

# Lend a Helping Hand: A Resource Guide for DSD Care<sup>®</sup>



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## Acknowledgements

This resource guide is the product of a rare collaboration among clinicians who care for the children, adolescents and adults with DSD, scientists who are working to extend our knowledge of these conditions, parents of children with DSD, and adults with the conditions that are the focus of this guide.

The task of creating a comprehensive resource guide for patients and families that was both accurate and balanced in perspectives was not always easy: there were differences of opinion on which resources to include. When opinions were not unanimous, we worked hard to achieve general agreement - a consensus.

As knowledge about DSD grows and as evidence and views about optimal care evolve, so will Lend a Helping Hand: A Resource Guide for DSD Care<sup>®</sup>.

This project was supported, in part, with a grant from the *Eunice Kennedy Shriver* National Institute of Child Health & Human Development (R01 HD068138).

*Created by members of the DSD-TRN Standard of Information Work Group with the support of the Psychosocial Work Group:*

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DSD-TRN: Improving health for people living with DSD

# Introduction

## WHAT is Lend a Helping Hand?

It's a guide to several resources about differences/disorders of sex development (DSD). These include books, articles, brochures, videos and trusted websites. We've written short "twitter-like" descriptions and grouped the resources to make it easy for you to decide what's relevant and helpful.

## WHO's it for? And by?

It's for people who have a DSD and their families and friends, and it's for health providers too. It's a project by people (advocates) who have a DSD working together with health providers. The advocates and health providers are part of a network of teams in the US, the *DSD - Translational Research Network* (<https://dsdtrn.genetics.ucla.edu>).

## WHY did Lend a Helping Hand happen?

We hope this guide will increase awareness about, and access to, many helpful resources about DSD, to provide:

- Information and education
- Emotional and peer support
- Better communication and care

It happened because of - and to encourage - *collaboration* between people who have a DSD and their health providers.

**Contact us** with suggestions as Lend a Helping Hand continues to be updated: [www.accordalliance.org](http://www.accordalliance.org) under "Contact Us"



# Use of Language - Sometimes Difficult to Agree

People may feel differently about what words to use when talking about DSD. Our goal is to respect, not resolve, different opinions, and to allow you to decide what words feel right for you. More importantly, we hope you will take valuable information away from the resources described.

- **Differences/Disorders of Sex Development (DSD)**
  - The term DSD is used in this guide to refer to a group of medical conditions sharing common features.
  - DSD are conditions present from birth in which the "development of chromosomal, gonadal, or anatomic sex is atypical."\*
  - These conditions sometimes need medical attention, but the term DSD does NOT in any way suggest that someone is "disordered" or abnormal.
- **Intersex**
  - The term DSD does not imply a person's identity. Some people prefer to use the term "intersex" instead of DSD. Some prefer not to use any umbrella term, instead choosing the name of their specific condition.
  - Our response: It is not always possible to avoid using an umbrella term because many people have a condition for which a genetic diagnosis is not known, yet that shares features with other well-understood conditions.

\*Lee PA, Houk CP, Ahmed SF, Hughes IA, the participants in the International Consensus Conference on Intersex. Consensus statement on management of intersex disorders. *Pediatrics*. 2006;118(2):e488-e500.

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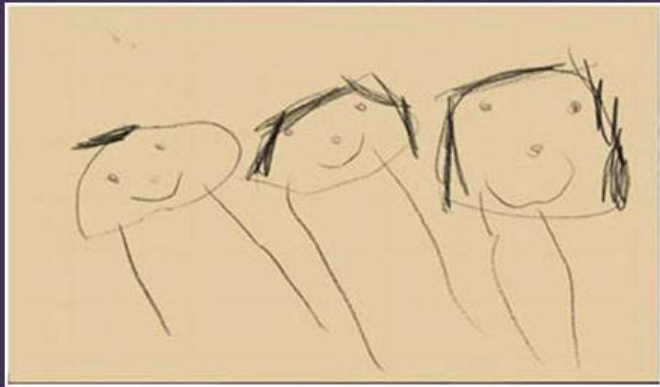
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## ADDITIONAL RESOURCES FOR PURCHASE

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# EDUCATIONAL & INFORMATIONAL RESOURCES

## Amazing you! The Story so Far... dsdFamilies



*My family,  
By Clara, 4,  
little sister  
of Lily, 8,  
PAIS*

Source:

[www.dsdFamilies.org/parents/telling\\_talking/amazing\\_you.php](http://www.dsdFamilies.org/parents/telling_talking/amazing_you.php)

*Amazing You! The Story So Far* is a personal and sensitive letter written by parents to their child. Co-written with help from a clinician, the letter shares age-appropriate information about how bodies develop and emphasizes a child's unique personality traits. It's an easy way to see how parents can share medical information with their children. Written in "British English."

