

APPM

Autumn Newsletter

Edited by H McCluggage

2014

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Anna-Karenia Anderson

Lynda Brook (secretary)

Pat Carragher (Chair)

Yifan Liang (CSAC Chair)

Emily Harrop

Sat Jassal (formulary)

Michelle Koh (vice-chair)

Susie Lapwood (revalidation)

Victoria Lidstone

Heather McCluggage (editor)

Katrina McNamara (TfSL)

Mike Miller

Dermot Murphy

Greetings from Pat Carragher, Chairman APPM

Dear APPM members

The APPM is now in its fifth year since the amalgamation of the British Society of Paediatric Palliative Medicine (BSPPM) and the Association of Children's Hospice Doctors. It has gradually established itself, with the definite highlight each year being its annual education day. There are firm plans for the next one on 28 November – the programme is included later in the Newsletter, and already a good number of attendees have signed up for the day.



To oversee the work of the APPM we have an executive comprising of twelve doctors, and additionally a non-voting representative from Together for Short Lives (TfSL). This group met for a first “away day” in June in Liverpool, in order to discuss strategic direction and priorities for the APPM.

The day was facilitated and we looked at, in no specific order:

- A 'SWOT' analysis of the APPM in terms of what it might mean for us all, and other key stakeholders, and who these stakeholders are.
- "What could be even better for/from the APPM?"
- Effective leadership in the field of Paediatric Palliative Medicine.
- Engagement with members of the APPM, and also others working in this field who were not members.

As a consequence, we agreed that communications should be very much encouraged on a two-way process to and from the APPM executive team, so there would be:

- Two Newsletters per year, as at present, but also a number of shorter updates for members between these times, sent out to all members by email.
- A longer Annual General Meeting at the education day in November 2014 when your executive officers would lay out a potential vision for the future, and very much invite your opinions and involvement in the APPM's development.

So, a series of statements and, if I may, some questions for all of us to consider that the APPM:

- Helps ensure optimal standards of education, training, practice and links in Paediatric Palliative Medicine including through the work of the Royal College of Paediatrics and Child Health (RCPCH), the Royal College of General Practitioners (RCGP), TfSL and other relevant organisations.
- Work is continuing in the following:
 - i. Revision of the Combined Curriculum in PPM will be completed in the next six months, under the leadership of Dr Yifan Laing, with significant contributions from APPM members ; also see the article in this Newsletter from Dr Mike Miller on the work of the College Speciality Advisory Committee (CSAC) of the RCPCH.
 - ii. 3rd edition of the APPM Formulary to be launched later this year, completed under the leadership of Dr Sat Jassal, with input from many others.
 - iii. Local and regional study days around Britain.

APPM is already working in a number of areas related to the above, but in the future are any of these areas in which you can contribute?

- Workforce planning for doctors working in NHS children's units and children's hospices – a group is beginning to look at this in conjunction with Together for Short Lives

Have you an interest in helping plan our workforce for the future?

- Identification of priorities for paediatric palliative care research, providing direction and facilitation for research as appropriate. APPM members are clearly involved in research, and some offer input into the Together for Short Lives Research Group,

But should APPM have its own parallel group or not?

What do you think?

In summary,

at the APPM AGM and education day in November, areas of the above will be discussed, and there will be an election for some places on the executive. Between now and then there will also be a call for more of our members to either stand for these places and/or to work on short life working groups related to the above areas. Please do consider the above, and if you have ideas or feedback, please reply to:

- Pat Carragher (patcarragher@chas.org.uk)
- Lynda Brook (Lynda.Brook@alderhey.nhs.uk)
- Dermot Murphy (dermotmurphy@nhs.net)

and/or offer views at the meeting in November in London.

I hope to see you there, or to hear from you before then.

Best wishes to all

Pat Carragher.

Chair of APPM

(on behalf of the APPM Executive)

So what's the CSAC got to do with PPM?

