

Lend a Helping Hand: A Resource Guide for DSD Care[®]

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Lend a Helping Hand: A Resource Guide for DSD Care[©]

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Second Edition September 2021

Published by the [DSD-Translational Research Network](#) in partnership with [Accord Alliance](#).

This resource guide is the product of a collaboration among clinicians who care for children, adolescents and adults with Differences of Sex Development (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 perspective 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[©].

This project was supported, in part, with a grant from the *Eunice Kennedy Shriver* National Institute of Child Health & Human Development (R01 HD093450).

First edition created by members of the DSD-TRN Standard of Information Work Group with the support of the Psychosocial Work Group:

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Introduction

WHAT is Lend a Helping Hand?

It's a guide to several resources about differences 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](#).

WHY did Lend a Helping Hand happen?

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

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

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

Contact us with suggestions as Lend a Helping Hand continues to be updated: 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 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 is not intended to suggest that someone has a “disorder” or is 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, and Hughes IA, and the participants in the International Consensus Conference on Intersex. Consensus statement on management of intersex disorders. *Pediatrics*. 2006;118(2):e488-e500.

Table of Contents

EDUCATIONAL & INFORMATIONAL RESOURCES

Pages 6-21

LIVING WITH DSD: YOUNG ADULT & ADULT VOICES

Pages 22-28

PEER SUPPORT & ADVOCACY GROUPS

Pages 29-40

CLINICIAN RESOURCES

Pages 41-46






















RESEARCH/REGISTRY LINKS

Pages 47-50

ADDITIONAL RESOURCES FOR PURCHASE

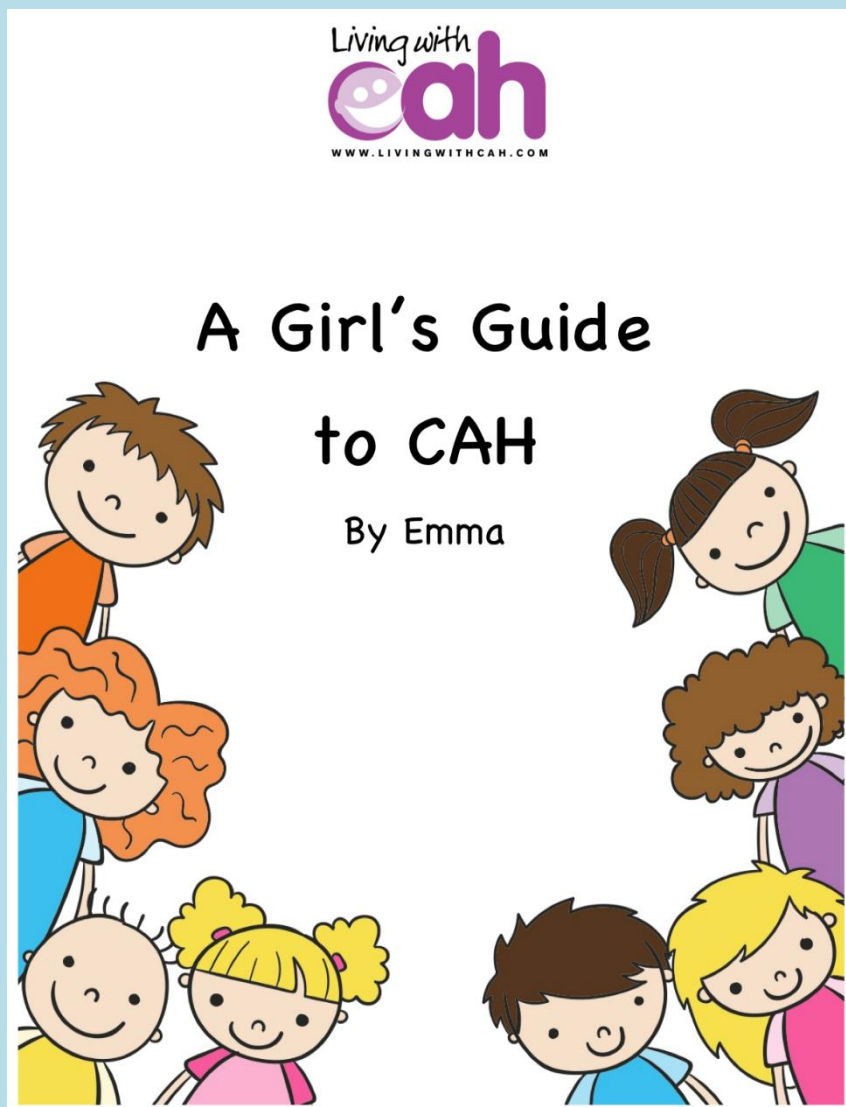
Pages 51-53

EDUCATIONAL & INFORMATIONAL RESOURCES INDEX

<p>A Girl's Guide to CAH</p> <p> (7) CAH</p>	<p>Katy no Pocket</p> <p> (15) ALL DSD</p>
<p>Amazing you! The Story so Far...</p> <p> (8) ALL DSD, AIS</p>	<p>Pipo and Pepo</p> <p> (16) AIS, DSD first identified as a hernia</p>
<p>Clinical Guidelines for the Management of DSD in Childhood: A Clinician's Handbook</p> <p> (9) ALL DSD</p>	<p>Puberty and You</p> <p> (17) ALL DSD</p>
<p>First Days-When Your Child is Born with Genitals that Look Different</p> <p> (10) ALL DSD</p>	<p>Sex Development-Genetics and Biology</p> <p> (18) ALL DSD</p>
<p>Handbook for Parents</p> <p> (11) ALL DSD</p>	<p>Story of Sex Development</p> <p> (19) ALL DSD</p>
<p>Hormones and Me</p> <p> (12) CAH</p>	<p>Supporting Your Intersex Child</p> <p> (20) ALL DSD</p>
<p>How Sex Development Works</p> <p> (13) ALL DSD, Hypospadias</p>	<p>Top Tips for Talking</p> <p> (21) ALL DSD</p>
<p>My Body and Me</p> <p> (14) ALL DSD</p>	<p>HEALTHCARE PROVIDERS  TEENS (13-18) </p> <p>PARENTS/CAREGIVERS  PRETEENS (9-12) </p> <p>ADULTS (18+)  CHILDREN (5+) </p>

EDUCATIONAL & INFORMATIONAL RESOURCES

A Girl's Guide to CAH (Living with CAH)



Written by a 10-year-old girl with CAH, this book discusses what CAH is, how it occurs, and living with CAH in a language that is easy for children to understand. It is light-hearted yet informational, and a useful resource for youth, parents, and families affected by CAH.

Who's This For?

- Parents & Caregivers
- Preteens
- Children

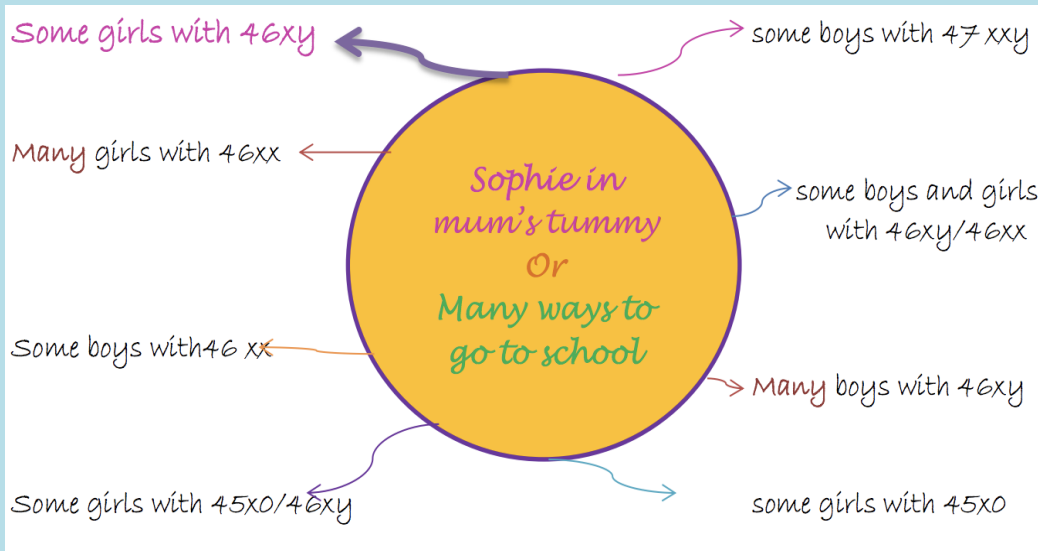
DSD Types

- CAH

Source:

[https://www.dsdamilies.org/application/files/2815/3803/4594/I have CAH with pictures1.pdf](https://www.dsdamilies.org/application/files/2815/3803/4594/I%20have%20CAH%20with%20pictures1.pdf)

Amazing you! The Story so Far... [dsdfamilies](#)



Source: [Amazing You! The Story so Far...](#)

Amazing You! The Story So Far is a personal and sensitive letter written by parents to their child with PAIS. 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 a way that parents can share medical information with their children.

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

Who's This For?

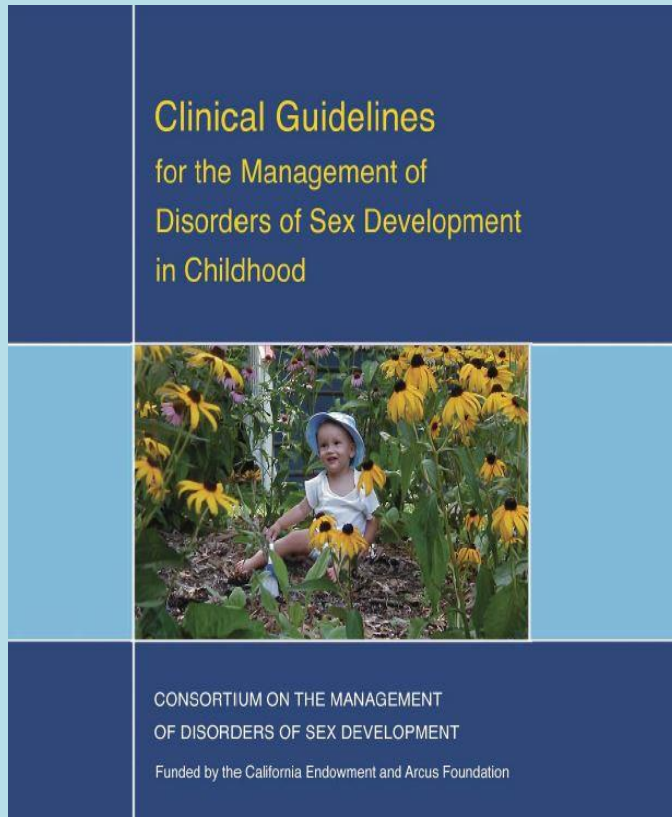
- Parents & Caregivers
- Preteens

DSD Types

- Partial androgen insensitivity syndrome (PAIS)
- Adaptable for all DSD

EDUCATIONAL & INFORMATIONAL RESOURCES (cont.)

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



A useful resource for clinicians, as well as parents and caregivers who have had medical training. This is 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?

- Healthcare providers
- Parent & Caregivers

DSD Types

- All types

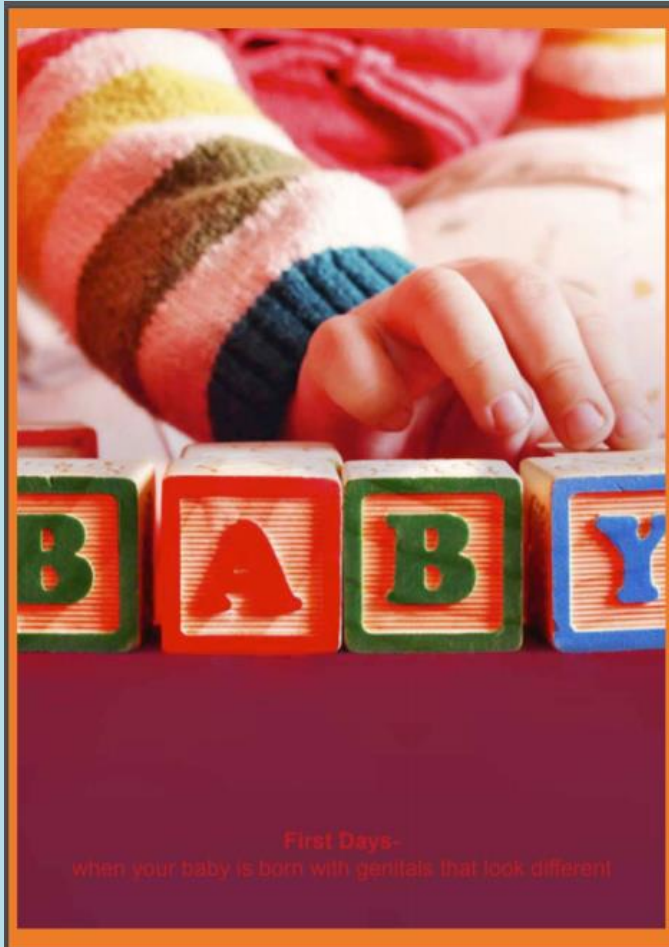
Source:

www.accordalliance.org/wp-content/uploads/2013/07/clinical.pdf

EDUCATIONAL & INFORMATIONAL RESOURCES (cont.)

First Days-When Your Child is Born with Genitals that Look Different

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



This is a wonderful brochure to support new parents of children born with genitals or reproductive parts that look different.

Medically accurate, yet written with the understanding of parents who have gone through this experience, it is 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 are provided, as well as 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.

Note: It is available in multiple languages.

Who's This For?

- Healthcare providers
- Parent & Caregivers

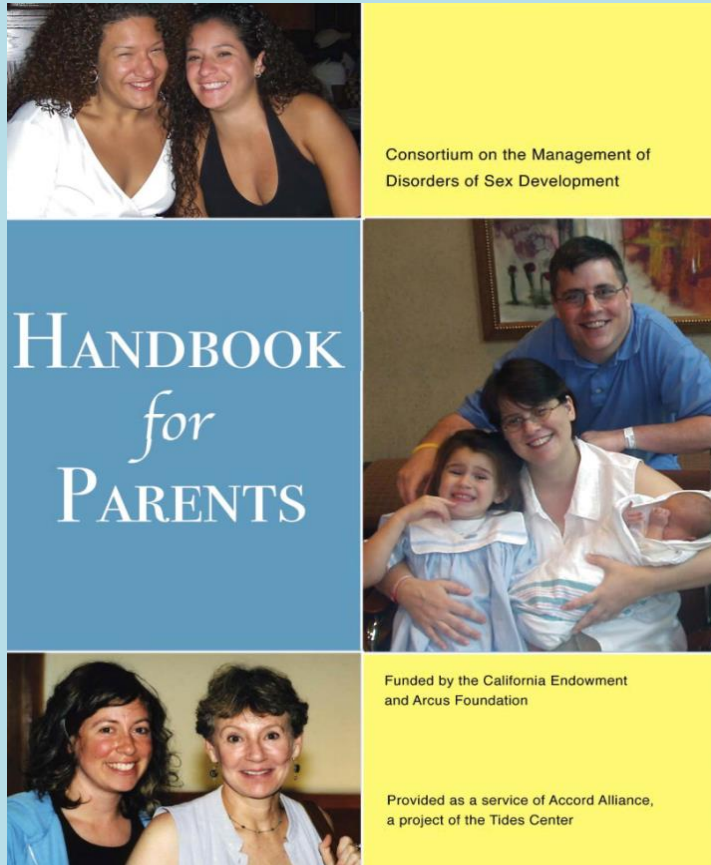
DSD Types

- All types

Source:

<https://www.dsdamilies.org/application/files/1615/4236/8548/firstdays-dsdamilies.pdf>

Handbook for Parents Accord Alliance



This is a useful handbook for parents of children with DSD of all ages, but especially for those with younger children. This resource combines medical information with family-centered ideas to support families in determining what treatments are in the best interests of their child. It also provides recommendations on how to discuss the DSD diagnosis with your child, family, and friends as the time arises. Made available by Accord Alliance, a non profit organization dedicated to improving DSD care and outcomes by bringing together stakeholders from diverse communities .

