

British Society for Paediatric Endocrinology and Diabetes

BSPED February 2024



Are you ready for BSPED 2024?

We are excited to announce that registration and abstract submission for the **BSPED 2024 meeting** will be open soon!

Set to take place from **Tuesday 8 - Thursday 10 October** in the vibrant city of **Glasgow**, this meeting promises to be an enriching platform showcasing the latest advancements in paediatric endocrinology and diabetes.

Don't miss your chance to be part of this dynamic gathering of experts and peers. **Register your interest** today to be kept up-to-date.

Join us for an opportunity to learn, network, and contribute to shaping the future of paediatric endocrinology.

News from the BSPED Office

New membership management system

We have now upgraded the system we use to manage membership subscriptions and members-only content on the BSPED website to **VeryConnect**



Please ensure you have followed the simple instructions in the email we sent you last week to set up your login for the new system. This will mean that you can access the members' area, easily renew your membership and edit your profile and settings.

When you come to renew in the summer, you can now choose to pay automatically each year via Direct Debit or subscription card payment for your convenience.

If you have any questions regarding your membership or the new system, please don't hesitate to contact our membership team on bsped@endocrinology.org

Digital and Information Officer Vacancy

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 Guftar.Shaikh@ggc.scot.nhs.uk

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 peter.laing@alderhey.nhs.uk and Karen Thompson karen.thompson@belfasttrust@hscni.net

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>.

Make the most of your membership benefits

The BSPED is an official endorsing society of the journal Endocrinology, Diabetes & Metabolism Case Reports (EDMCR). EDMCR is a unique, open access



resource that publishes and links together case reports, enabling practitioners to communicate findings, share knowledge and convey medical experiences efficiently and effectively; furthering both medical education and clinical practice.

Members of BSPED receive a 25% discount on the Article Publication Charge (APC) when their paper is accepted for publication in *EDM Case Reports*.

Help us keep in touch

As the BSPED communicates with members by email, please ensure that you notify the BSPED Office if your email address changes at bsped@endocrinology.org.



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

ACADEMIC OPPORTUNITY:

The Chan group at the William Harvey Research Institute, QMUL will be recruiting for an Academic Clinical Fellow under the NIHR theme of Endocrinology (2025 year recruitment). Applicants will need to be ST1-ST4 at the time of joining in Sept 2025. Anyone interested should contact l.chan@qmul.ac.uk at an early stage for further information. The Chan group works on adrenal and metabolic diseases in childhood.

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: https://eu.eventscloud.com/esurvey/hcp
Or find out more: https://eu-admin.eventscloud.com/docs/200007869/HCP

ANNOUNCEMENTS:

Congratulations to Dr Manju Chandwani for being appointed as Consultant in Paediatric Endocrinology and Diabetes at Bristol Royal Hospital for Children.

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 vpet.trainees@gmail.com.

BSPED Trainee Mailing List

We send regular email updates on courses, job opportunities and information on training to trainees who are on our mailing list. Please email bspedtraineerep@gmail.com for further details of how to join or if you have feedback on any training issues.

CSAC Diabetes and Endocrine Trainee Representatives:	
Katherine Hawton	
Salma Ali	

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
- Arabic

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).

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

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

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

We are conducting a survey 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)

Surveys

If you would like to include a survey in a BSPED newsletter to encourage responses from BSPED members, please submit it to the BSPED Office. 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





JDRF Small Grant Awards





Apply now to the JDRF UK Small Grant Awards!

Do you have a new and innovative research idea that has the potential to deliver significant contribution to the understanding or management of type 1 diabetes?

JDRF UK are delighted to announce their 2023 call for Small Grant Awards applications.

This funding opportunity offers competitive funding to support basic scientists, clinicians, or healthcare professionals (including allied health professionals) at an early stage of their research career for up to 12 months.

The scheme offers up to £20,000 for basic research projects or £30,000 for clinical research projects.

Please visit the JDRF UK Small Grant Awards webpage for more information and how to apply.

Deadline: Wednesday 13th March 2024 (5pm GMT).

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 <u>NICE's quality standard on transition from children's to adults' services</u>

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

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: https://www.gov.uk/government/news/publication-of-accias-2022-annual-report-and-2024-indicative-timelines

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

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

Meetings and courses

Success 7th Annual Conference

We are now pleased to extend a warm invitation to our 7th annual conference 'Successful Destinations' on Saturday March 2nd at 1 Wimpole St (the home of the Royal Society of Medicine)

success

Brighter Futures For Childhood Brain Tumour Survivors

Our conferences, this year with CPD, are an innovative opportunity for both patients and a diverse array of hospital and

community professionals, to network and share experience in the new emerging field of survivorship after childhood brain tumours, now that 80% survive and live long lives with the often forgotten, multi system consequences of the tumour and treatment.

Our unique offering is that of the survivor [from as young as 8] and family voice itself, and a chance to share experiences, foster education and collaboration in this new field with decision-makers and parliamentarians, helping all those who experienced a brain tumour under 25yr old, achieve 'brighter futures'.

This year we are building on SUCCESS' vision of a recovery pathway to cure, delivered in parallel with the acute treatment and beyond, and implementing the first worldwide children's pituitary tumour guidelines- led by SUCCESS, commissioned by the CCLG/ BSPED and endorsed by the RCPCH. They have just been published in Nature and the Lancet, and are long overdue for specialist commissioning to improve outcomes from these rare [10-15 p.a.] but potentially devastating tumours of the deep midbrain.

Please do find further information here https://successcharity.org.uk/success-conference/

One Day Conference First Do No Harm 23 Mar 2024 10:00 AM - 5:00 PM Central London, 30 Euston Square, NW12FB

First Do No Harm brings together clinicians, researchers, parents, patients and therapists to discuss current controversies in the care of children and young people with gender-related distress, safeguarding as it relates to sex and gender, sex-based language in healthcare, and addressing the impacts of gender medicine on same-sex attracted youth.

For conference tickets and more information click here

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! Click here for more information

RCPCH Conference 2024 25 March 2024 - 27 March 2024 - ICC Birmingham



This year's theme is 'Building a bright future together', and with the input *Leading the way in Children's Health* of more than 35 specialty groups you can update your knowledge on what matters to you.

RCPCH Conference

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

The annual North European Young Diabetologists (NEYD) meeting sees its' 30th 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.		

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 18th 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.



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







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

Further information is available at https://sdmregistries.org/11th-i-dsd-symposium-2024/

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/

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

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

Partner	Gold	Silver	Bronze
Merck	G yowa KIRIN	AstraZeneca Rare Disease	Abbott
Pfizer Rare Disease	SANDOZ		Diurnal
Rare Disease			Insulet