The General Medical Council (GMC) have the statutory responsibility of ensuring that all doctors are properly trained for the job they do. For post graduate training this duty is passed to the various Royal Colleges. The colleges then have Central Specialist Advisory Committees (CSAC) to advise them on the training and assessment of specialists. There are 23 subspecialists CSACs in the Royal College of Paediatrics and Child Health (RCPCH), with Paediatric Palliative Medicine (PPM) being one of the latest and smallest. These subspecialists train within a national structure organized by the CSAC and are known as Grid Trainees. This CSAC advises the college that a grid trainee has undertaken appropriate training and has passed the assessments at a sufficient level to be awarded a Certificate of Completed Training. They can apply for Consultant posts once they are within six months of acquiring a CCT.

NHS appointment committees interviewing for consultant posts in Paediatric Palliative Medicine should have a representative for the PPM CSAC on the committee to advise the committee if the successful applicant has the necessary qualifications. This forms part of the quality control to ensure that any doctors appointed as Consultants in PPM are able to work to the required standard. It is also recommended, but not mandatory, that hospices also involve the CSAC for support, advice and consistency over non NHS consultant posts

In order to set standards the CSAC establishes a curriculum. This states the knowledge, skills and attitudes doctors should have as they work at different levels in the specialty.

- a newly qualified doctor (level 1),
- a doctor who has completed post graduate general paediatric or GP training (level 2),
- a doctor who has a special interest in PPM, usually through some sessions in PPM in hospital community or hospice settings (level 3)
- A doctor working at specialist level in PPM (level 4).

The members of the CSAC recognize that the curriculum applies not only to paediatricians but to general practitioners and doctors primarily trained in other fields who work in children's hospices. Although it has no statutory power to control the quality of these doctors, it is working with the Association of Paediatric Palliative Medicine (APPM) and

Together for Short Lives to set standards to ensure that children with palliative care needs are well cared for.

More recently the CSAC has been asked to set standards for those consultants who wish to work in another branch of paediatrics (i.e. general, community or neurology) but obtain recognition that they have a Special Interest in (SPIN) PPM. At present this can be obtained without having a post in PPM as these are so rare. These doctors will need to find a doctor working at level 3 or above to support their training and assessment in PPM.

Balancing supply and demand is a fourth function of the CSAC. At present PPM seems to be in a 'Catch 22' situation of there being few posts being created as there are few doctors appropriately trained and few trainees considering taking up posts as there not many posts! There are three recognized training schemes for grid trainees at present with another two hopefully starting in the next two years. Funding is the main block. It should be possible for any trainee paediatrician to have some training in paediatric palliative medicine but it is advised that those wishing to have this formally recognized as a SPIN should contact the CSAC as soon as possible.

This structure may seem to be complicated (more information available on the RCPCH website www.rcpch.ac.uk) but in reality it is a fairly straightforward way of ensuring that doctors are well trained for the job they wish to do and children and young people are offered high quality medical care.

Mike Miller

Perinatal Palliative Care

There are now two more resources available from TfSL

Perinatal Palliative Care Framework, Goals and Standards for Perinatal Palliative Care
http://www.togetherforshortlives.org.uk/professionals/external_resources/3862_perinatal_palliative_care_framework

And

from Chelsea and Westminster Hospital NHS Foundation Trust

http://www.togetherforshortlives.org.uk/news/4293_palliative_care_on_neonatal_units_first_guidance_published

Law, Ethics, Intensive Care and APPM

A joint session between APPM, the Law and Ethics Forum, and Paediatric Intensive Care was held on the last day of the 2014 RCPCH conference 1 April of this year.

Because there was so much debate about “Because we can, should we?” there needed to be a delay on the publication of the College’s **“Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework in practice.”**

We hope that when this is published it will give many of us some very useful guidance.

Calling all APPM members – please read and cascade!

The RCPCH has agreed to the approach from APPM, the PICU specialty and the Respiratory specialty for a tripartite meeting at the College’s next spring meeting on the afternoon of Thursday 30 April. Last year we joined with PICU and with Law and Ethics which worked really well. The probable commonality between all 3 specialties remains as, with on-going medical advances, **“Because we can, should we?”**

There are likely to be no easy answers, and considerations will always need to be assessed on an individual basis, but does anyone from the APPM or your colleagues have work that they would like to present in these fields for a plenary session (if so, please contact Pat Carragher) or through the shorter presentations – please see the college website for details as they emerge of how to submit abstracts and for closing dates for these

To Russia with Love?