**NOTE:** Parents can easily change the letter for a child with any DSD with help of the clinical team.

### Who's This For?

- Youth (ages 8-11)
- Parents, caregivers, & families

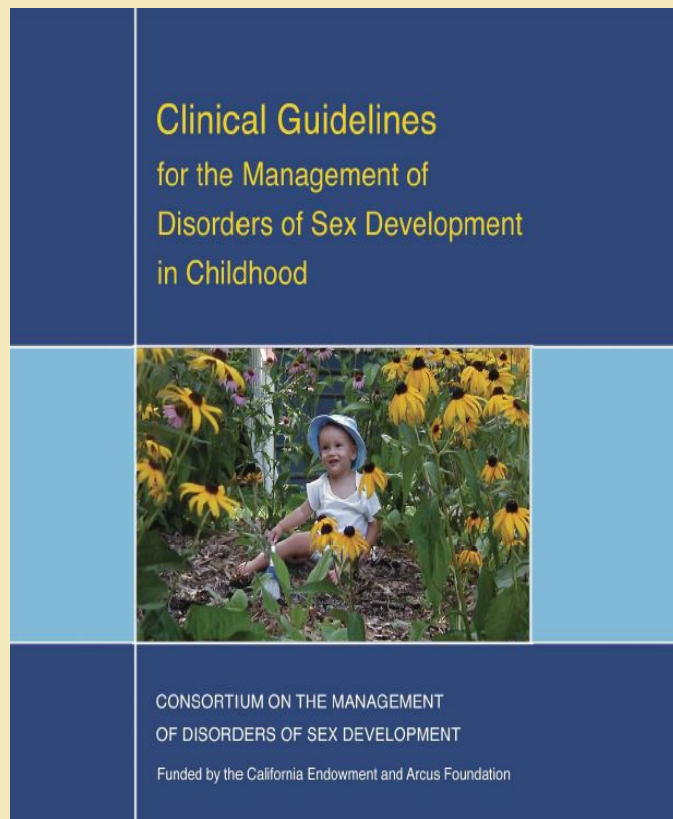
### DSD Types

- Partial androgen insensitivity syndrome (PAIS)



# EDUCATIONAL & INFORMATIONAL RESOURCES (continued)

## Clinical Guidelines for the Management of DSD in Childhood: A Clinician's Handbook Accord Alliance



A useful resource for clinicians, as well as parents who have had medical training. Distributed by Accord Alliance, a non-profit organization dedicated to improving DSD care and outcomes. This handbook brings together supportive and ethical perspectives to help clinicians (from primary care physicians to specialists) navigate medical care and support for people with DSD and their families.

### Who's This For?

- Parents, caregivers, & family members (who have had medical training)
- Healthcare providers

### DSD Types

- All types

Source:

[www.accordalliance.org/wp-content/uploads/2013/07/clinical.pdf](http://www.accordalliance.org/wp-content/uploads/2013/07/clinical.pdf)

# EDUCATIONAL & INFORMATIONAL RESOURCES (continued)

## Complete Androgen Insensitivity Syndrome

Royal Children's Hospital, Parkville, Australia, & Androgen Insensitivity Syndrome Support Group UK (AISSG-UK)

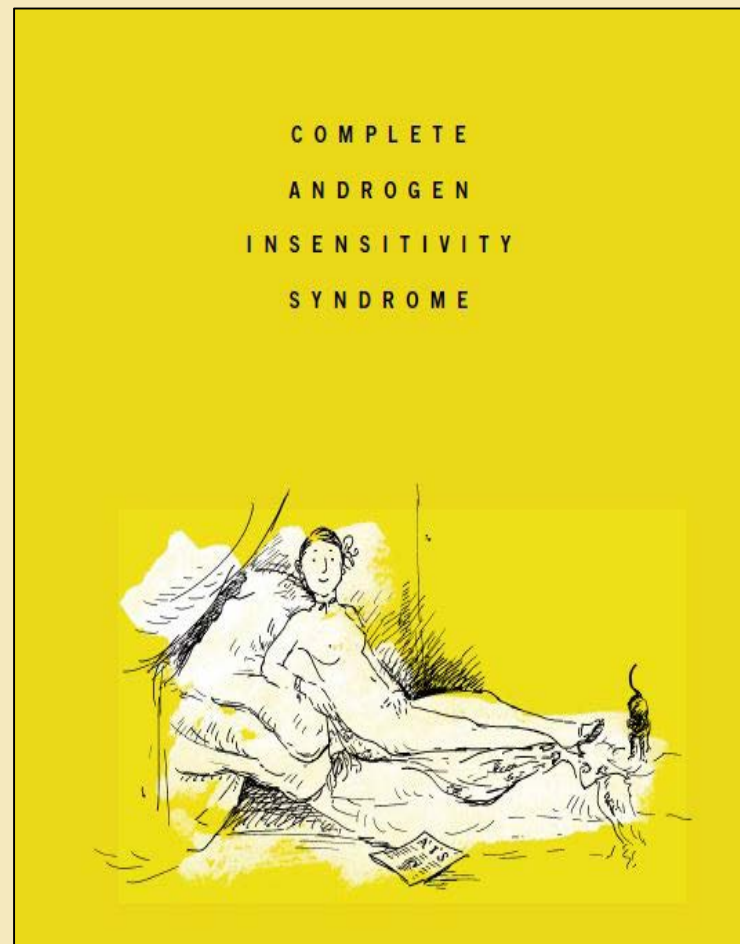
A 28-page booklet written in medical style by the AISSGUK and a health care team in Sydney, Australia. Created in 1997, the booklet still contains clear, detailed, factual, and (mostly) current information about complete androgen insensitivity syndrome (CAIS), including discussion about genetics, gonads, and common characteristics of CAIS. It features a variety of helpful drawings and is written in "British English."

