PAEDIATRIC ENDOCRINE NURSE SPECALISTS NEWSLETTER

MARCH 2026

WELCOME TO THE PENS NEWSLETTER

Welcome to the first edition of the PENS newsletter!
We hope that a newsletter will help us to strengthen the fantastic PENS network and become a helpful way to share best practice and updates in between meetings and conferences and all the great work everyone is doing!

BRITISH THYROID ASSOCIATION UPDATES

The BTF have a range of resources available to patients including teenagers on their website www.btf-thyroid.org

Here are links to some of the videos
https://www.btf-thyroid.org/children

https://www.btf-thyroid.org/teenagers

https://www.btf-thyroid.org/films-for-teenagers
https://www.youtube.com/playlist?list=PLDsRR5mxEnysi9NQRRX2mxQLIxATKZb33

Closed Facebook group for parents:
https://www.facebook.com/groups/690728267661367/

PENS COMPETENCIES UPDATE

The competency framework is developing nicely and has been sent to the BSPED medical advisors. We are starting the process of RCN accreditation which might take some time.
We have funding secured for medical writing and publishing once it has been approved.

Karen Thompson (Belfast)

ONLINE RESOURCES FOR PUBERTY

BSPED Evorel patches
https://www.bsped.org.uk/media/j54l32ve/evorel-patches-web-version.pdf

SPAG Precocious puberty in Boys
https://www.nn.nhs.scot/speg//wp-content/uploads/sites/36/2023/01/17.-2022-SPEG-Precocious-puberty-in-boys.pdf

SPAG Precocious puberty in Girls
https://www.speg.scot.nhs.uk/wp-content/uploads/sites/36/2022/12/6.-2022-Precocious-puberty-in-girls-Final.pdf

CGF Precocious Puberty
https://childgrowthfoundation.org/conditions/precocious-puberty/?gad_source=1&gad_campaignid=21849878593&gclid=EAIaIQobChMIs5z9-YKJkgMV3pKDBxlmihQtEAAYASAAEgJnHfD_BwE

RARE BONE NURSES NETWORK

The Rare bone Nurses Network (RBNN) was set up in 2019 as a group to support Nurses working in the rare bone field and develop resources for patients. The group currently meet every 2 months on Teams with different topics discussed/guest speakers at each meeting as well as updates on all specific areas of rare bone disease including Achondroplasia, Osteogenesis imperfecta, XLH and HPP, as well as other metabolic bone disease.

For further information or to join the group, please contact Robyn Gilbey Cross or Emma Snow (Chairs) on gstt.evelianEAB-gstt@nhs.net

MINI CASE STUDY

Patient profile

Milly, a 13-year-old girl, was referred to the Accident and Emergency department by her GP for fatigue and nausea, with episodic vomiting and some weight loss over the past 2 months. Her symptoms were initially thought to be due to anxiety, and she was on a waiting list for assessment of this, and possible neurodivergence with the Child and Adolescent Mental Health Team (CAMHS). However, as her symptoms were reported as quite severe by the family, bloods were taken.

Assessment and Diagnosis

Milly was alert and talking, but appeared very anxious. She was cool peripherally, but warm centrally with no complaints of pain. Initial blood tests showed hyponatraemia (low sodium) and mild hyperkalaemia (high potassium), with a very high ACTH of 3200ng/litre (normal range 0-46), and a synacthen test was carried out. The cortisol peak was 30nmol/litre, her adrenal cortex antibody level was positive, and a diagnosis of primary adrenal insufficiency was made (Addison's disease). Her parents later reported salt cravings, and she also had some generalised hyperpigmentation. Milly was referred to the Paediatric Endocrine team.

Management

Treatment was initiated with Hydrocortisone for glucocorticoid replacement and Fludrocortisone for mineralocorticoid replacement. Education on Hydrocortisone sick day rules and prevention of adrenal crisis was prioritised.

