



dsdfamilies.org is a new on-line information and support resource for families of children, teens and young adults who have a DSD (Difference/Disorder of Sex Development).

Ensuring parents and young people have **access to supportive and positive experiences** as well as **to the latest evidence-based information on the management of these conditions** is the main drive behind this families-led initiative.

Launched in July 2011 **dsdfamilies.org** has received **endorsements** from across the medical community:

“There can be few situations more worrying to new parents than being faced with ambiguous genitalia in their newborn baby with uncertainty of sex and diagnosis until tests have been carried out. Much information currently available on the web can be inaccurate and alarmist. There is a great need for improving not only the expertise and sensitivity of health care professionals who may be called on to deal with these uncommon but important conditions but, particularly, for providing factual information and empathetic support for parents, young people and families. The www.dsdfamilies.org website is being developed to provide just a resource for parents of DSD children and for DSD teens & young adults. It provides an important source of user-friendly support and information that will prove of benefit both to families and health care professionals.” **Chris Kelnar, Paediatric Endocrinologist, University of Edinburgh, President of the European Society for Paediatric Endocrinology (ESPE) 2011**

“This is simply excellent. It is really very different to other support websites and makes compelling reading, especially the personal experiences. Well done. I am proud to be a small part of this revolution.”
Imran Mushtaq, Paediatric Urologist, Great Ormond Street Hospital, London UK

“This site combines practical, down-to-earth and accurate information on DSD, with highly sensitive, personal testimonies from patients and parents. It is unique in addressing children, adolescents and parents, and in recognising the different challenges each faces.”

Martine Cools, Paediatric Endocrinologist, University of Ghent, Belgium

“A child with a diagnosis of 'dsd' is just as lovely and precious as a child without, but that realisation may be suspended by the shock and confusion that follows such a diagnosis. And, because the topic is so poorly understood in the public realm, parents have few people to share their concerns with. It is often during these challenging moments that parents feel under pressure to make treatment decisions to 'normalise' their child's anatomy. But what parents need first is support. Access to websites such as this is an important part of the support portfolio that parents need to build. These resources tell parents that they are not alone, that in time they too can become 'dsd' experts and make their own decisions about how best to take care of themselves and their children.”

Lih-Mei Liao, Clinical Psychologist, University College London, UK

“This website fills a gap in the support that is available to parents and their children with a DSD. The website is easy to navigate and has up to date information on current practice.”

Faisal Ahmed, Paediatric Endocrinologist, University of Glasgow, UK

“Parents who have a child with DSD can often feel overwhelmed by the amount of complex medical information they suddenly need to grasp. Changes in medical practice also mean that parents are now much involved in making decisions about their child's medical treatments. However the responsibility for this can be very daunting. This website provides factual information about all aspects of DSD in a clear and helpful way which will help inform parents making difficult decisions. Even more important is the opportunity to have contact with other families in similar situations which should help parents feel less alone at such a crucial time”

Sarah Creighton, Gynaecologist, University College London, UK

“I really love your new website, it is incredibly well thought out. The home page is just so appealing and I particularly loved the children's pictures - what a superb idea! Nothing to do with DSD of course, but I think new parents looking for information will feel relieved and heartened to come across this site and they won't be able to help but smile at the children's efforts at art, which reiterate how totally 'normal' they are. I liked the various sections too, general information as well as separate sections for families and teens/young adults. The basic information you have provided is excellent and it is good that you have personal stories included too. There is also room for growth and I feel many people will feel encouraged by what they read and perhaps feel they could help too, by providing their own experience for inclusion. Parents exploring this site will be relieved to have found somewhere so supportive, where their child's condition is understood and they will also be reassured their child still has a bright future ahead of them (whatever their diagnosis might be). Well done, I think it is one of the best websites I have ever seen.”

Sue Elford, Chair, CAH Climb Support Group, UK

“This is the first really practical resource written BY parents and families, FOR parents and families of children, teens and young adults who have differences of sex development.”

Charmian Quigley, Paediatric Endocrinologist, University of Indiana, USA

“Living with or supporting someone who has a non-standard sexual anatomy can feel challenging and scary. But with a supportive peer group, it doesn't have to be. This website is an informative and well-organised resource where families and individuals can share and receive good advice. Doctors now include access to peer support in their definition of best practice, and this website is a great place to start.”

Iain Morland, researcher and writer on the ethics and psychology of gender and sexuality, UK

“Created in response to families' need for practical knowledge, the dsdfamilies.org website addresses topics from both a clinical and a family viewpoint. Parents are often frustrated in their efforts to find straightforward information on these rare conditions, and there has long been a need for a centralized resource where they can find information from expert clinicians synthesized with the real-life experience of other parents regarding issues ranging from disclosure to vaginal dilation. Dsdfamilies.org improves caregivers' confidence that they *can* successfully parent children with a DSD. Combined with links to high-quality peer support groups, the site is an invaluable contribution to psychosocial assistance for families.”

Arlene B. Baratz, MD, DSD Committee: Children's Hospital of Pittsburgh, Accord Alliance, Moderator of the AIS/DSD Parent Email Group, USA

This leaflet has been produced with the kind support of the Scottish DSD Network - www.sdsd.scot.nhs.uk