BACCHNEWS

BACCH
British Association for Community Child Health

June
25

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BACCH is an organisation representing professionals working in paediatrics and child health in the community. It is a specialty group of the Royal College of Paediatrics and Child Health.

BACCH welcomes new members!

Benefits of membership

- 'BACCH News' BACCH's quarterly flagship magazine: paper copy posted to all members; e-version available to download for members only via the website. *(Student members will NOT receive a paper copy of the Newsletter.)*
- Monthly email updates.
- Reduced delegate rates to BACCH conferences.
- Option to subscribe to the Journal Child: Care, Health and Development, for the reduced rate of £20 per year. *(Not available for those who join as overseas members or student members.)*
- Regional coordinators organise local meetings and represents members' views to BACCH Council.
- Members' only content on the BACCH website.

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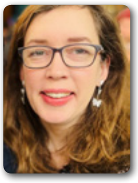

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https://www.bacch.org.uk/articles/category/26-nominations

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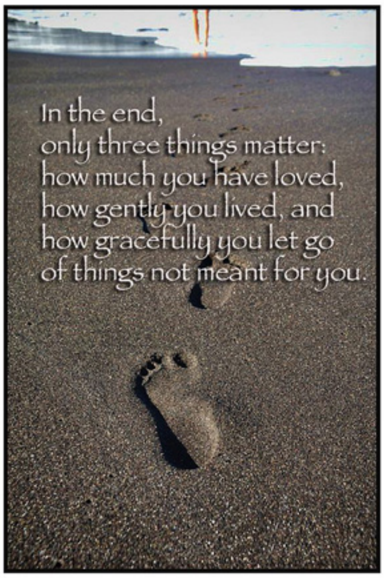
Adios Amigos! From the Editor

It has been a Privilege to have been the Editor for three years now, and this is my last edition. As you have probably noticed over the last few editions, it was only right that I stepped back to allow younger members of the team to flourish and rightly take the credit for all the hard work they put in. Once again, this trainee team of Thushara, Sunanda, TJ and our new Editor in Waiting, Jemma have put on a wonderful edition with the able support of Paul and Lucy. This is the "A team", and what a wonderful one. The team have reinforced belief in me, that we support each other no matter what; there is no glory hunting, but one common purpose, and that every opportunity is one of learning. Through the last year, I have had challenges in personal life and the team have ably stepped forward to keep the magazine going.

It is sad to leave such a team, but it is time, and I leave knowing that BACCH News is in great hands, ones that will take it to new heights and of course, keep us all yearning for more. I will eagerly look forward to reading the print version.

With the above in mind, I leave the exciting task of writing about the contents of this edition to Sunanda (my last perk as Editor!) who have led the curation of this edition, but would like to draw your attention to the very challenging phase that the NHS, and most importantly, children's services, are going through. In my 23 years in the NHS, finances have never been given more importance than children themselves, or the the care they receive. This is a very "unknown" (I went through a few emotive words and have settled on this one) territory and I feel quite uneasy traversing it. I will continue to put the child at the centre of what I do, daily, just like all of you will too.

Finally, let me not take away valuable print space from the edition and bow out with these words of Buddha, which have stood me in good stead.



Keep in touch, and I wish you all well.

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From the Trainee Editor

Welcome to our June's newsletter edition! Thank you for all your submissions and once again, it is a pleasure to work with the rest of the BACCH Team to put this newsletter together.

We all have been eagerly awaiting the sun to stay, so we can enjoy the outdoors. We have also eagerly been waiting for someone to join us as our BACCH Executive Officer. Lucy has already seamlessly immersed herself into the role and our team.

With every edition, we all learn something new, this is the beauty of our work and the teams and families we work with. There is just such a breadth of knowledge and clinical presentations we are exposed to.

For instance, Dr Ella Rachamim who previously introduced us to a wealth of information about the management of Down Syndrome via BUDDS (Barnet Unified Document for Down Syndrome). She has now written an article for this edition to raise awareness of Down Syndrome Regression Disorder (DSRD).

I recently attended a full day course on child sexual abuse, organised by the Havens specialist centre's team in London. They have together, as a team, provided a practical guide on implementing trauma informed care through a case-based scenario. This is very relevant for all of us as we often manage individuals and families who have experienced trauma in different forms.

Thinking now more broadly, Professor Michelle Heys and Dr Louisa Pollock have come together to shed light on implementing research within paediatrics; something that needs to continue to echo through us as a community in order to build a brighter future for our children (Pun intended!). The article in this edition on the importance of public health in community paediatrics complements this message, as it helps identify what areas need development and research. This is an exciting time to be in our speciality, as there is plenty of scope for change.

We have already included some talents, hobbies, and ways to de-stress by our peers in our light-hearted section. In this edition, Dr Laura Thomas, who is one of the consultants I work with at Chelsea and Westminster Hospital, has authentically described how we all need to find something that helps us truly switch off from work and life admin! She shares with us how she has been attending a pottery course regularly this year which she has found to be very therapeutic.

Dr Sunanda Bhatia
BACCH Trainee Newsletter Editor

Thank you! From the Trainee Editor

Being part of the BACCH NEWS Editorial Team as a Trainee Editor has been an incredibly rewarding journey filled with learning, growth, and meaningful connections. I'm deeply grateful to the entire Editorial team–past and present, and everyone who's been part of this experience over the past 3+ years. Massive thanks particularly to Deepak, Jemma, Sunanda,

Continues overleaf

TJ, Lucy and last but certainly not least, Paul (the current NEWS dream team) it's truly been a privilege to work with you all!

This role has meant so much more to me than just meeting deadlines and proofreading. It's been an exhilarating rollercoaster ride of building relationships, sharing knowledge, sparking ideas, and contributing to the creation of a newsletter that I hope our readers found engaging and eagerly anticipated each quarter (and no doubt, will continue to do so!).

Though I'm stepping away for now, this isn't goodbye, it's more like until the next time. I look forward to returning to the NEWS team in future and continuing to contribute to this amazing organisation that is BACCH in other ways.

I'd like to leave you with a story from Persian folklore, which has always felt to me as profound wisdom:

A powerful king, burdened by the fleeting nature of joy and the weight of sorrow, asked his advisors to create something that would help him find peace through life's ups and downs. After much reflection, they presented him with a simple ring engraved with the words: "This too shall pass."

At first, the king was puzzled. Over time, he came to understand its power. In moments of happiness, the words reminded him to stay humble and modest. In sorrow, they offered hope. And so, he found balance—not by clinging to highs or fearing lows, but by accepting that all things are temporary, and that each moment, whether joyful or painful, will pass.

Much like the king in the story, I've learned to embrace both the celebrations and challenges, knowing that each ending opens the door to a new beginning.

As I close this chapter, I carry this same sentiment. Thank you all for this unforgettable adventure and I can't wait to see what the next editions of the NEWS bring—from the other side of the envelope!

Dr Thushara Latha Perumal
BACCH Trainee Newsletter Editor

From the Chair

I am delighted that Lucy Doig has joined BACCH as Executive Officer. She has written an article introducing herself to you all in this edition of BACCH News. From my perspective, she has made an enormous difference to the office already and is a tremendous support to me in my role as Chair.

The role of BACCH Chair is very varied and I am often surprised by what comes across my desk. Currently, I am writing a witness statement for Module 8 of the COVID inquiry chaired by Baroness Hallett. Module 8 is concerned with the impact of the pandemic on children, and the questions I have to answer are both broad and specific. The most recent BACCH e-bulletin asked if any of you have evidence on the impact of the pandemic you can share with me. Don't do it after reading this article as I had to submit the statement on 30th May; all I am doing here is encouraging you to read the e-bulletin as it is a good way to keep abreast of the current urgent and important issues.

After I read the BACCH e-bulletin yesterday, I booked my place at the Annual Scientific Meeting on 30th September and 1st October 2025 in Nottingham. We have invited NHS Benchmarking to do a workshop on the findings from their data in Community Paediatrics (they have also done work on Speech and Language Therapy). It is an opportunity for you to engage with the data and its gaps to help produce high quality recommendations from the work. We have also invited colleagues from NHS England who are curating the best evidence for effective interventions in Community Child Health. Again, this is important, as we need to guide policy makers across the four nations as they commission community child health services. I commend that workshop to you too.

In my last column mentioned that NHS England's Getting It Right First Time (GIRFT) programme was developing a national waiting list prioritisation tool for children and young people. I want to thank those of you who responded to the opportunity to participate in this work and are part of the Delphi process refining the components of this tool. It will take time to emerge, but I think it is an opportunity to embed health equity in the clinical triage process.

I did speak to some people about the role of Chair after mentioning that my term is up at this year's ASM. Unfortunately, the post remains vacant as the candidate who applied had to withdraw for personal and professional reasons. This is an influential role and now is an important time in the development of community child health services. There is plenty of talent in the BACCH membership; please do consider if this (or another of the executive roles) is something you could do and contact me at ***d.e.simkiss@warwick.ac.uk*** if you would like to have a chat. The role is also advertised on the BACCH website at ***www.bacch.org.uk/pages/news*** if you would like to see a full job description.

Looking forward to seeing you in Nottingham on 30th September, the BACCH dinner will be fantastic so book early!

Professor Doug Simkiss
BACCH Chair
Email: d.e.simkiss@warwick.ac.uk

From the Convenor: Three Initiatives

During our work as community paediatricians, there are many instances where we evaluate the health of a child without medications being involved. The teachings of the philosopher-physician Galen of Pergamon (129-216 AD) influenced medical practice and the Western Medical Tradition for nearly 2000 years and can help us here. Galen described the six 'non-naturals' or 'Laws of Health' as those health-related factors that we, or others, could influence: air, motion and rest, food and drink, sleep and waking, evacuations and retentions, and 'passions of the mind'. Galen emphasised the individuality for each person's balance of the 'non-naturals' and their health, and the role of the physician to help maintain or restore this balance as 'hygiene'. Galen's influence on medical thinking is well described by the historian JW Berryman, and Robert Montraville Green's '*A translation of Galen's hygiene: de sanitate tuenda*' is a worthy read.

The principles of Galen are being revisited. In 2016, Canada released the first integrated 24-hour movement guidelines (for physical activity, sleep and sedentary time) for school-age children, youth and adults, followed by a version for preschoolers[1]. The evidence underpinning these guidelines has shown a monotonic relationship between the number of movement behaviour guidelines met by an individual and associated health indicators. That is, meeting all three guidelines is better than meeting any two, and meeting any combination of two guidelines is better than meeting just one, which in turn is better than meeting none. Many of our patients and their caregivers will struggle to meet these guidelines. For example, a study performed in the United States of America (USA) found 45% of children with autism spectrum disorder (ASD) met one of the three recommendations, 23% met two recommendations, and only 5% met all three recommendations[2]. A focus on these participations may help in our work as health promoters and is likely to require innovative practices, with new partnership working that involves teaching, training and coaching.

Dr Edward Estlin
BACCH Convenor

References:

1. 24-hour Movement Guidelines. Canadian Society for Exercise Physiology (CSEP). Available at: ***https://csepguidelines.ca/***
2. Healy S et al. Meeting the 24-hr movement guidelines: An update on US youth with autism spectrum disorder from the 2016 National Survey of Children's Health. *Autism Res.* 2019 Jun;12(6):941-951. Doi: 10.1002/aur.2095.Research

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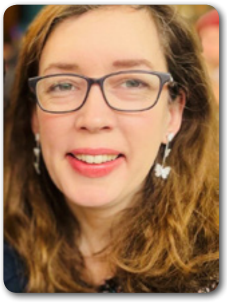
Introduction to new BACCH Executive Officer



I am delighted to have joined BACCH as the new Executive Officer in April this year, taking over from Isabelle Robinson. I know Isabelle was very popular with the members and she will certainly be a hard act to follow after 13 years in the role, but I am very excited to take on the challenge.

I have nearly 15 years' experience in the third sector, including six years managing the Friends Charity at Chelsea & Westminster Hospital, and eight years at the Sigrid Rausing Trust, a grant-making trust with a focus on human rights. Prior to this, I worked as a caseworker and office manager for two Members of Parliament.

In my spare time, I am a governor at my daughter's primary school and have seen first-hand the increasing numbers of children presenting with special educational needs and other challenges. I know that community paediatricians are under more pressure than ever, due to this greater level of need and the resulting increase in waiting lists. As BACCH Executive Officer, I look forward to supporting you in your vital work with some of the country's most vulnerable children and hope to meet many of you at the Annual Scientific Meeting at the end of September. If there is anything I can help with in the meantime, do feel free to contact me at ***lucy.doig@rcpch.ac.uk.***

Lucy Doig
BACCH Executive Officer

Clinical

An Overview of Non-Epileptic Seizures for the Community Paediatrician

What are functional seizures?

Functional disorders are conditions caused primarily by disordered nervous system functioning, rather than a clearly identifiable pathophysiological cause[1]. They can result in almost any symptom and include Irritable Bowel Syndrome, Fibromyalgia and Functional Neurological Disorder (FND), which incorporates functional seizures. Functional seizures are paroxysmal episodes which have no corresponding electroencephalogram (EEG) changes, unlike epileptic seizures. Functional conditions are more common in neurodivergent individuals, hence the relevance for community paediatricians[2].

Functional seizures have an incidence of 7.4 per 100,000. They predominantly affect older children and adolescents, with few diagnosed under 10 years and most over 12 years old. Females are more commonly affected than males[3].

