
PRESS RELEASE

Guideline revised for assessment of newborns and adolescents with atypical genitalia and sex development

Every hospital should have access to regional multidisciplinary teams that can provide expert advice for children and adolescents with concerns about sex development, and provide them and their parents with psychological support, according to a revised Society for Endocrinology guideline on disorders of sex development (DSD) published today in [Clinical Endocrinology](#).

Recommendations include:

- Expert input should be provided in all cases where sex assignment is delayed at birth
- In adolescents, DSD should be considered in boys and girls with abnormal pubertal progress
- Paying special attention to the initial conversations that are likely to make a life-long impact on parents' relationship with their child and healthcare professionals
- Keeping parents fully informed of the risks and benefits of any medical or surgical treatment
- A call for regional centres to work together to provide access to a comprehensive and multidisciplinary team of experts
- A call for researchers to participate and contribute their data to international initiatives that research the long-term outcome of these rare conditions

Atypical genitalia may occur in 1 in 300 births but truly ambiguous genitalia where the sex assignment may not be clear at birth is much rarer, perhaps occurring in 1 in 5000 births. The ensuing period of uncertainty is unsettling for new parents and the guideline emphasises the need for psychological support of parents of affected newborns, as well as referring them to specialist peer support groups.

The guideline also provides medical professionals with advice on which children or adolescents to investigate and to what extent their condition will need to be assessed by imaging as well as special biochemistry tests and genetic investigations.

“The Society for Endocrinology guideline was initially developed in 2011 because having a child with a suspected DSD is a very rare situation requiring multidisciplinary support”, said lead author Professor Faisal Ahmed. “We have now revised it because DSD is a rapidly moving field and medical professionals need to be equipped with the latest information to evaluate the child as quickly as possible”.

“A thorough systematic approach to evaluating DSD that takes the entire family into account is important so that the parents and health care staff are in an optimal position to make the right decisions for long-term care.”, he continued.

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Notes for editors:

1. For further information about the study please contact:

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2. The [Society for Endocrinology UK Guidance On The Initial Evaluation Of An Infant Or An Adolescent With A Suspected Disorder Of Sex Development](#) will be published in *Clinical Endocrinology* on Friday 14 August 2015.
3. For press enquiries, please contact the Society for Endocrinology press office:

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4. The Society for Endocrinology is a UK-based membership organisation representing a global community of scientists, clinicians and nurses who work with hormones. Together we aim to improve public health by advancing endocrine education and research, and engaging wider audiences with the science of hormones
www.endocrinology.org