

British Society for Paediatric Endocrinology and Diabetes

BSPED February 2025

REGISTRATION COMING SOON!

The 52nd Annual BSPED Meeting will take place in Sheffield, from **12 – 14 November 2025**. Please mark the date in your diaries. Further information will be announced soon.

News from the BSPED Office

New Awards Committee Chair

We are pleased to announce that Charlotte Elder has been offered the position of Awards Committee Chair to replace Nadia Amin. Please join us in welcoming Charlotte who will start her position from May onwards. We are very grateful to Nadia for all her work and leadership as outgoing Awards Committee Chair.



Website Refresh

You may notice that the BSPED website looks slightly different. The site has been upgraded by Bioscientifica, who manage it, to ensure accessibility, usability, mobile responsiveness and technical security are all optimised. The content remains the same and you should only notice slight aesthetic changes which make the site easier to use on all devices.



2025 Awards coming soon!

As we plan to launch the **2025 Awards** we asked Kate Davies, (BSPED Nurse and AHP Award winner in 2022) to tell us how her project "*The clinical validity and acceptability of alternative methods of monitoring for young people with Congenital Adrenal Hyperplasia (CAH)*" was impacted by winning the award.



The most common form of Primary Adrenal Insufficiency is Congenital Adrenal Hyperplasia (CAH), occurring in approximately 1 in 15,000 live births. In CAH due to 21-hydroxylase deficiency, blocks occur in the steroidogenesis pathway leading to a lack of cortisol formation, with mineralocorticoid production also affected.

Treatment is in the form of oral fludrocortisone to replace the salt loss, and oral glucocorticoid (GC) replacement therapy, such as hydrocortisone. This is frequently prescribed at 10-12 mg/m²/day in divided doses, but higher dosages may sometimes be required to suppress the adrenocorticotrophic hormone (ACTH) driven androgen production in CAH.

The signs and symptoms of under or over treatment may take months to detect, and could remain undetected in current monitoring programmes, which only gives a single snapshot view of a single timepoint. The goal of treatment is to achieve the best clinical outcome for the patient, with the lowest dose of GC possible, in order to reduce the potential side effects. Underdosing can result in a life threatening adrenal crisis, leading to hypovolaemic shock and ultimately death. Overdosing, especially in children, can result in growth failure, weight gain, hypertension, and the potential for cardiovascular disease as the child grows older. If replacement is not adequate, potentially due to non-adherence, this can lead to hyperandrogenism, leading to early puberty and later infertility, and testicular adrenal rest tumours (TARTs) in boys. If overtreated, hypercortisolism can result, leading to insulin resistance and obesity). It is therefore vital for children and young people (CYP) to adhere to monitoring and medication regimes, and understand the processes involved during the transitional process from paediatric to adult services.

Current monitoring in the UK involves regular biochemical analysis to assess the adequacy of replacement therapy. Practice varies between 24-hour cortisol assessments with 2 hourly cortisol and adrenal androgen measurements via an intravenous cannula, to occasional measurement of individual androgens: there is no consensus for optimum, effective, yet acceptable monitoring. Ultimately, there are unmet needs in the monitoring and long-term outcomes of CAH in young people.

However, there is growing interest in using alternative sampling methods to measure cortisol. Conventional methodologies for monitoring and management of CAH can potentially be replaced and / or used in conjunction by hair and / or salivary cortisol measurement, alongside focused anthropometrical measurements. This has a number of potential advantages including that it gives a long-term measure of cortisol replacement, is not invasive and could be performed without a need to visit the hospital clinic.

Hair cortisol analysis provides a longer read-out of cortisol exposure: the exposure time frame is dependent on the length of hair analysed, with each centimetre of hair being estimated to represent one month of exposure. This compares to monitoring in Type 1 diabetes, where HbA1c (glycated haemoglobin) measurements are taken every few months in order to gain an understanding of long-term glucose control.

Likewise for saliva cortisol analysis, which has also been shown as a non-invasive monitoring tool, although these do focus more on specific cortisol concentrations throughout the day. Nevertheless, salivary cortisol day curves can be undertaken throughout the day in the patient's home, compared to 24-hour venous sampling which would necessitate overnight hospital stays.

Anthropometric (non-painful and non-invasive) measurements during adolescence highlight inadequacies in cortisol replacement, which can invoke earlier nursing input in order to reduce the risk of metabolic syndrome and obesity long-term. However, this is not mainstream current practice, with body measurements only focusing on height, weight, and Tanner staging during puberty, alongside bone-age assessment.



