Guideline revised for assessment of children with disorders of sexual development

August 13 2015

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."

**More information:** 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.