Source:

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

Who's This For?

- Parent & Caregivers
- Adults

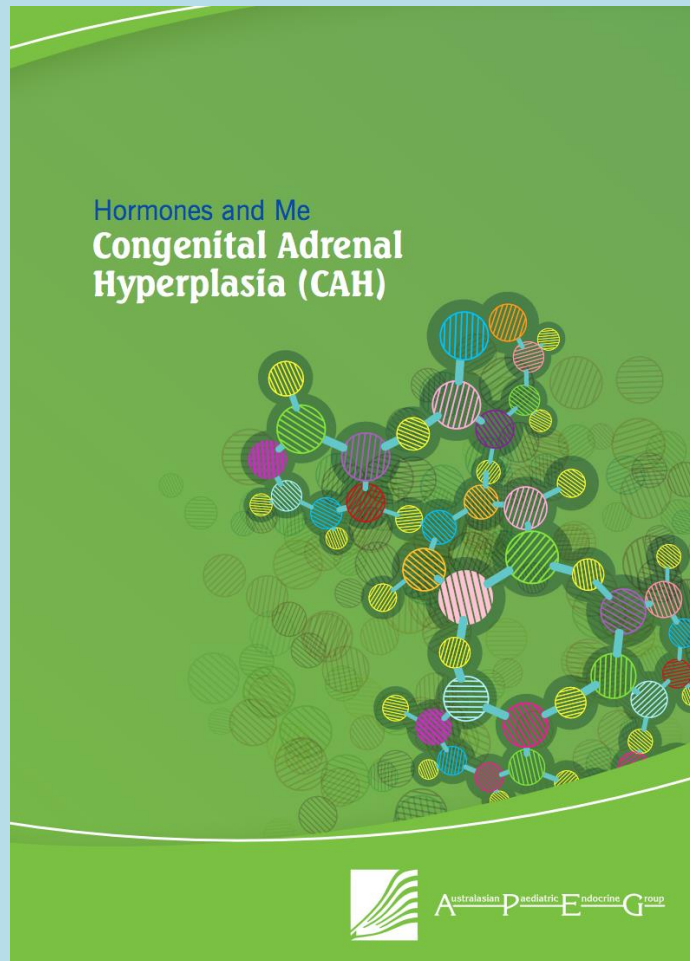
DSD Types

- Adaptable for all types

EDUCATIONAL & INFORMATIONAL RESOURCES (cont.)

Hormones and Me (CAH)

Professor Garry L. Warne: Australasian Pediatric Endocrine Group ([APEG](#))



A useful overview of congenital adrenal hyperplasia (CAH) for families and affected children. 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?

- Parent & Caregivers
- Adults

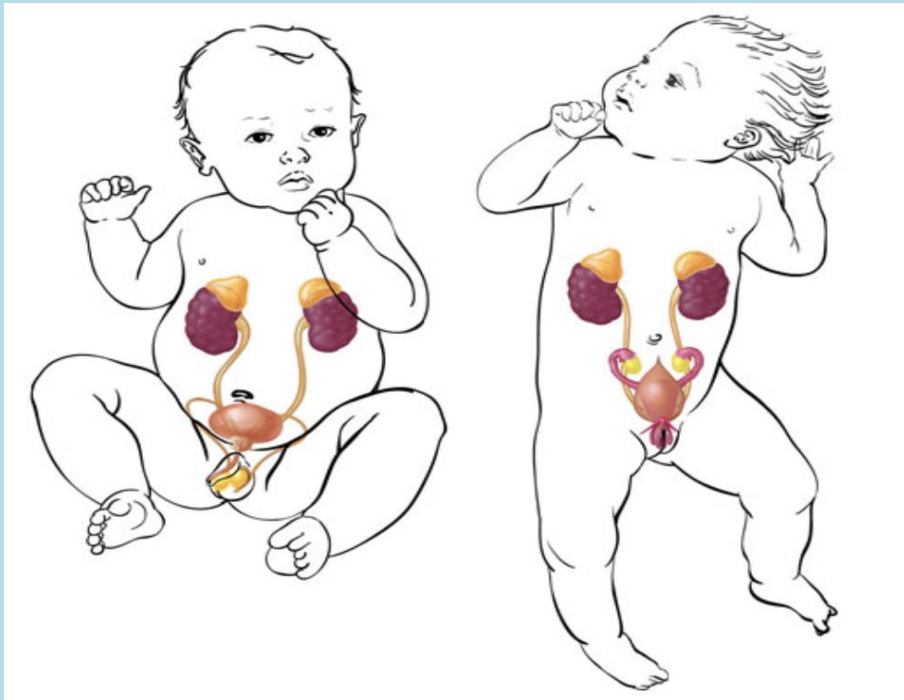
DSD Types

- Congenital Adrenal Hyperplasia (CAH)

Source:

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

How Sex Development Works About Kid's health



Source:

<https://pie.med.utoronto.ca/htbw/module.html?module=sex-development>

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 how DSD can happen.

Who's This For?

- Healthcare providers
- Parents & Caregivers
- Adults
- Teens

DSD Types

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

My Body and Me



An uplifting video produced by a mother and is geared towards young children with a DSD. It may help generate talking points for parents of young children. This is a helpful resource for an age-group that can be challenging for many when it comes to sharing age-appropriate information about DSD.

Source: <https://www.youtube.com/watch?v=CrtLx3bJokk>

Who's This For?

- Parent & Caregivers
- Children

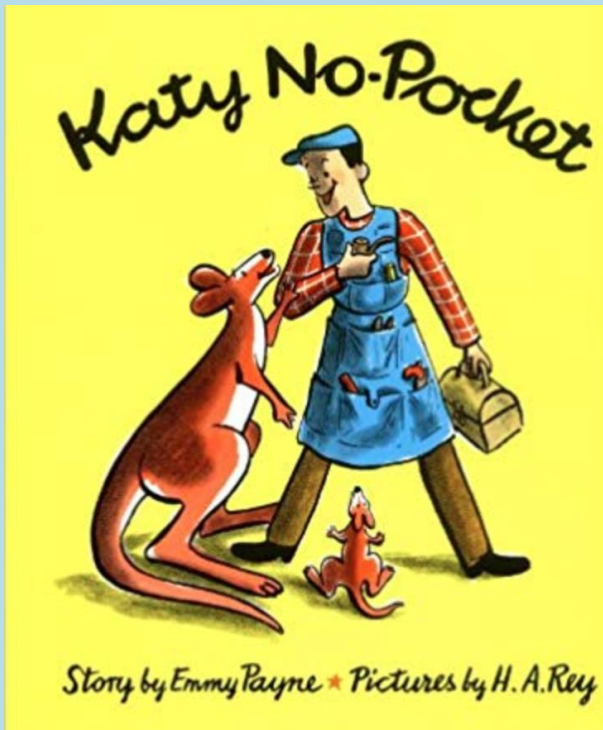
DSD Types

- All types

Katy No Pocket

Source:

<https://archive.org/details/KatyNoPocket/page/n3/mode/2up>



This is a cheery children's tale about a kangaroo named Katy that has no pocket in which to carry her child. Despite this variation, in the end, she finds an inventive way to carry her child, plus the children of other animals! This book could be used to discuss the various ways to have a family (adoption, assistive reproductive technology, etc.) in light of the fertility issues that children with DSD could face. You can access it for free through a public online archive, purchase it through Amazon or other booksellers, and it may be available at your local library.