The award from the BSPED has enabled me to undertake specific anthropometric training with the International Society for the Advancement of Kinanthropometry (ISAK), and also purchase the necessary equipment, such as a stadiometer and skinfold callipers. In addition, the funding will also go towards the development of a website for recruitment of patients within the two hospital Trusts I will be working with, which can be accessed through a QR code on specifically designed recruitment posters.

Review of BSPED Special Interest Groups

BSPED is now supporting a new Research SIG to ensure research in paediatric endocrinology and diabetes is encouraged and championed in the absence of the previous NIHR Clinical Studies Group. More information about this SIG can be found in the Clinical Committee section later in the newsletter.

BSPED is delighted to support its <u>Special Interest Groups (SIGs)</u> to collaborate and lead on the advancement of research and best practice in particular areas of paediatric endocrinology and diabetes. The BSPED SIGs were formalised with Terms of Reference in 2019 and these have recently been reviewed by the Executive Committee and Chair of the Clinical Committee. <u>The Terms of Reference can be found here on the BSPED website</u>. The BSPED's portfolio of SIGs is reviewed every year by the Clinical Committee. If you have an idea for a SIG that you wish to propose, please review the Terms of Reference and contact <u>bsped@endocrinology.org</u> with your proposal, which will be reviewed by the Clinical Committee in relation to the existing SIGs.

Virtual peer review – get involved as a reviewer

The BSPED Peer Review process provides centres with an excellent opportunity to learn from other centres, to gain support for resource requests and to ensure that they are operating to standards.

As a peer reviewer, you also gain experience, ideas and an insight into service management at other centres.

BSPED is now running a virtual peer review process, saving time for all involved.

We are looking for individuals to help with the review process, including nurses and DGH paediatricians. If you would like to be a peer reviewer, please get in touch and we will match you with a centre and date that works for you.

We also encourage trainees to get involved with the reviewing process – supporting the lead clinician with note taking and documentation, to build up experience.

We are looking forward to the peer reviews for Newcastle, Glasgow and Alder Hey this spring, and other centres are being booked in for the rest of 2025 and 2026. We will be in touch with centres who are due their next review and welcome proactive contact from centres.

Further details of the review process and what it entails can be provided. Please get in touch with Peer Review Officer **Dr Guftar Shaikh** on <u>Guftar.Shaikh@ggc.scot.nhs.uk</u>

Medical colleagues – if the nurses working with you do not receive this newsletter, please encourage them to join the BSPED, and contact the BSPED nurse representatives for further information: Peter Laing <u>peter.laing@alderhey.nhs.uk</u> and Karen Thompson <u>karen.thompson@belfasttrust@hscni.net</u>

Make the most of your membership benefits

The BSPED is an official endorsing society of the journal <u>Endocrinology</u>, <u>Diabetes & Metabolism Case</u> <u>Reports</u> (EDMCR). EDMCR is a unique, open access

<u>Reports (EDMCR)</u>. EDMCR is a unique, open access resource that publishes and links together case reports, enabling practitioners to communicate findings, share knowledge and convey medical experiences efficiently and effectively; furthering both medical education and clinical practice.

Members of BSPED receive a 25% discount on the Article Publication Charge (APC) when their paper is accepted for publication in *EDM Case Reports*.

Help us keep in touch

As the BSPED communicates with members by email, please ensure that you notify the BSPED Office if your email address changes at <u>bsped@endocrinology.org.</u>



Endocrinology,

CASE REPORTS

Diabetes & Metabolism

Trainee Update

COURSES AND EVENTS:

ACDC Annual Conference 16th May 2025

The 2025 19th ACDC Annual Conference will be held on the 16th May 2025, Friday at Conference Aston, Aston University Campus B74BL Birmingham in May 2025. Register to book your place via the Eventbrite link as tickets will be limited and on a first come first available basis. Tickets are limited and delegate fee of only £105 for the day includes a hot lunch buffet.

Click link to register for Conference – <u>Register for 2025 Conference</u> Programme is available here for <u>2025 ACDC Annual Conference Programme</u>

Congenital Hyperinsulinism Conference, Thurs 19th June 2025, 09:00-17:00 London and Online.

Join Congenital Hyperinsulinism (CHI) experts from Great Ormond Street Hospital and guest international speakers to explore the journey of an infant with Congenital Hyperinsulinism.