### Who's This For?

- Teens (ages 13+)
- Parents, caregivers, & families

### DSD Types

- Complete androgen insensitivity syndrome (CAIS)
- Partial androgen insensitivity syndrome (PAIS)



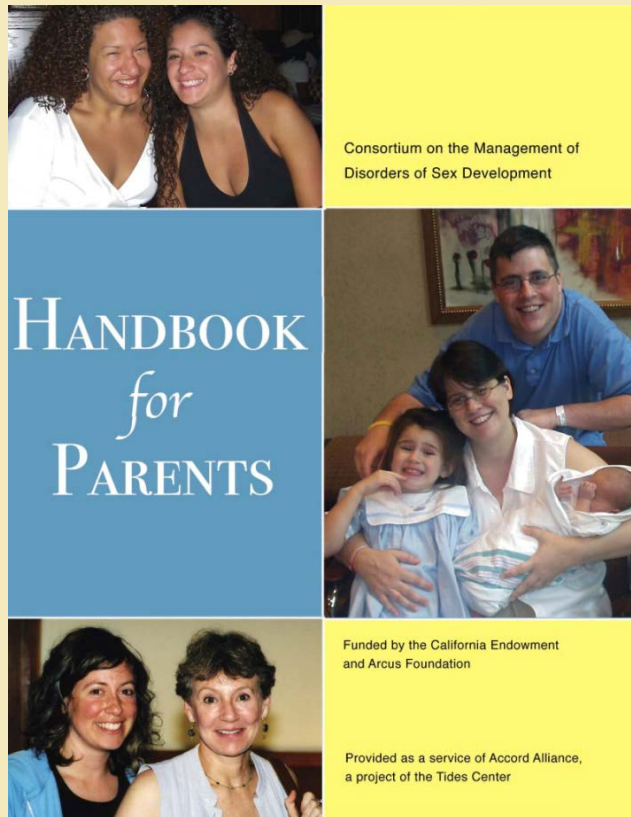
Source:

[ww2.rch.org.au/emplibrary/chas/CAIS.pdf](http://ww2.rch.org.au/emplibrary/chas/CAIS.pdf)



# EDUCATIONAL & INFORMATIONAL RESOURCES (continued)

## Handbook for Parents Accord Alliance



A useful handbook for parents of children with DSD of all ages, but especially for those with younger children. Made available by Accord Alliance, a non-profit organization dedicated to improving DSD care and outcomes by bringing together stakeholders from diverse communities. This resource combines medical information with family-centered ideas to support families in determining what treatments are in the best interest of their child. A useful read for every parent.

### Source:

<http://www.accordalliance.org/wp-content/uploads/2013/07/Hanbook-for-Parents.pdf>

### Who's This For?

- Adults (ages 18+)
- Parents, caregivers, & families

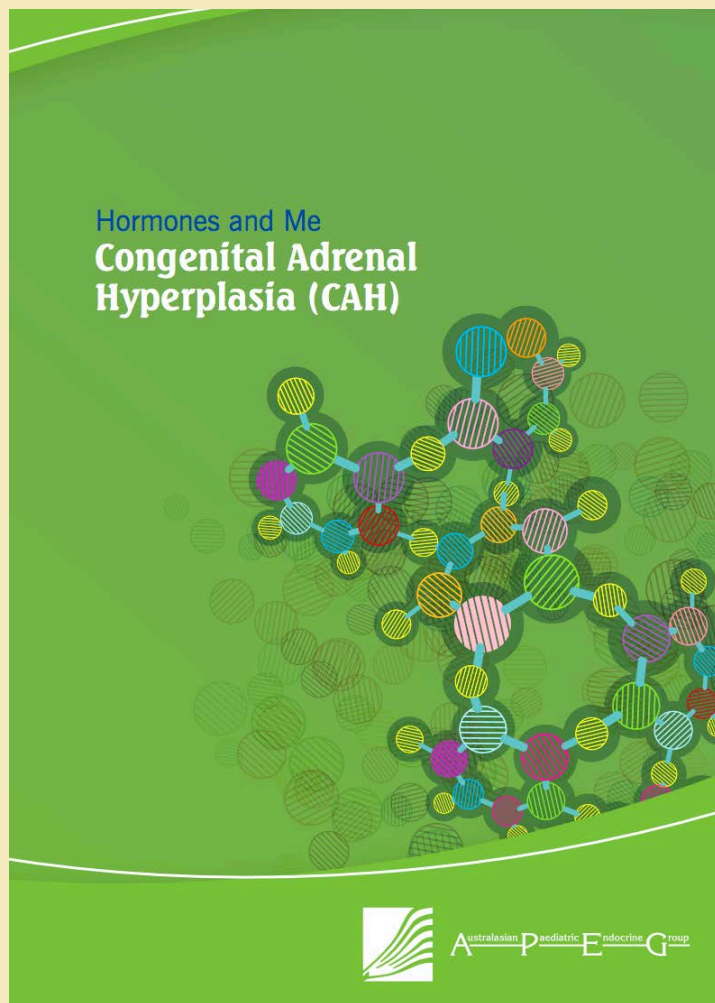
### DSD Types

- All types

# EDUCATIONAL & INFORMATIONAL RESOURCES (continued)

## Hormones and Me (CAH)

Professor Garry Warne: Australasian Paediatric Endocrine Group



A useful overview of congenital adrenal hyperplasia (CAH) for families and affected daughters or sons. It includes background information for readers to better understand adrenal glands and hormones. Also, the resource explains how CAH is inherited, course of treatment, fertility, and addresses some frequently asked questions.

**NOTE:** Contains terms such as "corrective surgery", and discusses prenatal treatment, which is an experimental intervention.

### Who's This For?

- Adults (ages 18+)
- Parents, caregivers, & families

### DSD Types

- Congenital Adrenal Hyperplasia (CAH)

Source:

<https://d192ha6kdpe15x.cloudfront.net/apeg/assets/uploads/2016/03/mer5333-saizen-hormones-and-me-cah-v3.pdf>

# EDUCATIONAL & INFORMATIONAL RESOURCES (continued)

## Info about Kids

Consortium for Science-based Information on Children, Youth and Families

A general website for parents and caregivers to understand healthy child and teen development. The site includes a range of science-based resources to learn more about a variety of topics, including: diet, motor skills, child development stages, behavioral health, emotions, peer relationships, and puberty.