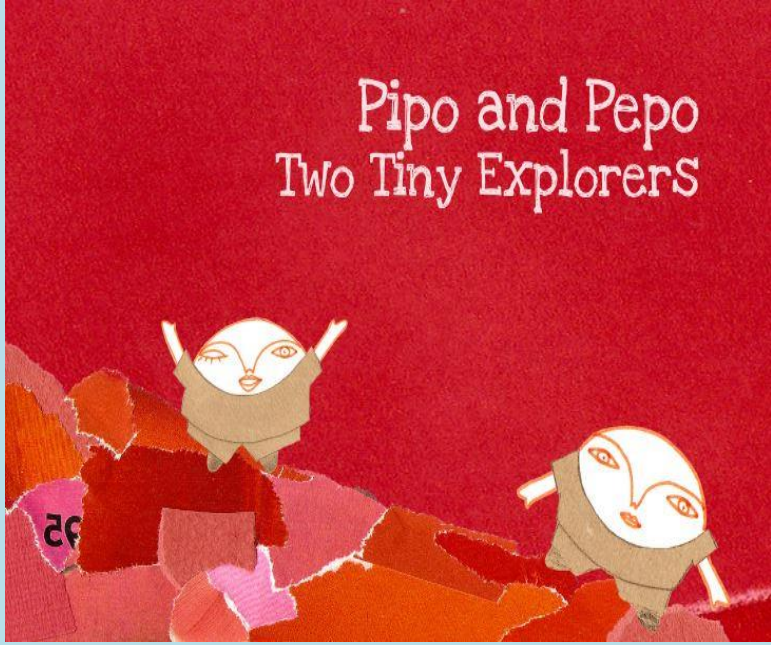
Who's This For?

- Parents & Caregivers
- Preteens
- Children

DSD Types

- All types

Pipo and Pepo



Pipo and Pepo Two Tiny Explorers

This is a make-believe, light-hearted children's 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.

Who's This For?

- Parents & Caregivers
- Preteens
- Children

DSD Types

- AIS
- DSD first identified as a hernia

Source:

https://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

To access the French translation:

grapsia.files.wordpress.com/2012/11/cuento_pipoypepo_fr.pdf

Puberty and You [dsdteens](http://www.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](http://www.dsdteens.org), a partner website of [dsdfamilies.org](http://www.dsdamilies.org), covers three sections ranging from puberty to growing up and was written by people and families with DSD with input from medical experts. Puberty & You explains changes that happen at puberty and how puberty may look in unique DSD conditions.

Who's This For?

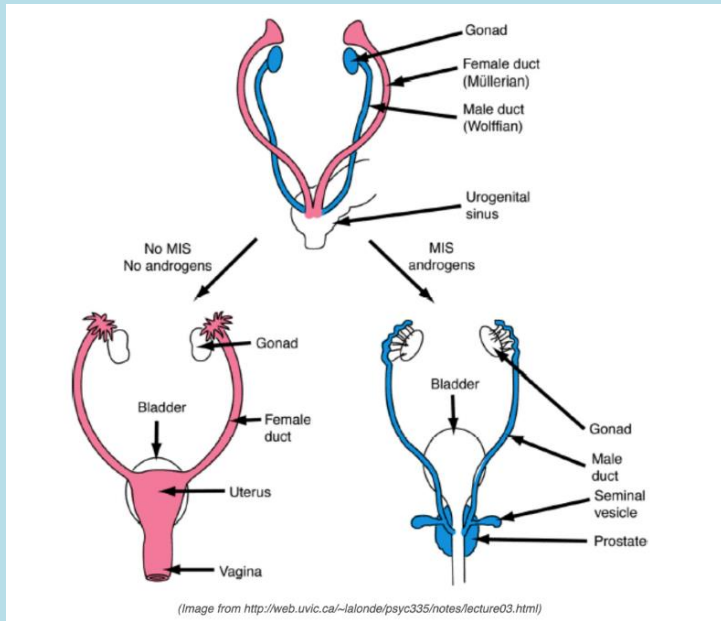
- Teens
- Preteens

DSD Types

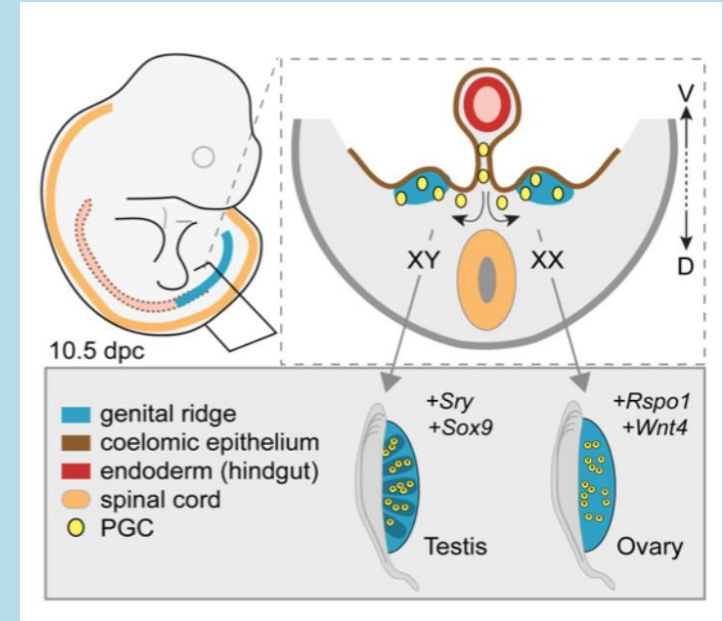
- All types

EDUCATIONAL & INFORMATIONAL RESOURCES (cont.)

Sex Development-Genetics and Biology



Source:
<http://www.dsdgenetics.org/index.php?id=2>



A helpful website that discusses the genetics and biology of general sex development and also addresses variations (such as clitoromegaly and hypospadias) that can sometimes occur. It provides detailed information that is presented in an easily navigable website. The language is clear and comprehensible. This website also provides additional resources for parents and families.

Who's This For?

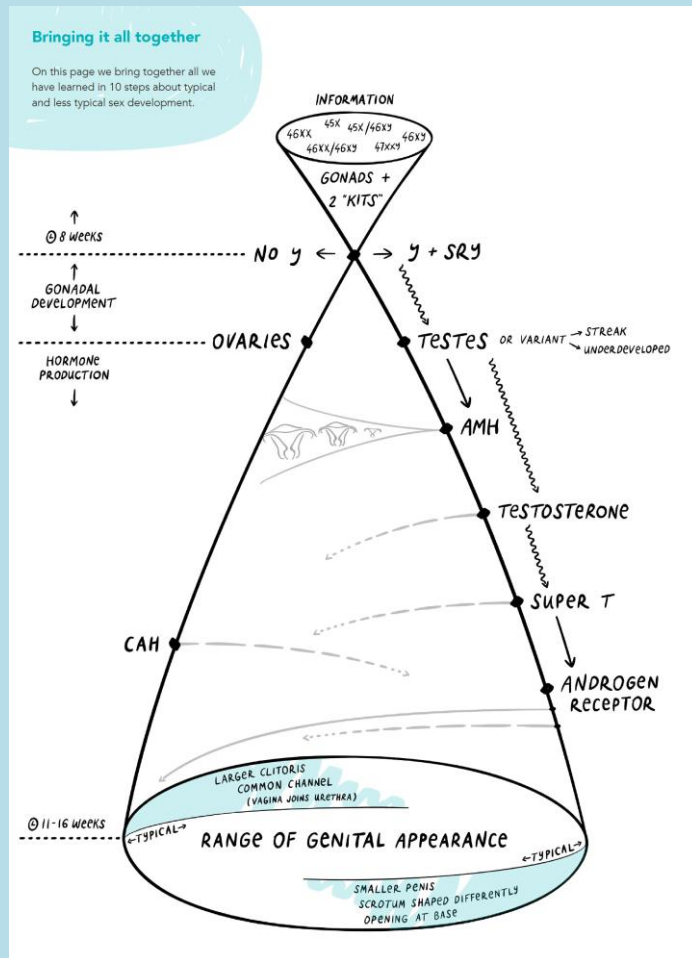
- Healthcare providers
- Parents & Caregivers
- Adults
- Teens

DSD Types

- All types

EDUCATIONAL & INFORMATIONAL RESOURCES (cont.)