This meeting provides a vital platform to enhance understanding and clinical awareness of hyperinsulinism—a rare but significant condition affecting infants, children, and young people. Through expert-led presentations and personal narratives, participants will gain insight into the journey from diagnosis to treatment, deepening their knowledge of the disorder's impact. The programme aims to empower healthcare professionals with the skills to identify and manage hyperinsulinism early, particularly at the bedside. This proactive approach is crucial in preventing potential complications, such as brain injury, associated with delayed or misdiagnosis. By combining expert perspectives with patient and family experiences, the event underscores the importance of holistic care in addressing this challenging condition.

Please book here: <u>Congenital Hyperinsulinism Conference | Great Ormond Street Hospital</u>

ANNOUNCEMENTS:

Trainee representatives for regional diabetes networks needed

All Regional Diabetes Networks, as part of the National Children & Young People's Diabetes Network, are seeking trainee representatives. If you are interested in applying for one of these roles, please contact the Network Manager of your regional network. Emails for all Network Managers can be found here: <u>NCYPD Network</u>

In addition, trainees are encouraged to join their regional networks during training as a useful learning opportunity. Please discuss with your supervisor or email your regional network manager to ask to be added to the regional circulation list.

Trainee involvement in Peer Review Process

The BSPED's national Peer Review programme started in 2011 and BSPED is seeking interested trainees to get involved with the reviewing process, supporting the lead clinician with note taking and documentation. This would provide an excellent learning opportunity and is open to any interested trainees from around the country, not limited to areas which are due a peer review.

If you are interested, please find further information here <u>(BSPED | Peer Review)</u> and contact Peer Review Officer Dr Guftar Shaikh <u>(Guftar.Shaikh@ggc.scot.nhs.uk)</u>.

VPET (Virtual Paediatric Endocrine Teaching)

The next VPET is Friday, 14 March 2025. Please click below for details of upcoming sessions: <u>https://docs.google.com/spreadsheets/d/1mqmkXh6DHqHkAAZIJURwJLEgP3-</u> <u>Z RVcC7M9L9GzRgE/edit?usp=share link</u> VPET relies on trainees and consultants to deliver valuable teaching sessions. Please email <u>vpet.trainees@gmail.com</u> to sign up to deliver a session (name, topic and facilitating Consultant (if delivered by a trainee)). or if you would like to be added to the mailing list.

BSPED Trainee Mailing List

We send regular email updates on courses, job opportunities and information on training to trainees who are on our mailing list. Please email <u>bspedtraineerep@gmail.com</u> for further details of how to join or if you have feedback on any training issues.

CSAC Diabetes and Endocrine Trainee Representatives: Katherine Hawton Salma Ali Tanya Bhagat

News from the Clinical Committee

DKA Calculator

The BSPED Paediatric DKA Calculator (<u>https://dka-calculator.co.uk/</u>) has been updated this month. You will notice a new update design with several new features, including:

- A new retrospective audit data submission process capturing modifiable factors which led to an episode of DKA, length of DKA episode and cerebral oedema data. Please encourage your teams to submit data, which takes only a minute or two, at the end of each DKA episode. Instructions for how to do this are shown on page 10 of care pathways generated using the calculator. In the future we hope to share this data with departments, network regions and national groups to help guide improvements in care quality and DKA prevention.
- A new tool to easily calculate the corrected sodium and effective osmolality from the measured sodium and glucose. Access the tool via a QR code on the serial data sheet of the care pathway, from the calculator home page, or via https://dka-calculator.co.uk/sodium-osmo.
- Selection of **DKA severity will now use bicarbonate** if provided by the user. If the bicarbonate and pH indicate different severity levels, the more severe option is used.
- Additional audit data are now being collected such as ethnicity, deprivation (IMD) and more. To improve data quality, users are asked to use an NHS number wherever possible when generating a care pathway to allow duplicate episodes to be discarded. The NHS number is not stored but is used to generate a cryptographic hash which preserves patient anonymity (read more about privacy here: <u>https://dka-calculator.co.uk/privacy-policy</u>.

You can read the full changelog at <u>https://github.com/dan-leach/dka-</u> <u>calculator/blob/main/changelog.md</u>. Please contact Dan Leach <u>admin@dka-calculator.co.uk</u> with any queries or suggestions.

NICE Guideline published: Vamorolone for treating Duchenne muscular dystrophy in people 4 years and over

The Final Guidance entitled Evidence-based recommendations on vamorolone (Agamree) for treating Duchenne muscular dystrophy in people 4 years and over has been published on the NICE website: www.nice.org.uk/guidance/TA1031 on Thursday 16 January 2025.