### Who's This For?

- Parents, caregivers, & families
- Health care providers

### DSD Types

- All types

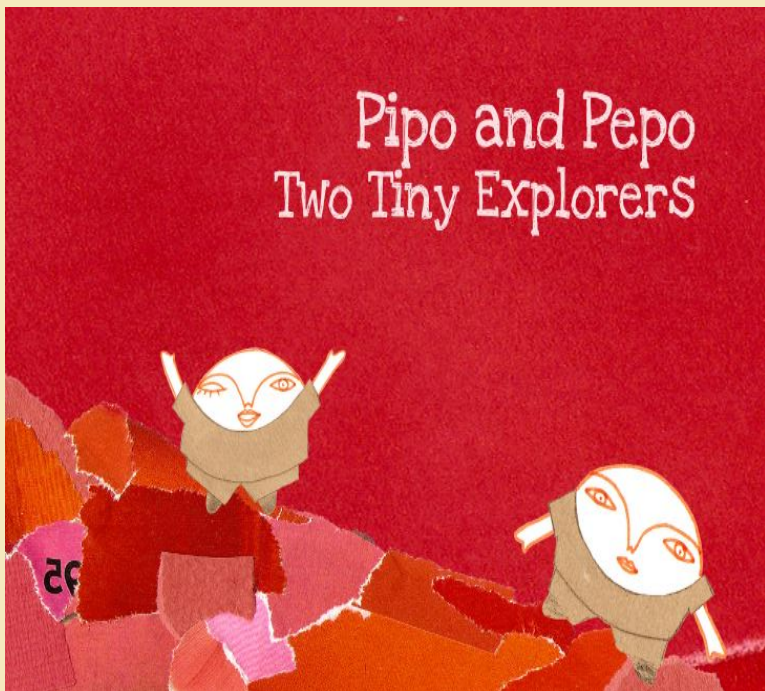


Source: [infoaboutkids.org](http://infoaboutkids.org)

# EDUCATIONAL & INFORMATIONAL RESOURCES (continued)

## Pipo and Pepo: A Tale of Two Explorers GrApSIA

### Pipo and Pepo Two Tiny Explorers



A make-believe children's story that explains gonads and hernias. It's a light-hearted story about two gonads that cause hernias and the curious little girl to whom they belong, who loves to explore and play. Please note that the story refers to "gonads" as "explorers". It might help a family explain about hernias to a child, but it is recommended that families first read through the book to consider if the story will be helpful to their child.

Source:

[grapsia.files.wordpress.com/2012/11/cuento\\_pipoypepo\\_en.pdf](http://grapsia.files.wordpress.com/2012/11/cuento_pipoypepo_en.pdf)

To access the Spanish translation:

[grapsia.files.wordpress.com/2016/07/cuento\\_pipoypepo\\_es.pdf](http://grapsia.files.wordpress.com/2016/07/cuento_pipoypepo_es.pdf)

To access the French translation:

[grapsia.files.wordpress.com/2012/11/cuento\\_pipoypepo\\_fr.pdf](http://grapsia.files.wordpress.com/2012/11/cuento_pipoypepo_fr.pdf)

### Who's This For?

- Youth (ages 2-12)
- Parents, caregivers, & families

### DSD Types

- Complete androgen insensitivity syndrome (CAIS)
- Partial androgen insensitivity syndrome (PAIS)
- DSD causing hernias in the groin



# EDUCATIONAL & INFORMATIONAL RESOURCES (continued)

## Puberty and You dsdteens.org



Source: <http://www.dsdteens.org/puberty-and-you>

Puberty & You is great resource for teens and pre-teens to help understand puberty. Dsdteens is a partner website of dsdfamilies.org, written by people and families with DSD with input from medical experts. Dsdteens covers 3 sections, ranging from puberty to growing up. Puberty & You explains changes that happen at puberty, and how puberty may look in unique DSD conditions.

### Who's This For?

- Youth and teens (ages 10+)

### DSD Types

- All types



# EDUCATIONAL & INFORMATIONAL RESOURCES (continued)

## Sex Development: An Overview About Kid's health

### Sex Development: An Overview

// How the Body Works / Sex Development



This module of How The Body Works contains information about sex development, sex differentiation, and the formation of the **genitals**.

This resource is intended to help caregivers teach parents about the typical development of a child's sexual anatomy before birth, and about some of the variations that can occur.

Some of these variations (called DSDs, or disorders of sex development) are explained in their own sections.

Please choose a topic from the menu on the left to learn about typical sex development, Congenital Adrenal Hyperplasia, or hypospadias.

A website that provides pictures and animations to explain how babies (with and without DSD) develop sex organs and genitals. It's a good one to go through with your doctor, family, and friends, to help understand about how DSD can happen.

#### Source:

[www.aboutkidshealth.ca/En/HowTheBodyWorks/SexDevelopmentAnOverview/Pages/default.aspx](http://www.aboutkidshealth.ca/En/HowTheBodyWorks/SexDevelopmentAnOverview/Pages/default.aspx)

### Who's This For?

- Parents, caregivers, & families
- Teens
- Adults
- Healthcare providers

### DSD Types

- All types
- Congenital adrenal hyperplasia (CAH)
- Androgen insensitivity syndrome (AIS)
- 5-alpha reductase deficiency (5-ARD)
- Hypospadias

# EDUCATIONAL & INFORMATIONAL RESOURCES (continued)

## What we wish our Doctors Knew interACT Youth

A brochure written by young people discussing “intersex” conditions. The handout reflects the experiences and opinions of those who created it. It is an important handout to make doctors aware of how some people with DSD may feel, and help doctors consider different viewpoints during shared and informed decision-making with families. The handout describes some of the challenges of DSD and how these young people believe health care can be improved.



