

Family resources about disorders of sex development (DSD) or sex chromosomes

Animations on Genitalia Development (Toronto Hospital for Sick Children)

<http://www.aboutkidshealth.ca/HowTheBodyWorks/Sex-Development-An-Overview.aspx?articleID=7671&categoryID=XS>

The Hospital for Sick Children in Toronto has prepared a very helpful interactive graphic that can help explain the development of external genitalia and internal reproductive organs before birth, and some of the variations that can occur. The site has also been gradually adding more detailed explanations of several specific conditions. As of April 2008, AIS ([androgen insensitivity syndrome](#)), CAH ([congenital adrenal hyperplasia](#)), [hypospadias](#), XY mosaicism, [gonadal dysgenesis](#), and [5-alpha reductase deficiency](#) were covered.

Accord Alliance

<http://www.accordalliance.org>

Accord Alliance opened its doors in March 2008 to promote comprehensive and integrated approaches to care that enhance the health and well-being of people and families affected by [sex development](#) (DSD, which includes some conditions referred to as "[intersex](#)").

We partner with patients and families, healthcare administrators, providers, and researchers to facilitate open communication and collaboration among all persons [working together to improve care](#).

Can download Handbook for Parents at this website.

Advocates for Informed Choice (AIC)

<http://www.aiclegal.org>

AIC offers legal information and referrals to children and families who are facing legal issues related to a DSD (school bullying, discrimination, medico-legal issues, etc.) They also provide consultation and training for medical providers on legal and ethical issues relating to DSD, including informed consent, legal aspects of gender assignment, legal and ethical aspects of sterilization, adolescent health care rights, and disclosure of diagnosis.

Androgen Insensitivity Syndrome Support Group (AISSG)

PO Box 2148 Duncan, OK 73534-2148

<http://www.aiissusa.org>

The Androgen Insensitivity Syndrome Support Group USA (www.AIISGUSA.org) provides support and information to women and families affected by DSD. Female-identified adults in the group live with complete and partial AIS; XY gonadal dysgenesis (Swyer's syndrome); Leydig cell hypoplasia, 5-alpha reductase deficiency; 17-beta hydroxysteroid dehydrogenase deficiency ovotesticular disorder; disorders of anti-Mullerian hormone (AMH) and AMH receptor; anomalous formation of the Mullerian structures, including MRKH syndrome; and with XY DSD or genital ambiguity caused by undiagnosed conditions .

Androgen Insensitivity Syndrome (AIS)/DSD Parent Support Group

This group is part of the AISSG USA and supports families affected by any DSD. Families of girls or boys as well as expectant parents are welcome. Contact AISPARENT@gmail.com

CARES Foundation (Congenital Adrenal Hyperplasia Education & Support)

189 Main Street, 2nd floor Millburn, NJ 07041

<http://www.caresfoundation.org>

CARES Foundation is a non-profit organization committed to improving the lives of families and individuals affected by [Congenital Adrenal Hyperplasia](#) (CAH) through proactively advancing research for better understanding of CAH, better treatments and a cure; educating the public and healthcare professionals about all forms of CAH; advocating for universal newborn screening; and providing support services and resources vital to the CAH community worldwide.

DSD Guidelines, a project of the Consortium on Disorders of Sex Development

<http://www.dsguidelines.org>

Very helpful handbooks for parents and clinicians.

Hypospadias & Epispadias Association (HEA)

240 W. 44th St. Suite 1A New York, NY 10036

<http://www.heainfo.org>

Intersex Society of North America (ISNA)

<http://www.isna.org>

ISNA is no longer operating, but this website has many resources that families and individuals may find useful.

Klinefelter Syndrome and Associates

11 Keats Court Coto de Caza, CA 92679

<http://www.genetic.org/ks/>

The Magic Foundation

6645 W. North Avenue Oak Park, IL 60302

<http://www.magicfoundation.org>

Focus: [AIS](#), [CAH](#), [epispadias](#), [hypospadias](#), [Klinefelter Syndrome](#), [Mayer-Rokitansky-Kuster-Hauser Syndrome](#), [Turner Syndrome](#)

Major Aspects of Growth In Children (MAGIC) is made up of 25,000 + families whose children (and affected adults) have growth hormone deficiency or other medical conditions which affect their growth. They have a subgroup called Genital and Reproductive Anomalies in Children.

MRKH Organization: Mayer-Rokitansky-Kuster-Hauser Syndrome

P.O. Box 301494 Jamaica Plain, MA 02130

<http://www.mrkh.org>

A support group for women with Mayer-Rokitansky-Kuster-Hauser Syndrome (also known as MRKH, [Mullerian Agenesis](#), Vaginal Agenesis, and Congenital Absence of Vagina).

Turner Syndrome Society of the U.S.

14450 TC Jester, Suite 260 Houston, TX 77014

<http://www.turner-syndrome-us.org>

XY Turner

Box 5166 Laurel, MD 20726

<http://www.xyxo.org>

Many clinicians were taught that only girls can have Turner's syndrome. While it is technically correct that pure Monosomy X always results in a girl with Turner's syndrome, children with XY/XO mosaicism, whether girls or boys, may have any of the symptoms associated with Turner's syndrome.

The mission of xyTurners is to provide information, advocacy, and networking for parents whose child has been diagnosed in utero as XY/XO, parents making decisions regarding childhood genital surgery, parents making decisions regarding XY/XO medical issues , parents of children with a [gender](#) identity disorder , XY/XO adults, physicians seeking information on XY/XO-related medical conditions, physicians seeking information on childhood gender disorders, students, researchers, and others studying XY/XO issues.