Story of Sex Development [dsdfamilies](https://www.dsdfamilies.org)



A helpful tool produced by the charity, dsdfamilies, that walks through the basics of typical sex development, to help explain how differences might occur. This is a great tool for facilitating conversations in clinic between providers and parents and/or patients to educate about DSD.

Who's This For?

- Healthcare providers
- Parents & Caregivers
- Adults
- Teens
- Preteens

DSD Types

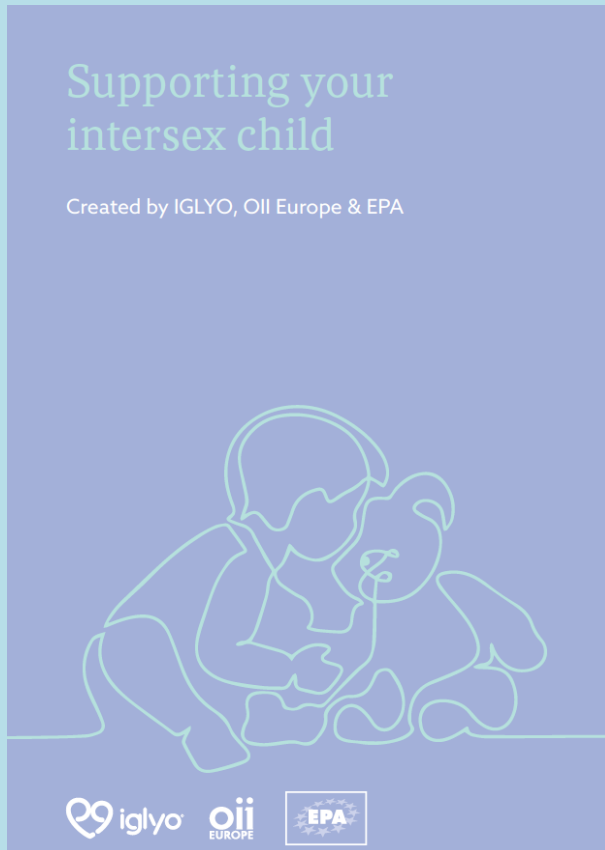
- All DSD types

Source:

[https://www.dsdfamilies.org/application/files/4915/7386/0021/ECOPY Story of Sex Dev Nov 2019.pdf](https://www.dsdfamilies.org/application/files/4915/7386/0021/ECOPY%20Story%20of%20Sex%20Dev%20Nov%202019.pdf)

f

Supporting Your Intersex Child



Source: <http://www.iglyo.com/wp-content/uploads/2018/10/Supporting-Your-Intersex-Child.pdf>

A European-based booklet for parents of children with intersex conditions. Themes include reassurance, natural variations, what parents should consider when faced with decisions regarding possible surgery, what to say to children and others, and frequently asked questions.

Who's This For?

- Healthcare providers
- Parents & Caregivers

DSD Types

- All types

Top Tips for Talking [dsdfamilies](#)



Source:

https://www.dsdfamilies.org/application/files/4115/3780/1476/Top_Tips_for_Talking.pdf

Who's This For?

- Parents & Caregivers

DSD Types

- All DSD types

This booklet is produced by *DSDfamilies* and offers advice on how to talk to your child about their DSD. It includes a timeline about how to gradually initiate the discussion, and sample conversation starters. As indicated in the booklet, additional resources for discussions about DSD are available online at dsdfamilies.org

LIVING WITH DSD: YOUNG ADULT & ADULT VOICES INDEX

I'm a Woman with Male Chromosomes	(23)	
● ★ ▲	AIS, XY Gonadal Dysgenesis	
Interface Project	(24)	ALL DSD
● ★ ▲		
Me, My Sex, and I	(25)	ALL DSD
+ ● ★ ▲		
What We Wish Our Friends Knew	(26)	ALL DSD
● ▲ ♥		
What We Wish Our Teachers Knew/What We Wish Our Parents Knew	(27)	ALL DSD
● ▲ ♥		
You Are Not Alone: Resources for Youth	(28)	ALL DSD
● ▲ ♥		

- HEALTHCARE PROVIDERS +
- PARENTS/CAREGIVERS ●
- ADULTS (18+) ★
- TEENS (13-18) ▲
- PRETEENS (9-12) ♥
- CHILDREN (5+) ■

LIVING WITH DSD: YOUNG ADULT & ADULT VOICES

I'm a Woman with Male Chromosomes Marie Claire



This magazine article from 2010 features 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.

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:
<https://www.marieclaire.com/sex-love/advice/a5183/woman-with-male-chromosomes/>

Who's This For?

- Parents & Caregivers
- Adults
- Teens

DSD Types

- Androgen insensitivity syndrome (AIS)
- Complete XY gonadal dysgenesis

Interface Project

"No Body Is Shameful"

Founded in 2012 by a group of individuals born with DSD, The Interface Project is a way to communicate stories of people's DSD experiences with others. Through their YouTube channel and website, over 20 people, all ages, from around the world have shared their personal stories and what it means to have DSD. Their overall mission is to "gather and share personal stories of people living with an intersex condition or difference of sex development (DSD), and to spread the message that 'No Body is Shameful.'"

The logo for the Interface Project is written in a black, cursive, handwritten style. The words "Interface" and "Project" are written in a fluid, connected script.

Source: <https://www.interfaceproject.org/stories>

Ali von Klan, U.S.A.

"Ali is a daughter, sister, friend, feminist, queer ally, animal-loving, passionate, optimistic, caring intersex person with Swyer Syndrome." See the rest of her story, and other DSD stories, on The Interface Project

[YouTube Channel](#) or [website](#).



Source: <https://www.interfaceproject.org/stories>

Who's This For?

- Parents & Caregivers
- Adults
- Teens

DSD Types

- All types

LIVING WITH DSD: YOUNG ADULT & ADULT VOICES

Me, My Sex, and I

British Broadcasting Corporation ([BBC](#)) & Oprah Winfrey Network ([OWN](#))



Source: www.youtube.com/watch?v=87XvVdLaWT8

This is 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, it offers a softer touch in the presentation of conditions, and each person’s individual challenges and celebrations.

Who’s This For?

- Healthcare providers
- Parents & Caregivers
- Adults
- Teens

DSD Types

- All Types

What We Wish Our Friends Knew interACT Youth



Let me know you appreciate how hard it might be to tell you these personal details, and that you're thankful I shared them with you.

This is a brochure by young affected individuals and advocates that highlights ways for youth and adolescents to approach conversations with their peers and close friends. It's a useful read for parents and caregivers too. The brochure encourages youth and adolescents to foster healthy, honest, and authentic relationships.

Source:

<https://interactadvocates.org/wp-content/uploads/2016/01/interact-what-we-wish-our-friends-knew-intersex.pdf>

Who's This For?

- Parents & Caregivers
- Teens
- Preteens

DSD Types

- All types

What We Wish Our Teachers Knew interACT Youth



Source: <https://interactadvocates.org/wp-content/uploads/2018/07/BROCHURE-interACT-Teachers-final.pdf>

Written by the same young affected individuals and advocates who wrote "What We Wish Our Parents/Doctors/Friends Knew", this brochure is helpful for parents, caregivers, and teachers. It discusses ways educators can make their classrooms more welcoming and inclusive for all kids and recommends terminology that young affected individuals may be more comfortable with.

Who's This For?

- Parents & Caregivers
- Teens
- Preteens

DSD Types

- All types

What We Wish Our Parents Knew interACT Youth



This is a brochure written by young affected individuals and advocates discussing intersex conditions. The handout reflects the experiences and opinions of those who created it. Geared towards parents.

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

Who's This For?

- Parents & Caregivers
- Teens
- Preteens

DSD Types

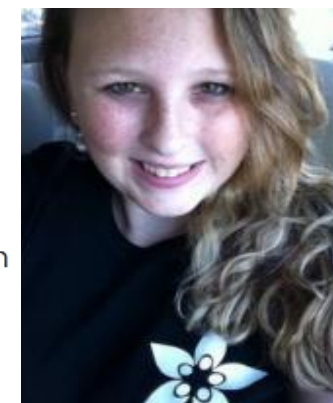
- All types

You Are Not Alone: Resources for Youth InterConnect



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: <http://interconnect.support/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 [InterACT 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?





