

## International collaboration release revised guideline for improved management of Turner syndrome

A comprehensive, international guideline that incorporates the most up-to-date knowledge on diagnosis, treatment and patient impact of Turner syndrome (TS) has been published in the [European Journal of Endocrinology](#). The guideline project was initiated by the [European Society of Endocrinology](#) (ESE) and the [Pediatric Endocrine Society](#) (PES), in collaboration with six other learned societies, to incorporate the latest evidence-based advice for diagnosis and treatment of girls and women with TS.

TS is a rare genetic disorder that affects only girls and occurs when all or part of one X chromosome is missing, affecting approximately 1/2,000 live female births. TS has many health implications for patients at different stages of their life – it alters growth during childhood and teenage years, delays puberty, and adversely affects cardiovascular health and fertility in adulthood. TS is also associated with neurocognitive issues, which can result in patients having difficulties in everyday tasks such as navigating through a city, or experiencing social interaction issues.

If not diagnosed and treated appropriately, TS can be associated with higher mortality rates and preventable complications. Although previous guidelines have highlighted the importance of a multidisciplinary approach to manage TS patients, there have been many recent advances since their publication. The revised guideline addresses all health issues related to the condition, including psychological and social implications, providing clinicians with recommendations on how to treat patients at all stages – from foetal life into old age. Using evidence-based advice the updated guidance includes improved recommendations on optimal growth-promoting therapy, dealing with cardiovascular problems and tackling infertility in TS patients.

Professors Claus Gravholt and Philippe Backeljauw, Co-Chairs of the guideline consensus working group, agree that in particular, “the new cardiovascular-related advice should lead to lower morbidity and mortality, while the recommendations on oestrogen replacement therapy and guidance for pregnancy consideration should lead to improved quality of life.”

The new guidelines were developed from the findings of over 576 TS studies. The project was led by ESE and PES, in collaboration with the Society for Endocrinology, the Endocrine Society, the European Society for Pediatric Endocrinology, the European Society of Human Reproduction and Embryology, the American Heart Association, and the European Society of Cardiology.

“We envision that these guidelines will be widely adopted around the world by the professional communities and become the framework to treat TS, however, more future well-

designed and large studies are needed in order to keep establishing evidence-based recommendations”, states Professor Gravholt.

The full guideline can be downloaded free from the [European Journal of Endocrinology](#), the official journal of the [European Society of Endocrinology](#).

-----ENDS-----

## Notes for Editors

1. The “**Clinical Practice Guidelines for the Care of Girls and Women with Turner Syndrome. Proceedings from the 2016 Cincinnati International Turner Syndrome Meeting**” were published on Friday 14 July 2017 and are available to download for free at <http://dx.doi.org/10.1530/EJE-17-0430>.
2. For other press enquiries please contact the European Society of Endocrinology press office:

**Lynsey Forsyth**

Communications Manager  
European Society of Endocrinology  
Tel: (+44) (0)1454 642252  
Email: [lynsey.forsyth@bioscientifica.com](mailto:lynsey.forsyth@bioscientifica.com)

**Aida de Heras**

Communications Executive  
European Society of Endocrinology  
Tel: (+44) (0)1454 642206  
Email: [aida.heras@bioscientifica.com](mailto:aida.heras@bioscientifica.com)

3. [European Journal of Endocrinology](#) (EJE) is the official clinical journal of the European Society of Endocrinology, publishing high-quality original research and review articles on all aspects of clinical and translational endocrinology from around the globe. *European Journal of Endocrinology* is published by [Bioscientifica](#).
4. At the [European Society of Endocrinology](#) (ESE), we are working together to develop and share the best knowledge in endocrine science and medicine. ESE represents a community of over 20,000 European endocrinologists, enabling us to inform policy makers on health decisions at the highest level through engagement in advocacy efforts across Europe. It is by uniting and representing every part of the endocrine community that we are placed in the best possible position to improve life for the patient.