Source: <http://interactadvocates.org/wp-content/uploads/2015/12/BROCHURE-interACT-Doctors-final-web.pdf>

## What we wish our Parents Knew interACT Youth

A similar brochure written by the same young people, but geared towards parents.



### Who's This For?

- Teens (ages 14+)
- Parents, caregivers, & families
- Healthcare providers

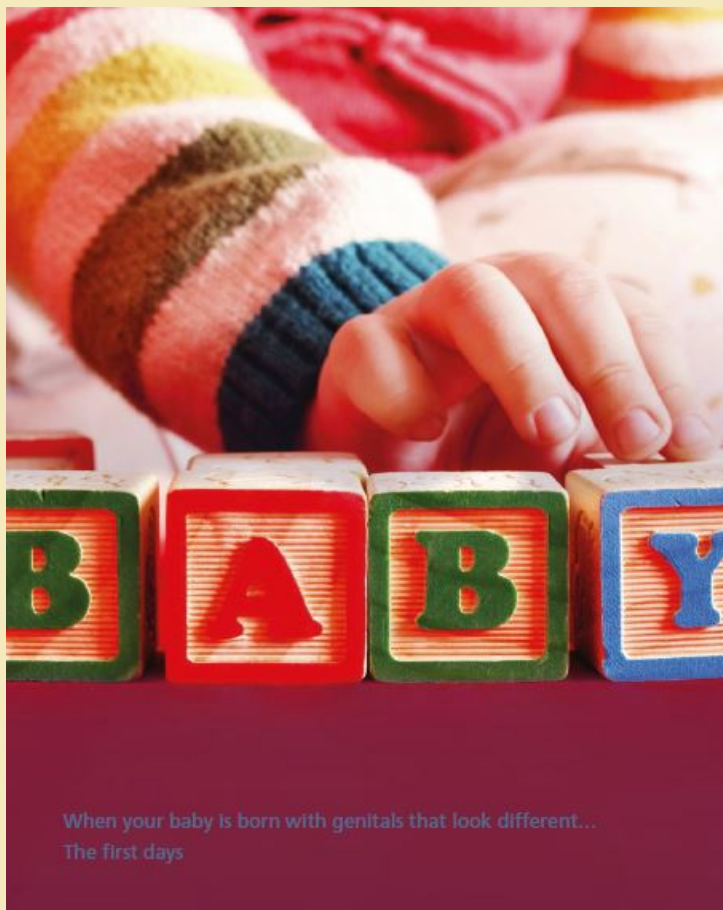
### DSD Types

- All Types

Source: <http://interactadvocates.org/wp-content/uploads/2015/12/BROCHURE-interACT-Parents-final-web.pdf>

# EDUCATIONAL & INFORMATIONAL RESOURCES (continued)

## When Your Child is Born with *Genitals that Look Different* dsdfamilies



A wonderful brochure to support new parents of children born with atypical genitals or reproductive parts. Medically accurate, yet written with the understanding of parents who have gone through this experience. A must for any parent of a child with an early diagnosis of DSD, and for medical teams caring for patients and families during the prenatal, newborn or early childhood periods. Important, positive and comforting messages for new families, including tips on what to say to others, how parents can be an important part of their child's health care team, the importance of bonding with and enjoying their baby, and focusing on raising a happy, healthy child. Translated into several languages.

### Who's This For?

- Parents, caregivers, & families
- Healthcare providers

### DSD Types

- All types, especially with genital difference

Source: [www.dsdfamilies.org/docs/brochures/DSD.pdf](http://www.dsdfamilies.org/docs/brochures/DSD.pdf)



# LIVING WITH DSD: YOUNG ADULT & ADULT VOICES

## I'm a Woman with Male Chromosomes Marie Claire

Katie Baratz thought she was a typical teenage girl — until her parents let her in on the shocking truth that changed her life forever.



Source:

[www.sindromedimorris.org/document/nov\\_2012/pdf/marie\\_claire.pdf](http://www.sindromedimorris.org/document/nov_2012/pdf/marie_claire.pdf)

A magazine article from 2010 featuring Katie Baratz, a woman who has complete androgen insensitivity syndrome (CAIS). Positive and thoughtful. Katie Baratz shares her experience as a woman with XY chromosomes and CAIS. Ideal for people new to understanding DSD.

### Who's This For?

- Teens (ages 13+)
- Parents, caregivers, & families

### DSD Types

- Complete androgen insensitivity syndrome (CAIS)
- Partial androgen insensitivity syndrome (PAIS)
- Complete XY gonadal dysgenesis

## Me, My Sex, and I

British Broadcasting Corporation (BBC) & Oprah Winfrey Network (OWN)



Source: [www.youtube.com/watch?v=87XvVdLaWT8](http://www.youtube.com/watch?v=87XvVdLaWT8)

An hour-long documentary featuring DSD-care advocates, Katie Baratz, Janet Green, and Tiger Devore. The advocates share "ups and downs" of their experiences with medical care, finding peer support, and building healthy relationships. Meant for general audiences, and offers a softer touch in the presentation of conditions and each person's individual difficulties and celebrations.

### Who's This For?

- Teens (ages 14+)
- Parents, caregivers, & families
- Healthcare providers

### DSD Types

- All Types

# LIVING WITH DSD: YOUNG ADULT & ADULT VOICES (continued)

## Real Voice Interview with Mia Big Picture Publications & the Wellcome Trust

Q-&-A style information for young women with complete androgen insensitivity syndrome (CAIS). The interview is clear, easy to understand, and takes a positive, "can-do" approach to discussing CAIS and the process of diagnosis, care, and what Mia's condition means for her.

