

# Association for Paediatric Palliative Medicine

**Annual General Meeting held on Thursday 18 May 2023 at 2.00 pm via Teams**

**PRESENT:** Anna-Karenia Anderson (in the Chair)  
John Allen  
Sophie Bertaud  
Jo Elverson  
Jo Griffiths  
Joanna Laddie  
Christine Mott  
Helen Queen  
Jill Yates  
Lizzie Bendle  
Anna Chadwick  
Lesley Fellows  
Emily Harrop  
Anton Mayer  
Laura Nohavicka  
Genevieve Southgate

In attendance: Sue Lakie (Minutes)

AK welcomed everyone to the meeting and gave a summary of events throughout the last year.

## **1. Report from the Chair**

### **Executive Team, Links and Affiliations, Constitution**

- One member has left the Team and so a vacancy for a General Paediatrician has arisen.
- Link roles include RCPCH, CYPACP, APM, APPM Formulary. Marian Williams and John Allen, who has recently joined, represent All Ireland. Together for Short Lives is represented and the APPM is affiliated with the European Association of Palliative Care and more recently with the British Association for Community Child Health.
- Membership has increased substantially since there has been a constitutional change that enables nursing and allied health professionals to join as fully paid up members.
- Looking at future APPM strategy with possible re-branding in view of the expanding Exec and expanding programme of paediatric palliative care throughout the UK and Ireland.

### **Membership benefits**

- The website is regularly updated and is being improved.
- Lizzie Bendle has taken over as Editor of the bi-annual newsletter.
- There is access to the Palliative Medicine Journal
- Networking opportunities through nursing and conference forums.
- Clinical support through the development of clinical guidelines
- APPM Formulary – next version to be released later this year.
- Nirusha Govender, our Pharmacy Lead, is encouraging increasing pharmacy support from amongst her national colleagues.
- Education and training opportunities including a non-medical prescribing education programme.

- First series of clinical guidelines published and second series to start in September on dystonia and pain, funded by NHS England.

#### **Sub-Groups**

- Hospice Medical Directors/Leads sub-group to start under the leadership of Christine Mott
- Neo/peri-natal sub-group started under the leadership of Lucy Perkins.
- Transition group which has formal links between the APPM and the APM led by Jo Elverson.
- Research group led by Emily Harrop which is joint with Together for Short Lives.
- Encouragement of the next generation including competitions in the following categories: under-graduate essay, a post-graduate audit and photography.
- Specialist Consultant group led by Joanna Laddie.

#### **Social media**

- Dedicated Twitter account
- Website

## **2. Treasurer's report**

Currently the bank account is showing a healthy £54K. Membership fees and other credits c£4K with 22 nursing groups joining in the last six months plus several Pharmacists. Subscriptions for members are now running from April to March with new members paying pro rata in their first year.

Expenditure during the year includes affiliation to the EAPC; Cochrane for their assistance on the clinical guidelines, the APPM Formulary (both of which are funded by NHS England) and also establishment of an opiate training programme on a digital platform which will start in September and will be free at the point of access. Next year, the budget will be much lower due to external funding (ie from NHS England) having been spent.

The APPM is a non-profit making organisation and does not need to register as an unincorporated association. Individual members (the Exec) are personally responsible for any debts and contractual obligations. It is therefore, necessary to maintain a baseline budget.

## **3. Education**

### **3.1 Medical education**

- **Opioid education programme** – the first course is planned to run in the autumn.
- **Virtual journal club** – hoping to be available in September
- **Education half day** (as part of the Conference in November) – Dr Ann Goldman will speak on her reflections on paediatric palliative medicine and Dr Rachel Clarke will talk about interaction with the public from her experiences as an adult palliative care physician. Options available during the day include representatives from King's and Cardiff talking about the Diploma and MSc and a CNS talking about the nursing Master's course and

how that is applicable to palliative care; sessions on simulation training and online learning packages. It is hoped that Alex Mancini will talk about her neonatal project and Lesley and Helen will be talking about the APPM nursing education programme.

