

British Society for Paediatric Endocrinology and Diabetes

BSPED August 2024



Have you seen the exciting programme for BSPED 2024?

Get ready for <u>BSPED 2024</u>, the premier meeting in the field of paediatric endocrinology! Join us from **Tuesday 8 to Thursday 10 October** at the Hilton Hotel in Glasgow. This year's theme is 'Learning from Local, National and Global Experiences' which is particularly important in the field of rare conditions where Glasgow has led the world.

Our dedicated Programme Organising Committee have crafted an engaging meeting programme that promises valuable insights and discussions.

Programme highlights:

How Do I? (Endocrine): Assessment of low trauma fractures. Speaker – Jarod Wong (Glasgow)

How Do I (Endocrine): Approach to hypoglaecimia. Speaker – Indi Bannerjee (Manchester)

How Do I? (Diabetes): Exercise in T1 D? Speaker – Francesca Annan (London)

How Do I? (Diabetes): Engage the disengaged teenager? Speaker – John Gregory (Cardiff)

Personal Practice Session: Management of abnormal TFT's – when to hold your nerve? Speaker:

Tim Cheetham (Nottingham)

Diabetes Symposium 2, Past, Present and future of Closed loops - Roman Hovorka (*Cambridge*) Endocrine Symposium 1, Management of phaeochromocytoma and lessons for paediatricians - John Ayuk (*Birmingham*)

Register today to secure your place and start planning your trip to Glasgow!

> View the full programme

>Register to secure your place



Free Registration



Advertisement

News from the BSPED Office

BSPED and ACDC Position statement on Medtrum pump and sensor

Paediatric diabetes centres will have received the list of approved providers of HCL systems under the NHSE procurement framework. Medtrum is included on the list but centres may not be aware that at present, Medtrum has also not provided any published evidence of safety and efficacy on the use of the system in children, despite multiple requests for them to do so. The Diabetes Technology Network (DTN) have also issued a statement raising their concerns around the inclusion of the Medtrum HCL in the list of approved systems. In line with the DTN, the BSPED and ACDC (Association of Children's Diabetes Clinicians) do not recommend that the Medtrum HCL system should be used for children and young people with diabetes in the UK until published evidence of its safety and efficacy is provided.

Dr Tabitha Randell, BSPED Chair Dr Fiona Regan, ACDC Chair

This position statement can be found on our website on the following link should you need to refer colleagues to it: https://www.bsped.org.uk/clinical-resources/position-statements/#Medtrum

Virtual peer review – ensure your centre has an up to date review and get involved as a reviewer

BSPED are now running a <u>virtual peer review process</u>. The following UK centres have an up to date peer review or a planned review in 2024/2025

- Birmingham, June 2022
- Leeds, 2024
- Leicester, January 2024
- Liverpool Alder Hey, 2024
- London Evelina Children's Hospital, June 2020
- London Gt Ormond Street, Nov 2021
- London: St George's Hospital, June 2021
- Manchester, June 2021
- Newcastle, February 2025
- Nottingham, July 2019
- Oxford, Feb 2021



- Southampton, Nov 2022
- Cardiff, December 2023
- Edinburgh: Royal Hospital for Sick Children, Apr 2024
- Belfast: Royal Belfast Hospital for Sick Children, March 2021
- Glasgow, February 2025

There are several UK centres overdue for a peer review! Please get in touch to let us know who would be the best person to contact in your centre.

We are also looking for individuals who would help with the review process, which includes nurses and DGH paediatricians. If you would also like to observe the review process, in preparation for your own centre's review, please let us know.

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

Further details of the review process and what it entails can be provided.

Please do get in touch with Peer Review Officer **Dr Guftar Shaikh** on Guftar.Shaikh@ggc.scot.nhs.uk

Tease do get in toden with reel neview officer broadland shakir on dartar. Shakir egge. Scot. In S. dk

Annual General Meeting 2024

Join us for our AGM at **17:30-18:30 on Wednesday 9**th **October**. This takes place on the second day of our Annual Meeting in **Glasgow** and is a great way to find out more about the activities of the society and to hear from those who run them on your behalf. All members with a current membership subscription are welcome to attend.