“  
*I'm like a flourless chocolate cake. I might not have flour, but it doesn't make me any less of an amazing cake.*  
”

Source:  
[bigpictureeducation.com/real-voices-interview-mia](http://bigpictureeducation.com/real-voices-interview-mia)

### Who's This For?

- Youth (ages 10+)
- Teens (ages 13+)
- Parents, caregivers, & families

### DSD Types

- Complete androgen insensitivity syndrome (CAIS)

## What we Wish our Friends Knew interACT Youth

A brochure by young DSD-care advocates that highlights ways for youth and adolescents to approach conversations with their peers and close friends. It's a useful read for parents or care providers too. The brochure encourages youth and adolescents to foster healthy, honest, and authentic relationships.



Source:  
<http://interactadvocates.org/wp-content/uploads/2015/12/BROCHURE-interACT-Friends-final-web.pdf>

### Who's This For?

- Teens (ages 13+)
- Parents, caregivers, & families
- Healthcare providers

### DSD Types

- All types

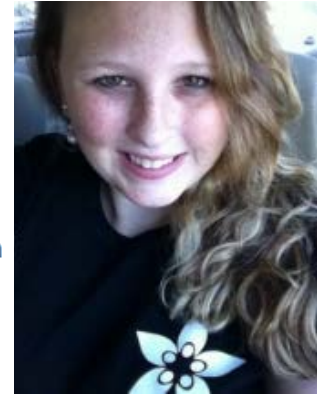


## You Are Not Alone: Resources for Youth Androgen Insensitivity Syndrome- DSD Support Group (AISSG-DSD)



### YOU ARE NOT ALONE

We have many valuable resources and support for young adults, teens and tweens including additional guides and websites. Reaching out and connect socially with peers and mentors in our private forum, Orchid Connect, is a great option for support. There you will find others who have shared similar experiences. More information about how to connect is available if you contact us above. Connection is also available face to face at regional and national annual meetings, which include many sessions and fun activities that allow you to make friends and share your experiences with others. In addition, you can find some great resources below, including the newly diagnosed teen brochure on the left.



Source: [aisdsd.org/resources/youth](https://aisdsd.org/resources/youth)

This website features a range of personal stories and educational resources for youth with AIS and related conditions. It includes links to youth peer support, related articles published in Marie Claire and Cosmopolitan, information and videos developed by Inter/Act Youth, and frequently asked questions. The site is ideal for young people wanting to connect with others or learn more general information.

### Who's This For?

- Teens (ages 16+)
- Parents, caregivers, & families

### DSD Types

- All types

# PEER SUPPORT & ADVOCACY GROUPS

## Accord Alliance United States

Accord Alliance promotes a comprehensive and integrated approach to care that enhances the health and well-being of people and families affected by DSD. This site provides a valuable parent handbook and guidelines for health care providers. The Accord Alliance website also hosts a useful glossary, summaries of recent research in DSD, and links to other sources of information and support.


### Who's This For?

- Teens (ages 14+)
- Adults
- Parents, caregivers, & families
- Healthcare providers

### DSD Types

- All types

Clinical Guidelines  
for the Management of  
Disorders of Sex Development  
in Childhood



CONSORTIUM ON THE MANAGEMENT  
OF DISORDERS OF SEX DEVELOPMENT  
Funded by the California Endowment and Arcus Foundation



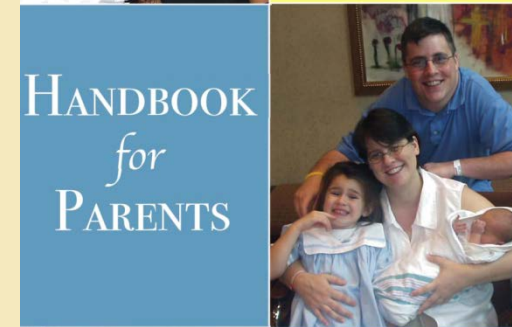
**Accord Alliance**

**better care. better outcomes. better lives.**

Source: [www.accordalliance.org](http://www.accordalliance.org)



Consortium on the Management of  
Disorders of Sex Development



**HANDBOOK  
for  
PARENTS**

Funded by the California Endowment  
and Arcus Foundation



Provided as a service of Accord Alliance,  
a project of the Tides Center

# PEER SUPPORT & ADVOCACY GROUPS (continued)

## Androgen Insensitivity Syndrome- Differences of Sex Development Support Group (AISSG-DSD) United States

Beginning as a support group only for women with AIS, this US-based peer support group now provides support to individuals with any DSD, and their families. It features extensive information and respected resources. The site offers ways to meet others with DSD and provides information about their yearly conference. Online groups for parents, youth, and adults are accessible, as well as regional get-togethers and 1-on-1 individual connections in cities around the US. Needs-based scholarships are available to attend conferences.

### Who's This For?

- Youth (ages 5+)
- Teens (ages 13+)
- Adults (ages 18+)
- Parents, caregivers, & families

### DSD Types

- All types



Source: [aisdsd.org](http://aisdsd.org)

## Androgen Insensitivity Syndrome Support Group of the United Kingdom (AISSG-UK) United Kingdom

### Who's This For?

- Youth (ages 12+)
- Adults (ages 18+)
- Parents, caregivers, & families

### DSD Types

- Androgen Insensitivity Syndrome (AIS)
- Related conditions



Picasso - Le Train Blue - 1924

Source: [www.aissg.org](http://www.aissg.org)

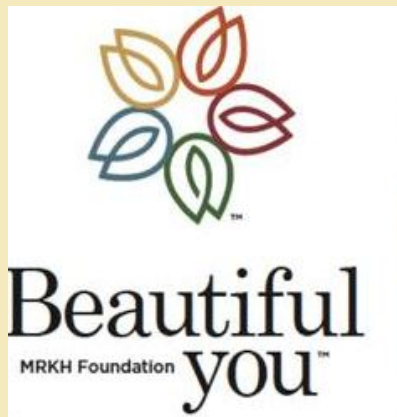
This is the site of the United Kingdom's AIS Support Group, one of the first in the world. It has information on AIS and other DSD, information resources, research articles, personal stories, and evidence-based information on a variety of topics. The group also offers 1-on-1 peer support and conferences for members. It is written in "British English" and has parts translated into German, Spanish, French, Italian, Dutch, Polish, Swedish, Flemish, and Hungarian.



