

Meeting of the Paediatric Continence Forum

Tuesday 16th February 2021, 13:00 – 15:00

Zoom

Attendees

- **Kim Baker** (KBa), Paediatric Specialist Continence Nurse, Anuerin Bevan University Health Board
- **Elaine Baptiste** (EB), North East London NHS Foundation Trust (CPHVA rep);
- **Kate Bourdeaux** (KBx), Paediatric Continence Clinical Nurse Specialist Team Leader, Cardiff and Vale University Health Board (All Wales Continence Forum – Paediatric Branch rep);
- **Gerald Chan** (GC), Head of Public Affairs, Coloplast;
- **Carol Joinson** (CJ), Reader in Developmental Psychology, University of Bristol;
- **Claire Lindsay** (CL), Senior Specialist Paediatric Bladder & Bowel Care Nurse, North Devon Healthcare NHS Trust;
- **Nick Madden** (NM), Consultant Paediatric Surgeon/Urologist (retired)
- **Laura McCarthy** (LMC), Secretariat;
- **Jordan Newfield** (JN), Secretariat;
- **Juliette Rayner** (JR), Chief Executive, ERIC;
- **Rhonda Reilly** (RR), Specialist Continence Nurse, Western Health and Social Care Trust, Northern Ireland
- **Davina Richardson** (DR), Children's Specialist Nurse, Bladder & Bowel UK;
- **Sharon White OBE** (SW) Chief Executive Officer, School and Public Health Nurses Association;
- **Chris Whitehouse** (CW), Secretariat;

Apologies received from:

- **Obi Amadi** (OA), Lead Professional Officer, Community Practitioners and Health Visitors Association;
- **Julie Cummings** (JC), Senior Product Manager, Essity;
- **Angela Downer** (AD) Clinical Nurse Specialist and a paediatric representative from the RCN;
- **Ingrid Ecklekamp** (IE), Paediatric Continence Nurse/Team Lead, Specialist Children's Services; West Glasgow ACH, PCF representative for Scotland;
- **Marta Longhurts** (ML), Marketing Manager DryNites, Kimberly-Clark
- **Stephanie Madrell** (SMa), Brand Manager, Kimberly-Clark Europe Ltd
- **Simon Moon** (SM), Group Brand Manager, Norgine;
- **Claire Sackett** (CS), Marketing Administrator, Ferring;
- **Sameena Shakoor** (SS), Consultant Paediatrician, Kent Community NHS Foundation Trust.

1) Introductions and apologies

DR welcomed members and noted apologies.

2) Minutes and Matters Arising ([Paper 1](#))

There were no comments to be made about the Minutes from the last meeting.

3) Political Update

CW discussed the White Paper from the Department of Health and Social Care, which outlines new proposals launched to join up health and care services and embed lessons learned from the coronavirus pandemic. It is

important to ensure that paediatric continence remains on the agenda in any discussions on NHS reform. CW said that Whitehouse have produced a briefing paper on the NHS reforms White Paper, which will be circulated with the Minutes.

EB said that continence issues have become worse during the pandemic, and more attention needs to be paid of the impact of COVID on children, who are struggling to cope with this new way of life.

Members discussed the need to collectively gather evidence on how COVID has impacted children across the country, including safeguarding children whose challenges are heightened by the pandemic.

ACTION

- WH to share The Whitehouse Consultancy's briefing note on the NHS reforms White Paper and continue to keep the PCF updated on this matter.
- WH to assess what data has been collected on how COVID-19 has impacted children across the country, as well as ask clinical supporters for feedback, and deciding what to do with that information going forward.

4) Reports from Members and allied organisations

Company Members

GC spoke about the NHS White Paper, NHS England's consultation on integrated care systems, and the Cabinet Office's Green Paper on transforming public procurement. He also spoke about how he'd been closely following the Medicines and Medical Devices Bill and has been working to minimize the impact of Brexit.

No other company members were present to provide an update.

Clinical Members

ERIC: JR spoke about the relaunch of the Health Conditions in Schools Alliance and updated on the National Bladder and Bowel Health Project, which is likely to receive funding for the paediatric workstream, particularly around constipation.