NEW Research SIG

BSPED is excited to announce the development of a new <u>Special Interest Group</u>, the Research SIG. This SIG takes over from the previous Clinical Studies Group, the research arm of BSPED supported by NIHR. The Research SIG will aim to develop ideas, collaboration and networks in research and innovation in multiple fields to raise the national profile of paediatric endocrinology. The SIG is looking for keen and enthusiastic members who are either experienced in research or are planning to undertake research

soon. All members are welcome, particularly those in training. If you believe research will power the future of paediatric endocrinology, then drop Indi an e-mail. The SIG will meet every 3 months virtually; the first meeting is likely on 6 March.

Please contact Indi Banerjee Indi.Banerjee@mft.nhs.uk if you would like further information about this group.

Patient information resources

A reminder that the BSPED has produced a suite of patient information leaflets covering a number of conditions and designed to give general information about a patient's condition and treatment. To access these leaflets for your patients, as well as the BSPED Adrenal Insufficiency Card, please visit the <u>Patient Information section of our website</u>.



You can also find links to relevant patient resources, such as patient support groups on our website.

Meanwhile, <u>www.explain.me.uk</u> was developed as part of a project to improve communication between young people, their parents/carers and healthcare professionals in endocrine clinics. The website is looked after by BSPED. <u>We'd love to know how you use this with your patients.</u>



Translations of Adrenal Insufficiency Steroid Card

With thanks to our members and their colleagues, we now have the following translations available for the BSPED Adrenal Insufficiency Card:

NEW Slovakian Arabic Greek Polish Romanian Turkish Urdu



CAN YOU HELP? So far, we have translators for the following languages but we are seeking reviewers for these:

- Mandarin
- French

Please note that you do not need to be a BSPED member to assist with translations.

If you are fluent in another language (or already have a translation within your trust) and could help us build our suite of translated cards, please get in touch with <u>Christine Desmond</u> who is coordinating this project. We would like to find two members for each language so that one can translate the card and the other check/review the translation.

<u>All translated cards will be available on the BSPED website</u>, once reviewed and approved.

Use of and comments regarding guidelines

BSPED guidelines have been commissioned and endorsed by the BSPED and reflect the Society's views on best practice for the majority of patients with that condition. However, each patient should be considered as an individual in the context of their condition and other medication and therefore the readers' discretion is required in the application of their use. Every effort has been made to ensure the factual accuracy of the contents but no liability can be accepted for any litigation, claims or complaints arising from the use of the guidelines.

If you have a query or comment, or would like to raise a concern regarding a BSPED guideline or any guideline on our website, please contact the <u>BSPED Office</u> who will ensure your message is passed to the BSPED Clinical Guidelines Officer and Clinical Committee.

Submitting items to the Clinical Committee

In order to manage the full agenda of this busy committee we request any items that members would like to be reviewed by the Clinical Committee should be submitted through the BSPED Office in good time.

Please submit items by 22 April 2025 for the Clinical Committee meeting on 14 May 2025.

Including your survey in the newsletter

If you would like to include a survey in a BSPED newsletter to encourage responses from BSPED members, it must first be reviewed by the BSPED Clinical Committee.

- Your survey should be reviewed by the Clinical Committee at a stage where it can still be amended and before it is circulated elsewhere.
- The Clinical Committee meets four times per year and the deadlines for submission of agenda items are published in the newsletter.
- Your survey should be submitted to the BSPED Office, in Word format.
- The introduction to the survey should explain its purpose and the closure date of the survey.
- The survey will either be approved for inclusion in the newsletter as it is, or feedback will be provided to the author.
- Survey owners should agree to report their findings back to the Clinical Committee 6 months after the survey closes.
- The BSPED should be acknowledged in any output (guidelines, publications, presentations, etc.) resulting from the survey and the BSPED Office informed of the output.



Announcements

Job Announcements

The following posts are being advertised at the University of Nottingham.

https://jobs.nottingham.ac.uk/Vacancy.aspx?ref=MED89125

https://jobs.nottingham.ac.uk/vacancy.aspx?ref=MED89425

Survey on Turners Fertility Preservation in Turners Syndrome

We are collecting anonymised information on fertility preservation practises for women and girls with Turner Syndrome in the UK. We would be really grateful if you could take **5 minutes to complete this short survey** to help us better understand what is happening in your area. The aim is to establish what options are currently available and discussed for these individuals across the UK.

https://forms.office.com/e/DqqJTxDg8J

RCPCH Survey on Digital Health Technologies

The aim of the programme is to develop resources for paediatricians and people working in child health to be able to harness digital health technologies effectively in clinical practice. The resources we want to develop will include:

1) A digital health technologies catalogue or library to access which technologies are available to use and how to access them

2) A Health Inequalities app that will support clinicians to better identify patients at risk of healthcare inequalities and find suitable healthcare services for them

3) A platform for digital health skills learning for clinicians and child health professionals

To help inform the development of these resources for members of the College, we have disseminated three core aligned surveys. The link to all three surveys is here: https://www.rcpch.ac.uk/news-events/news/let-us-know-your-experiences-digital-skills-solutions.

