

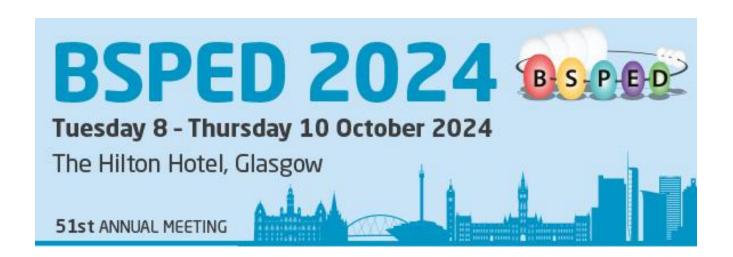
British Society for Paediatric Endocrinology and Diabetes

BSPED September 2024



Malcolm Donaldson 1949 - 2024

As many of you may know, we received the very sad news that Malcolm Donaldson passed away last week. Malcolm qualified in medicine at Bristol University in 1973 and from 1989 until his retirement in 2012, he worked as a Senior Lecturer in Child Health at Glasgow University. He received the BSPED James Tanner award in 2023 in recognition of an outstanding lifetime contribution to the field of paediatric endocrinology and diabetes. He will be greatly missed by all who knew him, and this loss will undoubtedly be felt throughout our paediatric endocrine community. Our thoughts are with his family, friends and colleagues at this extremely difficult time. An obituary will be published on the BSPED website in due course and tribute will be paid to him at the forthcoming Annual Meeting.



Are you ready for BSPED 2024?

We can't wait to see you all at the 51st Annual BSPED Meeting in Glasgow from Tuesday 8 – Thursday 10 October 2024!

Programme highlights:

- 'How Do I?' sessions on diabetes and endocrine topics
- CEW Symposium
- Top scoring abstracts as oral communications and virtual posters
- A variety of diabetes and endocrine expert talks and symposia
- Personal Practice session
- Presentations from previous year's BSPED Award winners
- Plenary talk by the James M Tanner Award winner
- BSPED 2024 Awards Session
- Industry sponsored Satellite Symposia
- BSPED 51st Annual Meeting Conference Dinner

> View the full programme

>Register to secure your place

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

Annual General Meeting 2024

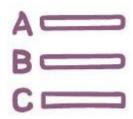
Join us for our AGM at **17:30-18:30 on Wednesday 9**th **October**. This takes place on the second day of our Annual Meeting in **Glasgow** and is a great way to find out more about the activities of the society and to hear from those who run them on your behalf. All members with a current membership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

Annual trainee dinner

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 being shared via trainee email lists and Whatsapp groups.

T2 diabetes study day

The next T2 diabetes study event hosted by the National CYP Diabetes Network T2 Diabetes Working Group will be held on **Wednesday 4 December**, **MS Teams**.

Registration is now open! Please register at <u>T2 Diabetes National Network Study day - National Network</u>

Topics so far include:

- T2 Diabetes Service development examples
- Adapting Dietetic care for neurodivergent patients with T2 diabetes in a young person's service
- TYA pilot focusing on T2 diabetes TYA service provision
- Complications management
- Updates since our last meeting

ANNOUNCEMENTS:

BSPED would welcome trainee involvement in regional diabetes networks – regional diabetes network trainee representatives will shortly be recruiting for these roles.

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

recommendations regarding safe implementation of the guideline.

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

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.

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 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. 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++ Romanian

++NEW++ Urdu

++NEW++ Greek

Turkish Polish



Arabic translation is close to being finalised.

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.

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

Approved surveys

National Electronic Growth Chart survey

The BSPED Growth Disorder Special Interest Group is collecting data to understand the availability and range of growth charts / software in use across the UK to try to standardise the recommendations, provision and accuracy of the charts we are using.

We are asking BSPED members from all the tertiary centres and colleagues from their affiliated networks to complete this simple survey. It only takes about 10 minutes - we would be really grateful if you could complete this as soon as possible and cascade it to your regional networks.

Thank you very much to those of you who have already completed this on behalf of your centre and distributed to your local networks.

Thank you in advance!

https://forms.office.com/e/4nG4mRSWuU

BSPED Growth Disorder Special Interest Group.

For any issues or questions please contact Helen Storr (h.l.storr@qmul.ac.uk), Justin Davies (Justin.Davies@uhs.nhs.uk), Rebecca Moon (rm@mrc.soton.ac.uk) or Reena Perchard (reena.perchard@manchester.ac.uk)

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

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.

Sponsor Spotlight:

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

Sandoz is a global leader in generic pharmaceuticals and biosimilars. Our purpose is to pioneer access for patients by developing affordable approaches that address unmet medical needs. Our ambition is to be the world's leading generics company and our broad portfolio of high-quality medicines covers major therapeutic areas.



https://www.sandoz.uk.com/ 278185 | April 2023

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) <u>Study Details | The ENERGY 3 Study: Evaluation of Efficacy and Safety of INZ-701 in Children With ENPP1 Deficiency | ClinicalTrials.gov</u>

• 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

Meetings and courses



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/

Successful Introductions 19 October, Manchester

We are pleased to extend a warm invitation to our annual roadshow, "Successful Introductions," on Saturday, October 19th, at the Holiday Inn City Centre, Manchester. This year, our conference includes CPD opportunities and serves as an innovative platform for patients and a diverse array of hospital and community professionals. Attendees will have the chance to network and share experiences in the emerging field of survivorship after childhood brain tumours.

Our unique offering centres on the voices of survivors and their families. This event provides a valuable opportunity to share experiences, foster education, and collaborate with decision-makers and parliamentarians. Together, we aim to support those who experienced a brain tumour under 25 years old in achieving 'brighter futures'.

Building on the vision of Success, we are focusing on refining a comprehensive recovery pathway that complements acute treatment and extends beyond it.

Please register and find further information here: Successful Introductions – Success Charity

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/

Thyroid nodules and goitre - live webinar 22 October, 7pm, Online

On 22 October the BTA/BTF will be hosting another webinar with MIMS Learning. The speakers are Prof Carla Moran (consultant endocrinologist), Mr Ram Moorthy (consultant ENT surgeon) and will be chaired by Prof Kristien Boelaert and Dr Carol Sinnott, GP. It is a free event (to watch live or on demand after the event) which attracts 1 CPD hour and is suitable for GPs, nurses, hospital doctors and any other healthcare professionals with an interest in looking after patients with thyroid diseases.

https://www.mimslearning.co.uk/courses/thyroid-nodules-and-goitre-live-webinar

GPED - First Virtual Annual Meeting on October 26-27 and November 2-3, from 13:00 to 17:00 GMT

Join us for this groundbreaking virtual event where leading experts, practitioners, and researchers from around the world will come together to share insights, advancements, and best practices in pediatric endocrinology and diabetes care with a focus on resource-limited settings!

https://site.pheedloop.com/event/GPEDAnnualMeeting/home

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/

1st Asian Conference on Innovative Therapies for Diabetes Management 18-20 November 2024, Singapore

ATTD-ASIA 2024 is where innovation meets cutting-edge diabetes technology. This premier event brings together top minds and emerging solutions in diabetes care, offering unparalleled opportunities to engage with the latest scientific advancements and technologies.

Don't let your members miss out on **registration savings until 29 October**. Explore the comprehensive **scientific program** for a detailed look at the impactful sessions and expert speakers lined up.

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-2024/

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/	

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

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