

Association for
Paediatric
Palliative
Medicine

APPM

NEWSLETTER SPRING 2016

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From the Chairman



Dear colleagues ,

As we go to press with this Newsletter another one quarter of a year has passed. I know that we all know this already but I wanted to state it - there is increasing evidence that children's palliative medicine has an increasingly accepted role, and with this the membership of the APPM is increasing too, with interest not just from within the UK and Ireland but also beyond this.

We had another excellent Annual Conference in November 2015, and on your behalf, I wish to thank all the speakers for their contributions, the hard-working organising committee of Tracy Blount, Anton Mayor and Renee McCulloch for

Executive Committee

2016

Pat Carragher (Chair)

A K Anderson (vice-chair)

Anton Mayer (Sec)

Dermot Murphy (treasurer)

Sat Jassal (formulary)

Susie Lapwood
(revalidation)

Emily Harrop

Tracy Blount
(GP involvement)

Jonathan Downie
(trainee rep)

Renee McCulloch

Yifan Liang (CSAC)

Katrina McNamara
(Together for short lives)

Heather McCluggage
(editor)

their work, and many of you for attending, as well as

the organisational skills from the Together for Short Lives team.

Plans are well in place for the next one at the [Hilton NEC Birmingham on Friday 2 December 2016 - please hold the date,](#) further details will follow, in 2017 the annual day education day will be in London, with a booking already provisionally organised.

In November you elected a new executive committee and its members have been hard at work since then, seeking to:

- **Increase links** with other professionals who care for babies, children and young people with palliative and end of life care needs, and we are looking for colleagues particularly from neonatology who may wish to offer input into the APPM.

- Work with the College of Paediatrics and Child Health as well as NHS England and other agencies to promote further **workforce development**

- Update the **APPM Master Formulary** for its 4th edition later this year - Sat Jassal has already approached a number of colleagues to input on this.

- **Strengthen links with General Practitioners** working within paediatric palliative care. Tracy Blount has contacted all children's hospices as well as other related organisations, and is developing the next steps.

- Build on Michelle Hills' excellent work in developing **trainee workshops and meetings** which have been very well received, to the

extent that they will now run twice yearly - and a welcome to Jonny Downie as the trainee representative as he seeks to continue this important work.

- Develop an increasing number of **regional meetings** which are relevant to the aims and objectives of APPM, not least in education and support of colleagues at the “clinical coal-face” of care for children with palliative and end of life care needs.
- Input into the development of the **Diploma on Palliative Medicine (Paediatric Option)** as its team ensures it is as relevant as possible to the needs of its students. Also into any **other relevant post-graduate course** as they develop.
- Update the **APPM website** to ensure its relevance to you and to others. Anton Mayor has been working directly with Together for Short Lives to so our website will work in parallel with theirs acting as a signpost to resources and information.
- Highlight the importance of **research within the APPM**, and to publicise that there are submissions for grants for work in paediatric palliative care from Liverpool, GOSH, Rainbows and Oxford - please do contact Susie Lapwood for more information. Dr Lorna Fraser (University of York) continues to develop work in the field of data collection, and the APPM / Together for Short Lives Research Group meets regularly to facilitate coordination of research in Paediatric Palliative Medicine. [see full article]
- To foster and develop our **international links**, in particular with the European Association for Palliative Care (EAPC) and the International Children’s Palliative Care Network (ICPCN) . Anton Mayor and I are working to forge closer links to the Association of Palliative Medicine (APM) - more on this soon.
- **Continue to work in close association with Together for Short Lives**, acknowledging the excellent administrative back up that “Together” continues to offer the APPM. We would like to thank Katrina McNamara, in particular, for her tireless efforts to ensure this is the case, as well as her contributions into much of the work of the APPM.
- Meet **monthly as an executive steering group** to ensure progress is ongoing in the above range of activities and ,very importantly, to consider how best to receive and action your ideas and comments, developing “task and finish” groups to achieve all this!

I will stop but this list is not exhaustive - however, I do want to mention that the **ChiSP study (Children in Scotland requiring Palliative Care: identifying numbers and needs)** was published in November 2015 - although its principal investigators, Lorna Fraser and Bryony Beresford, conducted this work in Scotland, I believe it has ramifications for the rest of the UK - if you haven't seen it, I commend it to you:

http://www.chas.org.uk/assets/0001/5573/ChiSP_report.pdf

So, best wishes for your continued work in the next ¾ of 2016!

Keep going, but do get in touch with new ideas or comments at either my new APPM email address of pat.carragher@appm.org.uk.

Pat

GPs!! Following a successful networking meeting at the last study day, the APPM executive team are pleased to be having increasing engagement with Hospice GPs. There are certainly more of you out there so please do contact Tracy (APPM GP) tracy.blount@appm.org.uk. We need to build a bigger picture of the varying roles GPs have in providing children's palliative care particularly in hospices. We aim to provide more accessible, relevant advice and support, collaborate more with the RCGP, and include more GP specific input in the annual APPM study days. All your thoughts and ideas are most welcome! The feeling from the ground is that a separate GP study day is not required but opportunity at the annual study day for specific GP focussed input and networking would be well received. Please let us know via the above address any specific teaching requests for this year's study day.

Also do not forget that your hospice role needs to be incorporated in the supporting information and discussion at your annual GP 'whole practice' appraisal. In particular, as with all medical roles, GPs need to provide hospice-specific colleague and patient/patient-proxy feedback at least once in the revalidation cycle. The GMC has recently put good practice examples (which includes a children's hospice) to help with systems for this on their website:

http://www.gmc-uk.org/doctors/revalidation/colleague_patient_feedback.asp

If you have any queries do contact Susie Lapwood (slapwood@helenanddouglas.or.uk).

*****SAVE THE DATE****

The APPM are pleased to announce the details for
the 7th annual study day.

For the first time it will be held out of London in response to multiple feedback requests and increasing delegate numbers.

DATE: Friday 2nd December 2016

VENUE: Hilton Birmingham Metropole, NEC (great for transport links!)

Members will receive further emails and booking information in due course.

Let us make it an even bigger success than 2015!

Apology

not all the presentations have been available from the 2015 study day. This is in respect to speaker autonomy and confidentiality. For the 2016 study day we will ask the speakers to provide a summary of the information but obviously this will be more work for them so we cannot guarantee it. Thank you for your understanding.

APPM / Together for Short Lives Research Group

- an introduction and update

Readers may not all be aware that there is a joint APPM and Together for Short Lives (TFSL) research group. This is a multidisciplinary group of researchers and practising clinicians set up to help develop a culture of research and build research capacity and awareness across the children's palliative care sector in Britain. The group is currently chaired by Professor Myra Bluebond-Langner.

Research is critical to the future development and success of children's palliative care services. There is a real need for evidence as to what interventions work, and to demonstrate the value, impact and cost-effectiveness of children's palliative care. It is also crucial that services understand the communities that they serve enabling them to adapt to changing demographics and medical advances. A recent editorial outlines the background of the group¹.

What does the group do?

Together for Short Lives has a section of its website devoted to research and the activities of the joint APPM TFSL research group:

<http://www.togetherforshortlives.org.uk/professionals/research>.

The group has recently reviewed our accomplishments to date, which provides a helpful summary (on the same link). For example:

- The group has developed a register of students undertaking doctoral studies in PPC, as well as a database of research networks relevant to PPC.
- An initial brainstorming meeting, discussed priorities in PPC research
- The group has provided input to consultations such as the revision of RCPCH guidance on ethics of research in children, and the Nuffield call for evidence on involving children in clinical research (through a separate short term research ethics task force).
- Advice has been given on individual research projects as requested (for example the BRAVES project, potential research into use of blended diets, TFSL BIG Study and STEPP Project) and the TFSL research strategy.

The research group includes a number of task forces, mostly 'task and finish' working groups, which have additional co-opted members according to the expertise required for each group. The current groups are:

- Task force on evidence to support service development and delivery (Chair Dr Lorna Fraser)
- Doctoral students' task force (intended to enhance awareness, networking and support for doctoral students). Chair Maddie Blackburn

- Task force to set up a Cochrane priority setting day for paediatric palliative care research. Short term group. Chair Dr Susie Lapwood.
- Publications task force (an ongoing group which produces Synopsis). Chair Lizzie Chambers.

Prominent APPM medical members on the joint research group include

Drs Lynda Brook,

Hilary Cass,

Ann Goldman,

Nicky Harris,

Susie Lapwood,

and Pat Carragher (APPM chair) as a corresponding member.

Other doctors are involved with individual task forces.

A subgroup within the APPM Executive is currently considering mechanisms to improve 2 way communication between the research group and the APPM Executive. More regular updates to APPM membership, both via the website and these newsletters can be expected. Watch this space and do let us know what might be helpful for you.

What can you do?

- Please do let us know if you are engaged in, or wanting to engage in an area of research around children's and young people's palliative care, as we seek to build an understanding of what research is currently being planned or undertaken, and to help network researchers sharing similar areas of interest. In particular if you are a doctoral student or hoping to be so, please get in touch.
- Please let us know if you have particular research interest or expertise, and would like to contribute to the group or one of its task forces as opportunities or vacancies arise (research group meetings are usually termly face to face in London. Task force commitment is variable according to the task).
- Please also let me know if you have any queries or suggestions about the research group or its work, or ideas about what information you would like to see accessible, for example via the APPM website or these newsletters.