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Meetings and courses



Registration now open!

This one-day national training event taking place on **4 July 2025** at Hallam Conference Centre, London, has been developed by the BSPED Growth Disorder Special Interest Group to directly address an unmet educational need in this field of paediatric endocrinology.

This meeting will highlight clinically relevant recent updates and advances in the management of childhood growth disorders at all stages of the management pathways. The day will encompass a combination of high-level talks from national growth experts and clinical cases to demonstrate key learning points.

This exciting new event is suitable for trainees, allied health professionals and consultants in paediatrics and paediatric endocrinology.

Register now!

Turner Syndrome Support Society UK "Meet the Experts Day" 7 March 2025, Glasgow

"Turner Syndrome Seminar Day" 8 March 2025, Glasgow

An Education Day open to all Healthcare Professionals involved in the care of girls or women with Turner Syndrome [TS]. The Turner Syndrome Support Society [UK] is proud to be hosting this event with support from Novo Nordisk. A Turner Syndrome Seminar Day on Heart & Fertility Risks in TS is open to adults with TS, their partners and families. Teens with TS may attend if they are fully informed of all implications of a TS diagnosis. Booking is available for both events <u>www.tss.org.uk</u>

SfE BES 2025 10-12 March 2025, Harrogate



SfE BES 2025 will be returning to Harrogate! Join us from 10-12 March for the largest gathering of endocrine professionals in the UK.

https://www.endocrinology.org/events/sfe-bes-conference/sfe-bes-2025/

VPEG

14 March 2025 2-4pm 19 June 2025 2-4pm



British Society for Paediatric Endocrinology and Diabetes

This meeting is designed for consultants delivering paediatric endocrine care (tertiary or special interest) to meet and share learning with each other from interesting endocrine cases. It is expected that primarily consultants will attend the meeting and do the case presentations - PGDIT can present with the presence and support of their consultant.

Please register your interest in attending using the links below. After registering, you will receive a confirmation email containing information about joining the meeting and please add the event to your calendars as a reminder!

If your team are interested in presenting a case on either date please get in touch with Renuka Dias (r.dias.1@bham.ac.uk) with email header VPEG. We are looking for at least 3 cases per date.

Friday March 14th 2025 2-4pm Thursday June 19th 2025 2-4pm

BritSPAG Annual Update in PAG 2025 17-18 March 2025, Liverpool

BritSPAG are delighted to announce that the Annual Update in PAG 2025 will be held as a face to face in Hope Street Hotel, Liverpool.

https://britspag.org/event/britspag-annual-update-in-pag-2025/

2025 Paediatric Endocrinology Study Day 2 May 2025, Liverpool

Alder Hey Children's Hospital endocrinology team are proud to announce Paediatric Endocrinology Study Day held in the state-of-the-art institute in the park. Join us for a full day programme consisting of lectures, case studies and q&a's with our experts. This study day is suitable for clinical staff with an interest in paediatric endocrinology.

https://www.eventbrite.co.uk/e/paediatric-endocrinology-study-day-tickets-1241922145569?aff=oddtdtcreator

EXTOD workshops for HCP for 2025

The one-day HCP event and Patient Day will be held in London (Watford), while our two-day event will take place in Liverpool. The HCP events are CPD-approved. Below are the links to the three events:

- Friday, 9 May, EXTOD One-Day HCP Conference (London): Link
- Saturday, 10 May, EXTOD Patient Day (London): Link
- 24-25 November, EXTOD Two-Day HCP Conference (Liverpool): Link

See more meetings and courses on the Other Meetings page on the BSPED website.

If you have any meetings, courses or events that you would like to add to this page, please <u>submit</u> them for review here

Sent by the BSPED Office BSPED c/o Bioscientifica Ltd Starling House, 1600 Bristol Parkway North, Bristol, BS34 8YU bsped@endocrinology.org Tel: 01454 642258

The BSPED would like to thank Sandoz for their generous support as a BSPED Partner this year:

