

### British Society for Paediatric Endocrinology and Diabetes

## **BSPED October 2024**

### Thank you for attending!





# Help us shape BSPED 2025 with your feedback

We hope those who attended BSPED this year had a great time exchanging knowledge, engaging in insightful discussions and strengthening collaborations with fellow paediatric endocrinology and diabetes professionals.

#### **Feedback**

Please give us feedback by 1 November using the post-event survey to receive your CPD certificate. We'd specifically love to hear your suggestions on speaker and programme ideas for the next BSPED conference.

Complete the post-event survey

The meeting successfully brought together 517 registered attendees, providing them with a platform to exchange knowledge, engage in insightful discussions, and strengthen collaborations with fellow paediatric endocrinology and diabetes professionals.

We would like to thank everyone who contributed to making the event a success, including our Programme Organising Committee, speakers, chairs, abstract submitters, abstract markers and sponsors.

### **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.

# Congratulations to all our award winners!

#### **James M Tanner Award**

Awarded to: Professor Nick Shaw

Professor Nicholas Shaw was a Consultant
Paediatric Endocrinologist based at Birmingham
Children's Hospital (UK) from 1996, and an
Honorary Professor within the Institute of
Metabolism and Systems Research at the
University of Birmingham from 2016. He has
been a consultant from 1994-2022 contributing
across the spectrum of Paediatric Endocrinology
both nationally and internationally,
including to BSPED and ESPE. Professor Shaw
graduated from the University of Birmingham,
Medical School in 1978, and developed his major
interest in paediatric calcium and bone
metabolism whilst a Lecturer at the Universities
of Leeds and Liverpool between 1985 and 1992,



prior to completing endocrine training in Birmingham. Professor Shaw established a service for children with metabolic bone disease in 1996 which in 2011 was subsequently designated as a national centre for Complex Childhood Osteogenesis Imperfecta. Professor Shaw pioneered the routine use of bisphosphonate treatment for children with Osteogenesis Imperfecta in the UK, significantly reducing pain and increasing mobility. He served as the BSPED peer review officer on the Clinical Committee (2011-2015).

He is a tireless advocate for his patients, and highly regarded by them, and passionate about the delivery of the highest quality of medical services. He is a phenomenal yet humble clinician who has always kept the child and family at the centre of his care. Witnessing his gentle patience, listening skills and empathy in consultations it has always been clear to see how Professor Shaw consistently and successfully works collaboratively with children, young people and their families to support decision making, and ensure the best possible outcomes. Professor Shaw has made all of those with whom he has worked more curious and compassionate doctors. Over and above this his mentorship of clinicians and clinician scientists over the years, and in different countries, who are now leading their own patient care and research across Paediatric Endocrinology will mean his legacy of thoughtful clinical care and academic rigour will continue.

#### Call for nominations for the 2025 James M Tanner Award

Deadline: 17:00 on 25 February 2025

<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.

#### **Research & Innovation Awards**

Awarded to: Rebecca Moon (Southampton)

Title: The effect of glucagon-like peptide-1 receptor agonists on musculoskeletal health in adolescents

living with obesity

Awarded to: Irina-Alexandra Bacila (Sheffield)

Title: Understanding the effects of excessive weight on gonadal development and function in males

with childhood obesity

#### Paediatric Endocrine and Diabetes Nurse and AHP Award

Awarded to: Sarah Worthington (Manchester)

Title: 'A real-time data collection App to improve clinical management of Congenital Hyperinsulinism'

#### **Abstract and Poster Awards**

**Best Oral Communication (Basic)** 

Awarded to: David Lim (Southampton)

Abstract No: OC5.6

**Title:** Diagnostic testing using gene panels for severe childhood growth failure and multiple pituitary hormone deficiency in England

**Best Poster** 

Awarded to: Danielle Mountain

Abstract No: P76

**Title:** The acceptability of preventative bisphosphonate therapy prior to fracture: perspectives of young people with Duchenne muscular dystrophy, parents/carers and health

professionals





Danielle Mountain & Sarah McCarrison collecting their awards

**Best Oral Communication (Clinical)** 

Awarded to: Kirsty Mobberley

**Abstract No: OC9.1** 

**Title:** Award-Winning Virtual Schools Training Package Creates Capacity to Enable 78% of Children to Access Hybrid Closed Loop Therapy

