

British Society for Paediatric Endocrinology and Diabetes

BSPED January 2025

SAVE THE DATE!

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

FINAL CALL FOR NOMINATIONS: BSPED James M Tanner Award

We are currently welcoming nominations for the next recipient of the James M Tanner Award, which is given in recognition of an outstanding overall contribution to the field of paediatric endocrinology and diabetes and to the BSPED. It is named after Professor James Mourilyan Tanner, the British paediatric endocrinologist best known for his seminal growth studies and development of the Tanner scale.



Prof N Shaw receiving his award in 2024

This award acknowledges many facets, including excellence in leadership, scientific research excellence, teaching and mentorship. It is awarded on an annual basis at the BSPED meeting. The deadline for nominations is **25 February 2025** and both nominees and their proposer should be BSPED members. <u>All details and the nomination form can be found on our website</u>.

We look forward to receiving your nominations for your inspirational colleagues.

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.



Transform your career: the Award that could be your next big step

We asked Dr Sasha Howard the recipient of the 2021 BSPED Research and Innovation Award what impact the Award had on her project.

Title - International Hypogonadotropic Hypogonadism Registry – I-HH: set up and development of a new rare disease registry.



"I received the Research and Innovation Award in 2021 to enable the development of a new module of the SDM Registries (<u>https://sdmregistries.org/</u>), which already includes I-DSD, I-CAH and I-TS. I am delighted to say that the I-HH registry is now live and available on the SDM registries website for new and existing users.

Hypogonadotropic hypogonadism (HH) is a severe disorder of the hypothalamic-pituitary-gonadal axis, resulting in gonadotropin deficiency. HH is a rare condition affecting 1-10 per 10,000. Patients with HH have absent or disordered puberty and sub- or infertility unless appropriately treated. Diagnosis is often not made until late adolescence or early adult life, despite potential for testing and intervention in mini-puberty in infants with "red-flags" such micropenis or cryptorchidism. Management of infertility and non-reproductive phenotypes is clinically challenging, particularly in severe gonadotropin deficiency. As a rare disease, numbers of individuals with HH cared for by anyone endocrine service are small and interventional studies would require coordination between multiple national or international centres with inherent cost barriers. The I-HH registry has been designed to support improvements in clinical practice, through a wide range of primary and secondary research and to act as a platform for pharmacovigilance, collecting real world patient data within a secure, ethics-approved virtual research environment.

Development of I-HH would not have been possible without this award, which has supported the design, build and ongoing support of the electronic database and website. It has enabled a multicentre collaboration between many expert colleagues from the University of Glasgow, the UK and Europe. It is available to any centre or clinicians who care for patients with HH, and data access requesting is open to all via the central registry. Our group has approval for an initial project to assess current practice in pubertal induction in patients with HH across centres. The I-HH registry will also be used to support clinical trials (e.g. the PinG study IRAS 1009018) to identify best practice in the use of gonadotropins to induce puberty in males with HH, particularly with respect to long term outcomes such as fertility and live birth rates."

The BSPED provides two, £15,000 grants each year and the call for applications will be made in Spring but if you have questions about any of the BSPED Awards available then please contact the Office and we would be happy to help.

https://www.bsped.org.uk/membership/awards/

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.



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.

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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

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

COURSE AND EVENTS:

Congenital Hyperinsulinism Conference Save the Date: 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. Registrations will open from December 2024; further details will follow. Any questions in the meantime? Email <u>events.gla@gosh.nhs.uk</u>

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 – Register for 2025 Conference

Programme is available here for 2025 ACDC Annual Conference Programme

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)

VPET is at 1-2pm on the second Tuesday of every even month (February, April etc) and second Friday of every odd month (January, March etc). Upcoming dates for 2025 are:

Tues 11 February	Fri 9 May	Tues 12 August	Fri 14 November
Fri 14 March	Tues 10 June	Fri 12 September	Tues 9 December
Tues 8 April	Fri 11 July	Tues 14 October	

VPET relies on trainees and consultants to deliver valuable teaching sessions. Please click below for a list of upcoming sessions:

https://docs.google.com/spreadsheets/d/1mqmkXh6DHqHkAAZIJURwJLEgP3-Z_RVcC7M9L9GzRgE/edit?usp=share_link

Please email to sign up to a date with your name, topic and facilitating Consultant (if delivered by a trainee). Email <u>vpet.trainees@gmail.com</u> to sign up to deliver a session 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

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 <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. <u>We'd love to know how you use this with your patients.</u>

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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

<u>Arabic</u> <u>Greek</u> <u>Polish</u> <u>Romanian</u> <u>Turkish</u> <u>Urdu</u>

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

• Mandarin

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.

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

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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 February 2025 for the Clinical Committee meeting on 26 February 2025.

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! <u>https://forms.office.com/e/4nG4mRSWuU</u>

BSPED Growth Disorder Special Interest Group. For any issues or questions please contact Helen Storr (<u>h.l.storr@qmul.ac.uk)</u>, Justin Davies (<u>Justin.Davies@uhs.nhs.uk</u>), Rebecca Moon (<u>rm@mrc.soton.ac.uk</u>) or Reena Perchard (<u>reena.perchard@manchester.ac.uk</u>)

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.

Announcements

APECED Working Group

A group of professionals from a range of specialities (endocrinology, immunology, gastroenterology, respiratory and rheumatology) are looking to develop a working group focused on APECED (Autoimmune Polyendocrinopathy-Candidiasis-Ectodermal Dystrophy). We are looking for interested paediatric endocrinologists to join the working group to collaborate with peers and contribute to the development of clinical guidelines and research initiatives.

If you're interested in joining this group, please send an email to Toby Candler toby.candler@uhbw.nhs.uk

We're eager to hear your thoughts and welcome your expertise!

Volunteering opportunity

We have an opportunity to join our team and be a part of the Clinical Quality in Practice Committee (CQIP) as a **Clinical Lead for Evidence-Based Clinical Practice:** <u>Clinical Quality in Practice Committee -</u> <u>volunteering opportunity | RCPCH</u>

Please share this opportunity to your group members and anyone else who may be interested (deadline 17 February 12:00).

The role consists of providing clinical leadership to workstreams, providing oversight on evidencebased guidance development and having involvement with College responses to national reports, amongst other responsibilities.

Harshna Ravindran (Clinical Guidelines Assistant Research and Evidence Team)

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 www.tss.org.uk

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/

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/

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</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:

