

# British Society for Paediatric Endocrinology and Diabetes

# **BSPED December 2023**

### **BSPED 2024 Save the Date!**

There is a change to the scheduling of the BSPED Meeting in 2024. The 51<sup>st</sup> Annual Meeting will take place from **Tuesday 8<sup>th</sup> – Thursday 10<sup>th</sup> October 2024 at the Hilton Hotel Glasgow.** 



# News from the BSPED Office

#### **BSPED Clinical Committee – Clinical Guidelines Officer Vacancy**

Applications are requested for the position of BSPED Clinical Guidelines Officer to join our Clinical Committee for a 3-year term from April 2024. Current Clinical Guidelines officer, Dr Jarod Wong is taking up a new role as Chair of the BSPED Clinical Committee.



The Clinical Guidelines Officer will attend 4 Clinical committee meetings a year and take specific responsibility for:

- responding to any Clinical Guideline queries
- overseeing the development of any new BSPED Clinical Guidelines.
- ensuring the review of all existing BSPED guidelines every 3 years
- Ensure that the guidelines on the website are up to date prior to every quarterly committee meeting.

For more information please see the <u>role profile on the website</u> or contact the BSPED office.

Applicants should send their CV including photo, together with a 200-word covering letter supporting their suitability for the position. All documents should be submitted electronically to the BSPED Office by **Wednesday 31 January 2024** 

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#### **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. 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 **20 February 2023** 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.

### BSPED funding available for new projects and grants – suggestions please!

The BSPED is now in a good position to provide funding for new projects and grants.

In the first instance, we would like to ask **our members to submit ideas and suggestions** for projects/grants that BSPED could fund in the coming years. The key criteria being that a project would bring benefit to BSPED and the wider Endocrine community.



Examples of previous funding include the sponsorship of an overseas trainee, patient leaflets/information and large-scale grants.

Please get in touch with your suggestions or submit a proposal to <a href="mailto:bsped@endocrinology.org">bsped@endocrinology.org</a> by 10 January 2024

#### 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> with a number of reviews taking place in early 2024.

There are now at least 10 UK centres overdue for a peer review, this list will shortly be available on the website with the date of their last 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 DGH paediatricians and nurses. If you would also like to observe the review process, in preparation of your own centre's review, please let us know.

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

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**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 <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*.

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## 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.



Join us on X

BSPED will soon be starting to do **X** tutorials and **X** segments to introduce you to the Committees and Special Interest Groups and give brief updates on our guidelines and BSPED events. It would be great if members joined the **X** account to keep up to date on opportunities.



If you are a member of **X**, please make sure you follow @Britsped.

# **Trainee Update**

### **Thyroid Education Day**

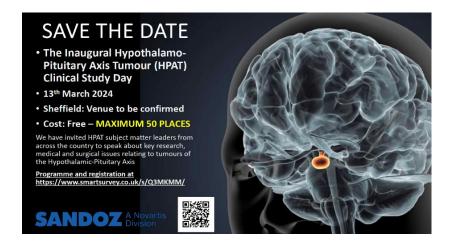
26<sup>th</sup> January 2024, Birmingham

Early bird deadline: 5th January 2024 (cost £195)

The first Thyroid Education Day is an interactive event aimed at adult and paediatric endocrinologists, thyroid surgeons and oncologists. It will discuss the latest developments and guidelines in the management of thyroid disorders with internationally renowned experts in the care of thyroid disorders.

Find out more: https://thyroideducationday.com

## **HPAT Clinical Study Day**



# 2<sup>nd</sup> Postgraduate Course in DSD

24-26<sup>th</sup> June 2024, Stockholm, Sweden

Application deadline: 31st January 2024 (cost £120)







All healthcare providers and researchers who are involved in the field of DSD will find the course useful for their own professional development. Preference will be given to those who have some clinical and academic experience of DSD, who are based at a centre that participates in I-DSD/I-CAH/I-TS related activities or those who are at an early stage in their career. However, none of these criteria are absolute and the Course Steering Committee will judge all applications on their own merits. The faculty

for the Course consists of a group of world-leading experts who shall cover all aspects of the multidisciplinary care provided in DSD.

To find out more please contact <a href="mailto:info@sdmregistries.org">info@sdmregistries.org</a> or visit <a href="https://sdmregistries.org/2nd-postgraduate-course-in-dsd/">https://sdmregistries.org/2nd-postgraduate-course-in-dsd/</a>

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### **Diabetes UK Summer Camps**

A great CPD opportunity, spending time with patients outside of a clinic setting and seeing their diabetes in real time.

