

APPM NEWSLETTER

Autumn 2019

www.APPM.org.uk

Tweet us @theAPPMuk

From the Chair



Anna-Karenia (AK) Anderson

It is less than 2 months away but the APPM study day and our new research day is shaping up to be our biggest yet. We look forward to seeing many of our members at the day since it is, we hope, not just an opportunity to update your practice but also to network. Paediatric Palliative Medicine is a small field and I am keen for the APPM to continue to promote a sense of community.

In keeping with this ethos, it was cheering to see that our members voted overwhelmingly for nurse and allied health professional colleagues to gain full membership to the organisation. Previously nurse and allied health professionals only had associate membership. It is a major change to our constitution but reflects the day to day multidisciplinary practice of paediatric palliative care. A few members highlighted the need to ensure that the APPM continue to represent and support the concerns of doctors working in the field. I want to reassure members that this continues to be at the heart of the APPM work. There are several subspecialist paediatric groups that have successfully expanded their membership and are reaped the benefits of multidisciplinary professional engagement.

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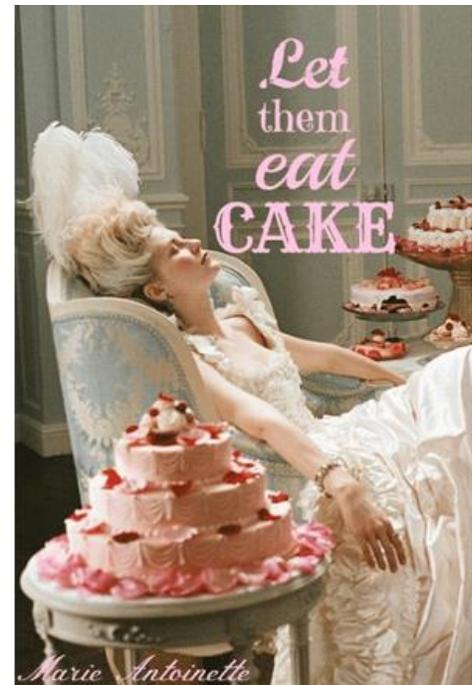
The new executive members have settled in well and are bringing fresh ideas and energy. As part of this, the APPM is holding a competition to promote our field positively to a new emerging generation of medical graduates (future GPs or Paediatricians). With the winners receiving book tokens from Oxford University Press. These tokens have been provided to us for sharing our newly updated APPM formulary for incorporation into one of their textbooks. This collaborative partnering is warmly welcomed and allows the APPM to start to promote paediatric palliative care at an earlier stage of medical training.

If you would like to be part of the executive we have two doctors, one nurse and one allied health professional vacancy on the executive committee. Please email admin@appm.org.uk for an expression of interest form (also available at the end of this newsletter). Details from your expression of interest form will be shared at the study day to allow consideration by the APPM members before formal voting at the AGM. I encourage you to put yourself forward. Fresh enthusiastic people are always wanted. I have included the executive membership guidance for workload and attendance (available at the end of this newsletter).

Sadly, Dr Sat Jassal is stepping down from the executive this November but he has reassured me that he will continue in his role as formulary lead. We are continually grateful to all the work Sat does for the APPM. Also Dr Richard Hain is stepping down. He has promised me to support the curriculum work for hospice GP and I am grateful for his support and guidance during his time on the executive.

With the Great British Bake Off returned to our tellies I realise that my initial volunteering to bake a birthday cake (10 year APPM anniversary) may not hold up to the public scrutiny. So if you are at the APPM study/research days, please come and say hello and practice platitudes about my baking!

See you in November



Guidelines

GUIDELINES SURVEY

You may remember a few weeks ago we sent out a brief survey regarding guidelines, looking at what guidelines people currently use, how they are reviewed and if there is any appetite for a more centralised pool of guidelines or some that are Nationally agreed rather than Locally?

If you have not yet had the chance to complete the survey and have 5 minutes to spare, it would be great if you can follow the link below. It is anonymous (with an option to let us know if you would like to get involved with any work on guidelines in the future).

<https://www.surveymonkey.co.uk/r/99CVSXD>

With massive thanks in advance for your help and time

Best wishes

The APPM Exec

Funding and Service Specification Update

In June 2019, NHS England announced a plan to incrementally increase children's hospice grant from £12 million to **£25 million** by 2023/24. This was in response to increasing calls about inequity between adult and children's hospices funding from statutory services and concerns about the sustainability of children's hospices in the face of a challenging charity funding environment. The discussions about the precise allocation, proportioning of this funding, to individual children's hospices is underway. Together for Short Lives and many children's hospices are actively engaged in these discussions with NHS England.