# PEER SUPPORT & ADVOCACY GROUPS (continued)

## The Beautiful You MRKH Foundation United States

The mission of the Beautiful You MRKH Foundation is to create a supportive community that also partners with health care providers to increase awareness and empower women of all ages with Mayer-Rokitansky-Küster-Hauser (MRKH) syndrome to feel beautiful, just as they are. The organization provides peer support, 1-on-1 support and hosts regional member conferences. The group supports women of all ages with MRKH and their families. Their site features personal stories by members, ways to get in touch with members, informational resources and global links to MRKH support and care. The group has a medical and research focus with articles available to view and a listing of research studies, should visitors to the website wish to participate.



Source:

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

### Who's This For?

- Youth (ages 10+)
- Parents, caregivers, & families

### DSD Types

- Mayer-Rokitansky-Küster-Hauser (MRKH) syndrome

## Cares Foundation United States



Source: [www.caresfoundation.org](http://www.caresfoundation.org)

This organization has information for parents and individuals with congenital adrenal hyperplasia (CAH). Meet-ups and conferences for this organization occur at varying times in the year, along with opportunities to connect with other families online, by phone, or in person.

### Who's This For?

- Youth (ages 10+)
- Adults
- Parents, caregivers, & families

### DSD Types

- Congenital adrenal hyperplasia (CAH)

# PEER SUPPORT & ADVOCACY GROUPS (continued)

## dsdFamilies United Kingdom



Source: [www.dsdfamilies.org](http://www.dsdfamilies.org)

A safe, nurturing site written by, and for, families and young people with DSD that draws you in as you read. It's a useful resource for parents, and has some resources for children too.

### Who's This For?

- Youth (ages 5+)
- Teens (ages 13+)
- Adults (ages 18+)
- Parents, caregivers, & families
- Healthcare providers
- Researchers

### DSD Types

- All types

## dsdteens United Kingdom



Source: [www.dsdteens.org](http://www.dsdteens.org)

A great resource for teens and pre-teens. Dsdteens is a partner site of dsdFamilies.org, written by people and families with DSD with input from medical experts. It covers 3 sections, from puberty to growing up:

1. Puberty & You explains changes that happen at puberty, and how puberty may look in unique DSD conditions;
2. Moving on Up talks about topics to think about in different situations, for example, in school, sharing with friends, and at the doctor's office;
3. Taking the Wheel explores relationships, treatment options and beyond.

### Who's This For?

- Puberty & You- youth & teens (10+)
- Moving on Up- youth and teens (11+)
- Taking the Wheel- teens (14+)

### DSD Types

- All types



# PEER SUPPORT & ADVOCACY GROUPS (continued)

## GrApSIA: Androgen Insensitivity Support Group Spain

### For Spanish speaking families:

This is an androgen insensitivity syndrome support group, located in Spain. Resources on this site include educational information, original books, and ways to connect with support from its members.

Website text is in Spanish, but can be easily translated to another language using a Google Chrome web browser.



Source: [www.grapsia.org](http://www.grapsia.org)

### Who's This For?

- Youth (ages 12+)
- Parents, caregivers, & families

### DSD Types

- All types

## Hypospadias and Epispadias Association (HEA) United States



Source: [heainfo.org](http://heainfo.org)

### Who's This For?

- Teens (ages 14+)
- Parents, caregivers, & families

### DSD Types

- Hypospadias
- Epispadias

The Hypospadias and Epispadias Association (HEA) was founded for the education and support of children who were born with hypospadias or epispadias, their families and loved ones. The group welcomes anyone affected by, or interested in, the physical and emotional issues sometimes associated with these conditions. HEA offers informational tools, personal stories, resources on how to approach medical decisions, and a message board forum. The group organizes conferences, opportunities for 1-on-1 support, and family, youth, and adult support.

# PEER SUPPORT & ADVOCACY GROUPS (continued)

## interACT United States

interACT (formerly known as Advocates for Informed Choice) is an organization that takes a legal approach to DSD advocacy and support. It focuses on the legal process of informed consent and shared decision-making in DSD. It is the parent advocacy organization to interACT Youth.



Source: [interactadvocates.org](http://interactadvocates.org)

### Who's This For?

- Teens (ages 14+)
- Parents, caregivers, & families

### DSD Types

- All types



Source: [interactadvocates.org/our-advocacy/youth](http://interactadvocates.org/our-advocacy/youth)

### Who's This For?

- Teens (ages 13+)
- Parents, caregivers, & families

### DSD Types

- All types

**interACT Youth** is the youth project of interACT. This group is not a support group, but instead it is more of an advocacy space for young people to share their stories and to help improve care and resources for young people. The group is made up of young people from ages 13 to 29 with DSD and uses a blog to show videos, posts, brochures, resources, and efforts of its members. The group is moderated and aims to help youth grow as individuals and advocates in diverse ways.