Register your interest here: <a href="https://eu.eventscloud.com/esurvey/hcp">https://eu.eventscloud.com/esurvey/hcp</a>
Or find out more: <a href="https://eu-admin.eventscloud.com/docs/200007869/HCP">https://eu-admin.eventscloud.com/docs/200007869/HCP</a>

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#### **ANNOUNCEMENTS:**

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

#### **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 Nicola Heddy

# News from the Clinical Committee

#### National reaudit of DSD standards

The DSD SIG group has agreed to proceed with a national reaudit of DSD standards. This cycle of Audit will be re-run and led by Liz Crowne <u>Liz.Crowne@uhbw.nhs.uk</u> and Danielle Eddy <u>Danielle.Eddy2@wales.nhs.uk</u>. We shall keep the centres and the clinical committee updated with the progress over the next three months.

Zainab Mohamed -Disorders of Sex Development (DSD) Special Interest Group Coordinator

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Emergency and perioperative management of adrenal insufficiency in children and young people: British Society for Paediatric Endocrinology and Diabetes consensus guidance.

# **Publication and updated BSPED AI card**

The paediatric adrenal insufficiency working group are pleased that the full paper has been published in Archives of Disease in Childhood and can be accessed <a href="https://example.com/here-page-12">here on the BSPED website</a> or via this link:

Emergency and perioperative management of adrenal insufficiency in children and young people:

British Society for Paediatric Endocrinology and Diabetes consensus guidance | Archives of Disease in Childhood (bmj.com)

The <u>BSPED Adrenal insufficiency card</u> has also been updated so that the pdf includes fillable fields.

Please use this latest version, which is also available at <u>BSPED | BSPED Adrenal Insufficiency Consensus Guidelines</u>.

#### 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.

### Survey on Service Provision for Patients with Turner Syndrome

A group of us would like to look at the way services are managed for patients with Turner Syndrome in Paediatric Endocrine Centres.

The information gathered from this survey will hopefully help us to better understand the national landscape for the care of patients with Turner Syndrome, which might enable us to identify needs for service improvement as well as formulate research questions relevant to our patients.

The service was developed with the support of the Turner Syndrome Support Society (TSSS), UK.

We would be grateful for your time in taking this survey; it takes about 15 minutes to complete. https://form.jotform.com/223294422603046

We would only require one response per centre, kindly agree with your colleagues who will answer for your centre to avoid multiple responses.

Many thanks for your help!

James Law, Elspeth Ferguson, Nadia Amin, Sasha Howard, Harshini Katugampola, Jan Idkowiak and Nils Krone

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#### Surveys

If you would like to include a survey in a BSPED newsletter to encourage responses from BSPED members, please submit it to <a href="the BSPED Office">the BSPED Office</a>. The survey will be reviewed at the next Clinical Committee meeting 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

## Competition Funded PhD Project at Queen Mary University of London (UK Students Only)

For more details and links to the institution website to apply.

<u>Targeting adrenal stem cells by gene therapy to rescue adrenal insufficiency in Familial Glucocorticoid</u>

<u>Deficiency at Queen Mary University of London on FindAPhD.com</u>

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## NICE Transition from children's to adults' services - update (QS140)

The updated quality standard <u>Transition from children's to adults' services</u> has been published on the NICE website. They have also published a blog about the update <u>Listening to patients and organisations</u> to update NICE's quality standard on transition from children's to adults' services

Also available on the website is the <u>consultation comments and responses</u> prepared by the NICE quality standards team.

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#### **ACDC Clinical Diabetes Grant Award**

ACDC is offering a small project grant every year. These grants are intended to:

- 1. Promote and support research in children's diabetes by providing funding to:
- 2. Promote and support surveys of clinical innovations in children's diabetes
- 3. Promote and support educational projects in children's diabetes



Applications must have the potential to change practice in paediatric diabetes and be applicable in other settings, Trusts and hospitals. This work may benefit patients and families, other health care professionals, schools or other groups. Successful applications are likely to include evidence of input from patients and the public and plans to evaluate the impact of the project. Proposals that encompass a national survey should clearly demonstrate the clinical question or the problem to be addressed.

There will be one ACDC Clinical Diabetes Grant awarded- up to a maximum of £15,000.

Please download the <u>ACDC Clinical diabetes grant application form</u> Deadline for application is **February 29th 2024** 

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### **Advisory Committee on Clinical Impact Awards update**

The 2023 awards round is now in its final stages, with results due to be shared with applicants in early 2024.