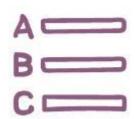


Medical colleagues – if the nurses working with you do not receive this newsletter, please encourage them to join the BSPED, and contact the BSPED nurse representatives for further information: Peter

Laing peter.laing@alderhey.nhs.uk and Karen Thompson karen.thompson@belfasttrust@hscni.net

Partner and sponsor resource library

You'll find the <u>latest information and resources from our partners and sponsors in</u> the <u>dedicated section of our members' area</u>. You will currently find resources from Kyowa Kirin (Select 'Partner & Sponsor Resources' at the top of the members' area).



Make the most of your membership benefits

The BSPED is an official endorsing society of the journal Endocrinology, Diabetes & Metabolism Case Reports (EDMCR). 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 bsped@endocrinology.org.



Trainee Update

COURSE AND EVENTS:

BSPED 8-10th October 2024, Glasgow

Continuing Medical Education (CME) Day - Tuesday 8th October 2024

BSPED | Welcome

Please save the date for the annual trainee dinner on Tuesday 8th October in Glasgow during BSPED. All GRID or SPIN trainees welcome. Further details will be shared soon.

ANNOUNCEMENTS:

Tanya Bhagat has been appointed as the new SPIN Diabetes trainee representative.

BSPED would welcome trainee involvement in regional diabetes networks. An advert for regional diabetes network trainee representatives will be circulated soon.

TRAINEE MAILING LISTS:

VPET (Virtual Paediatric Endocrine Teaching)

VPET now runs on the second Tuesday of every even month and second Friday of every odd month. If you would like to be added to the VPET mailing list or would like further information, please email vpet.trainees@gmail.com

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 bspedtraineerep@gmail.com 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

New Clinical Committee appointments

Thank you and congratulations to James Law, Nottingham who has been appointed as Clinical Standards Officer. James starts his three-year term of office on the Clinical Committee from November 2024, replacing Pooja Sachdev, who we also thank for all her contributions.

NICE guideline on adrenal insufficiency: identification and management

The BSPED is pleased that the NICE consultation on AI in children and adults has recommended management in line with the <u>BSPED guidance</u>. As stakeholders, the BSPED clinical committee and BSPED Adrenal SIG had provided feedback on the guideline and had raised some areas of concerns. Some of these were addressed and some contentious areas remain. The BSPED clinical committee will review the final guideline in detail. The clinical committee will discuss this in the upcoming clinical committee meeting and liaise with the Adrenal SIG, to determine if BSPED would like to make specific recommendations regarding safe implementation of the guideline.

This final guideline has now been published on the <u>NICE website</u> along with the <u>supporting evidence</u>, <u>tools and resources</u> as well as all the <u>stakeholder comments</u> received during consultation and the responses to these comments.

New rhIGF-1 guidance documents

The BSPED Growth Disorders Special Interest group (SIG) is delighted to share two new related documents recently approved by the BSPED clinical committee:

 BSPED Recommendations for Recombinant IGF-I Therapy in Children with Severe Primary IGF-I Deficiency (SPIGFD)

The aim of this recommendation document is to guide UK paediatric endocrinologists considering the use of rhIGF-I for severe primary IGF-I deficiency (SPIGFD). https://www.bsped.org.uk/media/fqlbtit1/recommendations-for-rh-igf-i-therapy-in-children-with-spigfd-15-05-24.pdf

 BSPED Recommendations for Recombinant IGF-I Therapy in Children with Severe Insulin Resistance Syndromes

This recommendation aims to guide UK paediatric endocrinologists who are considering the use of rhIGF-I for severe insulin resistance syndromes (SIR) secondary to insulin receptoropathies.

https://www.bsped.org.uk/media/ksdd4xmq/recommended-igf-1-therapy-in-children-with-severe-insulin-resistance-syndromes-10-03-24.pdf

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 Patient Information section of our website.



You can also find links to relevant <u>patient resources</u>, 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. We'd love to know how you use this with your patients.