As part of NHS long term plan, a further **£7 million** by 2023/24 of matched funding with CCGs and/or STPs was also announced. This funding is for new paediatric palliative care services, not funded by a CCG/STP previously. This new money is greatly welcomed and there is currently no specifications attached beyond the remit of it to being to support the development of new services.

Furthermore the Prime minister announced a further £25 million cash boost, to be spent within this financial year, to 'protect hospices and palliative care services'. This is a one-off payment with guidance on this cash boost to be announced soon. It does not specify whether the extra funds are for adult or children services but NHS England has indicated that there will be clarity about the funding purpose soon.

Finally, specialist paediatric palliative care services continue to feel under strain in the face of increasing service demands. NHS England has listened to concerns within the sector and is meeting with specialist services to better understand the issues. The new encompassing paediatric palliative care service specification, covering specialist, specialised and local services, was due out but has been held to enable time to bring clarity to the issues of specialist services. We watch this space but are pleased that NHS England are listening and working with us.

Author: AK Anderson

Are you a GP? Can your practice help?

The RCGP are looking to recruit GP practices to take part in a pilot to review resources and tools for a current project around Developing Positive Transitions into Primary.

It is well recognised that adolescents with chronic illness find the transfer of care from paediatric to adult services very difficult, one constant service is Primary care. The RCGP with Together for Short Lives has set up this pilot to examine how best to support primary care to not only improve the transition journey for the young patient and his/her family, but also to reduce the workload for primary care teams all over the United Kingdom.

The project aims to:

- Engage with key stakeholders, including young people and their families, to ensure we design the right solutions for improving care within the primary care environment.
- Develop processes that will integrate the care between health professionals and the community and providing safe and supportive outcomes for the young person.
- Inform and support GPs and the wider primary care team by providing them the training and tools they require.
- Support signposting, engage and link GPs and the wider primary care team with wider support services and programmes in their locality, supporting young people into those services and improving outcomes.

It is envisaged that Multidisciplinary Team Meetings (MDT) will be the core clinical management structure for the transition and ongoing care process, making MDT meetings the keystone for the transition proceedings.

Pilot practices will ideally be:

A rural practice without a care navigator

A large urban practice (ideally) with a care navigator

These practices will help to trial and test new processes in order to improve the needs of patients, parents, carers and GPs.

If you are interested in participating in this pilot, please contact Hayley Dunn, Knowledge Transfer Manager at the Royal College of General Practitioners Hayley.dunn@rcgp.org.uk to express an interest no later than **Monday 14 October 2019**. Practice involvement will be voluntary basis.

EDUCATIONAL OPPORTUNITIES

Please do let us know of anything you would like to contribute to future newsletter - we are always keen to share knowledge/opportunities. Email: newsletter@appm.org.uk

For those wishing to travel overseas...



11th World Research Congress of the European Association of Palliative Care

Palermo, Italy
14-16 May 2020

European Congress on Paediatric Palliative Care
02-04. Sept. 2020, Kristiansand, Norway

European Congress on Paediatric Palliative Care
02. - 04. September 2020
Kristiansand, Norway

#PPC2020

Share Tweet

SAVE THE DATE – ROME, OCTOBER 7TH – 10TH , 2020



Or closer to home...

It will not surprise you that our **number one** recommendation are the **APPM study days(!)** – only a few tickets left so secure your place now via our website.

10th APPM Paediatric Palliative Care Study Day and Research Day

Association for
Paediatric
Palliative
Medicine

14 - 15 November 2019 | London

Join the APPM as we mark our 10th Anniversary with two days of learning, discussion, networking and celebration.

Attend either day or the full event

(Reduced rates for combined days, early birds and APPM members)

Thursday 14 November 2019

APPM Research Day

Showcasing the latest developments in paediatric palliative medicine research.

Cicely Saunders Institute
King's College London
Bessemer Road
London SE5 9PJ

Friday 15 November 2019

10th APPM Paediatric Palliative Care Study Day

Presentations, discussion and seminars on all the key issues in paediatric palliative medicine.

30 Euston Square
London
NW1 2FB

Who should attend?