Functional seizures can have the appearance of any epileptic seizure type. Subtle motor activity and prolonged staring are more common in younger children. Teenagers commonly exhibit prominent motor activity, including generalized jerking or flailing movements[4].

Functional seizures are not "faked" or under conscious control. Fabricated illness, with deliberate falsification or exaggeration of symptoms, can lead to a similar clinical presentation, but is rare[5].

A note on nomenclature

Previously, functional disorders were called "psychosomatic", "psychogenic", "non-organic", "medically unexplained", "conversion disorder" and more historically, "hysteria". These terms are unhelpful in explaining the underlying aetiology and carry pejorative connotations, hence terms like "pseudo-seizures" and "psychogenic seizures" should be avoided.

There is ongoing debate regarding the preferred terminology. Studies have shown that "functional seizures", "non-epileptic attack disorder", "functional non-epileptic attacks" and "functional non-epileptic seizures" are the terms most widely accepted and understood by patients, and appropriately describe the underlying pathology[4, 6].

Feedback from families of paediatric patients diagnosed with functional seizures in Salford highlighted that terms including "non epileptic" are often misheard and assumed to be epileptic in origin, hence my preference for the term "functional seizures" in this article[7].

Why do functional seizures happen?

Advances in recent decades have furthered understanding and shifted the perception of functional neurological conditions from disorders of the "mind", to those resulting from complex interactions between biological (e.g. genetics, epigenetics and aberrantly functioning neural networks) psychological (e.g. expectations, attention and maladaptive coping strategies) and social (e.g. adversity and its neuroplastic consequences) processes[8, 9].

Functional neuroimaging studies in adult patients with FND have demonstrated dysfunction in the activation of various brain networks. This includes networks responsible for the early pre-conscious phases of motor planning and agency (the experience of controlling one's own actions or thoughts) with overactivity and interference from areas responsible for emotional processing. Such abnormalities were not seen in actors feigning symptoms[10, 11]. Functional seizures are more commonly seen in children who have history of adverse childhood experiences, mental health diagnoses (such as anxiety and depression), intellectual disability, and pre-existing neurological diagnoses. A considerable number of children diagnosed with functional seizures have co-morbid epilepsy (estimated to be between 12-44%)[3,4]. However, a diagnosis can still be made in the absence of these factors.

How are functional seizures diagnosed?

Functional seizures are not a diagnosis of exclusion. They are diagnosed clinically and "ruled in" based on the presence of

Continues overleaf

positive clinical signs and specific diagnostic features[5]. "Rule in" characteristics of functional seizures include eyes closed tightly, tearfulness, a long episode duration and side-to-side head shaking[1, 5, 12]. Video-EEG telemetry is the gold-standard investigation[13].

Functional seizures should be diagnosed and managed by a clinician with appropriate expertise, for example, a paediatric neurologist, or paediatrician with an epilepsy interest. It is necessary to consider alternative neurological diagnoses as part of the initial assessment, or if new symptoms subsequently arise[1].

Investigations should be utilised judiciously, to diagnose alternative or co-existing pathology. Over-investigation can delay diagnosis, consequently delaying treatment. There is also the risk of encountering false positives or incidental findings on investigation, which can result in anxiety and harm, though it can help to prepare patients of this possibility prior to investigation[1].

How are functional seizures managed?

Clear communication of the diagnosis is key and has been shown to independently decrease symptom severity[14]. A biopsychosocial formulation should be employed, taking into consideration predisposing, precipitating and perpetuating factors[12]. Psychotherapy, including cognitive behavioural therapy has been shown to improve outcomes[1]. Early recognition and management lead to a better prognosis[14].

Communication tips and management considerations

- Gain early patient and parental trust and demonstrate that they are believed[15].
- Use non-judgmental, respectful language and have a positive attitude towards the diagnosis from the initial consultation[9].
- Explore patient and parental ideas, concerns and expectations[1].
- Introduce the concept of functional seizures early in the assessment process; this encourages understanding and acceptance from the patient and family, improving prognosis, and managing expectations around investigations and management.
- Acknowledge that patients and families can fear a diagnosis that they had previously never heard of, or do not understand[7].
- If multiple professionals are involved, nominate a lead professional, and ensure that messages conveyed are consistent.
- Offer a careful, age-appropriate explanation.
- Provide support around explaining the diagnosis to healthcare professionals, friends or school[8].
- Functional seizures can be described as a physical manifestation of psychological distress, that has become automatic over time[16]. The analogy of a brain "software" rather than "hardware" problem can be helpful for older children[14]. This can help to explain why changes are not detectable on standard investigations, like EEG[1].
- Developing a patient-centred treatment plan, building on patient and parental understanding and expectations is key.

Resources for patients and their families to work through (see below) and sign-posting to support groups can also be valuable[17].

The following patient resources may be helpful:

https://www.gosh.nhs.uk/conditions-and-treatments/conditions-we-treat/functional-symptoms/

https://neurokid.co.uk/

https://neurosymptoms.org/

Summary

- ➢ Functional seizures are a relatively common presentation, with higher rates in neurodivergent individuals.
- ➢ Functional conditions are not "imagined", "faked" or under conscious control.
- ➢ Despite advances in understanding, functional seizures remain misunderstood by the public and clinicians, with persisting misconceptions and stigma
- ➢ Effective communication and careful choice of language is important from the start, to promote patient and parental acceptance, which is in turn, important for recovery.
- ➢ Further research is needed to better understand paediatric functional seizures, and the applicability of the findings in adult studies to the paediatric population.

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References:

1. Stone J, Burton C, Carson A. Recognising and explaining functional neurological disorder. *BMJ.* 2020 Oct 21;371:m3745.
2. Bennett K et al. A practical review of functional neurological disorder (FND) for the general physician. *Clinical Medicine.* 2021 Jan;21(1):28–36.
3. Hansen AS et al. Incidence rates and characteristics of pediatric onset psychogenic nonepileptic seizures. *Pediatric Research.* 2020 Nov 1;88(5):796–803.
4. Patel H et al. Nonepileptic Seizures in Children. *Epilepsia.* 2007 Nov;48(11):2086–92.
5. Yong K et al. Functional neurological disorder in children and young people: Incidence, clinical features, and prognosis. *Developmental Medicine & Child Neurology.* 2023; 65 (9): 1238-1246. DOI: 10.1111/dmcn.15538
6. Asadi-Pooya AA et al.. Terminology for psychogenic nonepileptic seizures: Making the case for "functional seizures." *Epilepsy & Behavior.* 2020. DOI: 104:106895.
7. Charlson S and Garner D. Salford Paediatric Epilepsy Service local survey of parental views. North West Children and Young People's Epilepsy Interest Group, March 2023 Conference.
8. Raper J et al. Long-term outcomes of functional neurological disorder in children. *Archives of Disease in Childhood.* 2019 Jul 20;104(12):1155–60.
9. Kozlowska K et al. Changing the Culture of Care for Children and Adolescents with Functional Neurological Disorder. *Epilepsy & Behavior Reports.* 2021 DOI: 10.1016/j.ebr.2021.100486
10. Aybek S and Perez DL. Diagnosis and management of functional neurological disorder. *BMJ.* 2022: 376. DOI: 10.1136/bmj.o64
11. Aybek S and Vuilleumier P. Imaging studies of functional neurologic disorders. *Handbook of Clinical Neurology.* 2016;73–84.
12. Kozlowska K et al. Evidence-Based Mind-Body Interventions for Children and Adolescents with Functional Neurological Disorder. *Harvard Review of Psychiatry.* 2023 Mar 1;31(2):60–82.
13. Gedzelman E and LaRoche S. Long-term video EEG monitoring for diagnosis of psychogenic nonepileptic seizures. *Neuropsychiatric Disease and Treatment.* DOI: 10.2147/NDT.S49531
14. Raynor G, Gonsalvez I, Baslet G. Treatment of Functional Seizures [Internet]. Practicalneurology.com. 2025 [Online] [cited 2025 May 1]. Available from: ***https://practicalneurology.com/diseases-diagnoses/epilepsy-seizures/treatment-of-functional-seizures/31888/***
15. Vassilopoulos A et al. Treatment Approaches for Functional Neurological Disorders in Children. *Current Treatment Options in Neurology.* 2022 Feb;24(2):77–97.
16. Yeom JS, Bernard H, Koh S. Myths and truths about pediatric psychogenic non-epileptic seizures. *Clinical and Experimental Pediatrics.* 2020; 64(6):251-259. DOI: 0.3345/cep.2020.00892
17. Reuber M. Dissociative (non-epileptic) seizures: tackling common challenges after the diagnosis. *Practical Neurology.* 2019;19(4):332–41 DOI:0.1136/practneurol-2018-002177

Down Syndrome Regression Disorder (DSRD), Part 1 of 2

Jude's story – as told by his mother, Ruth

Jude enjoyed being with family and friends, going swimming and playing basketball. He liked to play with his cars, listen to music and be on his iPad. He could use the toilet, have a shower, put his coat on, get changed for PE, go to bed, eat independently, and move around with ease. He was interactive and would regularly smile, intonate sounds and words despite having verbal dyspraxia.

In November 2023 Jude became withdrawn, he lost interest and joy.

"Within a week of him getting ill, I was telling doctors his brain had changed. My instincts were right. He became a different person. He was disappearing physically, mentally and emotionally before our eyes. I was begging doctors to listen."

Jude became mute - no sound was made at all. He usually hummed to himself, laughed, intonated words and sounds, but now, he was silent. He refused food and drink and became so dehydrated he was hospitalised.

"Putting cannulas in: the only way I knew he was in pain was his eyes. He didn't flinch or make a single sound. That image hasn't left me."

He was not able to feed himself and would have to be fed, he lost 9kg in 4 weeks. He was sad and would cry and not engage in any activity at school or at home. He became stiff and catatonic - losing the ability to balance and walk upstairs.

"To think of how Jude has been feeling with no means to understand or communicate has been heart-wrenching. He has been overcoming challenges for months, being poked and prodded with cannulas, CT scans, hospital admissions, psychiatric changes."

If we tried to move him, he would freeze; it would be a real physical task to move him. He would stare into space in the same spots for hours at a time. He wouldn't sleep in his own bed. He lost toileting functions and would soil and wet himself frequently. He then went from delirium to fatigued. After a few weeks, it changed again; he would scream, be very aggressive and angry. Then he began to barely sleep at all.

"*Watching my son deteriorate and be a shadow of who he was has affected my whole family profoundly." "No NHS Doctor or GP (or private specialist at the children's hospital) knew anything about DSRD… At times the feeling of isolation and despair was crippling." "One doctor just said, "Take him to a health food shop and give him freshly squeezed orange juice and stop treating him like he has Down Syndrome" ... Another said, 'Not to worry as when he turns 18 years old, he will be social care's problem'."*

Eventually we met a neurologist at Addenbrooke's hospital who said that *Jude was his first case in over 25 years*. His impression: *"Jude's symptoms fit a neuroregression syndrome associated with Down's Syndrome as described by other doctors in the USA." Honestly to finally find a consultant that listened made me cry with relief… I felt at times I was going mad! I never ever thought anyone would start listening."* He then discharged Jude. After a tip-off at the Down's Syndrome Medical Interest Group (DSMIG) conference, Jude was referred to Dr Maaike Kusters, consultant immunologist at GOSH.

"In the UK, there is currently no workup and treatment plan in place and several doctors including Dr Ella Rachamim are advocating for this condition and for trials/diagnostic and treatment options. Further investigation is required to confirm any underlying brain inflammation or other causes. There are no specific treatment or trials available in the UK currently, but data collection is ongoing currently for children with Down's Syndrome presenting with symptoms."

Although I am reminded by this statement in all of this, *"If this person didn't have Down Syndrome, we'd be rushing them to hospital. We'd be giving them a million-dollar workup,"* Dr Santoro, Director of Neuroimmunology at Children's Hospital, Los Angeles[1].

"Currently Jude is still not the Jude he once was. He isn't in an acute phase but remains in a chronic phase with some functioning being normal again such as walking up the stairs and toileting. For now, it isn't normal, but we are in a better place."

He is still having moments of delirium and sleeps for only 2-4 hours per night. He also becomes fixated on objects and hides them in his bag or luggage such as hairbrushes or toilet rolls. He constantly repeats what he is watching on TV, like parts of his favourite programmes and rewinds over and over and over again, to the same scene, to the exact moment. He can still be very aggressive and less tolerant, so he cannot be left alone with his twin little sisters as he can thrash out for no obvious reason.

What do I hope for by sharing Jude's story?