- Parents & Caregivers
- Teens
- Preteens







DSD Types

- All types

PEER SUPPORT & ADVOCACY GROUPS INDEX


<p>Accord Alliance</p> <p> (30) ALL DSD</p>
<p>AISSG Australia Inc.</p> <p> (31) ALL DSD</p>
<p>Beautiful You MRKH Foundation</p> <p> (32) MRKH</p>
<p>CARES Foundation</p> <p> (33) CAH</p>
<p>DSD Families/Teens</p> <p> (34) ALL DSD</p>
<p>GrApSIA: Androgen Insensitivity Support Group</p> <p> (35) AIS</p>
<p>Hypospadias and Epispadias Association (HEA)</p> <p> (36) Hypospadias, Epispadias</p>

<p>InterConnect</p> <p> (37) ALL DSD</p>
<p>interACT</p> <p> (38) ALL DSD</p>
<p>interACT Youth</p> <p> (39) ALL DSD</p>
<p>MAGIC Foundation</p> <p> (40) CAH</p>

- HEALTHCARE PROVIDERS 
- PARENTS/CAREGIVERS 
- ADULTS (18+) 
- TEENS (13-18) 
- PRETEENS (9-12) 
- CHILDREN (5+) 

PEER SUPPORT & ADVOCACY GROUPS

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



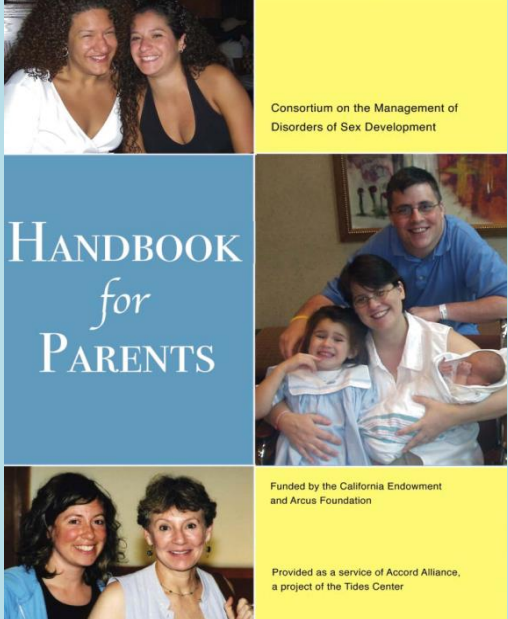
CONSORTIUM ON THE MANAGEMENT
OF DISORDERS OF SEX DEVELOPMENT
Funded by the California Endowment and Arcus Foundation

Accord Alliance United States



Accord Alliance
better care. better outcomes. better lives.

Source: 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

Accord Alliance's mission is to promote comprehensive and integrated approaches to care that enhance the health and well-being of people and families affected by DSD by fostering collaboration among all stakeholders.

This site provides valuable resources for clinicians and families. The Accord Alliance website also hosts a useful glossary, summaries of recent research in DSD, and links to other sources of information and support.

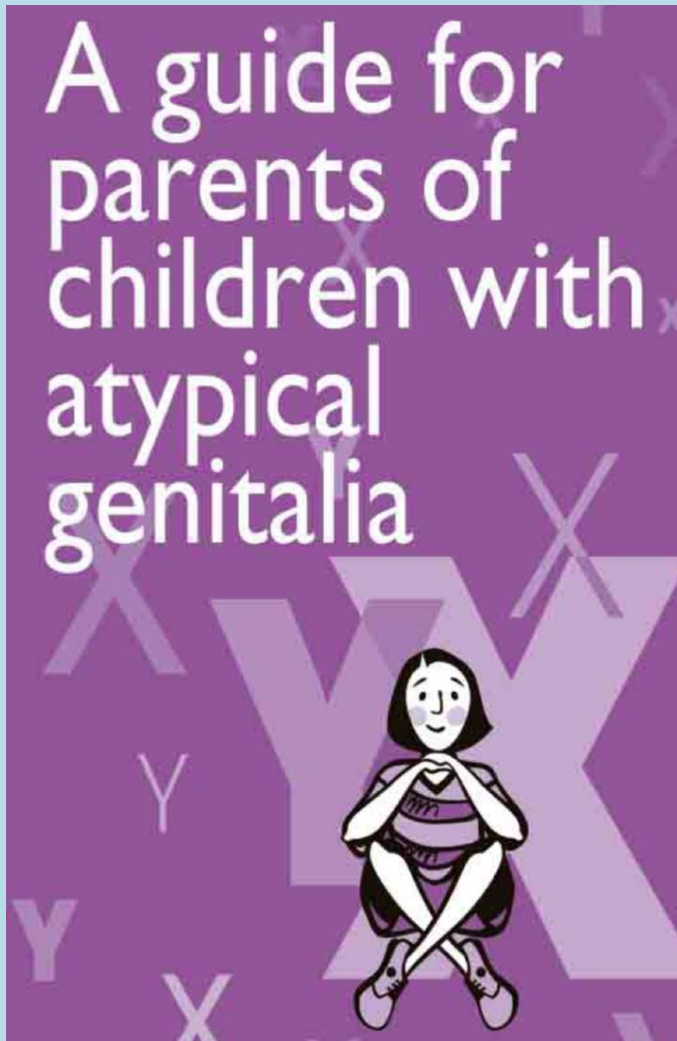
Who's This For?

- Healthcare providers
- Parents & Caregivers
- Adults
- Teens

DSD Types

- All types

AISSG Australia Inc.



Source: <https://www.aissg.org/>



This website is an Australian-based support group for people with AIS or any type of DSD. It offers fact sheets about AIS, a guide for parents of children with genitalia that look different, extensive personal biographies, tips for parents in terms of discussing their child's DSD, and more.

Who's This For?

- Parents & Caregivers
- Adults
- Teens

DSD Types

- All types

Beautiful You MRKH Foundation

United States



Source:

<https://www.beautifulyoumrkh.org/>

Who's This For?

- Parents & Caregivers
- Adults
- Teens
- Preteens

DSD Types

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

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 also has a medical and research focus with articles available to view and a listing of research studies, should visitors of the website wish to participate.

CARES Foundation

United States



Source: <http://www.caresfoundation.org/>

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

Who's This For?

- Parents & Caregivers
- Adults
- Teens

DSD Types

- Congenital adrenal hyperplasia (CAH)

PEER SUPPORT & ADVOCACY GROUPS (continued)

[dsdFamilies](#) United Kingdom

The logo for dsdfamilies features the word "dsd" in orange and "families" in purple, both in a lowercase, sans-serif font.

Source: www.dsdfamilies.org

This is a safe, nurturing site written by and for families and people with DSD, with input from medical experts, that draws you in as you read. It is an excellent place to start learning more about DSD and provides helpful information and recommendations on how to approach your child's DSD. It's a useful resource for parents, clinicians, and teens and has some resources for children too.

Who's This For?

- Healthcare providers
- Parents & Caregivers
- Adults
- Teens
- Preteens

DSD Types

- All types

[dsdteens](#) United Kingdom



Source: www.dsdteens.org

This is 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 (recommended for ages 10+)
2. *Moving on Up* discusses topics to consider in different situations, for example, in school, sharing with friends, and at the doctor's office (recommended for ages 11+)
3. *Taking the Wheel* explores relationships, treatment options and beyond (recommended for ages 14+)

Who's This For?