- Paediatric palliative care doctors; encompassing paediatricians, hospice doctors, specialist GPs and trainees.
- Senior nurses and nurse consultants as well as specialist allied professionals working at a senior level in paediatric palliative medicine.
- Open to APPM members and non-members.

Email appm@togetherforshortlives.org.uk to register for updates on programme developments and discounts.



RCPCH Conference and exhibition

It was a successful 2019 Conference where delegates enjoyed inspirational talks and workshops from our membership, young people and the wider child health community. We're excited that planning for next year's flagship event has started, and we want you to get involved!

28 April 2020 - 30 April 2020 | ACC Liverpool

SAVE THE DATE: There will be a dedicated session for Paediatric Palliative Care.



The Together for Short Lives national conference

TIME FOR CHANGE?

A new vision for children's palliative care

25 & 26 March 2020
Manchester UK

Children's palliative care is changing

- The number of babies, children and young people requiring palliative care is growing
- It's becoming harder to secure statutory funding for respite care
- We're seeing more and more high-profile cases with complex ethical challenges.

Find out how we need to prepare and adapt so we can give seriously ill children and families the best possible care.

Who should attend:

- Practitioners delivering care and support to seriously ill babies, children and young people, including nursing teams, doctors, social care professionals and therapists
- Chief executives, senior decision makers, and leaders of care in voluntary sector children's palliative care and hospice services
- Academics with an interest in child health or children's palliative care.

Visit www.togetherforshortlives.org.uk/conference for more information, event booking and opportunities to share your work or exhibit at the conference.

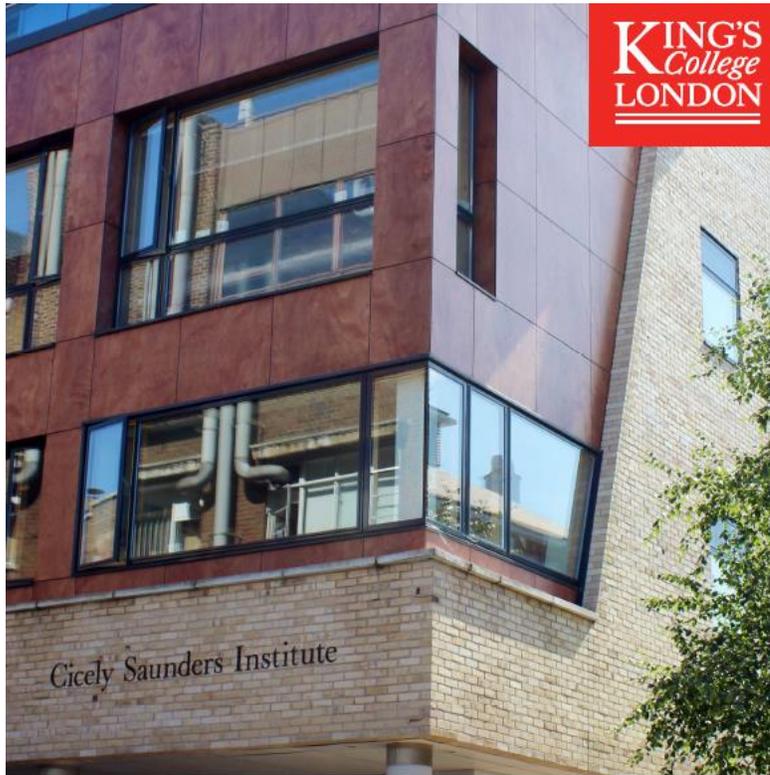
 #TFSLconf @Tog4Shortlives

 0117 989 7831

 conference@togetherforshortlives.org.uk

Together for Short Lives is a registered charity in England and Wales (1144022) and Scotland (SC044139) and is a company limited by guarantee (7783702).

More commitment than a conference but why not aspire to a higher degree?
We have been asked to advertise this course (other courses are available from other providers).