Sat Jassal writes,

I have helped out the children’s hospice in Moscow and given them our old Graseby syringe drivers.

They have never used them until we introduced them.

Obviously they have been invaluable

From an email from Russia “Currently the First Children Hospice in Moscow supports 180 children in Moscow and 100 in other regions. We have 6 syringe drivers (thank you for this opportunity) and all of them are in use at the patients’ homes providing them better living conditions. With syringe drivers they live almost like healthy children, one of them even go swimming in the sea.”

Do you have any Graseby syringe drivers that are no longer in use? Could they be donated to our colleagues in Russia? Please contact Dr Sat Jassal sat.jassal@gmail.com

Dates for your Diary 2014

8th October:

Neonatal Palliative Care Interest Group,
Donna Louise Children’s Hospice, Stoke on Trent.

14th October:

Journeys and Destinations,
Ty Hafan Conference, Cardiff

16th October:

Current and future perspectives in palliative care on clinical outcomes for palliative care,
Alder Hey Children’s NHS Foundation Trust, Liverpool

14th November:

ASCS conference: Person Centred Healthcare for Children and Young People, Myth or Reality?,
Edinburgh

19th – 21st November:

European Paediatric Palliative Care Conference,
Rome

27th November TfSL:

Reaching out – for equity, effectiveness and efficiency in children’s palliative care,
London

5th APPM Paediatric Palliative Care study day

28th November 2014 Park Crescent Conference Centre, 229 Great Portland St, London, W1W 5PN

Programme

0900-0930		Registration and coffee	Chair:
0930-1015	Neurobiology aspects of pain in childhood		Prof Maria Fitzgerald, Prof Developmental Neurobiology, UCL
1015-1100	Palliative Care and Cardiology		Dr Joyce Lim and Dr Caroline Jones, Consultant Cardiologists, Liverpool
1150-1120		Coffee and Networking	
Chair:			
1120-1200	Fatigue in the teenage and young adult population		Dr Anna Spathis, Consultant in Palliative Medicine, Cambridge
1200-1230	APPM formulary: Updating drug information and new drugs		Anita Aindow, APPM formulary Pharmacist, Liverpool
1230-1330		Lunch	
1310-1410	Concurrent sessions:		Pat Carragher, Chair of APPM
1330-1410	APPM Annual General Meeting (AGM) (during end of lunch)		Dr Yifan Liang
	- Including paediatric palliative care training		Julie Bayliss, Nurse Consultant, GOSH
1410-1450	Nurses forum Workshop 1:		Maggie Breen & Julie Mycroft, CNS and Paediatric Pharmacist, Surrey
	a) Drug compatibilities and other infusion issues		Alex Mancini, Lead Nurse for neonatal complex, palliative and bereavement care, London
	b) Practical guidance on managing palliative care on the NICU		Louise Simmons, Senior Specialist Nurse for inborn metabolic disorders, Birmingham
	c) Metabolic disease in palliative care setting		

1450-1520

Coffee and Networking

1520-1600

Workshop 2:

Maggie Breen, CNS and Julie Mycroft,

a) Drug compatibilities and other infusion issues

Alex Mancini

b) Practical guidance on managing palliative care on the NICU

Louise Simmons

1600-1700

c) Metabolic disease in palliative care setting
Complex case series (Group with expert panel input):

Expert Panel: TBA

a) Complex pain

b) Neuroenteric failure

c) Breathlessness

d) Vomiting

1700-1710

Feedback and close of day

Places still available... for you?

2015 DATES.

22nd January 2015

Helen and Douglas House “Making a Difference Conference”

The King’s Centre, **Oxford**

For more information and to book your place please visit:

www.helenanddouglas.org.uk/conference2015

14th – 15th April 2015 :

Together for Short Lives Conference,
Birmingham

28th – 30th April 2015 :

RCPCH conference,
Birmingham

If you have comments, thoughts constructive criticism please contact the editor

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