This condition was first described in 1946, in a paper on 26 patients with what was called catatonic psychosis. But after that, there was essentially no research on it for 70+ years. Patients have been misdiagnosed with schizophrenia, early-onset Alzheimer's disease or late-onset autism. Basically, families have been told, "This is just part of Down syndrome.[1]"

We want to:

- Create more awareness to professionals that are first point of contact for families experiencing the sudden onset of symptoms
- Get a faster diagnosis for our children
- Find emotional and wellbeing support for families impacted like we are
- Find a doctor to confirm our initial suspicions – to listen and believe us
- Find out how we can try and seek help
- Push for more research into causes and potential treatments for DSRD

"Essentially, we are asking governments and medical institutions to listen and help change the lives of families just like mine, who are affected by this under-researched debilitating condition. There are so many families right now alone, isolated and not being listened to whilst watching their loved one disappear in-front of them. I ask would this be the case if this was happening in the 'typical population'?"[2]

Continues overleaf

Other young people with DSRD in the news:

"Sara's decline had been sudden and devastating, it was like she had died, and I didn't have time to mourn her because I had this stranger in my midst who needed a lot of care." - Dr Quinn, mother to Sara and Developmental Paediatrician at the University of Toledo, Ohio.[3]

"A mystery illness stole her son. Doctors in Canada couldn't find the answer, but she wouldn't give up. Mackenzie Wright joined a clinical trial that is bringing hope to Down Syndrome families who have struggled with sudden, mysterious regressions." [4]

Dr Jonathan Santoro's first patient was *"a previously high-functioning young man who had been in a lot of mainstream classes at school. And then, out of the blue, he completely regressed over a few weeks. By the time I met him, he hadn't spoken or moved in two years. The family had been flying all over the country to see Down Syndrome specialists but had come away with no answers. We treated him, and three weeks after his first IVIG (intravenous immunoglobulin) infusion, he was talking and running down the hallway. It was really striking. Seeing him after treatment was like meeting a different person."* [1]

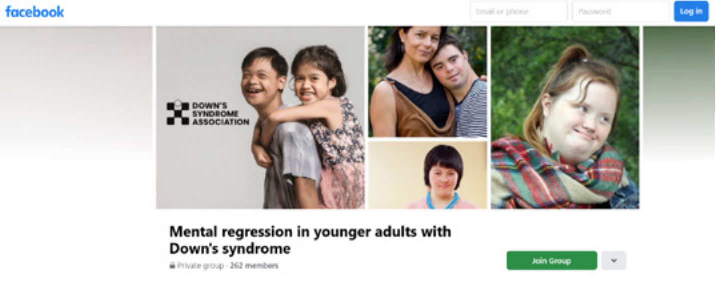
What support is available?

Support groups:

Down's Syndrome Association (UK): Regression Support Group – e.g. Tuesday 17 June 2025 | 10.30 – 11.45am | FREE.

This is a new online support group for parents of those who have experienced rapid regression in the last few years.

Facebook Groups:



Mental regression in younger adults with Down's syndrome

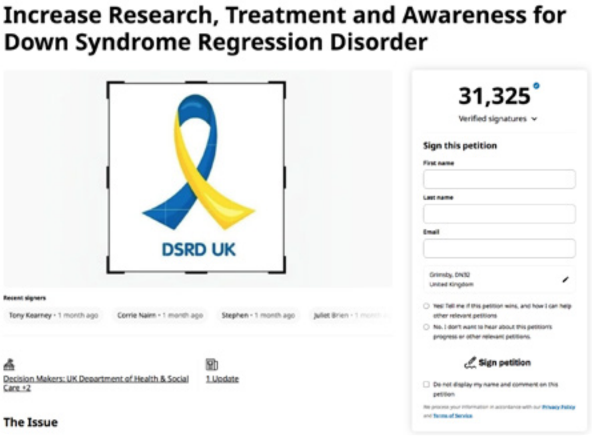
Private group · 262 members

Petitions:

Down Syndrome Regression Disorder has eight core features, each of which devastate the abilities of those affected:

Altered mental status or behavioural dysregulation
Cognitive decline
Social withdrawal
Focal neurological issues
Sleep problems/ chronic insomnia
Language deficits
Psychiatric symptoms
Movement disorder

"The sum total of all those symptoms is that your child is gone."[2]



Increase Research, Treatment and Awareness for Down Syndrome Regression Disorder

31,325

Recent signers

Tony Kearney · 1 month ago
Corrie Nairn · 1 month ago
Stephen · 1 month ago

Grimsby, DN32
United Kingdom

Decision Makers: UK Department of Health & Social Care +2

1 Update

The Issue

Resources compiled together for your reference: ***https://www.budds.org.uk/ds-regression-disorder***

Acknowledgement: Thank you, Jude and Ruth, for your phenomenal courage and resilience in sharing this story. I feel very honoured to have been trusted with it.

Dr Ella Rachamim
Specialist Doctor in Community Paediatrics
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Please watch out for Part 2, coming out in the September edition:

Studies, diagnosis and management of DSRD by Dr Abinaya Seenivasan, ST6 GRID Paediatric Neurology Registrar, Royal Manchester Children's Hospital.

References:

1. Under the Microscope: Unlocking the Mystery of Down Syndrome Regression Disorder. Children's Hospital Los Angeles. 2023. Available from: ***https://www.chla.org/blog/experts/research-and-breakthroughs/under-microscope-unlocking-mystery-down-syndrome-regression***
2. Morgan R. Increase Research, Treatment and Awareness for Down Syndrome Regression Disorder. Change.org. 2025. Available from: ***https://www.change.org/p/increase-research-treatment-and-awareness-for-down-syndrome-regression-disorder***
3. Sima R. A mystery illness stole their kids' personalities. These moms fought for answers. Washington Post. The Washington Post; 2024. Available from: ***https://www.washingtonpost.com/wellness/2024/05/12/down-syndrome-regression-disorder-mothers-support/***
4. Raven AD. A mystery illness stole her son. Doctors in Canada couldn't find the answer, but she wouldn't give up. Toronto Star. 2025. Available from: ***https://www.thestar.com/news/gta/a-mystery-illness-stole-her-son-doctors-in-canada-couldnt-find-the-answer-but-she/article_9dfff7d0-63b3-11ef-b1a2-936fa34e1412.html***
5. Barnet Unified Document for Down Syndrome. Down Syndrome Regression Disorder. BUDDS, appendices. Available from: ***https://www.budds.org.uk/ds-regression-disorder***

Ethics and the Law in Paediatric Palliative Care: A Practical Guide for Clinicians

Paediatric palliative care often involves some of the most ethically and emotionally complex decisions in medicine. These decisions are shaped not only by clinical judgment but also by a robust legal framework and deeply rooted ethical principles. Understanding how to navigate this landscape is essential for delivering compassionate, appropriate, and legally sound care to children and their families.

Balancing Ethics and Law in Clinical Practice

In the UK, paediatric care is governed by legislation such as the Mental Capacity Act 2005 and the Adults with Incapacity (Scotland) Act 2000, alongside case law. While these laws apply across all age groups, this article uses the term “child” to refer to any baby, child, or young person.

Ethically, the child’s wellbeing is paramount. While the needs of parents and carers are important, they must not override what is in the child’s best interests. Ethical decision-making must consider both clinical outcomes and non-clinical factors such as emotional wellbeing, quality of life, and, where possible, the child’s own views.

Capacity and Consent in Children and Adults

Adults with capacity have the legal right to make their own healthcare decisions, even if those decisions seem irrational. When an adult lacks capacity, decisions must be made in their best interests, ideally by someone with legal authority such as a Lasting Power of Attorney or a Court Appointed Deputy. If no such person exists, an Independent Mental Capacity Advocate (IMCA) may be appointed to support decision-making by the multidisciplinary team.

For children, capacity is assessed based on their ability to understand, retain, and weigh information relevant to a decision. Children with capacity can consent to treatment, but refusal – especially if life-shortening – may be overridden by parents or the courts. When a child lacks capacity, parents or guardians usually make decisions, though their ability to act in the child’s best interests may be questioned in complex cases.

Advance Refusal of Treatment

Advance refusals of treatment can only be made by individuals with capacity. Adults may plan for future care by appointing attorneys, recording preferences, or making advance decisions to refuse specific treatments. In England and Wales, a valid and applicable advance refusal is legally binding, particularly if it concerns life-prolonging treatment - provided it is in writing, signed, and witnessed. In Scotland and Northern Ireland, such refusals may be binding, though this has not yet been tested in court.

Children, even if deemed ‘Fraser competent’, cannot make legally binding advance decisions. If a child under 18 refuses treatment, this can be overridden by parental consent or a court order. There is no legal precedent for a parent or legal proxy to make a binding advance refusal on a child’s behalf. The Mental Capacity Act 2005 confirms that only individuals aged 18 or over can make advance decisions.

An individual with capacity can revoke an advance refusal at any time. Even if not legally binding, written or verbal refusals should be considered as expressions of the person’s wishes.

If there is uncertainty about the validity or applicability of an advance refusal, professionals should presume the individual had capacity when it was made and assess both aspects carefully. Where an advance refusal does not apply, an advance care plan may still guide care. In emergencies, if there is any doubt, treatment should be provided if it offers a realistic chance of benefit, until further advice can be sought.

Withholding or Withdrawing Treatment

Withholding or withdrawing life-prolonging treatment is one of the most difficult decisions in paediatric care. According to the Royal College of Paediatrics and Child Health (RCPCH), treatment may be withheld or withdrawn when life is limited in quantity (e.g., brainstem death or imminent death), when life is limited in quality (e.g., treatment is overly burdensome), or when a competent young person refuses treatment. In these situations, the focus of care should shift to comfort and symptom management, ensuring that the child’s remaining time is as peaceful and pain-free as possible.

Nutrition, CPR, and Advance Care Planning

Clinically assisted nutrition and hydration (CANH) is considered a medical treatment under UK law. It can be withheld or withdrawn if it is not in the patient’s best interests. A second opinion from an independent physician is recommended. Since 2018, court approval is no longer required for withdrawing CANH in patients in a persistent vegetative state, provided there is agreement among professionals and family.

Cardiopulmonary resuscitation (CPR) must be assessed like any other medical intervention. If it is unlikely to succeed or would cause more harm than good, it need not be provided – even if requested. Individuals with Lasting Power of Attorney or Court Appointed Deputies can contribute to discussions but cannot make the final decision to withdraw life-sustaining treatment. Clear documentation and communication with families is essential.

Advance Care Planning (ACP) is a proactive process that guides care during emergencies. While ACPs are not legally binding, they are critical in ensuring that care decisions reflect the child’s condition and the family’s wishes. If an ACP is unclear or unavailable, life-sustaining treatment should be provided until further guidance can be obtained.

Resolving Disagreements

Disagreements about a child’s care can arise due to differing interpretations of best interests. These situations can be emotionally charged and ethically complex. Resolution strategies include independent advocacy, second opinions, mediation, and case conferences. If unresolved, court intervention may be necessary – particularly in cases involving the withdrawal of life-sustaining treatment.

When parents disagree with each other or with the medical team, the situation becomes more complex. While consent from one parent is usually sufficient, all efforts should be made to contact all individuals with parental responsibility, especially in high-risk or end-of-life decisions.

Reviewing and Revisiting Decisions

Decisions in paediatric palliative care must be regularly reviewed as the child’s condition evolves. This ensures that care remains appropriate and reflects the current clinical picture, the child’s needs, and the family’s views.

Healthcare professionals must also care for their own wellbeing. The emotional toll of end-of-life decisions can be significant. Parents may seek reassurance rather than aggressive treatment, and healthcare teams may experience moral distress. Psychological support and open communication are essential for sustaining compassionate care.

Conclusion: Compassionate, Legally Sound Care

Delivering ethical and legally sound care in paediatric palliative settings requires a careful balance of compassion, clarity, and collaboration. By grounding decisions in best interests, respecting the evolving capacity of children, and fostering open dialogue with families, healthcare professionals can navigate these challenges with confidence. Ultimately, the goal is to ensure that every child receives care that honours their dignity, supports their family, and reflects the highest standards of ethical and legal practice.

Dr Lynda Brook | Paediatric Palliative Care Consultant
Alder Hey Children’s Hospital

Continues overleaf

References:

1. Mental Capacity Act 2005. Available from: https://www.legislation.gov.uk/ukpga/2005/9/contents
2. Adults with Incapacity (Scotland) Act. 2000. Available from: https://www.legislation.gov.uk/asp/2000/4/contents
3. General Medical Council (UK). Treatment and care towards the end of life: good practice in decision making. 2010. Available from: https://www.gmc-uk.org/professional-standards/the-professional-standards/treatment-and-care-towards-the-end-of-life
4. Office of the Public Guardian. Making Decisions: Independent Mental Capacity Advocate Service (OPG606). 2007. Available from: https://www.gov.uk/government/organisations/office-of-the-public-guardian
5. Nuffield Council on Bioethics. Critical care decisions in fetal and neonatal medicine: ethical issues. 2007. Available from: https://cdn.nuffieldbioethics.org/wp-content/uploads/Critical-care-decisions.pdf
6. Larcher V, Craig F, Bhogal K, Wilkinson D, Brierley J. Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice: Archives of Disease in Childhood [Internet]. 2015 Mar 23;100(Suppl 2): s1–23. Available from: https://adc.bmj.com/content/100/Suppl_2/s1
7. An NHS Trust and others v Y (by his litigation friend the Official Solicitor) and another. 2018. UKSC 46. Available from: https://www.supremecourt.uk/cases/uksc-2017-0202
8. British Medical Association, Resuscitation Council UK, and Royal College of Nursing. Decisions relating to cardiopulmonary resuscitation: Guidance. 4th edition, 2016.
9. Department of Health and Social Care. Advance Decisions to Refuse Treatment: A Guide for Health and Social Care Professionals. 2008. Available from: https://www.england.nhs.uk/improvement-hub/wp-content/uploads/sites/44/2017/11/Advance-Decisions-to-Refuse-Treatment-Guide.pdf

Public Health

Have you discovered the 'Embedding Public Health in Paediatric Training Toolkit[1]'?

Every day in our Community Child Health clinics across the country we see children, young people and their families who are impacted by wider determinants of health. We are aware of the limitations of our clinical knowledge and skills as we seek to walk with these families through times of personal, economic and political difficulty - often knowing that interventions in the community to change health behaviours and lifestyles, and closer integration of health and social care might have a more positive impact than any medical care we can offer.