The Cicely Saunders Institute

Palliative Care

MSc/PG Dip/PG Cert and other short courses

Developing Leaders in Palliative Care across the world

kcl.ac.uk/palliative



Core modules:

- Research Methods & Statistics in Palliative Care
- Biology & Management of Symptoms in Advanced Disease
- Psychosocial, Cultural, Ethical & Spiritual Care
- Service Organisation and Policy in Palliative Care

Optional modules:

- Advanced Psychosocial, Ethical and Spiritual Care
- Applying Epidemiology in Palliative Care
- Service Development and Management
- Advanced Pain and Symptom Control

Florence Nightingale Faculty of Nursing, Midwifery & Palliative Care

King's College London's well-established MSc in Palliative Care, developed with St Christopher's Hospice, has supported the career development of hundreds of healthcare professionals who are now advancing palliative care practice, research and policy nationally and internationally. The programme is designed to enable health and social care professionals to develop skills to critically appraise research and evidence on palliative care, conduct high quality research, improve clinical practice, and develop services across the world. This course is suitable for all doctors, nurses and other professionals working in palliative care, other specialties, research and more.

What we offer?

- High quality teaching by world leading experts
- A qualification that has a positive effect on career development
- Supportive learning environment
- Comprehensive and balanced curriculum.
- Flexible study (full time and part time options) available.

Why choose King's?

The Cicely Saunders Institute, King's College London, is the first purpose built institute for research in palliative care, delivering worldleading research, education and multi-professional care. Alumni of the MSc have gone on to: become clinical leaders and innovators across the world; pursue further studies as PhD students; and become eminent researchers, clinical academics and professors in palliative care.

Find out more:

- kcl.ac.uk/palliative
- [/PG/CicelySaundersInstitute](https://www.facebook.com/PG/CicelySaundersInstitute)
- [@GSI_KCL](https://twitter.com/GSI_KCL)

This leaflet was printed in the Spring of 2018. Although it was up-to-date at the time it was produced, please make sure you check our website (kcl.ac.uk/study) or contact us directly for the very latest information before you commit yourself to any of our courses.

Voice of the student

This course has been a fantastic opportunity to study in an exciting multidisciplinary environment and learn from experts in clinical and academic palliative care. Having the modular approach to teaching has also made the course more feasible, as it allowed me to fit my studies around my work and home life.

Lisa, Part-time UK student

Application:

Applications can be made via apply.kcl.ac.uk

Please email mscpallcare@kcl.ac.uk for more information.

For interested trainees: the next APPM Trainee Study Day will take place on **Friday December 13th 2019** at the RCPCH in London.

Provisional plan for the day:

- Syringe drivers and PCAs: prescribing principals and practicalities
- Non-invasive ventilation, cough-assist machines and suction apparatus in the palliative care setting
- Managing tracheostomies and their complications
- The TENS machine and beyond: a look at TENS, nerve blocks, epidurals and intrathecal pumps

For further details and to book, contact one of the APPM Trainee reps: Trainee@appm.org.uk

Competition time

We are pleased to announce three new, exciting, annual APPM competitions (open to members and non-members).

Firstly, a **photography** competition. We are looking to improve and expand the photos on the APPM website, and so are inviting entries for a photography competition. Please send us your entries on a theme of “What Paediatric Palliative Care Means to Me” by 5pm on Wednesday 6th November 2019. The entries will be viewed and scored by members of the APPM executive committee. All suitable entries will be displayed at the November 2019 study day the following week. The winning entry will be given a prize of £50 of



Oxford University Press vouchers, and the photograph will be used on the APPM website. The winner will be announced at the study day. Runner-up photographs will also be considered for use on the website. Please email chair@appm.org.uk with any entries (and to request a copy of our consent form for use of the photographs in the APPM display and website). Please also adhere to your local consent policy if taking or sharing photographs of patients or families.

Secondly, an **undergraduate essay writing** competition. Open to all medical undergraduate students in the 2019-2020 academic year. Please write a 500 word essay entitled “What Paediatric Palliative Care Means to Me”. Please send your entry to chair@appm.org.uk by 31st July 2020. The essays will be reviewed and scored by members of the APPM executive committee, and the winner will be contacted by email by end of September 2020. The winning entry will receive £50 of Oxford University Press Vouchers and will have their essay printed in the APPM autumn 2020 newsletter, as well as a free place at the APPM 2020 study day (excluding travel and accommodation), where they will receive a certificate and the voucher prize (these can be posted if the winner is unable to attend). The prize for the essay judged to be in 2nd place is £25 of Oxford University Press vouchers.