University of Bristol: CJ spoke about University of Bristol's work to assess the risk factors and outcomes of continence problems in children and said that evaluating the effectiveness of URApp has been delayed.

SAPHNA: SW said that fewer nurses have been redeployed than earlier on in the pandemic. SAPHNA's digital training offer is about to be launched, and she will keep the PCF updated when it is.

CPHVA: EB said the annual professional conference went well, and they are now looking at holding more sessions online.

Bladder & Bowel UK: DR said that B&BUK are updating a lot of their information, including the national product guide for children and young people. She mentioned that June Rogers has retired, and she received a card, flowers and chocolates from the PCF.

There were no representatives from RCPCH or RCN.

5) Reports from the Devolved nations

Wales: KB said that the All Wales Continence Forum are reviewing the containment product guidance, and are trying to agree a national assessment document for children across Wales to ensure everything is in line

with best practice.

Northern Ireland: RR said there have been some issues with supply of medical devices. There are still issues with redeployment, with capacity quite stretched.

There was no Member from Scotland present.

6) Activity Reports (October 2020 – January 2021) ([Paper 2](#))

NSPCC Engagement

LMc said the PCF worked with the NSPCC to develop new guidance on understanding continence issues, safeguarding and providing care. This has now gone [live on the NSPCC website](#). She encouraged Members to share this guidance as widely as possible.

7) Website

LMc outlined the changes that have been made to the PCF website to ensure that the information is neater and more presentable. We have emailed members to ask them to ensure the information about themselves is correct, and have asked members to send a biography of the organisation they are representing, a logo of the organisation and a quote as to why membership of the PCF is important for the organisation. The PCF website will also be used as a platform for members to advertise any upcoming events from their own organisations.

Members approved of the approach the PCF have been taking to update the PCF website. DR said this is an ongoing piece of work.

ACTION:

- WH to recirculate request for information from members for website.

8) Communications

Membership (and key gaps) ([Paper 4](#))

JR said that the membership of the PCF has been reviewed to ensure appropriate clinical representation across the four nations as well as expertise, knowledge and skills from leading groups and bodies with an interest and responsibility for improving outcomes for children with continence conditions.

NM said that the PCF should look into getting a representative from BAPU (or BAPS). DR said she will contact a GP she has been made aware of to ask if they are interested in membership.

EB said there are potentially gaps with education, but members agreed that it might be best to bring in education specialists as and where necessary, with the PCF remaining as a clinical and corporate network.

ACTION:

- NM to help recruit a representative from BAPU/BAPS to join the group.

Membership Roles and Responsibilities ([Paper 3](#))

JR spoke through Paper 3, and explained in more detail the role of the clinical network.

Clinical Supporters ([Paper 5](#))

JR said that the PCF are looking to have a more active relationship with clinical supporters, making the most of their expertise and knowledge of local policy and practice and regularly keeping them updated on the work that the PCF are doing.

SW said it will be great to have a reciprocal link to the PCF to add to their own websites.

ACTION:

- All Members to add a link to the PCF website on their own site and send the PCF their website links to be added to PCF site

9) AOB

NM said that he drafted a briefing for the NHS and NICE to call for a daytime wetting guidance. Members agreed that there is definitely scope for guidance on this.

GC said that the White Paper says the Government will have the power to intervene on hospital reconfigurations, and there might be scope for the PCF to engage with this particular area.

SW and CL raised the issue of GPs prescribing bedwetting alarms, and DR explained that the PCF do not exist to promote or reject any particular treatment.

DR urged members to get in touch in between meetings with any questions or concerns that they have.

ACTIONS:

- PCF to look to push for NICE guidance on daytime wedding
- PCF to look to engage with the issue of hospital reconfigurations following changes introduced in the White Paper.
- PCF to add bedwetting alarms as an agenda item for the next meeting.

10) Dates of future meetings

Upcoming meetings dates

22 June 2021, 1pm-3pm (Location TBC)

19 October 2021, 1pm-3pm (Location TBC)

Contact Details

Jordan.newfield@whitehouseconsulting.co.uk

020 3855 5760