**Best CME Day Presentation** 

Awarded to: Claire Room (Oxford)

Title: Diabetes & deafness: not just Wolfrom

#### 2nd place CME Day Presentation

Awarded to: Sarah McCarrison (Glasgow)

Title: Phenotypic features of two brothers with a rare X-linked insulin receptor substrate 4 (IRS4) mutation and the suspected role of IRS4 in the HPT axis

**3rd place CME Day Presentation** 

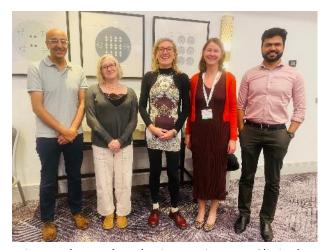
**Awarded to:** Catriona McKay (Belfast) **Title:** 16 Years of Learning: The First Patient
Treated with Asfotase Alfa for Perinatal

Hypophosphatasia

# News from the BSPED Office

#### **New Chair and Secretary Elect**

BSPED formally welcomed Dr Talat Mushtaq (Chair) and Dr Senthil Senniappan (Secretary) to the Executive Committee at the AGM in Glasgow. Talat and Senthil have shadowed Dr Tabitha Randell and Dr Melanie Kershaw respectively for the last year and will remain in post until 2028. Dr Talat Mushtaq is a Consultant in Paediatric Endocrinology and Honorary Senior Lecturer at Leeds Teaching Hospitals. Dr Senthil Senniappan is a Consultant Paediatric Endocrinologist at Alder Hey Children's Hospital, Liverpool and Honorary Associate Professor at University of Liverpool. We extend our thanks again to Tabitha and Melanie who have



contributed so much to the Society during their time and various roles and Melanie continue as Clinical Guidelines Officer.

#### Call for expressions of interest to host BSPED

We are seeking conveners to host the BSPED Annual Meetings from 2026-2028. If you think you could help bring a novel/regional flavour to the programme and support the Programme Organising Committee Chair, then we ask that you consider this rewarding role. We welcome interest from all areas of the UK. We know that it is difficult to find the right venue for the size of the BSPED Annual Meeting. Therefore the host will <u>not</u> be responsible for sourcing a venue, although suggestions are welcome if you have had a great experience somewhere. Bioscientifica as Professional Conference Organiser will identify suitable venues nationally and the venue will be in the same <u>region</u> as the host, but not necessarily the same city. The deadline for expressions of interest is 10 December. <u>More information and expression of interest form.</u>

#### **Call for nominations for Awards Committee Chair**

Would you like to be at the heart of BSPED's activities to recognise, reward and fund excellence in paediatric endocrinology and diabetes? Applications are requested for the position of BSPED Awards Committee Chair, to begin in May 2025 (attending the Awards Committee meeting in March to hand over). The vacancy has arisen as a result of the completion of the term of office of Dr Nadia Amin. The position of the Awards Committee Chair has a term of 3 years. For more information and to apply please read the <a href="mailto:committee vacancy page">committee vacancy page</a> or contact the <a href="mailto:BSPED Office">BSPED Office</a>.

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#### BSPED James M Tanner Award – call for nominations

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.



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. All details and the nomination form can be found on our website.

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

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#### **Review of BSPED Special Interest Groups**

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>.

BSPED is now supporting up to eight SIGs (increased from six). Our newest SIG is the Pre-Type 1 diabetes Special Interest Group, led by Dr Rachel Besser and Dr Tabitha Randell (see p.11 for more info). We are also currently discussing the formation of a Research SIG to ensure research in paediatric endocrinology and diabetes is encouraged and championed in the absence of the previous NIHR Clinical Studies Group. 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 <a href="mailto:bsped@endocrinology.org">bsped@endocrinology.org</a> with your proposal, which will be reviewed by the Clinical Committee in relation to the existing SIGs.

#### 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 (2020-2024) 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: <a href="https://www.bsped.org.uk/clinical-resources/position-statements/#Medtrum">https://www.bsped.org.uk/clinical-resources/position-statements/#Medtrum</a>

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#### Virtual peer review – ensure your centre has an up to date review and 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 <u>virtual peer review process</u>, 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.

#### 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, March 2025
- 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 let us know who would be the best person to contact in your centre.

