

### British Society for Paediatric Endocrinology and Diabetes

## **BSPED March 2024**



# Registration and Abstract submission is now open!

We're excited to announce that registration and abstract submission for BSPED 2024 are officially open! Mark your calendars for an engaging and insightful meeting set to take place from **Tuesday 8** to **Thursday 10 October** in the dynamic city of **Glasgow**.

#### Why attend:

- **Innovative learning:** Discover the latest advancements and research.
- Networking opportunities: Connect with leading experts and colleagues from around the globe.
- Showcase research: Present your work to a dedicated audience of professionals.
- Social programme: Network and catch-up with fellow colleagues at the Welcome Reception (Tuesday 8
  October) and Conference Dinner (Wednesday 9 October). More details to follow soon!

This is your chance to be part of a community dedicated to advancing paediatric endocrinology and diabetes. Don't miss out; register and submit your abstract now  $\rightarrow$  <u>BSPED | Registration</u>

Early Bird registration deadline: Monday 12 August 2024 (11:59 BST)

Abstract submission deadline: Friday 14 June 2024 (11:59 BST)

# News from the BSPED Office

#### **Research and Innovation Award 2024**

Applications for the BSPED | Research & Innovation Award are now open

This year there will be **two BSPED Research and Innovation Awards granted up to a maximum of £15,000 each**. The total amount for each grant can be allocated to one recipient or split between 2 or more projects. These grants are intended to:



- 1. Promote and support academic research by its members by providing funding to:
  - > Obtain preliminary data which will support an external funding application
  - Conduct a small project
  - Purchase equipment
- 2. Promote and support surveys of rare diseases
- 3. Promote and support surveys of clinical innovations
- 4. Promote and support educational projects

The BSPED strongly encourages any BSPED member to submit a proposal including nurses, research fellows, and specialist trainees, DGH consultants, allied health professionals and clinical Networks. Please submit your application to <a href="mailto:bsped@endocrinology.org">bsped@endocrinology.org</a> by Monday 8<sup>th</sup> July 2024 5pm

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#### Digital and Information Officer Vacancy – deadline approaching

We have a vacancy for a BSPED member to join the Clinical Committee in May 2024, focusing on how BSPED's information and news is communicated. If you're a social media enthusiast and are passionate about disseminating important information in the field, we'd love to hear from you. As a member of the Clinical Committee you would be at the heart of BSPED's activities, whilst also posting and engaging via social media, having an overview of the website and liaising with the media as appropriate.



For more information please see <u>the role profile</u> or contact the BSPED Office. Application deadline 5pm Wednesday 10th April 2024

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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.

#### The following UK centres have an up to date peer review or a planned review in 2024

- Birmingham, June 2022
- Leeds, January 2024
- Leicester, January 2024
- London Evelina Children's Hospital, June 2020
- London Gt Ormond Street, Nov 2021
- London: St George's Hospital, June 2021
- Manchester, June 2021
- Nottingham, July 2019
- Oxford, Feb 2021
- Southampton, Nov 2022
- Cardiff, December 2023
- Edinburgh: Royal Hospital for Sick Children, Apr 2024
- Belfast: Musgrave Park Hospital, March 2021



**There are now at least 10 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 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>

#### **Updated BSPED Byelaws**

The BSPED byelaws have recently been updated by the Executive Committee to ensure they accurately represent current membership systems and processes. Small changes have been made to clauses 3 (regarding membership fees), 4.5 (regarding new membership approval) and 5.3 (regarding membership renewals and lapsing). The <u>updated byelaws can be found on the BSPED website</u>.

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#### 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*.

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



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#### 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

### **COURSES AND CONFERENCES:**

# News from the Clinical Committee

#### Wanted: Translators of Adrenal Insufficiency Steroid Card

The BSPED <u>adrenal insufficiency steroid card</u> for sick days and emergencies has been extremely well received by health care professionals nationally. We have had several requests for translated versions of the card and are therefore looking for BSPED members who are willing and able to translate the card into a different language.

If you are fluent in another language (or already have a translation within your trust), 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.

So far, we have translators for the following languages so are just seeking a reviewer for these:

- Slovakian
- Romanian
- Turkish
- Urdu

We already have Arabic and Polish translators and reviewers.

For other languages we seek two fluent speakers.

The translated cards will be available on the BSPED website in due course, once reviewed and approved. Please contact Christine Desmond, Southampton to offer your services.

**The BSPED Growth Disorders Special Interest group (SIG)** is delighted to share two related new documents:

 Position statement: 'BSPED recommendations for the use of once-weekly long-acting growth hormone therapy in children with growth hormone deficiency'

https://www.bsped.org.uk/media/pk3hsjeh/lagh-guideline-05-02-2024.pdf

Long-acting growth hormone (LAGH) is now available in the UK and is recommended by NICE (2023) as an option for the treatment of growth hormone deficiency for children and young people aged three years and over.

A clinical practice guideline for the use of LAGH was identified as an unmet need by BSPED and Growth Disorders SIG members. This new position statement aims to summarise the latest data and provide recommendations on dosage and surveillance for clinicians prescribing LAGH. Currently only one LAGH preparation is licenced, but other preparations are likely to become available. We will update this guidance when new LAGH preparations are accessible to patients in the UK.

'Shared care guidelines for paediatric use of daily and long-acting recombinant human growth hormone'.

https://www.bsped.org.uk/media/alxow2wv/gh-shared-care-guidelines-20240206.pdf

This document replaces 'Shared Care Guidelines: Paediatric use of Recombinant human Growth Hormone (r-hGH, Somatropin)' produced by a BSPED Clinical Committee working group in 2017. The latest document incorporates updated shared care guidance for somatropin and its current licenced indications. The latest iteration also includes long-acting growth hormone preparations (LAGH).

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# Clinical Standards for GH Treatment of Growth Disorders in Childhood and Adolescence excluding GHD

The BSPED Growth Disorders Special Interest Group (SIG) recently shared the updated 'Clinical Standards for GH treatment of GH deficiency (GHD) in Childhood and Adolescence' which was adopted and published on the BSPED website in 2022:

https://www.bsped.org.uk/media/iczlv32f/clinical-standards-for-gh-treatment-of-ghd-in-childhood-and-adolescence-v1.pdf

We are now delighted to share the recently developed Clinical Standards for GH treatment of Growth Disorders in Childhood and Adolescence excluding GHD:

#### Find the full clinical standards document here (bsped.org.uk)

This guidance covers the clinical standards including eligibility for treatment, and monitoring/management recommendations of rhGH therapy for the other conditions licensed/treated by growth hormone:

- 1. Turner syndrome
- 2. Prader-Willi syndrome
- 3. Chronic renal insufficiency
- 4. Born small for gestational age with subsequent growth failure at 4 years of age or later
- 5. Short stature secondary to homeobox-containing gene (SHOX) deficiency
- 6. Noonan syndrome

#### 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

#### **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 see below the deadline for submission for the upcoming Clinical Committee meeting:

15 April 2024 for Clinical Committee meeting on 10 May 2024

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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.

#### **SURVEYS**

#### 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**

UK Experience in Management of Growth Hormone Secreting Pituitary Adenoma in Children

We are conducting a piece of work to gather valuable insights on **UK Experience in Management of Growth Hormone Secreting Pituitary Adenoma in Children**, from medical professionals who have encountered this condition.

Your expertise and feedback are highly appreciated. If you are interested in participating, please contact us at m.altowati@nhs.net for more information.

Thank you for your consideration

Mabrouka Atowati, -Endocrine Grid, Leicester Royal Infirmary Dr Subbarayan (Supervisor)

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#### **MedEA Live Webinar Series**



Embracing technology to help diagnose, treat and monitor Growth Disorders

1st webinar - 21 June 2024 from 14.00 to 15.00 CEST 2nd webinar - 20 September 2024 from 14.00 to 15.00 CEST

For Pediatricians, endocrinologists and general practitioners involved in growth management. More information and registration click here

New members needed for the NIHR CRN: Paediatric Endocrinology Clinical Studies Group



The Paediatric Endocrinology NIHR-Clinical Studies Group (CSG) is looking for trainees interested in research to join the group. If you have an interest and you think you might want to contribute, please apply with instructions in the NIHR advertisement - link below.

#### **NIHR CSG Trainee Advert**

For an informal discussion, you may wish to contact the CSG Chair Indi Banerjee at indi.banerjee@mft.nhs.uk.

#### 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 **April 29th 2024** 

#### **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 <u>ACCIA homepage</u> 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: <a href="https://www.gov.uk/government/news/publication-of-accias-2022-annual-report-and-2024-indicative-timelines">https://www.gov.uk/government/news/publication-of-accias-2022-annual-report-and-2024-indicative-timelines</a>

# 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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#### **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 <a href="mailto:catherine.nester@inozyme.com">catherine.nester@inozyme.com</a>

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# Meetings and courses

# NEYD 2024 (North European Young Diabetologists Meeting) 22-24th May, Stratford Upon Avon

The annual North European Young Diabetologists (NEYD) meeting sees its' 30<sup>th</sup> year of supporting early career researchers in diabetes (clinicians, scientists and medical students) from the United Kingdom, Netherlands and Denmark. The nature of the meeting allows for discussion of research in an intimate and stimulating setting for young researchers. Participants present their own research (selected from submitted abstracts) and discuss it with peers and senior established scientists. The meeting facilitates networking and collaboration opportunities with peer young scientists and senior experts.

NEYD covers the spectrum of diabetes research from bench to bedside. This year the UK are hosting the meeting in Stratford-upon-Avon, the birthplace of Shakespeare.

For further information click here.

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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.

For registration and programme details click here

# 18th ACDC Annual Conference, Friday 17 May 2024 Conference Aston, Aston University Campus B74BL

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 <a href="here.">here.</a>



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







11th I-DSD Symposium 2024 Programme (sdmregistries.org)

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

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#### 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/

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 them for review here</u>.

#### **Sent by the BSPED Office**

BSPED c/o Bioscientifica Ltd Starling House, 1600 Bristol Parkway North, Bristol, BS34 8YU bsped@endocrinology.org

Tel: 01454 642258

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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
Pfizer Rare Disease	SANDOZ		Diurnal
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