The NHS Long Term Plan[2] published in 2019 recognised that 'the needs of children are diverse, complex and need a higher profile at a national level' and so the Children and Young People's Transformation Programme was created to oversee the delivery of services focussing on immunisation, management of long term conditions (with the hope to reduce unnecessary presentations to emergency services) and movement towards services for 0-25 years of age, whilst admitting that 'better healthcare can never fully compensate for the health impact of wider social and economic influences.'

The Royal College of Paediatrics and Child Health's long-term strategy 'Paediatric 2040: A Vision for the Future of Paediatrics in the UK'[3] highlights that by 2040; the role of the paediatrician will look quite different to how it did in 2000. As a result, it emphasises that every paediatrician will need to be trained to address the social determinants of health and to work with families to support children's wellbeing.

To guide the training of future paediatricians, the Progress+ Curriculum Learning Outcome 5 details the following:

- Core trainees are expected to gather skills to 'Promote healthy behaviour in conversations with children, young people and their families/carers, from early years through to adulthood; taking into account the potential impact of cultural, social, religious and economic factors on the physical and mental health of children and families'.[4]
- Specialty trainees are expected to develop skills in 'working with the wider healthcare community promoting wellbeing, physical and mental health to improve the health of babies, children and young people' (generic syllabus). Key capabilities range from understanding barriers to healthcare to demonstrating leadership skills in health promotion and epidemic preparation.[5]

It is important for paediatric trainees and their supporting supervisors/trainers to make the most of the varied learning opportunities to achieve the above curriculum outcomes and develop the skills required for Paediatricians of the Future[6]. With this in mind, the '*Embedding Public Health into Paediatric Training Toolkit*' was co-authored by members from RCPCH, British Association for Child & Adolescent Public Health, The Faculty of Public Health and NHS England. It serves as a very valuable resource for trainees of all stages and their supervisors. The remainder of this article will explain the key topics covered by the toolkit and why it should be saved on your favourites list for ease of reference.

The toolkit is 100 pages in length and offers guidance on how to meet curriculum 5 domains for trainees at any training level and in any setting through case studies and examples of good practice. Following an excellent summary of the importance of public health and wider determinants of health, the Learning Toolkit is divided into 3 main sections which are easy to glance through at the Trainee's/Trainer's convenience:

> **Section A** outlines the areas of clinical practice where paediatric trainees can gain experience through person-centred approaches to assessment and identification of children, young people and families whose health behaviours may pose increased risk using a biopsychosocial model and gives examples of how to use conversations to invite change. It recognises the role that paediatric health professionals play in preventing illness in children and young people. It highlights various publications about health inequalities, including the Health Inequalities Dashboard, to enable data-informed engagement in discussions on an individual basis (including case studies on the topics of mental health, weight, smoking, alcohol, immunisations, oral health and disability). Trainees are encouraged to develop their system leadership skills to address the complex public health issues at a population level. For many this can be daunting, but it is broken down into 3 main areas for learning accompanied by many recommended resources to facilitate culture change, forge partnerships and learn about relevant strategies and policies.
>
> **Section B** provides a range of ideas (case studies, self-directed learning, shadowing and project suggestions), which can be used by trainees to demonstrate reflective learning based on clinical experiences alongside formal teaching. For those involved in arranging formal teaching sessions, there are many suggestions as to how to incorporate public health teaching and multidisciplinary collaboration into local training programmes, conferences and simulations.
>
> **Section C** contains guidance for educators/supervisors to *Learn* alongside their trainees, *Enable* trainees to access learning opportunities by breaking down existing barriers and *Collaborate* with other Supervisors/Training Programme Directors to share good practice.

The final 9 pages of the toolkit contain all the resources that a trainee or trainer may wish to access to aid their learning and development. These are also valuable references for any future health promotion and prevention projects.

As a ST6 working in Community Paediatrics/Paediatric Neurodisability (with an interest in International Child Health), I am grateful for all the time and work that the team have put into producing this clear and helpful resource to help navigate these curriculum learning outcomes. I hope that my career and that of my 'future paediatrician' peers will emulate the quote from Sarah Birks cited at the start of the toolkit: "When paediatricians are enabled to focus on preventing illness as well as treating it then they will be able to make a truly positive impact on the health and wellbeing of the children they care for and the local communities they serve". Whilst many things feel uncertain, we as paediatricians should never stop advocating for children and young people's health and wellbeing and this toolkit gives a helpful springboard to enable us to do exactly this.

Dr Rebecca Rhodes | Paediatric Registrar in Neurodisability
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References:

1. NHS England, Embedding Public Health into Paediatric Training, A Toolkit for Paediatric Trainees and Educational Supervisors Edition. August 2023. Available at: ***https://london.hee.nhs.uk/sites/default/files/toolkit-jun_2023final.pdf***
2. The NHS Long Term Plan. January 2019. Available at: ***https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf***
3. Royal College of Paediatrics and Child Health, Paediatrics 2040 Forecasting the Future: Our Vision for the Future of Paediatrics in the UK, Executive Summary. Published February 2021. Available at: ***https://paediatrics2040.rcpch.ac.uk/wp-content/uploads/sites/14/2021/02/Paediatrics-2040-Executive-Summary-Report-RCPCH-Feb-2021.pdf***
4. RCPCH Progress+ Core Syllabus for Paediatric Training Version 2 Approved for implementation from August 2023. Available at: ***https://www.rcpch.ac.uk/sites/default/files/2024-11/Core%20Syllabus%20for%20Paediatric%20Training%202023%20V2.pdf***
5. RCPCH Progress+ Generic Syllabus for Specialty Paediatric Training for Paediatric Trainees Version 3 Approved for implementation from August 2023. Available at: ***https://www.rcpch.ac.uk/sites/default/files/2024-11/Generic%20Syllabus%20for%20Specialty%20Paediatric%20Training%202023%20V3.pdf***
6. Royal College of Paediatrics and Child Health, Paediatrician of the Future, Delivering really good training. Version 1.0 October 2020. Available at: ***https://www.rcpch.ac.uk/sites/default/files/2021-03/rcpch-paediatrician-of-the-future-delivering-really-good-training.pdf***

Safeguarding

Child Sexual Abuse (CSA) and Trauma-informed Care

It is essential when working with children who have experienced sexual abuse, that trauma informed care is provided to prevent re-traumatisation, reinforcing the consequences of their abuse. It is crucial that health-care professionals working with children are knowledgeable about how trauma impacts children and their families.

Trauma effects

The effects of early childhood trauma are well-documented. The seminal Adverse Childhood Experiences study[1] described the links between traumatic experiences in childhood and adult ill health, with a strong positive correlation between experiencing trauma and developing non-communicable disease in adulthood. As well as consequences on a person's physical health, trauma impacts all aspects of the developing brain, resulting in challenges across many domains, including memory, cognition, social communication skills, and psychological wellbeing.

Whilst the link between early childhood trauma and adult health outcomes is well-demonstrated, trying to address it is complex. As well as implementing focused interventions for patients who have disclosed specific traumas, it is important to understand that adverse experiences in childhood are common, and that our approach to all patients should be underpinned by the consideration of the impact of trauma on their lived experience.

Trauma-informed care principles

Trauma-informed care was first described in 2001 by Harris and Fallot[2], two mental health practitioners who discovered that many of their patients were survivors of abuse. They highlighted the need for clinicians of all disciplines to understand the impact of trauma on patients in all clinical interactions. They proposed a model encompassing six key principles with which to approach healthcare in a trauma-informed way. These are:

1. **Safety** – promoting a culture of physical and psychological safety within healthcare spaces
2. **Trust** – establishing safe and authentic relationships between patients and healthcare professionals
3. **Choice** – honouring the voices and wishes of all patients (when possible)
4. **Collaboration** – working together to formulate plans of care
5. **Empowerment** – validating and championing the thoughts and feelings of patients
6. **Cultural consideration** – actively rejecting cultural stereotypes and biases, creating a safe space for all

Ultimately, trauma-informed care empowers clinicians to provide routine healthcare within the context of a patient's lived experience, without relying on disclosure and the potential for subsequent re-traumatisation. Instead, the focus is shifted towards the clinician to be confident in recognising and responding to the signs and symptoms of trauma and understand how these may be impacting health.

Case study: A 10-year-old girl is seen for her initial looked-after child health assessment. She has recently entered care due to concerns regarding neglect, exposure to domestic violence and parental substance misuse. During your assessment she shares that she has been sexually abused since the age of 6 by her father.

What would you do next?

Listen. Allow her to tell her story in her words, recording this verbatim. Remember it is not your role to investigate, and questioning details should be left to police and social care. It is important to acknowledge that she has been brave in sharing this with you.

Be open and honest about what happens next, including referral to statutory agencies. Do not promise her things that may not be achievable as this can damage the trust in you and in professionals in general. We would encourage you to attend the strategy meeting that will be organised between statutory agencies, to advocate for the child.

It is important that you know your local pathways for referring for a sexual abuse examination (acute or non-acute). Seek advice from CSA services early – this increases the chance of the child being able to be seen in the right place at the right time. You may need to instigate medical care.

All children who have experienced sexual abuse should be offered the opportunity for a medical examination. Children should be given time and space during the assessment and be in control of what happens next. Consent and assent are vital and should be taken before each part of the assessment in a developmentally appropriate way.

Continues overleaf

There are two types of sexual abuse medical assessment:

1. Forensic medical examination (FME):
    a. The purpose of an FME is to gather physical evidence from the victim, including a suspect's DNA, and to document any injuries that may have been caused by the assault. A FME can only be offered within certain timeframes, according to the evidence-based likelihood of DNA being retrieved. These time frames vary according to the type of assault and pubertal status of the child. A holistic health assessment will also be undertaken. Emergency medical care will be considered, such as emergency contraception and prophylaxis for infection, including Hepatitis B immunisation and HIV-post exposure prophylaxis – these may need to be provided in the emergency department, walk-in centres or GP services if the child presents there first or does not wish to have an FME.
2. Non forensic/non-recent CSA assessments:
    a. These are holistic health assessments that can be done at any time, usually after the child has given their video-recorded interview with the police (if involved). The genitalia can be examined for evidence of old injuries. The focus here is more therapeutic than diagnostic and is an opportunity to validate the experiences of children who have disclosed sexual harm. In most cases, children can be reassured that their bodies are normal and healthy, and that the abuse they have experienced will not have long-term consequences on their sexual and reproductive health. These assessments are also an opportunity to address unmet health needs, which are prevalent in abused children, and explore the impact of trauma on their physical and psychological health. Screening is offered for sexually transmitted infections.

Following either type of medical assessment, tailored psychological support will be offered. In this case, with her knowledge and assent, you informed her social worker, police and foster carer, so that trauma-informed care could continue at home. She welcomed the opportunity to speak to a doctor about the worries she had about her body and mental health, while being screened for sexually transmitted infections and supported with longer-term care through school.

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Dr Briony Arrowsmith
Consultant Paediatrician
The Havens Sexual Assault Referral Centre
King's College Hospital NHS Foundation Trust

References:

1. Felitti, VJ, Anda, RF., Nordenberg, D., Williamson DF., Spitz, AM., Edwards, V., Koss, MP, Marks, JS. (1998). Relationship of childhood abuse and household dysfunction to many of the leading causes of death in adults. The Adverse Childhood Experience (ACE) Study. *American Journal of Preventative Medicine.* 14(4), pp. 245-258.
2. Harris, M., Fallot, RD. (2001). Envisioning a trauma-informed service system: a vital paradigm shift. *New Directions in Mental Health Services.* 2001(89), pp. 3-22.

Training

Update from the Community Child Health (CCH) College Specialty Advisory Committee (CSAC)

The last few months have been busy for the CCH CSAC. Our role is to ensure that the curriculum is fit for purpose, and to ensure that the trainees completing the curriculum have done so to a standard to satisfy the General Medical Council (GMC).

We also support the recruitment and retention of trainees to specialty CCH training and ensure that the jobs are suitable for training. This includes looking at the time spent in the specialty versus on call and other non-specialist work.

Changes to the CSAC

We have had a lot of changes to the committee in the last few months. I have moved from being deputy chair to a Co-Chair with Sharmi Sivakumaran, and we have new training advisers – Joe Clarke for trainees with surnames beginning A – L and Alison Kelly for trainees with surnames M – Z.

Paul Wright is our new Assessment Advisor, and our Quality Advisor post is out to advert.

Our trainee rep remains as Rushvini Ambihaipahan, and our AVM (audio-vestibular SPIN) Lead is Shailaja Kottapalli.

You can get in touch with any of us – our email addresses are all on the CCH CSAC web page on the College website – available here: ***https://www.rcpch.ac.uk/membership/committees/community-child-health-csac***

Enormous thanks to our predecessors – Nia John, John Agbenu, Subbu Ganesan and Serena Haywood. They have left us big boots to fill.

Recruitment

Recruitment is the focus of the first couple of months of the year as we go through the specialty application process. We were delighted to receive a very high number of applications – a marker that trainees are actively choosing to pursue a career in our specialty.

We received 68 applications this year and all were shortlisted. We interviewed almost all and sadly had more appointable applicants than we had posts. We managed to appoint to 39 out of our 40 potential posts. Congratulations to all those who gained a post, and thank you to all the others whose obvious hard work and preparation made our interview days so interesting and enjoyable.

On-calls: 70:30 split

There remains a challenge in some posts to ensure adequate time in the community setting. We continue to ensure that we only approve posts which are compliant with the mandated 70:30 split. We are happy to support trainees in reviewing posts with their TPDs (Training Programme Directors) if they are not compliant.