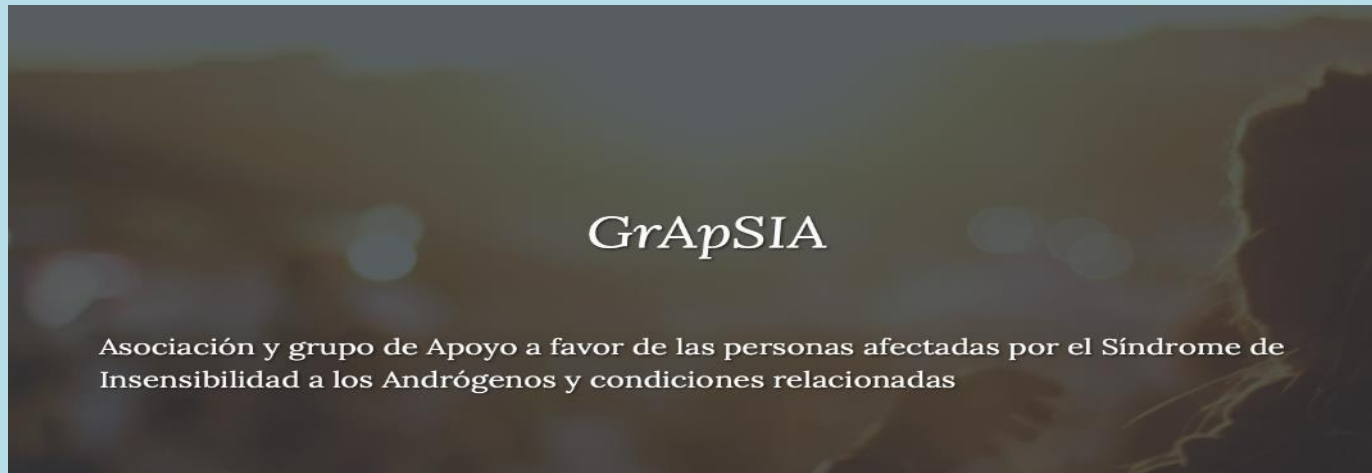
- Teens
- Preteens

DSD Types

- All types

PEER SUPPORT & ADVOCACY GROUPS (continued)

GrApSIA: Androgen Insensitivity Support Group Spain



Source: www.grapsia.org

For Spanish speaking families:

This is an androgen insensitivity syndrome support group, located in Spain. Resources on this site include educational information, original books, "testimonials" from individuals (and parents of individuals) with AIS, and ways to connect with support from its members.

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

Who's This For?

- Parents & Caregivers
- Adults
- Teens
- Preteens

DSD Types

- AIS

Hypospadias and Epispadias Association ([HEA](#)) United States



Source: heainfo.org

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, as well as family, youth and adult support.

Who's This For?

- Parents & Caregivers
- Adults
- Teens

DSD Types

- Hypospadias
- Epispadias

InterConnect United States



Source: <https://interconnect.support/>

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. This support group was formerly known as AIS-DSD. It features extensive information and respected resources. The site offers ways to meet others with DSD and provides information about their annual 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?

- Parents & Caregivers
- Adults
- Teens
- Preteens

DSD Types

- All types

[interACT](#)
United States



Source: interactadvocates.org

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 processes of informed consent and shared decision-making in DSD. It is the parent advocacy organization to [interACT Youth](#).

Who's This For?

- Parents & Caregivers
- Adults

DSD Types

- All types

PEER SUPPORT & ADVOCACY GROUPS (continued)

interact YOUTH United States



Source: interactadvocates.org/our-advocacy/youth

interACT Youth is the youth project of [interACT](https://interactadvocates.org/). This group is *not* a support group, but instead it is an advocacy space for young people to share their stories and help improve care and resources for young people. The group consists 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.

Who's This For?

- Parents & Caregivers
- Adults
- Teens

DSD Types

- All types

The MAGIC Foundation



Source: <https://www.magicfoundation.org/Growth-Disorders/Congenital-Adrenal-Hyperplasia/>

The MAGIC Foundation is a US-based nonprofit organization that provides support services to families of children impacted by medical conditions that can affect a child's growth, including CAH. It provides extensive information about CAH, recommended reading, clinical guidelines, and a closed CAH Facebook group for parents.











Who's This For?







- Healthcare providers
- Parents & Caregivers
- Adults

DSD Types

- CAH

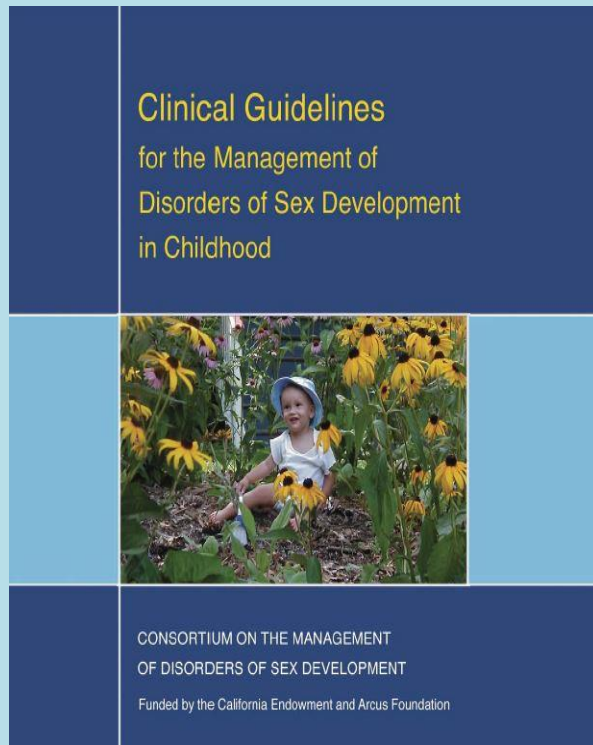
CLINICIAN RESOURCES INDEX

<p><i>Clinical Guidelines for the Management of DSD in Childhood: A Clinician's Handbook</i></p> <p>  (42) ALL DSD</p>
<p><i>Implementing Curricular and Institutional Climate Change to Improve Health Care for Individuals Who are LGBT, Gender Nonconforming, or Born With DSD</i></p> <p> (43) ALL DSD</p>
<p><i>Teaching Differences of Sex Development Parts 1 & 2</i></p> <p>  (44) ALL DSD</p>
<p><i>Viewpoints on DSD Care: A Range of Perspectives</i></p> <p> (45) ALL DSD</p>
<p><i>What We Wish Our Doctors Knew</i></p> <p>    (46) ALL DSD</p>

- HEALTHCARE PROVIDERS 
- PARENTS/CAREGIVERS 
- ADULTS (18+) 
- TEENS (13-18) 
- PRETEENS (9-12) 
- CHILDREN (5+) 

CLINICIAN RESOURCES CONT.

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



Source:

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

A useful resource for clinicians, as well as parents and caregivers who have had medical training. This is 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?

- Healthcare providers
- Parents & Caregivers

DSD Types

- All types

CLINICIAN RESOURCES

Implementing Curricular and Institutional Climate Change to Improve Health Care for Individuals Who are LGBT, Gender Nonconforming, or Born With DSD Association of American Medical Colleges ([AAMC](#))



Implementing Curricular and Institutional Climate Changes to Improve Health Care for Individuals Who Are LGBT, Gender Nonconforming, or Born with DSD

A Resource for Medical Educators



Source:

https://store.aamc.org/downloadable/download/sample/sample_id/129/

This is a (free) book by the Association of American Medical Colleges that provides an outline for teaching DSD, as well as issues pertaining to LGBT health concerns. This could be a useful resource for clinicians who wish to educate fellows, residents, and/or medical students about the sensitive nature of DSD, and how they can provide effective care. Each chapter also contains suggested readings from selected scientific journals.

Who's This For?

- Healthcare providers

DSD Types

- All types

CLINICIAN RESOURCES CONT.

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



In this response, 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 past and current medical models for treating and supporting patients with DSD in a clinical environment. It also proposes a plan for medical institutions to include DSD-oriented learning modules. This is a two-part video.

Who's This For?

- Healthcare providers
- Parents & Caregivers

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 CONT.

Viewpoints on DSD Care: A Range of Perspectives Accord Alliance

Viewpoints on DSD Care

This purpose of this page is to provide visitors with the opportunity to learn about the wide range of perspectives regarding optimal care in DSD. Do not look for agreement across all sources: some viewpoints are clearly in conflict with one another. However, consistent with our Mission, Accord Alliance seeks to be the “go-to” organization for information and resources for all stakeholders.