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++ <u>Urdu</u>
++NEW++ <u>Greek</u>
<u>Turkish</u>
Polish
```



Arabic and Romanian translations are on their way.

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

- Mandarin
- Slovakian

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 Christine Desmond 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.

All translated cards will be available on the BSPED website, 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. The deadline has now passed for agenda items for the Clinical Committee meeting on 13 September 2024.

Please submit items by 1 November 2024 for the Clinical Committee meeting on 27 November 2024.

Approved surveys

Survey on sleep disordered breathing in Prader Willi Syndrome

We would be grateful if everyone who looks after children with Prader Willi Syndrome would consider completing this survey on investigations for sleep disordered breathing. This is being undertaken in collaboration with colleagues from the British Paediatric Sleep Society.



https://docs.google.com/forms/d/e/1FAIpQLSdin9jylFgq9DXQIfzBfl8 nfDCpLgBzlkIrSqHew45ec1xmw/viewform

Thank you! Guftar Shaikh, Royal Hospital for Children Glasgow

Including your survey in the newsletter

If you would like to include a survey in a BSPED newsletter to encourage responses from BSPED members, please submit it to the BSPED Office. The survey will be reviewed at the next Clinical Committee meeting (see deadline for submission above) and included in the newsletter if approved. 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

MCT8 deficiency Research

- MCT8 deficiency is a rare, X-linked disorder caused by mutations in the thyroid hormone transporter MCT8. The condition results in chronic thyrotoxicosis resulting from elevated levels of the active thyroid hormone T3 in the blood and neurodevelopmental impairment arising from low levels of thyroid hormone in the brain. The disorder has a severe impact on quality of life and reduces life expectancy, with around 30% of patients not reaching adulthood, due to a wide range of severe clinical sequelae.
- Tiratricol is being developed by Rare Thyroid Therapeutics for the treatment of MCT8 deficiency and the ReTRIACt study is a key randomized placebo-controlled study within the development program which is currently recruiting in the UK, Netherlands and US.
- The recruiting UK site is Prof Chatterjee at Addenbrookes Hospital, Cambridge and any UK patients would be referred to this site for study participation.
- The study is approximately 4-6 months duration and is primarily conducted in the home/living institution of the patient via home-based nursing visits.
- Post study participation, access to long term Tiratricol treatment would be offered via a managed access program at the UK referral site.

If you have you have patients with MCT8 deficiency (or considering a diagnosis) who may be suitable for the study, please contact Professor Chatterjee by e-mail: kkc1@medschl.cam.ac.uk

PhD Study -Transition from Paediatric to Adult Services: Experiences of Healthcare Professionals

- Are you a healthcare professional who is currently involved in transitional care provision for young people with pituitary conditions?
- Would you be interested in being interviewed on your experiences of transitional care provision for young people moving from a children's hospital to an adult hospital?

If you can answer yes to both these questions, we would like to talk to you.

Yolanta Breese, a PhD researcher from the University of Plymouth, is working with The Pituitary Foundation to understand young people's experiences of transitional care and would also like to hear your views on transition to adult services, as a healthcare professional. If you would be willing to talk to us about your transitional care provision experiences in an online interview, please contact Yolanta on this email address: yolanta.breese@plymouth.ac.uk <u>Please note</u>: Ethical approval to advertise this part of the study, to healthcare professionals, has been obtained for four months only, which is no later than **17 November 2024**. Thank you.

ENPP1 Deficiency – Active UK Clinical Trials

- ENPP1 deficiency presents as a spectrum of rare conditions characterised by abnormal mineralisation of soft tissues, ranging from potentially life-threatening arterial calcification in infants (GACI) to disabling hypophosphatemic rickets in children and adults (ARHR2).
- Clinical trials are now open in 1-12 months and 1-12 years age groups.

GACI (1-12 months) <u>Study Details | The ENERGY Study: Evaluation of Safety and Tolerability of INZ-701 in Infants With ENPP1 Deficiency or ABCC6 Deficiency | ClinicalTrials.gov</u>

ARHR2 (1-12 years) Study Details | The ENERGY 3 Study: Evaluation of Efficacy and Safety of INZ-701 in Children With ENPP1 Deficiency | ClinicalTrials.gov

• If you are aware of any potential subjects for these studies, please contact the Principal Investigator in Manchester, Dr Amish Chinoy Amish.Chinoy@mft.nhs.uk

.....

SS163 Paediatric Endocrinology Service Specification

