Insights into MAnaging Growth for Endocrine Nurses

November 17-18 2016, Lyon, France

An Independent Medical Education Event For Paediatric Nurses



Meeting summary, by programme director Martin Savage

The third annual conference of <u>Insights</u> into <u>MAnaging Growth for Endocrine Nurses</u> (IMAGE) was held in Lyon on 17–18 November 2016, and led by Kate Davies from London, UK. Over 60 paediatric endocrine nurse specialists (PENS) from eight countries attended. This year's theme was: **Puberty and its disorders: roles and involvement of the paediatric endocrinology nurse specialist.**

The first lecture, by Jean-Pierre Bourguignon (Liège, Belgium) and Martin Savage (London, UK), set out the clinical and biological origins of puberty and discussed the changes in the central nervous system (CNS) that trigger its onset.

The activation of the hypothalamic-pituitary-gonadal (HPG) axis, leading to full reproductive maturity in both sexes, was differentiated from the changes induced by adrenal androgen secretion, so-called "adrenarche", characterised by mild virilization in the form of pubic hair growth, greasy and oily skin and body odour. The presence of these two independent, yet overlapping hormonal axes is often not appreciated by parents and paediatricians.

The conference continued with the tradition of nurses leading most of the sessions. In three parallel break-out groups, PENS presented their experience on one of the following topics: practical procedures and responsibilities; human growth hormone device choices; and education and PENS leadership opportunities – nurse-led clinics, competence framework and prescribing. Interaction and discussion aimed to share practices, promote the status of nurses, stimulate the development of their specialist roles and promote the advance of the PENS political agenda.

In the next session, clinical disorders of precocious and delayed puberty were addressed. With reference to precocious puberty, Bourguignon explained that there were factors facilitating early development such as international adoption, increased body mass index, endocrine disruptors, CNS lesions mostly in boys and rare mutations in genes such as *MKRN3*. Central precocious puberty that is abnormally progressive requires specialist care and treatment with gonadotropin-releasing hormone analogues. Physiological early puberty, which is much more frequent, is a benign non-progressive phenomenon and does not require therapy.

Delayed puberty was addressed by Malcolm Donaldson (Glasgow, UK), who described the relatively common entities of constitutional delay and chronic illness where the HPG axis is intact and the rarer causes where an organic or developmental lesion of the axis causes impaired luteinizing hormone and follicle-stimulating hormone secretion.





Delayed puberty can cause emotional disturbance, which in many cases can be improved by sex steroid replacement. The theme of psychological symptoms in abnormal puberty was further developed by John Chaplin, psychologist from Gothenburg, Sweden, who presented examples of aggressive and competitive behaviour with impaired sibling and peer relationships associated with early puberty. This contrasted with lack of confidence, anxiety and social withdrawal in adolescents with delayed puberty.

The characteristics and management of two syndromes with effects on puberty, namely Turner syndrome (TS) and Silver-Russell syndrome (SRS), were then discussed by Malcolm Donaldson and Justin Davies (Southampton, UK), respectively. The multi-system aspects of TS and the importance of committing time to discussing the diagnosis and management plan with the family were emphasised.

Growth hormone therapy can improve height, but adult priorities such as effective oestrogenisation and the management of cardiovascular problems require specialist transitional care. SRS is an example of a small for gestational age disorder that also presents to the paediatrician.

A consensus statement on its diagnosis and management was recently published (Wakeling et al. *Nat Rev Endocrinol* 2016). SRS has complex genetic associations and requires multi-disciplinary management. Feeding difficulties, intellectual development and short stature are areas of concern. Two parallel sessions with presentations by nurses featuring cases of TS and SRS then followed.

The final session consisted of two further topics of pubertal concern. In the first, Stephen Shalet (Manchester, UK) discussed abnormal puberty following successful treatment of childhood cancer. An increasingly large group of adolescents are cancer survivors. Central and peripheral precocious puberty may follow treatment of CNS and gonadal tumours respectively.

Delayed puberty occurs after chemotherapy or gonadal irradiation. In the final presentation, Martin Savage described impaired puberty development, usually associated with delayed growth, in chronic inflammatory diseases such as coeliac and Crohn's disease, juvenile arthritis and cystic fibrosis. Pro-inflammatory cytokines, eg, interleukins and tumour necrosis factor- α , interfere with the growth hormone–insulin-like growth factor-1 axis and impair HPG axis function. Effective treatment of the primary inflammation will give the best chance of releasing normal growth and puberty potential.

A summary of the conference focused on plans for future meetings and topics requested by delegates. The last three meetings have addressed growth and growth hormone therapy, pituitary pathology and transitional care, and now pubertal disorders. In future, the aim is to follow a curriculum-oriented programme, with topics such as the adrenals scheduled for next year. The challenges, responsibilities and roles of PENS will remain the priorities when planning future IMAGE conferences.

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