Accord Alliance does not endorse any particular position regarding specific clinical practices beyond supporting the principles described in the DSD Consensus Statement¹. One way that we hope to achieve “better care, better outcomes, and better lives” for people living with a DSD — and their families — is by providing all relevant information in one location.

This page includes a list of key position statements and articles that have been written by medical and surgical professional societies and organizations such as Human Rights Watch. It’s a useful go-to site for quick access to updated information, and helpful for DSD teams as they engage in shared decision-making with patients and families.



Accord Alliance

better care. better outcomes. better lives.

Source:

<https://www.accordalliance.org/resources/viewpoints-on-dsd-care/>

Who's This For?

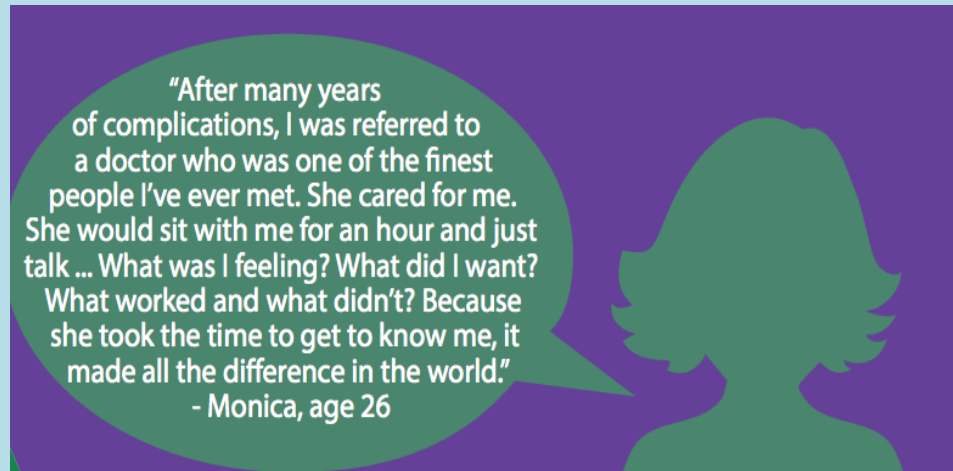
- Healthcare providers

DSD Types

- All types

CLINICIAN RESOURCES CONT.

What We Wish Our Doctors Knew interACT Youth



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

As a brochure written by young affected individuals and advocates 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 affected individuals may feel, and to help doctors consider different viewpoints during shared and informed decision-making with families. The handout describes some of the challenges of these conditions and how these young people believe health care can be improved.










Who's This For?

- Healthcare providers
- Parents & Caregivers
- Adults
- Teens

DSD Types

- All types

RESEARCH/REGISTRY LINKS INDEX

DSD-TRN			
  	(48)		ALL DSD
I-CAH			
  	(49)		CAH
I-DSD			
  	(50)		ALL DSD

HEALTHCARE PROVIDERS 

PARENTS/CAREGIVERS 

ADULTS (18+) 

TEENS (13-18) 

PRETEENS (9-12) 

CHILDREN (5+) 

RESEARCH/REGISTRY LINKS

DSD-TRN



Source: <https://dsdtrn.org//>

The DSD-TRN (Differences in Sex Development-Translational Research Network) is a partnership of medical centers across the US that are working together to improve knowledge and standardize care for patients with DSD. At each of the medical sites, patients are cared for by a multidisciplinary clinical team, with expertise in the care of patients with DSD. For patients and families, a list of TRN hospitals with contact information is provided. For providers, information is available on care of patients with DSD, as well as access to DSD-specific panels for genetic testing, and access to a clinical registry for investigators.

Who's This For?

- Healthcare providers
- Parents & Caregivers
- Adults

DSD Types

- All types

International Congenital Adrenal Hyperplasia (I-CAH)



Source: <https://home.i-cah.org>

A subset of the I-DSD Registry, the I-CAH Registry provides a means of connecting clinical and research centres around the world within a virtual environment and allows these experts to enter standardised information that will improve clinical practice, research and understanding of Congenital Adrenal Hyperplasia. I-CAH also provides links for patients to access their records and provides additional resources, support groups, and information about CAH.

Who's This For?

- Healthcare providers
- Parent & Caregivers
- Adults

DSD Types

- CAH

I-DSD



The International DSD (I-DSD) Registry is a world-wide registry of cases of DSD led by clinicians and researchers in the UK and Europe. It serves as a means of connecting clinical and research centers across the globe and provides an opportunity to compile standardized information to facilitate research and improve clinical practice regarding DSD. A symposium is hosted every 2 years, where providers and researchers can present their research and attend informational sessions. Advocacy and support group representatives also attend.

Source: <https://home.i-dsd.org/>







Who's This For?

- Healthcare providers
- Parents & Caregivers
- Adults

DSD Types

- All types


ADDITIONAL RESOURCES FOR PURCHASE INDEX

Disorders of Sex Development: A Guide for Parents and Physicians	 	(52)	ALL DSD
iNTERSExION (Documentary)	   	(53)	ALL DSD

HEALTHCARE PROVIDERS 

PARENTS/CAREGIVERS 

ADULTS (18+) 

TEENS (13-18) 

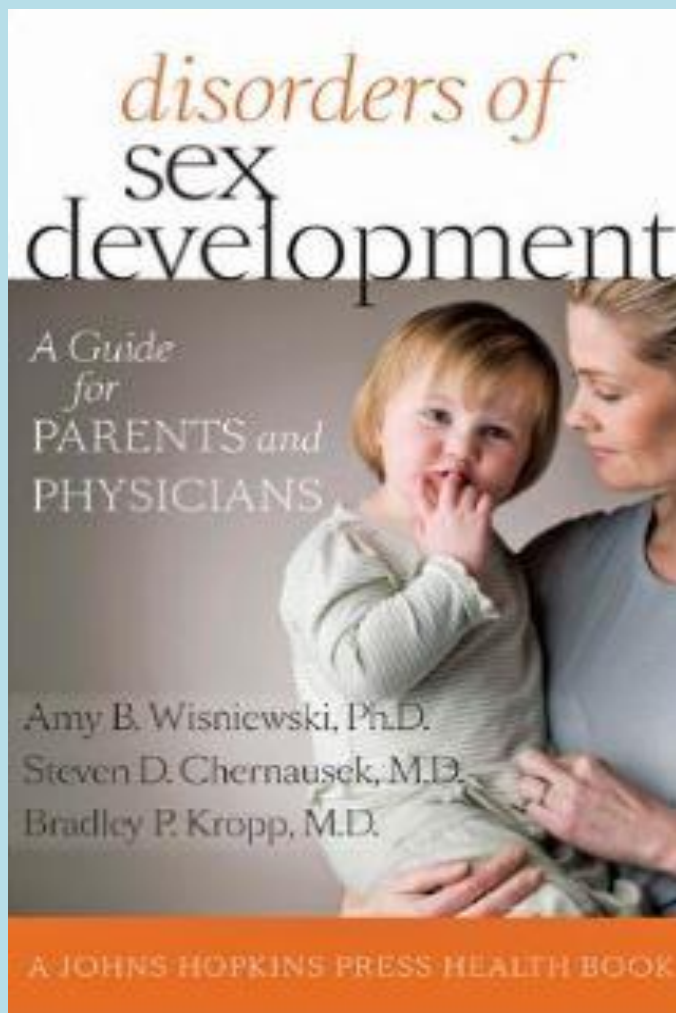
PRETEENS (9-12) 

CHILDREN (5+) 

ADDITIONAL RESOURCES FOR PURCHASE

Disorders of Sex Development: A Guide for Parents and 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 about care.

Who's This For?

- Healthcare providers
- Parents & Caregivers

DSD Types

- All types

Source: [DSD: A Guide for Parents and Physicians on Amazon.com](#)

ADDITIONAL RESOURCES FOR PURCHASE

iNTERSExION (Documentary)

Ponsonby Productions Ltd.



Source: www.intersexionfilm.com/

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, it is not patient/family-support oriented.

Who's This For?

- Healthcare providers
- Parents & Caregivers
- Adults
- Teens

DSD Types

- All types