# CLINICIAN RESOURCES

## Clinical Guidelines for the Management of DSD in Childhood: A Clinician's Handbook Accord Alliance

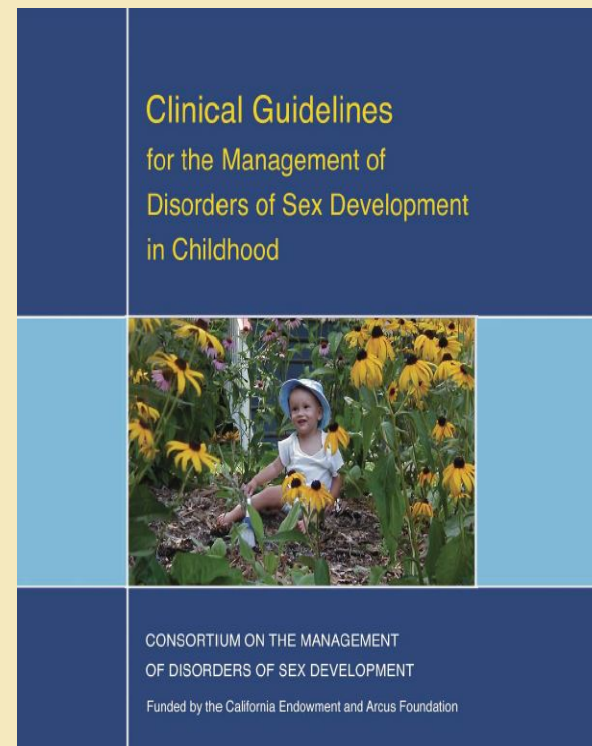
A useful resource for clinicians, as well as parents who have had medical training. Distributed by Accord Alliance, a non-profit organization dedicated to improving DSD care and outcomes. This handbook brings together supportive and ethical perspectives to help clinicians (from primary care physicians to specialists) navigate medical care and support for people with DSD and their families.

### Who's This For?

- Parents, caregivers, & family members (who have had medical training)
- Healthcare providers

### DSD Types

- All types



Source: [www.accordalliance.org/wp-content/uploads/2013/07/clinical.pdf](http://www.accordalliance.org/wp-content/uploads/2013/07/clinical.pdf)

# CLINICIAN RESOURCES (continued)

## Teaching Differences of Sex Development Parts 1 & 2 Association of American Medical Colleges (AAMC)



Jennifer Potter, M.D. and Katie Baratz-Dalke, M.D. discuss effective ways to teach DSD to medical students and patient providers. The video describes the historical impact of past medical models for treating DSD, on current DSD care, ways to successfully support patients with DSD in a clinical environment, and proposes a plan for medical institutions to include DSD-oriented learning modules. A two-part video.

### Who's This For?

- Healthcare providers
- Parents, caregivers, & families (who have had medical training)

### DSD Types

- All types

Click here for Part 1:

<https://www.aamc.org/initiatives/diversity/431350/teachingdspdpart1.html>


Click here for Part 2:

<https://www.aamc.org/initiatives/diversity/431358/teachingdspdpart2.html>



## CLINICIAN RESOURCES (continued)

### What we Wish our Doctors Knew InterACT Youth



"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

Source: <http://interactadvocates.org/wp-content/uploads/2015/12/BROCHURE-interACT-Doctors-final-web.pdf>

A brochure written by young people discussing "intersex" conditions (another term for DSD). The handout reflects the experiences and opinions of those who created it. It is an important handout to make doctors aware of how some people with DSD may feel, and help doctors consider different viewpoints during shared and informed decision-making with families. The handout describes some of the challenges of DSD and how these young people believe health care can be improved.

#### Who's This For?

- Healthcare providers
- Parents, caregivers, & families (who have had medical training)

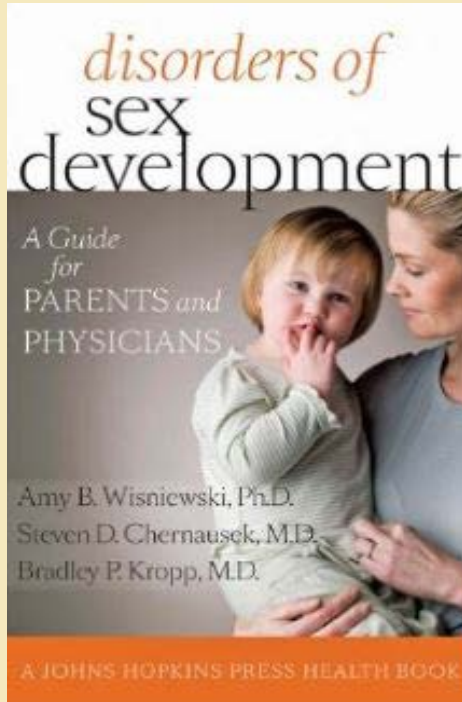
#### DSD Types

- All types

# ADDITIONAL RESOURCES FOR PURCHASE

## *Disorders of Sex Development: A Guide for Physicians*

Amy B. Wisniewski, Steven D. Chernausek,  
Bradley P. Kropp



A book produced by health care providers from the SUCCEED team (a multidisciplinary DSD health care team) describing DSD for parents, including recent evidence and discussions of care.

## iNTErSExION (Documentary)

Ponsonby Productions Ltd.



Source: [www.intersexionfilm.com/](http://www.intersexionfilm.com/)

### Who's This For?

- Healthcare providers
- Teens (ages 17+)
- Adults (ages 18+)
- Parents, caregivers, & families

### DSD Types

- All types

Narrated by Mani Mitchell, a DSD/intersex activist from New Zealand, the film features personal stories told by people with DSD/intersex variations from around the world. It focuses on the journey into adulthood from an advocacy point of view and describes relationships with family members and healthcare providers. An overview of sex, gender, and sexuality is discussed. Meant for general audiences, and is not patient/family-support oriented.

### Who's This For?

- Healthcare providers
- Parents, caregivers, & families (who have had medical training)

### DSD Types

- All types