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 <a href="mailto:Guftar.Shaikh@ggc.scot.nhs.uk">Guftar.Shaikh@ggc.scot.nhs.uk</a>

**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 <a href="mailto:peter.laing@alderhey.nhs.uk">peter.laing@alderhey.nhs.uk</a> and Karen Thompson <a href="mailto:karen.thompson@belfasttrust@hscni.net">karen.thompson@belfasttrust@hscni.net</a>

#### 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 <a href="mailto:bsped@endocrinology.org">bsped@endocrinology.org</a>.



# **Trainee Update**

#### **COURSE AND EVENTS:**

#### 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

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#### **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 events.gla@gosh.nhs.uk

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#### **BSPED 2024**



Thank you for such fantastic attendance at the trainee meeting at BSPED. There was some really useful feedback regarding training and ideas for improvement, which are being shared with the CSAC and BSPED.

In addition, we had a really enjoyable annual trainee dinner on the evening of the CME day in Glasgow!

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#### 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: NCYPD Network

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.

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#### **Trainee involvement in Peer Review Process**

The BSPED's national Peer Review programme started in 2011 and is now a Virtual Peer Review Process encompassing the following domains of clinical care:

- 1. Access to specialised paediatric endocrine services
- 2. Resources of specialised paediatric endocrine services
- 3. Environment and facilities, care of the child and family/patient experience
- 4. Communication
- 5. Clinical governance, professional education, training and evidence base

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>).

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#### **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 <a href="mailto:vpet.trainees@gmail.com">vpet.trainees@gmail.com</a>

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#### **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 <a href="mailto:bspedtraineerep@gmail.com">bspedtraineerep@gmail.com</a> 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

#### Diabetes update: New Pre-Type 1 diabetes Special Interest Group (SIG)

The BSPED Pre-T1D group has officially been approved as a SIG. The group is led by Dr Rachel Besser (BSPED Diabetes Officer and Endocrinologist in Oxford) and Dr Tabitha Randell (past BSPED Chair and Endocrinologist in Nottingham), and is made up of representatives from the Scottish Study Group, Northern Ireland, English and Welsh Networks, primary care, NHS England, and ACDC, with representation from medical, nursing and psychology.

#### Aims, to:

- 1. Establish a pre-clinical Type 1 diabetes pathway for children and young people < 18 years in the UK.
- 2. Build expertise in the field of pre-clinical Type 1 diabetes across the four nations.
- 3. Participate in relevant research related to pre-clinical Type 1 diabetes.

#### Objectives, to:

- 1. Establish a steering group of relevant stakeholders across the four nations to provide oversight and leadership to the delivery of the working group aims.
- 2. Establish a task and finish working group on a pre-clinical Type 1 diabetes management pathway.
- 3. Expand on an earlier survey to determine the current number of CYP in the UK with one or more islet autoantibodies to understand the impact on service provision.
- 4. Establish pre-Type 1 diabetes champions across the four nations to build expertise within clinical teams.
- 5. Participate (through guidance or as collaborators/applicants) on relevant research proposals.
- 6. Create support materials for healthcare professions/parents relevant to pre-clinical Type 1 diabetes.

Objectives 1-3 are complete. The pathway has been adapted from international consensus for the UK (doi: 10.2337/dci24-0042). Whilst being prepared for publication, it is available for comment and on request through regional leads, from November 2024.

The survey was presented at BSPED 2024 (DOI: <u>10.1530/endoabs.103.P95</u>) and demonstrates that children and young people with pre-T1D are being identified in the UK from research platforms, and primary/secondary clinical care settings, and highlights the need for a UK consensus on a monitoring and follow-up clinical care pathway.

There will be an announcement to widen the SIG later this year. For further expressions of interest or enquiries please contact: <a href="mailto:rachel.besser@ouh.nhs.uk">rachel.besser@ouh.nhs.uk</a> or <a href="mailto:Tabitha.Randell@doctors.org">Tabitha.Randell@doctors.org</a>.

#### **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.

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#### 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.

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#### 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 <a href="Patient Information section of our website">Patient Information section of our website</a>.



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:

Romanian
Urdu
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

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 <a href="Christine Desmond">Christine Desmond</a> 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.

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#### **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 29 November 2024.