Looking ahead to the 2024 round, the application window is likely to open in early March and close in mid-April. Keep a look out on the ACCIA homepage for the updated applicant and employer guides, which will be published in the next few weeks. Key updates in these guides include further clarity on what is meant by clinical relevance and further information on eligibility to keep an award following taking up flexible retirement.

More information: https://www.gov.uk/government/news/publication-of-accias-2022-annual-reportand-2024-indicative-timelines

### **RCPCH Volunteering Opportunities**

We are currently seeking a dedicated individual to serve as the Clinical Lead for our Clinical Quality in Practice Committee. This committee plays a pivotal role in supporting the development of standards and guidelines while fostering a culture of continuous quality improvement within our organisation.



Please find attached a link to the volunteer application form and the required criteria:

Clinical lead: Evidence-Based Clinical Practice - Clinical Quality in Practice Committee - volunteering opportunity | RCPCH

Please forward this on to relevant members of your organisation who would be interested.

**Paediatric Endocrine Nurse Role** 

The Pituitary Foundation are recruiting for a paediatric endocrine nurse to run their helpline service. The Nurse will be paediatric endocrine clinical lead amongst the staff team and part of the organisation's Medical Committee. The role includes working closely with the Head of Patient and Family Services and Endocrine Specialist Nurses, to provide medical information and guidance for parents, and contribute overall to the charity's patient and family support services.



For more information about the role click here

# TSSS (UK)

The **Turner Syndrome Society** is carrying out a survey to generate an up-to-date list of the clinicians and where they are now based. To be added to our Paediatric Growth Clinic List. Please complete our 1-minute survey, thank you



https://www.surveymonkey.co.uk/r/GROWTHCLINICS

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# **EnprEMA:** paediatric cross-border clinical trials initiative



The European Network of Paediatric Research at the European Medicines Agency (Enpr-EMA) is a network of research networks and centres with recognised expertise in performing clinical studies in children, aiming to promote research into medicines for children.

A working group of Enpr-EMA analyses the obstacles and hurdles that children and families face, when a child participates in cross-border clinical trials (i.e. travels to another country for participating to clinical trial).

The main goal of this working group is to develop consensus guidance to facilitate the inclusion of paediatric patients in cross-border clinical trials in Europe, aiming to avoid discrimination based on language, culture, or other factors. This may be especially relevant for children living with rare diseases. To achieve this goal, the working group aims to identify current practices on inclusion and exclusion of potential child participants from abroad in a clinical trial by collecting paediatric clinical study data from the period of 2017-2022. Additionally, the group will analyse if there are explanatory reasons from a scientific and ethical perspective and identify good practices.

If you are a Clinical Research Unit (CRU) Coordinator or have a similar role, please complete this questionnaire for CRU. Deadline for completion is 30<sup>th</sup> December 2023.

Additionally, please share these 2 questionnaires to the staff of your CRU / Organisation. Each site can report a maximum of 10 studies. It is essential to get accurate data from various trial experiences. This project has been approved by the Ethics Committee at Sant Joan de Déu Research Foundation (Barcelona, Spain), regarding study protocol, anonymising, and analysing the data to guarantee the confidentiality of the personal data and information collected.

For the confidential data analysis, you need to create a site specific 6 DIGIT CODE at the beginning of each survey (e.g. 123456) that you and the rest of the staff of your site have to use in each survey. Questions with no data, please use N.A. Completing each questionnaire takes up to about 15 minutes. You can also download the questionnaires before filling them in via the web interface to ease the process. Deadline for completion these questionnaires is **30**<sup>th</sup> **December 2023.** 

- Link to questionnaire of clinical trials to collect good practices and
- Link to questionnaire of cases of discrimination in clinical trials.

For any additional information, please contact Begonya Nafria (Chair of the Paediatric Clinical Trials Cross-Border Access – Enpr-EMA Working group): <a href="mailto:begonya.nafria@sid.es">begonya.nafria@sid.es</a>

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#### **GACI/ENPP1** clinical trials update



<u>Click here to read a press release</u> outlining the clinical trials program with ENPP1 enzyme replacement therapy for patients with Generalised Arterial Calcification of Infancy (GACI)/ENPP1 deficiency. Circulating this information to your network in clinical genetics, neonatology, and paediatric cardiology, intensive care and endocrinology would greatly help increase awareness of our work with this very rare condition.

