports. Includes descriptions of historical events, discussion of athletic eligibility policies, and policy recommendations and best practices.

Kenney, Rick and Kimiko Akita. 2013. "‘Is She a Man? Is She a Transvestite?’: Critiquing the Coverage of Intersex Athletes." In *Queer Media Images: LGBT Perspectives*, edited by Jane Campbell and Theresa Carilli, pp. 137-146.

Lanham, MD: Lexington Books.

Focusing on sprinters Santhi Soundarajan and Caster Semenya, this chapter discusses sex testing, critiques problematic media coverage, and suggests an alternate journalistic model to respect the dignity of marginalized people.

Morland, Iain. 2012. "The Injured World: Intersex and the Phenomenology of Feeling." *Differences: A Journal of Feminist Cultural Studies* 23(2), 20-41.  
Critically analyzes the role of feelings in debates over intersex treatment.

Morland, Iain. 2011. "Intersex Treatment and the Promise of Trauma." In *Gender and the Science of Difference: Cultural Politics of Contemporary Science and Medicine*, edited by Jill A. Fisher, pp. 147-163. New Brunswick: Rutgers University Press.  
An ethical and political critique of the medical discourse around anatomy and clinical treatment of intersex people.

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## **Multimedia**

Chase, Cheryl. 2002. *First Do No Harm: Total Patient Care for Intersex* [Film]. Boston: Fanlight Productions.  
Based on a panel discussion, this film provides guidelines for intersex patient care standards.

Clearway, Ajae. 2006. *One in 2000* [Film]. Boston: Fanlight Productions.  
Documentary focusing on how intersex children and their parents cope and make decisions.

Gale, Porter and Gender Soomekh. 2005. *XXXY* [Film].  
This short film tells the stories of two intersex people and their feelings of disempowerment from having no choice in their gender assignment surgeries.

Goodman, Dana Min and Julia Wolov (Creators). 2014-2016. *Faking It* (Television series). New York: MTV.  
In this romantic comedy geared toward high schoolers, a group of friends navigates popularity and identity. *Faking It* includes two characters who are intersex, one of whom is played by an intersex actor—a historic first for television.

Intersex Society of North America (ISNA). 1996. *Hermaphrodites Speak!* [Film]. Ann Arbor, MI: ISNA.  
Seven intersex people discuss their negative childhood surgical experiences.

Keir, John. 2006. *Mani's Story* [Film]. Ann Arbor, MI: ISNA.  
Documentary about the life of intersex activist Mani Bruce Mitchell.

Murphy, Ryan (Writer/Director). 2014-2015. *American Horror Story: Freak Show: The Complete Fourth Season* (Television series). Beverly Hills: Fox.  
In this horror drama, a killer preys on the performers of a traveling freak show. Desiree Dupree, played by Angela Bassett, is an intersex woman.

San Francisco Human Rights Commission. 2004. *Intersex Hearing* [Television broadcast]. San Francisco: SFGTV.  
Commissioners investigated intersex surgical treatment and informed consent.

Ward, Phyllis. 1999. *Is it a Boy or a Girl?* [Television broadcast]. Bethesda, MD: Discovery Channel.  
Television documentary that explored intersex medical management.

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## **Internet**

Accord Alliance. [www.accordalliance.org](http://www.accordalliance.org)

The Accord Alliance “promotes comprehensive and integrated approaches to care that enhance the health and well-being of people and families affected by disorders of sex development.”

Advocates for Informed Choice. [www.aiclegal.org](http://www.aiclegal.org)

Advocates for Informed Choice uses innovative strategies to advocate for the legal and human rights of children born with intersex traits.

American Association for Klinefelter Syndrome Information and Support (AAKSIS).

[www.aaksis.org](http://www.aaksis.org)

A “national volunteer association with the mission of education, support, research, and understanding of 47 XXY and its variants, collectively known as Klinefelter syndrome.”

Androgen Insensitivity Syndrome Support Group. [www.aissg.org](http://www.aissg.org)

A UK-based group that plays a “dual role in providing support and comfort to affected adults/families all over the world, as well as fighting for and contributing to a better understanding of the various conditions, and of how they should be ‘treated’ by the medical community.”

AXYS. [www.genetic.org](http://www.genetic.org)

“AXYS is the nation’s oldest and largest non-profit organization addressing the needs of the approximately 1 out of 500 individuals who were born with one or more extra X and/or Y chromosomes, as well as their families and the clinicians, educators and research scientists serving them.”

Congenital Adrenal Hyperplasia (CAH) Education and Support Network.

[www.congenitaladrenalhyperplasia.org](http://www.congenitaladrenalhyperplasia.org)

Includes comprehensive medical resources, a glossary, links to support groups, and message boards.

Eminism. <http://eminism.org/>

Personal website of Emi Koyama, multi-issue social justice activist. Includes presentations, zines, publications, a blog, and more.

Hida Viloría. <http://hidaviloria.com/>

Intersex writer and activist. Website includes news, videos, and a blog.

Hypospadias and Epispadias Association (HEA). [www.heainfo.org](http://www.heainfo.org)

A non-profit organization that provides support and education for people with hypospadias and epispadias and their families and loved ones.

InterACT: Advocates for Intersex Youth. <http://interactadvocates.org/>

Advocates for human rights of children born with intersex traits.

Interface Project. <http://www.interfaceproject.org>

Multimedia project with the mission to demystify and humanize the experiences of intersex individuals by affording each voice a space of its own.

Intersex Initiative. [www.intersexinitiative.org](http://www.intersexinitiative.org)

A Portland, Oregon based national activist and advocacy organization founded by Emi Koyama.

Intersex Society of North America: [www.isna.org](http://www.isna.org)

The (now defunct) Intersex Society of North America (ISNA) was devoted to systemic change to end shame, secrecy, and unwanted genital surgeries for intersex people. Website remains up with resources and definitions.

Intersex UK. <https://www.facebook.com/intersexuk>

An organization that works to protect the bodily autonomy of intersex children, teens, and adolescents through government lobbying and educational outreach in the United Kingdom and Ireland.

MRKH Organization. [www.mrkh.org](http://www.mrkh.org)

Resources and support for people with Mayer-Rokitansky-Küster-Hauser Syndrome.

Organisation Intersex International (OII). [www.intersexualite.org](http://www.intersexualite.org)

OII was established to give voice to intersex people, including those speaking languages other than just English.

Temko, Susannah. Chemosabe (blog). <http://chemo-sabe.tumblr.com/>

Personal blog of intersex cancer survivor Susannah Temko.

Temko, Susannah. XYSuz (website). <http://www.xysuz.com/>

An educational website about intersex conditions. Includes news and resources.

Turner Syndrome Society of the United States. [www.turner-syndrome-us.org](http://www.turner-syndrome-us.org)

“The Turner Syndrome Society of the United States creates awareness, promotes research, and provides support for all persons touched by TS.”

UK Intersex Association (UKIA). <http://www.ukia.co.uk/>

An education, advocacy, campaigning and support organization which works on behalf of intersex people.

Vaginal Davis. <http://www.vaginaldavis.com/>

An intersex and genderqueer artist and activist. Website includes films, zines, exhibitions, performances, and a blog.

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