CCH Leads Day

We had a very enjoyable and informative CCH Leads afternoon in March. March. At this meeting, the regional leads all gathered to think about how we can make CCH training even better, and ways to support trainees and colleagues. We have set up a CSAC WhatsApp group for the regional leads and CSAC, which allows queries to be shared and trainee CSAC forms to be swapped when there is a conflict of interest such as the regional lead also being the educational supervisor.

We continue to discuss the possibility of advertising Less than Full time (LTFT) posts for specialty training – this is not permitted by the College as it would discriminate against those working full time. It continues to be discussed at a high level, but we need to ensure equity of access to all trainees.

There is an excellent new resource being finalised at present to support trainees in covering the curriculum – this has been developed by the BACCH Trainee Reps team and looks as though it will be extremely helpful in working out how to cover some of the 'less frequently seen in clinic' parts of the curriculum.

The new CSAC team are looking forward to getting to know all of our trainees and trainers – please do get in touch if you have any suggestions for us to consider.

Emma Bradley and Sharmi Sivakumaran
CCH CSAC Co-Chairs

Update from BACCH Trainee Reps

What's New to Support GRID CCH Trainees?

We are Claire and Vicki, the two National BACCH Trainee Reps. Vicki has been a champion for trainees for over two years now but will be handing over the baton in October (please do apply if interested in this role – full details are on the BACCH website at ***www.bacch.org.uk/pages/news).*** Claire is new, having just started 6 months ago… but what a busy year 2025 has already been! We are really excited to give an update on some of the work that's been going on, which so many incredible trainees have been involved with, to improve the Community Child Health (CCH) training experience.

National Network for CCH Trainees

One of Vicki's original objectives within her tenure was to create a shared CCH trainee network to facilitate sharing of resources, teaching, pathways, and improve communication between trainees. It has been amazing to see how well the National BACCH Trainee Network WhatsApp group has been received and how it has evolved to become an integral platform to connect trainees over multiple aspects of our training, whether this be advice and guidance, sharing of resources, promotion of educational events or START preparation groups. More recently, this network has also been key to raising awareness of and responding to areas for improvement. We would encourage any trainee who is considering a career in Community Paediatrics and any CCH sub-speciality trainees to join this group, if not a member already, and a link can be found below.

National BACCH Trainee Network
WhatsApp group

Trainee's Guide to the Community Child Health Curriculum

Creating the Trainee's Guide to the CCH Curriculum

This project started in response to feedback from trainees that there is a lot of discrepancy between placements, in terms of training experiences and expectations. To help address this, in January, we set up a Working Group of trainees nationally and divided this into five groups to explore each of the learning outcomes in the CCH GRID curriculum.

These trainee teams met to collate examples of ways to achieve each competency and compile a list of recommended resources to read and reflect on. Bringing together everyone's ideas from across the UK led to the creation of the 'Trainee's Guide to the CCH Curriculum'. This was then presented to the BACCH Executive Committee in March and subsequently shared with the College Specialty Advisory Committee (CSAC) and representatives from all affiliate groups (British Association of Childhood Disability, British Association for Child & Adolescent Public Health, Paediatric Mental Health Association, Child Protection Special Interest Group, British Association of Paediatricians in Audiology, and Association for Paediatric Palliative Medicine) to ensure that the wording is accurate, no learning needs have been missed and all available resources to signpost trainees to have been included. The final version of the resource will be ratified at the BACCH Council meeting on June 3rd and available on the website shortly after.

This is very much a resource created for trainees, by trainees, to ensure everyone training in CCH has a clear, shared understanding of required competencies, feels supported in knowing how to achieve these and has equal access to the resources and opportunities available. The examples in the guide are not exhaustive but suggestions which other trainees have found useful. As we were all once beginners, through sharing our experiences and advice, we hope this resource will help ensure everyone feels supported to embrace and make the most of their training journey.

Monthly National Lightning Learnings on Topics Chosen by Trainees

Another recent change to be more responsive to our trainees' learning needs has been to introduce monthly National CCH Lightning Learnings. These 30-minute sessions are on the first Wednesday of every month from 13:30-14:00 and focus on one of our CCH sub-speciality learning outcomes 1-5 on a rotational basis. The specific topic within these learning outcomes is voted on by trainees through a monthly poll on our National BACCH Trainee Network. These sessions are delivered by experts and multidisciplinary team members from across the country to bring different perspectives to some of the most challenging cases or issues in CCH, as chosen by trainees. To maximise inclusivity, they are all virtual and recorded so all trainees can benefit.

April Lightning Learning - LO1

Chosen Topic: Learning Disabilities
Speakers:

Dr Ashley Liew, Consultant Paediatric Neuropsychiatrist (London)
Dr Sophie Carter, Consultant Community Paediatrician (Birmingham)

Key Discussion Points:
Definitions

- Internationally recognised term is Intellectual Disability and using this is now encouraged
- ICD-11 and DSM-5 Criteria both state that there needs to be an impairment of both intelligence and adaptive functioning (conceptual, social, practical); both of which onset in childhood and adolescence

Continues overleaf

Training: Update from BACCH Trainee Reps

Terminology

- We discussed the terms learning disability (used in health in the UK) and learning difficulties and specific learning disorders (used in education), and how terms from health and education may not align
- Advised using the diagnosis – Learning Disability (Intellectual Disability) in clinical letters to include terms used in the UK and internationally recognised
- Global developmental delay is often used <5 yrs and that >5yrs, we should consider if this diagnosis should be converted to a diagnosis of intellectual disability
- The concept of provisional intellectual disability was also discussed in situations where we may not have detailed/sufficient evidence to make a diagnosis

How to Diagnose

- Impairment of intelligence - IQ more than 2 standard deviations below mean – use of cognitive assessments (psychology)
- Adaptive functioning (Vineland and Adaptive Behaviour Assessment System)
- Recognising the challenges of accessing these standardised assessments, alternatives which can be performed within a typical clinic through history, observation and information gathering were suggested

May Lightning Learning – LO2

Chosen Topic: Attachment Disorder

Speakers:

Dr Clare Sheahan, Consultant Community Paediatrician (Bristol)
Shannon Porter, Clinical Psychologist (London)

Key Discussion Points: Case based example given

Concept

- The concept of attachment, as a deep connection between child and main carer, which makes us feel safe capable and loved, and if not formed well/disrupted, emotional and behavioural difficulties may result which can result in insecure attachment/attachment disorder

Presentation

- The different stages of attachment were summarised and how insecure attachment might present at different ages was discussed
- Baby – fearful of carer, distress if left, non-responsive to carer, loss of interest in exploring environment
- Older child – difficulties asking for help, struggling to sustain positive relationships, attention/concentration difficulties, emotional dysregulation, withdrawn or disengaged, daydreaming or fidgeting

Trauma and Adverse Childhood Experiences

- Concept of acts of commission and omission
- Key determinants that impact on how a child manages trauma:
- How alone they are (at time and after)
- Whether child is heard and protected
- Quality of relationships around the child, and that if children can express appropriate trauma responses, it might not lead to long term consequences
- The flight/fight/freeze cycle was outlined, and risk of a cycle of unresolved trauma

How to Diagnose

- Highlighted many more children may have attachment needs/difficulties but don't have attachment disorder
- 2 most common attachment disorders: Reactive attachment disorder and Disinhibited social engagement disorder
- Resources e.g. Coventry Grid for exploring autism and attachment difficulties discussed
- Psychological perspective in terms of formulation and how we can structure our referrals so that they are triaged appropriately

We are hopeful that these sessions will provide an amazing resource to reflect on and a catalogue for continuous professional development. Recordings of the monthly sessions can be found on the BACCH website (Members area > Conference Materials). Thank you to all the consultants supporting this initiative and sharing their expertise!

National Study Mornings for Harder to Reach Areas of the Curriculum

We recognise that with the centralisation of some services come new challenges for trainees in terms of getting sufficient experience to feel confident and competent in that area. To help address this need, we have set up termly half study days focusing on these harder to reach areas of the curriculum e.g. palliative care, public health and child sexual abuse. Each will have a focus on the learning objectives of CCH trainees covering skills specific to the community paediatrician's role. The webinars will be led by national experts in the field and include multidisciplinary, third sector and family perspectives. One study day a year will also be a 'trainee choice' day, empowering our current trainees to dictate what they are finding a 'hard to reach' area to gain sufficient experience in through a trainee poll, so we can ensure learning needs are being addressed. It was the preference of trainees that these days be virtual, recorded and kept to a half day to be as accessible as possible. The next Study Morning will be on 18 June on Palliative Care – please register online to attend at: ***www.bacch.org.uk/pages/events***

BACCH Palliative Care for CCH Trainees National Study Morning 18 June

9.00 - 9.30 How to talk about children's palliative care - Heard: A UK charity founded from parental experience to shift the narrative about care for very unwell children
9.30 - 10.30 Advanced Care Plans - Dr Ella Aidoo, Head of Service for Paediatric Palliative Care at the Evelina London Children's Hospital
10.30 - 11.00 BREAK
11.00 - 11.30 Supporting families in the community with children with life-limiting conditions - Dr Jonathan Downie, Clinical Lead for Paediatric Palliative Care at the Royal Hospital for Children in Glasgow and Chair of the RCPCH Palliative Care Medicine CSAC
11:30-12:30 Symptom management in the community - Nicki Corrigan, Service Manager for Outreach at Children's Hospices Across Scotland
12.30 - 13.00 Question time

Registration is free for BACCH trainees.

Trainee-led Events to Drive and Support Recruitment

With more CCH posts vacant than in any other paediatric sub-speciality, we wanted to do our bit to address the workforce crisis and help attract our colleagues of the future. Our fantastic team of BACCH trainee regional reps are now working together to deliver a national cycle of recruitment events including Considering Community, Applying to Community, CCH Interviews, and 'Welcome to the Team' sessions for new CCH starters. This aims to ensure all applicants have access to the same information and support regardless of where they are currently working and can speak to CCH trainees from across the country. 37 trainees benefitted from our recent 'Welcome to the Team' event in May for new CCH starters and it was lovely to see so many new faces joining our team! We hope these events will help create a sense of community within the community, and that those who've benefitted will help pass that benefit on in due course.

Upcoming dates for recruitment events:

11 June (13:00-14:00) Considering Community Paediatrics: An insider's guide on why it's the best subspeciality
17 September (13:00-14:00) Applying to CCH: Advice from current trainees
19 November (13:00-14:00) CCH Interview Prep

Regional Trainee Representatives – Your Chance to Shape What we Change Next!

The BACCH trainee regional reps from across the country are the backbone behind these initiatives! As a trainee rep team, we now meet monthly for a thought-provoking half hour where feedback is reviewed, ideas are brainstormed (however big, small or off the wall – all are welcome!) and action plans drafted. As is the nature of training, people are constantly moving on and many of us are training flexibly, we are always looking for new regional reps to join the team (or pair up!). If you would be interested in getting more involved and helping to shape our sub-speciality, we would love to hear from you (*bacch@rcpch.ac.uk*)

Dr Claire Stewart

Dr Victoria Smith

Dr Claire Stewart & Dr Victoria Smith
BACCH Trainee Representatives

Specialty and Specialist (SAS) Doctors Survey

Please can all community paediatric SAS doctors complete this survey before the end of June to enable us to collate the results before the British Association for Community Child Health (BACCH) Annual Scientific Meeting in September 2025. Here is the survey link and QR code:
https://www.surveymonkey.com/r/T8V6TS5

Thank you for taking the time to complete this survey to enable us to compare the results with the last SAS survey in 2015 and guide my future work as BACCH SAS rep.

Dr Fatima George
BACCH SAS Representative

Paediatric Doctors Survey: Police Statements and Court Evidence

Ensuring the safety and wellbeing of children is a core responsibility for all paediatric doctors. Understanding our confidence and experiences with legal proceedings is vital to improving support and training in this area.

I am conducting a survey to understand how confident doctors working in paediatrics are in providing police statements and evidence in court. Safeguarding knowledge is a vital skill, and while many of us have been trained on identifying child abuse, communication in safeguarding, and child protection medicals, there has been limited free or subsidised training specifically focused on writing police statements and giving evidence in court.

My survey will explore the confidence and experience of paediatric doctors in these crucial legal processes. Findings from this survey will be used to advocate for dedicated teachings and support for doctors in this area.
My name is Odirichi Andrew, and I am a community paediatrics GRID registrar in the West Midlands. I would be grateful if you would take approximately 2-3 minutes to complete my anonymous survey.

Please see the attached survey link and QR code:
https://forms.gle/vpTWum87g6xTQPdk9

Thank you for taking the time to complete my survey. Your valuable insights will contribute directly to advocating for better training and support for paediatric doctors in this crucial aspect of safeguarding.

Odirichi Andrew
Community Paediatrics GRID Registrar | West Midlands

Advanced Clinical Practice (ACP) role in Community Paediatrics

I am an Advanced Clinical Practitioner (ACP) in Community Paediatrics in Kent Community Health NHS Foundation Trust (KCHFT). I previously worked as a Health Visitor and Learning Disability nurse.

The purpose of this short article is to provide an introduction to my role and reach out to out to all colleagues working within the Community Paediatric setting who are working as Trainee ACPs or ACPs. My role in British Association for Community Child Health (BACCH) is to identify ACPs in Community Paediatrics and bring ACP workforce development forward for the sustainability of Community Paediatric services in the future.

What are ACPs?

ACPs can have experience in a variety of professional backgrounds such as, for example (but not limited to), nursing or physiotherapy - with more roles becoming identified. ACPs have to work in the four pillars of practice (Health Education England (HEE), 2017):

1. Clinical practice (largest component of role)
2. Leadership and Management
3. Research
4. Education

Continues overleaf

All four pillars of practice need to be factored into the ACPs job plan and time to be given to undertake research and education in practice is essential to upskilling ACPs and developing the workforce in Community Child Health.

What do I do as an ACP in Community Paediatrics?

- Run special school clinics for attention deficit hyperactivity disorder (ADHD) and sleep medication
- Non-medical prescribing
- Initial assessments for ADHD
- Developmental assessments
- Line management for members of the nursing team
- Clinical lead for the nursing team
- Re-design of accessible information for families e.g. ADHD behavioural workshop
- Re-mapping of service delivery with increased ADHD medication review clinics in schools
- Education and staff training related to neurodevelopment
- Oversight and lead on audits in practice
- Research in practice: Currently in receipt of funding from the National Institute for Health and Care Research Applied Research Collaboration Kent, Surrey, and Sussex (NIHR ARC KSS) to undertake the following study: "How can we support adolescents with ADHD to engage in learning about themselves and their condition?"
- Leading on medication workshops for families

Why ACPs in Community Paediatrics?

The National Health Service (NHS) Long Term Plan (2019) encourages for an expansion of multi-professional credentialing to allow clinicians to build on their new capabilities in practice within a key area of competence.

BACCH (2019) workforce strategy for Community Paediatrics:

- "BACCH will develop opportunities for skill mix in Community Child Health…"
- "BACCH will collaborate with British Association for Childhood Disability/Royal College of Paediatrics & Child Health/Health Education England to establish a role for specialist and/or ACPs in Community Child Health, leading to training programmes for Advanced Clinical Practice"
- ACPs undertake a three-year part-time MSc course at university building on their previous professional role and experience.

Has the impact filtered down to your service?

Please contact me if you are aware of any ACPs working in community paediatrics who would like to form a new BACCH ACP network. I would be keen to hear your practice experiences and roles within Community Paediatrics. *If you would like to contact me, please do so via the email address below.*

Gill Middleditch | Advanced Clinical Practitioner
Kent Community Health NHS Foundation Trust
E-mail: Gill.middleditch@nhs.net

References:

1. British Association for Community Child Health (BACCH) (2019). A workforce strategy for community paediatrics. Available at: ***https://hubble-live-assets.s3.amazonaws.com/bacch/file_asset/file/75/BACCH_Workforce_strategy_for_community_paediatrics_2019_final__endorsed_.pdf***
2. Health Education England (HEE) (2017). Multi-professional framework for advanced clinical practice in England. Available at: ***https://www.hee.nhs.uk/sites/default/files/documents/Multi-professional%20framework%20for%20advanced%20clinical%20practice%20in%20England.pdf***
3. National Health Service (NHS) Plan (2019). NHS Long Term Plan. Available at: ***https://www.longtermplan.nhs.uk/*** .

Child Adolescent Psychiatry Surveillance System (CAPSS) celebrates 15th Anniversary

The Child and Adolescent Psychiatry Surveillance System (CAPSS) held a symposium on 2nd April 2025 to mark 15 years of the service. The chair, Dr Aditya Sharma and the CAPSS Executive Committee welcomed a range of guests and speakers from psychiatry, academia, charities and funding organisations that support mental health research.

The event opened with a warm introduction from the RCPsych President, Dr Lade Smith, and Professor Steve Turner, President of Royal College of Paediatrics and Child Health, officially marking the release of the CAPSS 15-year anniversary report. The report included illustrations from the young artists and winners of the 15th Anniversary Art Competition, who attended with their families.

The symposium served to highlight some of the important areas of research facilitated by CAPSS on the epidemiology of rare mental health conditions and clinical events amongst children and adolescents.

CAPSS is based on the methodology of the British Paediatric Surveillance Unit (BPSU) and is unique in facilitating the surveillance of rare paediatric mental health conditions across the UK and Republic of Ireland.

CAPSS studies, many of which have been undertaken with the involvement of the BPSU and British Association for Community Child Health (BACCH) members, have addressed significant knowledge gaps on the presentation, management and diagnosis of a range of rare mental health conditions and clinical events, often devastating for the young people and families affected. BACCH members have been central in reporting conditions such as attention deficit hyperactivity (ADHD) and eating, transition and mood disorders.

Left-Right: ***Dr Steve Turner****-RCPCH President,* ***Dr Eleanor Smith****-Consultant in Child & Adolescent Psychiatry at Cumbria, Northumberland, Tyne & Wear NHS Foundation Trust,* ***Dr Lade Smith*** *CBE- RCPSych President,* ***Dr Aditya Sharma****-Chair of CAPSS Executive, Clinical Senior Lecturer and Honorary Consultant in Child and Adolescent Psychiatry, Translational and Clinical Research Institute, Newcastle University, Wolfson Research Centre*

As well as raising awareness of studies supported by CAPSS, a series of panel discussions with representatives from NHS England, National Institute for Health and Care Research (NIHR), MQ Mental Health Research and the Colleges' Child and Adolescent

Training: ACP poster presented at BACCH – 2022

Kent Community Health
NHS Foundation Trust

Advanced Clinical Practice:
Community Paediatrics

by **Gillian Middleditch** and **Dr Kim Blackwell**

Introduction:

The decision by the trust to trial recruitment for trainee advanced clinical practitioners (ACP) was taken because of recruitment difficulties for community paediatrician roles.

It is further recognised that the Community Paediatrics Service recognises a want and need to expand the role of the nurse, because of demand and capacity on existing colleagues.

Aims:

Having a trainee ACP in the team allows them to collaborate. It builds and instils new ways of working to help provide timely service delivery.

There are some noted advantages of the trainee ACP role:

- a keen eye for service improvement
- seeking creative ways to develop the service through quality improvement, evaluation and audits
- collaboration between health care assistants, doctors, nurses and administration
- networking with other ACPs to find new ways to trial in practice.

While there is also some apparent disadvantage of the trainee ACP role:

- feeling of role isolation
- an evolving role, to meet the demands and capacity of the service
- gaining clinical competencies (some of which are adult focused)
- being pulled from previous role as a nurse and current trainee role (easy to want to go back to comfort zone).

Some key aims of the trainee ACP role include:

- new ways of working
- collaboration with wider services
- bolster in-house developments through audits, service evaluation and Barnardo's training for promoting the child's voice in practice.

Methods:

The course structure consists of a three-year, part-time course. While the taught content is part-time between four to six hours per week. The intensity of additional self-directed study is on average 20-hours of study per week.

First year: Clinical skills, advanced decision making and developing the four pillars in practice.

Second year: Research proposal on either an audit in practice, change management project or critical review of the literature – to be widely shared in practice. Further intense module on non-medical prescribing.

Third year: Dissertation and end-point assessment for the apprenticeship route.

Results:

Developing the four pillars of practice (Health Education England, 2017), so far, the following areas have been achieved in practice.

Pillar one: Clinical practice

- Attention Deficit Hyperactivity Disorder (ADHD) medication reviews
- Initial assessments for ADHD
- Initiation of ADHD medication
- Cardiovascular health checks
- Quantitative behaviour feedback
- Supporting the duty nursing team handle patients queries
- Working in accordance with the Nursing and Midwifery Council (NMC) (2018) code
- Non-medical prescribing working with National Institute for Health and Care Excellence (NICE) (2018) guidance on management of ADHD, at the forefront.

Pillar two: Leadership and management

- Clinical rota
- Staff one-to-one
- Staff team meetings
- Wellbeing work lunches
- Quality improvement project - nursing duty
- Leading on developing a new nurse-led clinic, for ADHD medication in a specialist behavioural school
- Working more closely with local school SENDco's - trialling ADHD medication clinic in mainstream school
- Audits, for example, include record-keeping, leading on safeguarding audit.

Pillar three and four: Education and research

- Evaluation of service in specialist school
- Bolstering research in practice
- Submitting research posters to RCPCH and NIHR ARC
- Presentations, such as after-action review report - Admin Team
- Quality Improvement – nursing duty.

Conclusion and recommendations:

Next steps: Developing the four pillars of practice (Health Education England, 2017)

Pillar one: Clinical practice

- Neurological and developmental assessments
- Supporting the duty doctor and nurse with patient queries
- Initial assessments for autism and developmental delay.

Pillar two: Leadership and management:

- Following evaluation of service offer in schools, to consider if there is more scope for this offer from the wider nursing team
- Supervise and mentor future trainee ACP's
- Lead on change to current nursing practice (Kotter 1996 and 2005)
- Developing nursing team practice through research and evidence-based medicine.

Pillar three and four: Education and research

- Further embedding evidence-based medicine into practice
- Future service evaluation of nurse-led clinic in specialist behavioural school
- Audits.

Reference list:

Health Education England (HEE) (2017) Multi-professional framework for advanced clinical practice in England. Available at: https://bit.ly/3QLP3QP

Kotter, J. (1996) Leading change. Boston: Harvard Business School Press.

Kotter, J. (2005) Our iceberg is melting. New York: St. Martlings Press.

National Institute for Health and Care Excellence (NICE) (2018) Attention deficit hyperactivity disorder diagnosis and management NICE guideline NG87. Available at: https://www.nice.org.uk/guidance/ng87

Nursing & Midwifery Council (2018) The code: Professional standards of practice and behaviour for nurses, midwives and nursing associates. London: Nursing & Midwifery Council.

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Continues overleaf

Psychiatry Faculty helped emphasise the need for increased funding for mental health research, underpinning improvements in patient care.

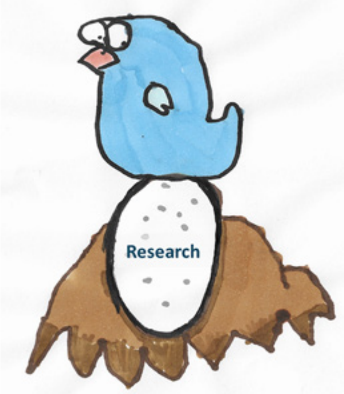
The Executive Committee would like to extend their thanks to all those who have contributed to the success of CAPSS over the years. They would particularly like to thank Richard Lynn, co-founder of CAPSS, whom you will all know from the BPSU, who is now stepping down from the Executive role.

Gavin Herrington | Programme manager
College Centre for Quality Improvement
Royal College of Psychiatrists

Dr Richard Lynn | CAPSS Executive
Hon Senior Research Fellow
University College London-Institute of Child Health

Research

Incubating the future: New collaboration to build capacity in general and community paediatric research



Artist: Jaxson Brown Pollock, 9 years old

In the last edition of the BACCH newsletter, we shared some of the exciting work the Strategic Research Group has been undertaking to enhance research in community child health. Today, we are thrilled to announce that BACCH Strategic Research Group is partnering with GAPRUKI (General and Adolescent Paediatric Research Collaborative UK and Ireland) to advance research capacity in general and community paediatrics – a much-needed initiative given the significant evidence gaps in managing common childhood conditions.

Despite the importance of research to improving clinical care, many general and community paediatricians face barriers such as limited time, training, and resources to actively engage in research. This is concerning, as community child health plays a pivotal role in addressing the health challenges faced by children within their local contexts. We firmly believe that all children deserve access to research that reflects their needs and contributes to equitable healthcare practices. To achieve this, we must foster a culture where research becomes a seamless part of clinical practice, especially in community settings.

Change is on the horizon. Beginning July 2025, a new General Paediatric Incubator, funded by the National Institute of Health and Care Research (NIHR), will launch to enhance research capacity in general paediatrics and community child health.
The NIHR Incubator programme is designed to overcome research barriers in priority areas of health and social care by developing collaborative research communities. Through annual open competitions, funding is awarded to projects for three years. A notable example is the Paediatric Critical Care Incubator, awarded in 2023, which has successfully established research training, mentoring, and networking opportunities in paediatric critical care[1,2].

Recognising the underrepresentation of research in general paediatrics and community child health, NIHR specifically encouraged bids in 2024 for an incubator focused on "General Paediatrics and moving research across the age range." Led by Drs Katrina Cathie and Lee Hudson, our team embraced this vision with enthusiasm. What began as a collaboration between GAPRUKI and the BACCH Strategic Research Group quickly evolved into a multidisciplinary initiative, united by the common goal of advancing general and community paediatrics research.

We placed a strong emphasis on including under-represented voices, particularly those of children and young people (CYP). This aligns with best practices in child health research, which values co-production and engagement with CYP and families as vital stakeholders. Input from young people will come via the Leeds Young Research Owls Patient and Public Involvement (PPI) group and Lifelab. Additionally, our team spans professionals from nursing, pharmacy, primary care, psychology, and more, representing diverse expertise and settings in both hospital and community environments.

Our key aims for the Incubator include:

- Map the research landscape to identify gaps and barriers specific to general and community paediatrics.
- Engage and collaborate with children and young people to determine research priorities that reflect their lived experiences and health needs.
- Expand research networks and strengthen collaborative efforts across the UK and increasing representation from under-served groups and areas.
- Build research capacity and develop new training and mentorship opportunities across the multidisciplinary team (MDT), including those working in community child health.

Join us on this exciting and challenging journey and let's create the high-quality evidence-base for the care we deliver that children and young people deserve.

To join GAPRUKI scan this QR code:

Dr Louisa Pollock
General Paediatrics & Paediatric Infectious Diseases Consultant
Royal Hospital for Children | Glasgow

Prof Michelle Heys
NIHR and UCL Global Health Research Professor in Child Health
Honorary Community Paediatrician
East London NHS Foundation Trust
Email address: m.heys@ucl.ac.uk

Spotlight on… Dr John Hutchins

Born and bred in Ealing, West London, I was honoured to return both as a registrar and a consultant to serve my local population. I did give serious thought to studying philosophy instead of medicine when leaving school.

I have been a Designated Doctor for Safeguarding Children since my consultant appointment in 1995 which might make me the longest serving in London. Retired in 2024 and now in post retirement role as Designated Dr.

I've held a variety of managerial roles – the highest being Medical Director in 1999-2000 but as I have never had managerial ambitions, I tend to just help organisations over difficult periods before stepping down in favour of more competent people who can do those roles properly (I've literally not done a single managerial course in my life).

I'm married with three grown up children and now, have a grandson. I'm a long time Brentford Football Club supporter and also lifelong personal pacifist.

Toju (Assistant Trainee Newsletter Editor): Describe your job in three words.

John: Only. Three. Words?

Toju (sighing): Not literally! Three words *about* your job. Whose idea was it to interview you, anyway?

John: It was your idea. I did warn you this would be a car crash waiting to happen…

Toju: So your three words?

John: Fun. Worthwhile. Rewarding.

Toju: Who has been your greatest inspiration and why?

John: Could be several contenders for this. One would be. Dr Alex Poteliakhoff, a founding member of the Medical Association for the Prevention of War (MAPW) who introduced me into the medical peace movement. He's now 106 years old – 107 by the time this is published. I still visit him to have chats. I carry on his work in the Lionel Penrose Foundation and with *Medicine, Conflict & Survival* as best I can.

For paediatrics, it would be Dr Martin Bax who ended up at Chelsea & Westminster. He recently passed away. I also met him via MAPW and later was privileged to work under him. Martin achieved so much and was senior editor of the Journal of *Developmental Medicine and Child Neurology* as well as the book series *Clinics in Developmental Medicine*. Martin refused to sit any postgraduate exams but still rose to the top of his field. For him, it was about knowledge, rather than letters after your name or positioning yourself to try to get a MBE or knighthood.

Toju: What has been your biggest challenge of your career and how did you overcome it?

John: I've had a career? Blimey, I thought I was just winging it for the last 40 years…

Toju: What is the highlight of your working day?

John: If I can get someone to transiently believe something which is patently untrue or surreal! Don't worry – I always let them know before they act on it.
Possibly.
Well, most times, unless of course watching them act on it will be even funnier… - for legal and HR reasons I have to add the word "allegedly" here…

Toju: What is the best advice you have received so far as a doctor?
John: Well of course everyone sees me as an exemplary model of professionalism and good behaviour and please can you now pick yourself up off the floor and stop laughing, Toju???

So numerous times people, ranging from patients' parents to staff of all disciplines, have said either "*don't change*" or "*we're not sure how you get away with that but we're glad someone does*". So I follow that advice, despite the consternation of numerous HR Directors with whose offices I became very unaccountably familiar…

Toju: What is the single, most encouraging thing that one of your colleagues can do to make your day?

John: Make coffee. Like a decent one. Not like the ones I tend to receive.

Toju: After a hard day at work, what is your guilty pleasure?

John: In the summer, I'll potter around in the garden pretending there are essential jobs that need doing. In the winter, watch comedy – anything of the Monty Python or Stewart Lee style. Actually I do both in all weathers! But guilty? Strewth, didn't realise either was a crime. Better say "allegedly" again. You're not showing this to my wife, are you?

Toju: If you had a super power, what would it be and why?

John: What do you mean, *if* I had a super power? Why do you think I am wearing my pants on the outside of a pair of tights and have this ridiculous cape? I will now deploy my super power of treating your question with disdain.

Toju: What advice would you give to inspire the next generation of community paediatric trainees?

John: I would advise them to go and ask someone else for advice. Why on earth would you ask me? Of course, that creates an interesting paradox as if they do ask someone else, technically they have followed my advice. So they have to ask me for advice to avoid asking me for advice. Are you regretting your question?

Toju: More than you can possibly imagine. Finally, (thank god), if you were stranded on a desert island, what three luxury items would you take with you? And please remember, your choices have to be non-incriminating for you or the newsletter.

John: So music to listen – I think traditionally I'm only allowed one record. I would take *Tales from Topographic Oceans* by Yes. Four tracks all about 20 mins long (so lots to listen to) and lyrics inspired by the four Hindu shastras. Reading material – I would take Frank Coplestone's History of Western Philosophy. It has 9 volumes so that'll keep me going and I'll have so much reflection time. Lastly, my infinite-coffee-making machine that magically grows its own beans. Admittedly, I'm still trying to invent that one.

Toju: Thank you. Now excuse me whilst I contact my senior editor to see if we had a backup for this edition's spotlight…

Exploring... Pottery

Until recently, if you'd asked me about my hobbies, I would have said running and baking and left it at that. I still love both—but they no longer offer the same escape from work and the mental load of daily life that they once did. Running is great, of course, and still helps me burn off stress, but more and more I find myself ruminating rather than escaping my thoughts. As for baking… well, becoming a mum changes things. Suddenly, baking isn't just for fun—it's functional, often met with a small critic offering unsolicited "feedback."

So, a few months ago, when I finally arranged my job schedule to have one day a week off (and after my husband and I agreed there was no real need to reduce our sons' nursery days) I decided to sign up for pottery classes.

For years, I've been a dedicated viewer of *The Great Pottery Throw Down*. Every season, at least once an episode, I'd turn to my husband and say, "I really want to try that." I've never considered myself particularly artistic, so I had no illusions about hidden talent—but it looked like fun. And who wouldn't want an excuse to get a little messy? During the last season, I started seriously researching local courses and, to my delight, found one that was affordable and fit perfectly into my new schedule. So, I joined.

Now, that Monday afternoon session has become one of my favourite parts of the week. For two and a half hours, I park outside the local college and immerse myself in the world of clay. The early classes covered the basics—hand-building, coiling, glazing, and finally a turn at the wheel. After that, we were largely left to explore on our own.

And honestly? It's incredibly therapeutic. Pottery demands my full attention, pulling me completely out of my everyday worries. Because nothing about it comes naturally to me, I have to focus—on each step, each technique, and the shape I'm trying to form. As a lifelong perfectionist (like many medics, I suspect), that's a shift. But because I'm learning something new, I can let go a little. My teacher encourages us to "go with the flow," and I find that deeply refreshing. Still, there are rules (important ones, like how to avoid your pot exploding in the kiln) which appeals to the structured part of me too.

After a few months, I've completed two pots, with two more waiting to be glazed. They're not masterpieces, but I'm proud of them—and my sons think they're wonderful, which is all the praise I need.

If pottery is something you've ever considered, take this as your sign: go for it. And let yourself enjoy the perfectly imperfect creations you make along the way.

Dr Laura Thomas
Consultant Community Paediatrician
Chelsea & Westminster Hospital, London

Erratum

In the March edition of our newsletter, we incorrectly stated Dr Laura Thomas's place of work in the Path to CCT article. The correct affiliation is Chelsea & Westminster Hospital, London.

We sincerely apologise for the error and any confusion it may have caused.

— The BACCH News Team

The Veggie Prescription

The sun is out, and salads are in! This pear salad is so simple and refreshing - you need to try this! Pair it with pasta/pizza/risotto/bruschetta, whatever takes your fancy.

Salad:

- Wild Rocket.
- Pears.
- Spring onions.
- Optional:
  - Choice of nuts: toasted pecan or pine nuts work great!
  - Goats cheese/mozzarella.
  - Protein of your choice.

Dressing:

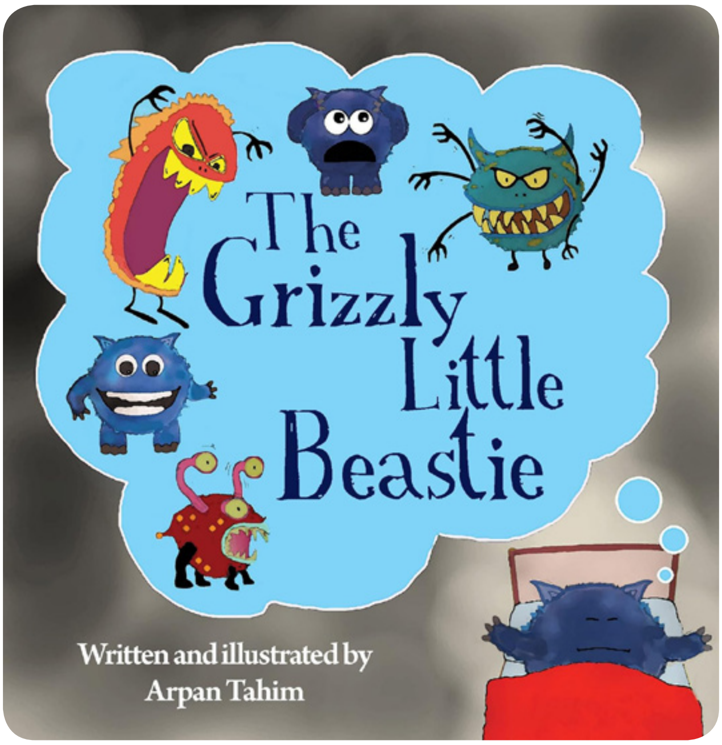
Honey and chilli oil / olive oil.

Sunanda Bhatia
BACCH Trainee Newsletter Editor

Book Review: The Grizzly Little Beastie by Arpan Tahim

Winner of the Child's Eye International Book Award 2022 for children's literature

Arpan is a doctor, a dentist and a dad to his two children. With a huge passion for professional education and inspiring those in the next generation, he's authored scientific papers, medical textbooks and is an award-winning children's book author who has spent many years helping others make sense of the world around them.



This book is about a brave monster called the Grizzly Little Beastie. He is a good monster, and he was feeling unwell in the story. His jaws were hurting badly. His mum said he could not go outside, and he had to stay in bed. He had bad dreams all night. But, when he woke up, he had a nice, shiny tooth and he felt better!

At the end of the book, there was some information for my parents to read with advice about teething.

I liked the book because it tells you not to worry about your jaws aching. I think the pictures explained a lot of the story and showed the monster's feelings, when he was sick and when he was happy afterwards. I would recommend this book to other children so they would know when their jaws hurt, it could be because a new tooth is coming. Maybe when your mouth is hurting, the Grizzly Little Beastie might visit to calm you down!

Mithra Sodeyfi (7 years old)

DOI: The reviewer received a complimentary copy of this book in exchange for an honest review.

Advert

BACCH is looking for 2 trainee editors to work with the Editor and Assistant editor for the BACCH newsletter published 4 times a year.

The current trainee editors end their term in December 2025, but the role will include a handover period from September 2025 onwards.

This role is aimed at ST6-ST8 trainees in Community Paediatrics. GRID or non-GRID trainees in Community Child Health and Neurodisability are welcome to apply. We ask that applicants are either current members of BACCH or are willing to join.

How to apply: Please send a CV (three pages max) along with a brief statement (250 words max) outlining your experience and reasons for wanting to take up the role.

Send applications and queries to the BACCH Office: ***bacch@rcpch.ac.uk*** and cc your application to **BACCH editor.**

Application deadline: **31 July 2025**

A full job description is available via the BACCH website at ***https://www.bacch.org.uk/articles/bacch-trainee-editors-from-september-2025-.***

DSMIG
UK & IRELAND

Jennifer Dennis Award

The Down Syndrome Medical Interest Group (DSMIG) are delighted to announce that the Jennifer Dennis Research Award for research in healthcare to children with Down Syndrome will be awarded later this year (2025).

Jennifer was a principal founding member of the Down Syndrome Special Interest Group and remained central to its activities for two decades, eventually standing down from active involvement in 2015. She sadly passed away in 2023.

This Award encourages research that advances specialist medical management or health outcomes of children with Down Syndrome.

The Award includes a monetary prize of £350, free DSMIG membership for one year and free attendance at the DSMIG Winter Scientific Symposium. Shortlisted finalists will be asked to present at the Winter DSMIG Symposium.

Applications from **all** healthcare professionals are welcome. Applicants should submit an abstract (up to 500 words) detailing their research, and how this will have an impact on improving the lives of individuals with Down Syndrome. **Submissions should be made by 1 September 2025.**

For further information and to make an application, please visit: *www.dsmig.org.uk/about-dsmig/jennifer-dennis-research-award-3-2/*

Events Calendar

- If your organisation would like to list an event on the BACCH website (free of charge) please contact ***bacch @rcpch.ac.uk***.
- If you are interested in placing a full advert in the Newsletter, please see prices and deadlines on page 2.
- The events section on the website is regularly updated: ***www.bacch.org.uk/pages/events***
- BACCH does not endorse external or affiliate group events - listings are for information only.

BACCH events

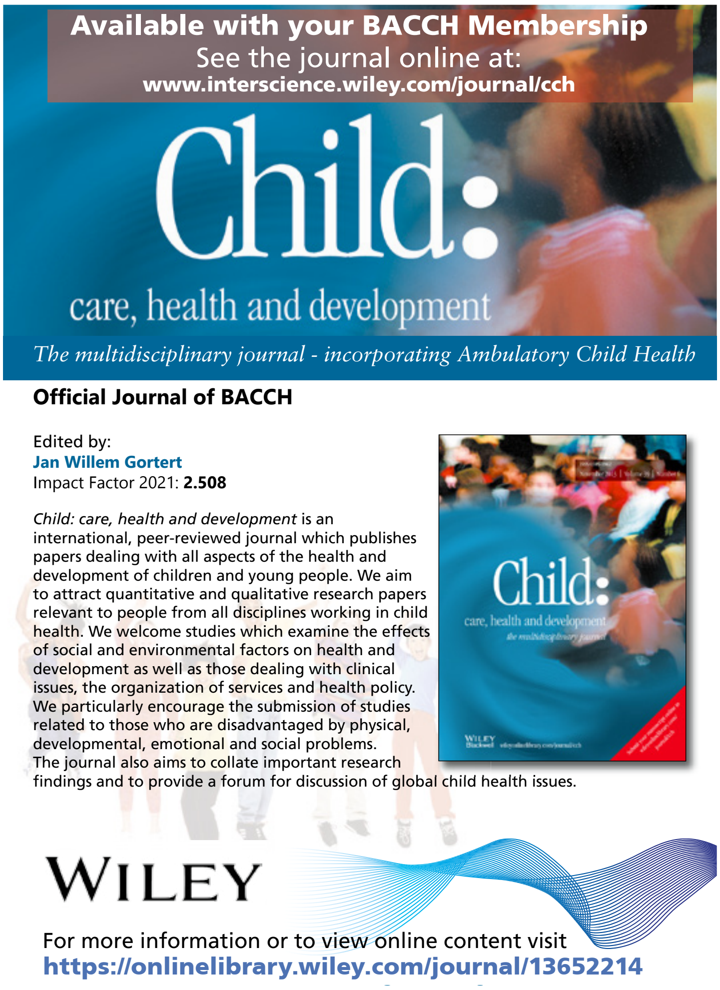
Date	Event	Location
18 Jun 2025	National Trainees' Study Morning: Palliative Care for Community Child Health Trainees ***https://www.bacch.org.uk/events/bacch-palliative-care-for-community-child-health-trainees-national-study-morning-online***	Online
2 Jul 2025	Monthly Lightning Learning Sessions for Trainees held first Weds of every month. July topic: How to Run a (Mini) Public Health Project ***https://www.bacch.org.uk/events/bacch-national-monthly-lightning-learning-session-jul-2025***	Online
17 Sep 2025	Online Trainee Event: Advice from Current Trainees on Applying to CCH GRID ***https://www.bacch.org.uk/events/trainee-led-virtual-events-to-support-recruitment-online***	Online
30 Sep-1 Oct 2025	BACCH Annual Scientific Meeting 2025 ***https://www.bacch.org.uk/events/bacch-asm-2025***	Nottingham & Online
6 Nov 2025	BACCH Northern Regional Meeting 2025 ***https://www.bacch.org.uk/events/bacch-northern-regional-meeting-durham***	Durham

Affiliate group events

Date	Organisation	Event	Location
25 Jun 2025	British Association of Paediatricians in Audiology (BAPA)	Midlands, London, East & South-East Forum & Peer Review ***https://www.bapa.org.uk/events/regional-forum-peer-review-june25***	Online
13-14 Nov 2025	Association for Paediatric Palliative Medicine (APPM)	APPM Conference 2025 ***https://www.appm.org.uk/events***	Birmingham

External events

Date	Organisation	Event	Location
17-20 Jun 2025	ISPP	International Symposium on Paediatric Pain (ISPP) 2025 ***https://inconference.eventsair.com/ispp-2025/mar-register-interest/Site/Register***	Glasgow
25 Jun 2025	Evelina	Selective Feeding Study Day ***https://www.eventbrite.co.uk/e/evelina-selective-feeding-study-day-tickets-1280847793229***	London
11 Jul 2025	Healthcare Conferences UK (HC-UK)	CAMHS National Summit 2025 ***https://www.healthcareconferencesuk.co.uk/conferences-masterclasses/camhs-national-summit***	Online
29 Jul 2025	Child and Adolescent Psychiatry Surveillance System (CAPSS)	Masterclass in Assessment and Management of Mental Health Disorders in Autistic Young People ***https://www.rcpsych.ac.uk/events/conferences***	London
25-26 Sept 2025	George Still Forum	Annual Scientific Meeting 2025 ***https://georgestillforum.org/***	London & Online



BACCH Annual Scientific Meeting

Community Child Health: Our Role in a Healthier Tomorrow

30 September and 1 October 2025, **Nottingham & online**

Programme

Talks *(all delegates – all final titles TBC)*

- ***BACCH: Where we have come from and where we are going*** (Professor Doug Simkiss)
- ***Safeguarding concerns in families after adoption or special guardianship order*** (Dr Joanna Garstang)
- ***Young adults share their experience of autism diagnosis*** (Dr Ian Male and service users)
- ***Unaccompanied Children Seeking Asylum: The Kent experience*** (Nancy Sayer)
- ***Health Outcomes of Young People Throughout Education (HOPE) Study*** (Dr Will Farr – tbc)

Further talks to be confirmed.

Personal Practice Workshops *(in-person only – some final titles TBC)*

- ***PMHA: Developing a mental health toolkit for community paediatricians***
- ***Paediatric palliative care (topic tbc)***
- ***CSAC: current training issues/challenges and sharing suggestions of how to mitigate***
- ***Down Syndrome (topic tbc)***
- ***Paediatric audiology (topic tbc)***
- ***How to write an abstract***
- ***Advanced Clinical Practice (ACP) in Community Paediatrics: roles, experiences and opportunities***
- ***Spines, curves, leans and deformities - what is it helpful for a community paediatrician to know? NHS benchmarking in community paediatrics***
- ***Public health: preparing for future practice***
- ***Child protection (topic tbc)***

Further workshops to be confirmed.

Abstract submissions

Abstracts are a vital part of the BACCH ASM and offer an opportunity for delegates at all levels to share their research at a national conference. We welcome submissions from members and non-members for oral and poster presentations. You can submit applications online on the BACCH website.

Abstract submission deadline is 14 July.

Further information & booking

In-person and virtual attendance options are available:

- ***In person: lectures, abstract presentations, afternoon workshops, posters, annual dinner and catch up with colleagues***
- ***Virtual: lectures and abstract presentations only, workshops NOT available***

BACCH members can book at reduced rates, including further discounts for trainees, medical students and Allied Healthcare Professionals.

www.bacch.org.uk/events/bacch-asm-2025

CEYESTO®
Melatonin 1mg/ml Oral Solution

Preferred. Flexible. Affordable.

✓ **Preferred**
Oral solutions are the preferred dosage form for children under 12.

✓ **Flexible**
Simple and convenient, allowing titration of melatonin dose without changing preparation.

✓ **Affordable**
Unmatched value and least expensive way to titrate doses of melatonin.

Ceyesto 1mg/ml has a wide range of licensed indications

References

1. Alessandrini E et al. Children's Preferences for Oral Dosage Forms and Their Involvement in Formulation Research via EPTRI (European Paediatric Translational Research Infrastructure) Pharmaceutics 2021, 13, 730. https://doi.org/10.3390/pharmaceutics13050730
2. Electronic drug tariff available at https://www.drugtariff.nhsbsa.nhs.uk/#/00885392-DC/DC00885259/Part%20VIIIA%20products%20D Date accessed May 2025
3. Ceyesto Oral Solution SmPC available at https://www.medicines.org.uk/emc/product/15067/smpc#grefhttps://www.medicines.org.uk/emc/product/15067/smpc#gref date accessed May 2025

Abbreviated Prescribing Information

Product name: Ceyesto® 1mg/ml Oral Solution.

Composition: Each ml of solution contains 1 mg of melatonin. Ceyesto also contains sucralose, benzyl alcohol, sodium ascorbate, propylene glycol, strawberry flavour, purified water

Therapeutic Indication: Ceyesto is indicated for Delayed Sleep Wake Phase disorder (DSWPD) in children and adolescents aged 6-17 years and adults up to 25 years of age where sleep hygiene measures have been insufficient, for insomnia in children and adolescents aged 6-17 years with Attention Deficit Hyperactivity Disorder (ADHD) where sleep hygiene measures have been insufficient. Ceyesto is also indicated for short-term treatment of jet lag in adults and single use for short-term sedation under medical supervision to facilitate electroencephalograms (EEG) in children and adolescents from 1 to 18 years.

Posology: *DSWPD in children and adolescents aged 6-17 years and adults up to 25 years of age:* Treatment should be initiated by physicians experienced in DSWPD and/or paediatric sleep medicine. The recommended starting dose is 1 to 2 mg once every day, 1-2 hours before the fixed desired bedtime. The dose of melatonin should be adjusted individually until effective up to a maximum of 5 mg per day, independent of age. The lowest effective dose should be sought and taken for the shortest period. After the achievement of advanced sleep-wake phase for 6 weeks, treatment should be stopped to evaluate if the patient can independently maintain an advanced sleep-wake schedule. In adults whose symptoms persist past the age of 25 and who have shown clear benefit from treatment, it may be appropriate to continue treatment. However, initiation of treatment in adults over 25 years of age is not appropriate. *Insomnia in children and adolescents 6-17 years with ADHD:* Treatment should be initiated by physicians experienced in ADHD and/or paediatric sleep medicine. The recommended starting dose of Ceyesto is 1-2 mg, 30-60 minutes before bedtime. The dose of melatonin should be adjusted individually until effective up to a maximum of 5 mg per day, independent of age. The lowest effective dose should be sought and taken for the shortest period. The physician should evaluate the treatment effect at regular intervals and consider stopping treatment if no clinically relevant treatment effect is seen. In adolescents whose symptoms persist into adulthood and who have shown clear benefit from treatment, it may be appropriate to continue treatment into adulthood. However, initiation of treatment in adults is not appropriate. *Single use for short-term sedation under medical supervision to facilitate EEG in children and adolescents from 1 to 18 years:* Ceyesto should be given 30-45 minutes before the anticipated start of the procedure as a single dose of 3mg for children weighing less than 15 kg and 6 mg for those weighing more than 15 kg. One further dose at 50% of the initial dose - 1.5 mg (<15 kg) or 3 mg (>15 kg) may be given if sleep is not achieved after 45 minutes. For information on other indications, please consult full Summary of Product Characteristics.

Method of Administration: Ceyesto is for oral use only. A plastic 5 ml oral syringe (graduated every 0.5 ml from 0.5 to 5 ml) is provided with the product. It is recommended that food is not consumed approximately 2 h before or 2 h after Ceyesto intake. If necessary, Ceyesto can be administered via a silicone gastric, duodenal or nasal feeding tube.

Contraindications: Hypersensitivity to the active substance or any excipients.

Special warnings and precautions: May increase, decrease or have no effect on seizure frequency in patients who experience seizures (e.g. epileptic patients). Some caution should be exercised in people with epilepsy. Ceyesto is not recommended in patients with autoimmune diseases, moderate or severe hepatic impairment, or severe renal impairment. Caution is advised when resulting drowsiness is likely to be associated with a risk to safety. Currently there is insufficient long term data for melatonin use in children and adolescents, so treatment should be taken for the shortest period and evaluated at least every 6 months. Caution is advised in the elderly and individual dosage is recommended. Long-term melatonin use may negatively affect blood glucose control, pubertal development and sexual maturation. Ceyesto contains benzyl alcohol and should not be used in pre-term or full-term neonates (up to 4 weeks) unless strictly necessary. Large volumes should be used with caution and only if necessary in liver or kidney impairment or those that are pregnant or breast-feeding. Caution is also advised in young children (< 3 years) due to the risk of accumulation.

Interactions: Ceyesto's metabolism is mainly mediated by CYP1A enzymes, hence interactions as a consequence of the effect of other active substances on CYP1A enzymes are possible. CYP1A2 inhibitors may increase Ceyesto levels and CYP1A2 inhibitors may reduce Ceyesto levels. Avoid concomitant use with fluvoxamine due to a significant increase in Ceyesto levels. Caution is advised with concomitant 5- or 8-methoxypsoralen, cimetidine and oestrogen therapy as Ceyesto levels may be increased. Ceyesto may enhance effects of other sedative substances e.g. benzodiazepines and non-benzodiazepine hypnotics. Alcohol should not be consumed when taking Ceyesto. Ceyesto may enhance the effect of anticoagulants such as warfarin.

Pregnancy & Lactation: Ceyesto is not recommended in pregnant and lactating women, women intending to become pregnant or in women not using contraception. Ceyesto is not recommend in men planning pregnancy.

Undesirable effects: No very common (≥1/10) undesirable effects listed. The most common (≥1/100 to <1/10) reported adverse effects are headache or somnolence. A low frequency of generally mild adverse reactions have been reported in the paediatric population. The number of adverse reactions has not differed significantly between children who have received placebo compared to melatonin. The most common adverse reactions were dizziness, headache, gastrointestinal symptoms and increased excitability. For information on other undesirable effects, please consult full Summary of Product Characteristics

NHS price: 150ml bottle: £25.65

Legal classification: POM

Marketing Authorisation Holder: Alturix Limited, 287 Upper Fourth Street, Milton Keynes, MK9 1EH, UK

MA number: PL 44490/0001

Date of revision of the text: August 2023

Job Code: CEL001

Reporting adverse effects: Adverse effects should be reported. Reporting forms and information can be found at https://yellowcard.mhra.gov.uk or search for MHRA Yellow Card in the Google Play or Apple App Store. Adverse events should also be reported to Alturix Limited at safety@alturix.com and +44 (0)1908 038 083

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CEL068 Date of preparation May 2025