Education and Family Support

The Endocrine Nurse plays a central role in the education for these families, and responsibilities include:

•Patient education- using age-appropriate language to explain Addison's disease and the importance of medication adherence.

•Medication Management- Teaching correct Hydrocortisone dosing, including adjustments for 'sick day rules.'

•Adrenal crisis prevention- educating Milly and her family on early warning signs of an adrenal crisis and the use of emergency intramuscular Hydrocortisone.

Psychological support

Milly was struggling to attend school in view of her new diagnosis, and she was referred to Psychology to help support her with this. She was also given the contact details for the Addison's Disease Self-Help group, as she was keen to be in contact with other teenagers with the same diagnosis.

Coordination of care

The family were encouraged to get a medical alert bracelet and to download the MyCortisol app. A written sick-day management plan and steroid card was provided, as well as information for Milly's school. Regular follow up in the Endocrine clinic to monitor her growth, development and medication was implemented.

Outcome

Milly and her family are now confident at managing her condition. She slowly returned to school with the support of Psychology and has had no adrenal crises. Milly's case highlights the important role of the Endocrine Nurse. Through monitoring, education, emergency planning and psychosocial support, families are empowered to safely manage a lifelong condition and improve long term outcomes.

Jennifer Gilbert (Oxford)

HOW DO I.....? EXPLAIN CAH

CAH (Congenital Adrenal Hypoplasia) is a life long condition and therefore, it is important that patients understand their condition and how to manage it.

Genetics

Genetics can be hard for children (and adults!) to understand. Using an analogy can help, like in this one below using lego blocks.

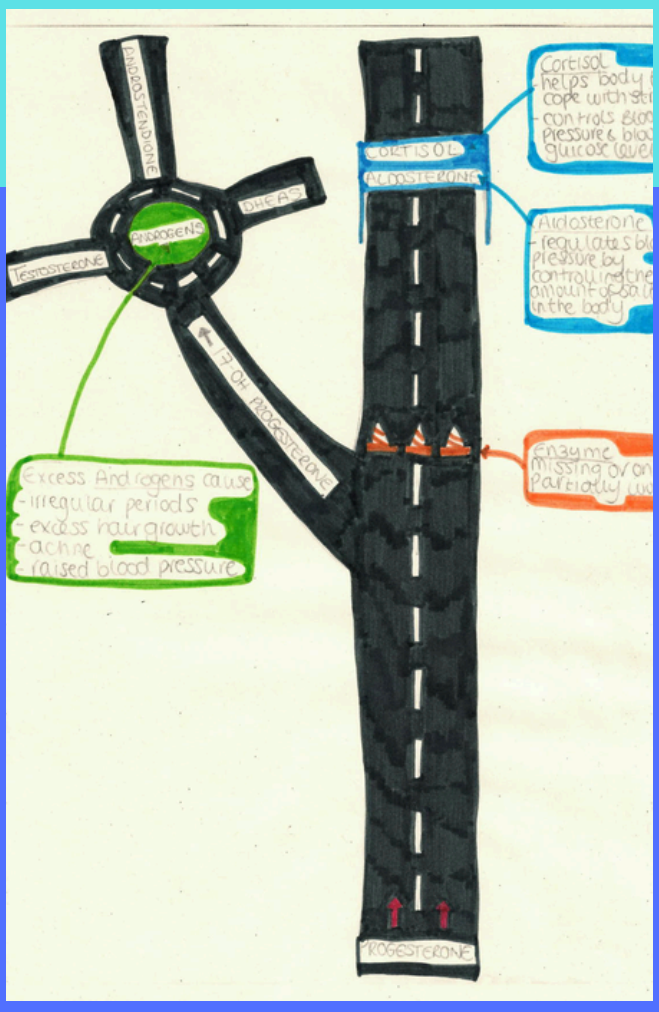
Genes, the building blocks which make people, can be likened to those of a Lego model. A Lego model can be made using the blocks in the pack, but if some of the blocks are swapped for those of a different colour, it will still make the model but it will be slightly different. Sometimes the building blocks of people have differences and this can lead to medical conditions. It might helpful to then ask the patient to think of other differences between people, such as eye colour, hair colour, height, left or right handedness.