ENERGY 1 Ages 1-12 months, 8 patients Phase 1b, underway, recruiting NCT05734196

ENERGY 2 Ages birth-12 months, up to 12 patients, pivotal study

ENERGY 3 Ages 1-12, up to 30 patients, commencing October 2023

ENERGY 4 Ages 13+, up to 30 patients, under regulatory discussions

A brief description of GACI and the 'red-flag' presenting symptoms are included on the Think GACI card

If a case of GACI is suspected, rapid genetic testing via the Rady Institute is available to facilitate participation in the trials program. Clinicians should contact catherine.nester@inozyme.com

# SPRINGER NATURE

<u>Springer Healthcare IME</u> is the Independent Medical Education unit of Springer Healthcare, part of the <u>Springer Nature</u> group, providing healthcare professionals the very latest clinical information from the world's leading experts in key therapeutic areas.

This programme is an online hub intended for healthcare professionals to explore the <u>latest news</u> on paediatric endocrinology including features such as <u>expert reviews</u> and <u>case studies</u>.

This programme is made possible thanks to an educational grant received from Merck Healthcare KGaA."

# Meetings and courses

# Thyroid Education Day 26 January 2024, Birmingham

The first Thyroid Education day is an interactive event aimed at adult and paediatric endocrinologists, thyroid surgeons and oncologists. It will discuss the latest developments and guidelines in the management of thyroid disorders with internationally renowned experts in care of thyroid disorders.

Link: <a href="https://www.thyroideducationday.com">https://www.thyroideducationday.com</a>

Extended Early Bird Deadline: 5th January 2024 (£195)

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# Turner Syndrome Support Society UK Meet the Experts Day 9 February 2024

Bolton Stadium Hotel, De Havilland Way, Bolton, (near Manchester) BL6 6SF

An Education Day open to all Healthcare Professionals involved in the Care of a girl or a woman with Turner Syndrome

The Turner Syndrome Support Society [UK] is proud to be hosting this event with support from Novo Nordisk. This is a day that was planned for the 10th Turner Syndrome International Conference [TSI2020] but it had to be cancelled because of the pandemic. Our Clinical Advisory Board are helping us plan the programme we are pleased to confirm we have some wonderful speakers.

#### Click here for the full programme information and to register

# **Turner Syndrome Seminar Day 10 February 2024**

Bolton Stadium Hotel, De Havilland Way, Bolton (near Manchester) BL6 6SF.

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. Please note we are not able to provide any childcare facilities

Click here for the full programme information and to register

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### SfE Clinical Update 2024

### 25-27 March 2024, Birmingham

Providing the gold standard for endocrine training and an indispensable update for consultants, Clinical Update, covers the endocrinology topics of the national curriculum in endocrinology and diabetes, issued by the Joint Royal Colleges of Physicians Training Board, over a three-year programme cycle.

Registration is now open!

https://www.endocrinology.org/events/clinical-update/clinical-update-2024/

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#### **ECE 2024**

# 11-14 May 2024, Stockholm, Sweden

Be a part of the largest endocrine event in Europe.

We are pleased to announce that ECE 2024 will be held in Stockholm, Sweden from 11-14 May 2024. We will, once again, be offering the hybrid format so you can join us in person in Sweden or remotely with ECE@Home.

https://www.ese-hormones.org/education-and-training/european-congress-of-endocrinology/ece-2024/

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# 18th ACDC Annual Conference 17 May 2024

The 2024 18<sup>th</sup> ACDC Annual Conference will be held on the 17th May 2024, Friday at Conference Aston, Aston University Campus B74BL Birmingham in May 2024. 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. Registration and the Programme is available via our ACDC website here

https://www.a-c-d-c.org/forthcoming-acdc-meetings/

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# 11th I-DSD Symposium 2024 26-28 June 2024, Stockholm, Sweden

What is the aim of the symposium?

- To provide an update on conditions affecting sex development and maturation
- To facilitate networking of professionals involved in the care of people with conditions affecting sex development and maturation
- To promote high quality research in the field of sex development and maturation Who is the symposium aimed at?
- Health care staff
- Clinical and basic scientists
- Parent & patient support groups

Further information is available at <a href="https://sdmregistries.org/11th-i-dsd-symposium-2024/">https://sdmregistries.org/11th-i-dsd-symposium-2024/</a>

# 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/

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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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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

 $\underline{bsped@endocrinology.org}$ 

Tel: 01454 642258

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# The BSPED would like to thank the following benefactors for their generous support this year:

Partner	Gold	Silver	Bronze
Merck	<b>G</b> yowa KIRIN	AstraZeneca Rare Disease	Abbott
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