Dr Susie Lapwood

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1. Promoting high quality research with life-limited children and their families: Establishment of a joint research group between Together for Short Lives and the Association for Paediatric Palliative Medicine <http://onlinelibrary.wiley.com/enhanced/doi/10.1111/jan.12857/>

British Academy of Childhood Disability 2016 Clinical Excellence Awards

BACD have recently had the following in their E news

“Clinical Excellence Awards recognise and reward NHS consultants and academic GPs who perform ‘over and above’ the standard expected of their role. The Advisory Committee on Clinical Excellence Awards gives awards for quality and excellence, acknowledging personal contributions. The number of new national awards in the 2016 round will remain at 300 for England.

The latest round of National Clinical Excellence Awards opened on Friday 11 March 2016 and will close at 5pm on Monday 16 May 2016. The onus is on you, as the applicant, to submit your completed online application form to ACCEA by the allotted date and time. Failure to do so means that your application will not be accepted for the 2016 National Awards Round.

All applications, new or renewal, must be made on the online system The Advisory Committee on Clinical Excellence Awards (ACCEA) has published guidance. If you would like to apply for BACD support to your application, please complete the form(s) and return to bacd@rcpch.ac.uk by **Monday 25th April**.

Master Formulary

Sat Jassal is already hard at work on the next APPM master formulary.

This one will be available on line in an active form which will allow real time updates as information/ recommendations change.

Web site Upgrade

Dr Anton May will be updating the APPM website in the next couple of months.

Photographs and mini biographies of all the exec members will be available.

There is a members only area planned.

If you have any suggestions as to what you would like on the website please contact anton.mayer@appmorg.uk

Upcoming Events



Friday 20th May 2016
Education Centre
Alder Hey Children's Hospital
Liverpool
L12 2AP

A Palliative Care Journey

National

Paediatric and Neonatal

Palliative Care Conference

Hosted By:




- 26-28 Apr
_RCPCH Annual Conference
- 28-29 Apr
_GOSH
Managing Children with Cerebral Palsy - more than a movement disorder
- 20 May
_BACCH
Trainees Day
- 1-4 June
_EACD 28th Annual Meeting
- 15-16 Sep
_BACCH Annual Scientific Meeting 2016

Development of a nationally agreed ECTP form

Many readers will be aware of the current work to develop a nationally agreed all age Emergency Care and Treatment Plan (ECTP) form.

A national Working Group was established in February 2015, with representation from Resuscitation Council UK, several Royal Colleges and other national groups. The group was set up to work collaboratively and build on major work already undertaken, in

order to develop a national form to apply to patients of all ages, to record anticipatory decisions about CPR and other life-sustaining treatment, and to guide decision-making in emergency situations in which the patient lacks capacity. Although not compulsory, the group hope that the form and decision-making processes would be accepted in all areas and all clinical settings, from home to hospice to hospital.

Six documents (including the proposed form itself and associated guidance for patients, relatives and health care professionals) were available for comment via Public Consultation which closed on 29 February 2016. <https://www.resus.org.uk/consultations/emergency-care-and-treatment-plan/> Collated feedback was due to be presented to the national Working Group at the end of March. The intention is that the documents will then be revised in the light of feedback. Pilot sites will then be identified, and educational resources developed.

There is no direct representation from APPM on the Working Group, although there are 2 paediatricians on it, including the chair of the Children's and Young People's Advance Care plan (CYPACP) collaborative. APPM Executive members have discussed and responded robustly to the detailed consultation: many of us in the APPM have found existing advance or emergency care planning documents to be working well, and much effort has gone into developing and improving these in recent years.

We look forward to seeing the finalised ECTP documents and to then discussing ways to work with them constructively. We do hope in due course a revised national ECTP form (or a recognisable simple adaptation of it for paediatrics) will be considered acceptable to colleagues working in paediatric palliative care, and indeed the paediatric sector more widely. If so, we would seek to incorporate a version of the new form into a revised CYPACP in due course.

Do be in touch with me if you have any specific queries or concerns, and watch this space!

Dr Susie Lapwood

Helen and Douglas House Hospices, Oxford
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slapwood@helenanddouglas.org.uk

Are you a PPC trainee and would like to attend a social function with other trainees?
Contact Jonny Downie. jonny.downie@appm.org.uk

If you would like to submit an article for the newsletter or make a comment
please contact the editor heather.mccluggage@appm.org.uk. thank you