### **3.2 Trainees**

- Rolling two-year programme – blended learning which has had good feedback
- Mentoring forums – which have been well received.
- Face to face study day at Martin House on 14 July.

### **3.3 Nurse education**

- Since 2019 when Lesley and Helen joined the Exec, there has been an increase from 5 to 134 nurse members with 22 teams of nurses now holding membership.
- The programme of nurse teaching sessions has been well-established this year and there are 250 nurses on the mailing list who receive links to these sessions – with about 30-40 attending each time.
- Unfortunately, an event in Birmingham had to be cancelled in March owing to heavy snow, but this has been re-booked for 19 June with speakers - Gareth Jones from NHS England and Jan Sutherland-Oaks from Claire House. Linda Maynard will be talking about RCN competencies and the afternoon session will showcase innovative models of 24/7 end of life care from across the country.

Thank you to everyone who has contributed to these sessions and anyone else who would like to offer to speak would be most welcome.

## **4. Pharmacy**

### **4.1 Pharmacy Group**

The Pharmacy Group, led by Nirusha Govender, has about 15 members all working directly within the paediatric palliative care specialty group or within a wider group linked with acute hospitals and/or hospices. Their aim is to provide clinical and professional expertise in medicines optimisation for paediatric palliative care. The pharmacists have been involved with the APPM Formulary work and have also provided medicines related updates and support to the nurse teaching programme.

### **4.2 Formulary**

- The formulary is undergoing a revision which will be available in the autumn.
- Translations of the Formulary are available in English, Greek, Ukrainian, Russian and German.
- A charge is made for a printed copy. The price for the new version has yet to be decided.
- The new version will include
  - An improved section on midazolam
  - A few extra monographs
  - Streamlined reference section with all references available online.

- Greater support for non-medical prescribers
- Longer term strategy is to cover costs by meeting print costs and seeking other streams of income to ensure the ongoing survival of the Formulary.

**5. Hospice Medical Directors/Leads Sub-Group**

17 hospices have responded to an email asking for representation on this group. Christine Mott is leading, and the first meeting is planned for late June. If anyone is keen to join this group, please contact [admin@appm.org.uk](mailto:admin@appm.org.uk)

**6. Research Group**

Joint research group with Together for Short Lives:

- Work on getting evidence synthesis together from EACH, and the Bodleian Library which will be available on the website.
- Work on what has been done against research priorities agreed by previous groups in the last 10 years.
- Work with Cardiff understanding the role in supporting MSc students.
- Planning a research half day at the APPM 2024 conference.
- Examining overlap between NIHR clinical studies and CoPPAR
- Symptom day at Noah's Ark on 6 July for anyone interested in symptom management research. Toolkit to be launched on 8 June.
- AK and Emily involved in developing a protocol for midazolam observational research work.
- CPOS is open and recruiting.

**7. APPM Conference 2023**

- 16 and 17 November. Bookings are open and early bird registration is available until 1 August. Submissions for poster presentation of abstracts are open - theme is supporting children and young people to transition from paediatric to adult care.
- Number of excellent speakers including Baroness Ilora Finlay of Llandoff, Alex Ruck-Keene KC (Hon), a barrister and educator specialising in mental capacity and mental health. Various break-out sessions including young people talking about their lived experience, managing fatigue, end of care models for young adults, and a pharmacological topic to be confirmed. Quick fire journal club, specialist nurse and allied health professional groups, some oncology updates and a psychologist specialising in care of young adults.
- Dates for 2024 – 21 and 22 November in London.

**8. Neonatal Sub-group**

A new group is getting together in June and the initial work will concentrate on the new BAPM framework which should be finalised by August. Anyone who is interested in joining this group to get in touch via [admin@appm.org.uk](mailto:admin@appm.org.uk)

The meeting closed at 2.31 pm.