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#### **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 (<a href="https://hil.storr@qmul.ac.uk">h.l.storr@qmul.ac.uk</a>), Justin Davies (<a href="mailto:Justin.Davies@uhs.nhs.uk">Justin.Davies@uhs.nhs.uk</a>), Rebecca Moon (<a href="mailto:rm@mrc.soton.ac.uk">rm@mrc.soton.ac.uk</a>) or Reena Perchard (<a href="mailto:reena.perchard@manchester.ac.uk">reena.perchard@manchester.ac.uk</a>)

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#### **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

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#### 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 <u>the BSPED Office</u>, 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**

# BPSU Surveillance of Rapid-onset obesity with hypoventilation, hypothalamic dysfunction and autonomic dysregulation (ROHHAD) to commence in November 2024

Rapid-onset obesity with hypoventilation, hypothalamic dysfunction and autonomic dysregulation (ROHHAD) is a rare syndrome associated with significant morbidity and mortality, and up to half patients develop neuro-endocrine tumours. The cause is currently unknown, diagnosis is often challenging, and treatment is largely symptomatic. Incidence and prevalence are not known.

BPSU Surveillance of ROHHAD syndrome, funded by the BSPED, is due to commence in November 2024. All Consultant Paediatricians in the UK and Republic of Ireland (RoI) will be asked to report cases each month via the BPSU Orange e-card reporting system.

#### Surveillance criteria:

All existing and new cases seen in the last month (in the UK/RoI) fulfilling this case definition of ROHHAD not previously notified. Please report any patients under the age of 15 years with:

- i) Rapid onset of obesity in childhood after 12 months of age in a previously healthy child
  - a. Evidence of crossing three major centile lines for weight within a 12-month period (e.g. 9th to 75th centile)
  - b. Or family photographic evidence of highly significant weight gain in 12 months, if no baseline weight measurement

AND

ii) Sleep disordered breathing requiring overnight respiratory support

#### Exclusion, any of:

- i. Evidence of structural abnormality of hypothalamic-pituitary axis on MRI
- ii. Congenital structural brain abnormality eg, septo-optic dysplasia
- iii. Acquired brain injury e.g., craniopharyngioma
- iv. Other cause identified for obesity eg, Prader Willi syndrome, monogenic obesity
- v. PHOX2B variant associated with congenital central hypoventilation syndrome

This aims of this study are to estimate incidence and prevalence, understand more about the condition and how it is being managed. Longer-term aims are to help to improve care and outcomes for children living with ROHHAD syndrome and raise awareness about the condition.

For further information please click here (BPSU study - Rapid-onset obesity with hypoventilation, hypothalamic dysfunction and autonomic dysregulation (ROHHAD) | RCPCH) or contact Dr Katherine Hawton (Lead Investigator) by emailing ROHHAD@uhbw.nhs.uk.

#### **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!

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#### 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

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#### 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.

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#### **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

## Meetings and courses



Register your interest for brand-new BSPED endorsed event, Focus on Growth Management – Disorders in Childhood!

This one-day national training event taking place on 4 July 2025 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 your interest

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/

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#### 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/

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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.

Explore the comprehensive <u>scientific program</u> 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/

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# Nurse Prescribing in Paediatrics & Child Health 5 December 2024, Online

**20% discount** with code *hcuk20*bsped

This important national conference provides an essential update for nurse prescribers in paediatrics and child health.

Through national updates and practical case studies delegates will hear how to develop and maintain prescribing competence, meeting the NMC revalidation requirements for prescribing and medicines management, and how to develop effectiveness in post qualification practice. The conference will look at current issues and challenges for nurse prescribers in paediatrics and child health. The conference will include an extended session focusing on maintaining and demonstrating prescribing competence using the National Framework for Prescribing, developing confidence in prescribing practice and maintaining safety. Practical interactive sessions will focus on nurse prescribing for pain, and case studies in the Paediatric Emergency Department, Critical Care and in the Community. The conference will close with a session focusing on demonstrating improvement in patient outcomes and evaluating your prescribing practice.

#### For further information and to book your place visit

https://www.healthcareconferencesuk.co.uk/virtual-online-courses/nurse-prescribing-paeds email aman@hc-uk.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/

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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.

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#### Sent by the BSPED Office

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Tel: 01454 642258

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