Visual Diagrams

Often a picture can be very useful and make more sense than words.

In the picture below, CAH is drawn as a motorway. Progesterone signals travel down the road but come to traffic cones acting as a road block preventing it from being converted into cortisol and aldosterone. Depending on which enzyme is missing or only partially working, will affect how blocked the road is by the cones. Instead, the progesterone comes off at the junction turning into 17-OHP and then into androgens. The body still needs cortisol and aldosterone, so it sends more signals down the road but they are still unable to get through so come off at the junction and make yet more 17 OHP and androgens. This continues until the missing hormones are replaced and the body can then go back to sending regular signals.

Samantha Gorman (Cambridge)



BSPED NURSE PRIZE

The BSPED Nurse Prize will be running again this year. so this is advanced notice to start thinking about applying! All the details can be found at:

https://www.bsped.org.uk/membership/awards/nurse-and-ahp-awards/

JOURNAL CLUB

Collaer, M., Spencer, D. et al (2026) Early androgens and development of social personality traits: Evidence from classical congenital adrenal hyperplasia Hormones and Behaviour Jan 22:178:105875. doi: 10.1016/j.yhbeh.2025.105875. Online ahead of print

Article overview – Kate Davies

It has clearly been identified that early exposure to androgens can play a part in influencing sex specific characteristics and personality traits. My special interest is adrenal disease, namely congenital adrenal hyperplasia (CAH), which we all know has increased androgen exposure in-utero.

I have weekly article alerts set up to my email, and this one really caught my eye. With the knowledge that early androgen exposure can influence behaviour, this study looked at the evidence for this in people with CAH. The study looked at 53 men and women (20 men), with classic 21-hydroxylase CAH, with an average age of 30 years, alongside evenly matched controls, based on age, sex, education, and an estimation of verbal intelligence. All CAH patients identified with their original sex of rearing.

The study took six years to complete, and a total of five personality questionnaires were given to the patients and the controls, focusing on their personality, as well as motor, cognitive, and psychosexual characteristics.

Key results highlighted:
-Control men scored higher in physical aggression than control women.
-CAH women scored higher than control women.
-Control men scored higher in a dominance trait to control women, but women with CAH also scored higher than control women. CAH men did not differ to the control men.
-Control women scored higher in a 'tender-mindedness' trait, than CAH women and, again, there was no difference between CAH men and control men.

This study confirmed the researchers' hypothesis that prenatal exposure to androgens influence personality traits, and that women with CAH develop more 'male styled' traits, compared to control women – but men with CAH were no different in their traits and behaviours compared to their controls. They conclude that girls growing up with CAH may then actually experience some difficulties in some areas of social interaction: girls and their families may need further input from psychological services, or even Paediatric Endocrine Nurses, in advising how to manage potentially challenging situations. It is important to note that the patient support group, Living with CAH, supported and contributed to the research, emphasising the importance of patient advocacy and support.

FUTURE NEWSLETTERS

WHAT WOULD YOU LIKE TO SEE IN FUTURE NEWSLETTERS?
DO YOU HAVE SOME LOCAL RESOURCES YOU'D LIKE TO SHARE?
WOULD YOU LIKE TO WRITE A REGULAR COLUMN?
WE'D LOVE TO KNOW YOUR THOUGHTS ON WHAT YOU'D LIKE TO SEE IN THE NEXT EDITION OF YOUR NEWSLETTER!

HOW TO JOIN BSPED

We'd like to encourage as many people as possible to join BSPED. Membership | BSPED. Please do ask in your departments and teams to see if they can sponsor your membership. The more members we have, the stronger our voice will be within BSPED and also widen the number of people able to undertake committee roles and peer reviews.