The revised NHS Wales Joint Commissioning Committee Paediatric Endocrinology SS163 has now been published. A copy can be accessed here.

https://whssc.nhs.wales/commissioning/whssc-policies/all-policy-documents/paediatric-endocrinology-service-specification-ss163-june-2024/

Klinefelter syndrome - Symptoms, diagnosis and treatment | BMJ Best Practice

Newly published evidence-based, peer-reviewed guidelines on Klinefelter syndrome.

https://bestpractice.bmj.com/topics/en-us/3000332





Advertisement

Meetings and courses



Pituitary Masterclass
16 September 2024, London or via Zoom



This one day meeting, which you can attend either in person or online, will include interactive case presentations, submitted by delegates, for multidisciplinary discussion with presenters and the audience. Learn from guest speakers about the role of transitional endocrine services in supporting young people with pituitary disease and a practical overview of outpatient care in managing patients with pituitary disease.

https://www.impendo.co.uk/pituitary-masterclasses

MedEA Live Webinar Series



Embracing technology to help diagnose, treat and monitor Growth Disorders

Register for the MedEA Medical Education Academy Live Webinar on "Digital technology and support for patients and healthcare professionals in the diagnosis and treatment of growth disorders" scheduled on 20 September 2024 from 14.00 to 15.00 CEST.

For more information and registration click here

Endocrine Genetic Testing 26 September 2024, Birmingham



This one-day training event will equip you with essential skills in using the new national Genomic Laboratory Hubs, and you'll also have the opportunity to form collaborative networks with fellow specialist clinicians to help improve patient diagnosis and care. You can bring these skills back to your clinic to prepare you for the future of endocrine genetic testing! This will appeal to consultants, clinical geneticists and trainees working in paediatric and adult endocrinology.

https://www.endocrinology.org/events/endocrine-genetic-testing/endocrine-genetic-testing-2024/

National Training Scheme for the Use of Radioiodine in Benign Thyroid Disease 1 October 2024, Birmingham



https://www.endocrinology.org/events/national-training-scheme-for-the-use-of-radioiodine-in-benign-thyroid-disease/national-training-scheme-for-the-use-of-radioiodine-in-benign-thyroid-disease/

Joint Irish-UK Endocrine Meeting 2024 14 October 2024, Belfast

With SfE BES reverting back to the Spring from 2025, next year sees the Society working with the IES to run a special joint meeting in Belfast in October. More details will be available in early 2024.



https://www.endocrinology.org/events/joint-irish-uk-endocrine-meeting/joint-irish-uk-endocrine-meeting-2024/

National Endocrinology and Diabetes Taster Sessions 2024

22-23 October, Virtual



Tuesday 22 October, 17:00-18:15pm

Why Endocrinology: Career Insights and Top Tips

Wednesday 23 October, 17:00-18:15pm
Why Diabetes: Career Insights and Top Tips

If you are looking to choose your specialty, attend our free taster sessions held in collaboration with the Young Diabetologists and Endocrinologists' Forum (YDEF), to hear from inspiring experts as to why they chose to specialise in endocrinology and why it remains a lifelong passion.

https://www.endocrinology.org/events/national-endocrinology-and-diabetes-taster-sessions/national-endocrinology-and-diabetes-taster-sessions-2024/

What's new in diabetes and endocrinology Royal Society Medicine 4 November 2024, London

Join us in-person to hear experts in their fields examine the latest updates in endocrinology and diabetes in 2024. Speakers will highlight what has been recently shown to influence practice and how this can change management, with frequent panel discussions throughout the event enabling tricky issues and practical points to be explored. Additionally, participants will learn from specialists about new publications, examine data from clinical trials and basic science and their effect on current management, and gain an update on treatment strategies. This meeting is an association with the Society for Endocrinology (SfE) and the Association of British Clinical Diabetologists (ABCD). https://www.rsm.ac.uk/events/endocrinology-and-diabetes/2024-25/edt01/

ESPE 2024 16-18 November 2024, Liverpool



Join us for the 62nd ESPE Meeting 2024!

The theme chosen for the ESPE 2024 Meeting is "Lifelong endocrine care through collaboration, discovery and innovation".

https://www.eurospe.org/event/62nd-espe-meeting/

Reproductive Endocrinology 2024 3 December 2024, London



New for 2024, attend this event to boost your confidence and master the management of complex reproductive endocrine disorders.

https://www.endocrinology.org/events/reproductive-endocrinology/reproductive-endocrinology-

SFE BES 2025 10-12 March 2024, 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/

15

See more meetings and courses on the <u>Other Meetings</u> 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 them for review here</u>.

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:

