

Paediatric Neurology Related Charities Meeting
Being held in parallel with the
British Paediatric Neurology Associate 2020 Belfast conference
at
Meeting room 7, Assembly Buildings, 2-10 Fisherwick Place, Belfast, BT1 6DW
On
Thursday 30 January 2020

Join via Zoom:

<https://zoom.us/j/453429464?pwd=Z3M2aVE1ZVFTWU1rbkR6ekNad2N5QT09>

Attendees

1. Alex The Leukodystrophies Charity (joining via Zoom)
2. British Paediatric Neurology Association (BPNA)
3. CDKL5 UK, Carol-Anne Partridge
4. The Children's Trust
5. Dravet Syndrome UK
6. Epilepsy Action
7. Epilepsy 12
8. European Paediatric Neurology Society (EPNS)
9. The Lily Foundation
10. Matthew's Friends
11. Mac Keith Press
12. Muscular Dystrophy UK
13. Niemann-Pick UK
14. Ring 20 Research & Support UK
15. Shine (Spina bifida & hydrocephalus)
16. Spinal Muscular Atrophy UK (joining by Zoom)
17. Sudep Action
18. Thinking Autism
19. Unique Rare Chromosome Disorder Support Group
20. Young Epilepsy

Programme

The aim of the meeting is to bring together paediatric neurology related charities to share what we are doing and identify how we can help each other

9.30 – 9.35	Welcome and aims <i>Mrs Philippa Rodie, Executive Director, BPNA</i>
9.35 – 9.40	Who is the BPNA? <i>Professor Finbar O’Callaghan, President of the BPNA & Chair of Neurosciences, Institute of Child Health, London & Hon Consultant Paediatric Neurologist, Great Ormond Street Hospital, London</i>
9.40 – 10.10	What do the BPNA do? <ul style="list-style-type: none"> • Training – Dr Anne-Marie Childs, National Training Advisor (Leeds) • Education – Professor Martin Kirkpatrick, BPNA Chair of International Education (Dundee) • Professional support & clinical governance – Dr Ailsa McLellan, BPNA Professional Support Officer (Edinburgh) • Research – Professor Manju Kurian, BPNA Chair of Research (ICH & GOS, London)
10.10 – 10.20	What can the BPNA offer to other charities? <i>Dr Andrew Mallick, BPNA Secretary</i>
10.20 – 10.45	What help does the BPNA need? <ul style="list-style-type: none"> • Launch of the Childhood Neurological Conditions Priority Setting Partnership (PSP) - <i>Dr Ming Lim, PSP Co-Lead & Consultant Paediatric Neurologist, Evelina London Children’s Hospital</i> • Survey of patient groups – <i>Professor Finbar O’Callaghan, BPNA President</i>
End 10.45	To give people the chance to get a cup of tea and get back to their stands
11.00-11.30	Tea break and exhibition
11.40-12.30	What is happening in paediatric neurology? Updates from special interest groups: <ul style="list-style-type: none"> • Cerebrovascular – Dr Dipak Ram (Manchester) • British Paediatric Movement Disorders – Dr Dan Lumsden (Evelina, London) • British Paediatric Epilepsy Group (BPEG) - Dr Sarah Aylett (GOS, London) • Children’s Headache Network - Dr William Whitehouse (Nottingham) • Fetal & Neonatal Neurology • Genetic White Matter Disorders (Leukodystrophies) • Muscle - Prof Tracey Willis (Robert Jones & Agnes Hunt Hospital) • UK Neurorehabilitation • UK Childhood Inflammatory Demyelination
End 12.30	To give people the chance to get lunch before the lunch break at 12.45
12.45-13.45	Lunch and exhibition
14.00-15.45	Presentations by paediatric neurology charities <ol style="list-style-type: none"> 1. Karen Harrison, Support Services Manager, Alex The Leukodystrophies Charity (via Zoom) 2. Rishwa Vithlani, The Children’s Trust 3. Emma Williams, CEO, Matthew’s Friends 4. Mike Fulton, Marketing Manager, Epilepsy Action 5. Helen Evans, Director, Dravet Syndrome UK 6. Carol-Anne Partridge, Chair, CDKL5 UK 7. Jackie Imrie, Healthcare Advisor, Niemann-Pick UK 8. Dr Beverly Searle, CEO, Unique – Rare Chromosome Disorders 9. Jane Hanna, CEO, SUDEP Action 10. Helen Stacey, Project Manager, Epilepsy12, RCPCH 11. Allison Watson, Ring20 Research & Support UK 12. Natasa Blagojevic, Advocacy Lead, Thinking Autism 13. Ann-Marie Halligan, Managing Director, Mac Keith Press 14. Marie McGonnell, SHINE Northern Ireland

	15. Alison Maguire, Head of Research, The Lily Foundation 16. Rob Burley, Director of Campaigns Care & Support, Muscular Dystrophy UK 17. Rosemary Pardington, Director of Integrated Care, Young Epilepsy
End 15.45	To give people the chance to get a cup of tea and get back to their stands
16.00 - 16.30	Tea break and exhibition
16.30 – 16.50	How can we support each other's work to better benefit children with neurological conditions?
16.50-17.00	Round up and feedback
17.00	End