Finally, a **postgraduate audit** prize. Open to all postgraduate doctors who are in foundation or paediatric training posts (or doctors in non-training posts who have not reached the level of Consultant) in the 2019-2020 training year. Please complete an audit, on a topic of your choosing, that is relevant to Paediatric Palliative Medicine. Please send a powerpoint presentation of your audit (maximum of 20 slides) to chair@appm.org.uk by 31st July 2020. The audits will be reviewed and scored by members of the APPM executive committee, and the winner and runner-up will be contacted by email by end of September 2020. The winning entry will receive £50 of Oxford University Press vouchers and will receive a free place at the APPM 2020 study day (excluding travel and accommodation), where they will receive a certificate and the voucher prize, and will have the opportunity to do an oral presentation of their audit. The prize for the audit judged to be in 2nd place is £25 of Oxford University Press vouchers.

APPM Master Formulary

The APPM is delighted to announce that it will be launching the **fifth** edition of the master drug formulary at the APPM conference in November in London.

The formulary has been compiled by a list of national experts both medical and pharmacists. This addition has also been subjected to international peer review as well as peer review from the membership of the APPM. Every entry within a formulary has been extensively reviewed and updated with the latest research evidence. A number of drugs have been removed from the formulary as there are no longer used in paediatric palliative care and one new drug Tapentadol has been added. Following feedback we have also added new appendix on conversion of gabapentin to pregabalin and back as well as use of benzodiazepines.

A hard copy of the formulary will be given free to all attendees of the APPM national conference in London. Additional copies may be purchased at the meeting or by post.

Please let us know what you think about the newsletter, and send any suggestions/requests for content

by email: newsletter@appm.org.uk or tweet: [@theAPPMuk](https://twitter.com/theAPPMuk)

Obituary for Dr Alison Guadagno (1970–2019), an APPM member

Words by Ellie Bond

In Palliative Care we get used to Dying, Death & Bereavement, and helping folk through the deep, dark pains of loss, but suddenly it all doesn't make sense when it's one of your own.

Alison Guadagno lived life like she worked; at full throttle! She packed it full with energy, humour, creativity and passion, heading home after a diligent day on the wards to whip up a quick show-stopper cake for a school project that would've made Paul Hollywood weep! Her passion as a medic was only surpassed by her presence for her children as a Supermum.

Her commitment to her work and her support for her patients and colleagues was indefatigable, and she was known to scoff at a day's absence for a mere marathon-induced metatarsal break; her juniors soon learnt to wear trainers just to keep up with her!

She studied at Glasgow Medical school in the 1990's where she met her wonderful husband, Joe (Neurologist) and they truly lived the dream of the bright and beautiful couple going places; Cambridge, for a quick PhD for Joe, and Ali completing her Paediatric Neuro-disability specialty training with a certain Michelle Hills.

Then up to Newcastle for a Consultant post at The Great North Children's Hospital, with additional sessions in Paediatric Palliative Care, which soon became her devotion.

Onwards and upwards, she drove her vibrant, energetic passion for her Neuro-disabled patients, and to pave the way for a better, funded Paediatric Palliative Care service in Newcastle.

In December 2017 she texted me at Martin House with the heart-breaking news "Got a Brain tumour; No, not a joke!"

Sadly, being married to a Neurologist doesn't protect you from the heinous evils of a GBM, but does get a rapid service to the MRI scanner.

Ali threw herself into staying fit whilst completing her chemo and Radiotherapy, and was supported throughout by the "Incredibles" lady runners of Ponteland who helped her train and complete the Great North Run last year in full Lycra superhero outfits.

Regrettably, the London marathon was a feat too far for this Incredible Lady, but some of the Lycra ladies still ran it this year in her honour.

Ali was told just before she died that her drive and perseverance in producing a detailed business plan for NHSE and a funded Palliative service for children in Newcastle was soon to be granted in the year that she died. If she could have she would've celebrated in style with some champagne and cheers!

She died beautifully peacefully in a hospice in Newcastle with Joe by her side. She leaves behind her gorgeous family including 3 children and her dear Joe. She is hugely missed by us all.



‘Call for expressions of interest in APPM executive membership’

Dear APPM members,

We have two medical, one nurse and one allied health professional executive member vacancies. The nurse and allied health professional executive members are new roles on to the executive.

Please see below a description of the APPM exec role and commitments.

If you are interested in being involved please fill out the attached form and send back to admin@appm.org.uk **by Monday 11th November 2019.**

We provide information on all nominees at the APPM study day on Friday 15th November 2019. A vote will be held at the AGM on the day.

I am happy to talk to individuals further about the roles available and would encourage people to apply.

Kind regards

AK Anderson

Consultant in Paediatric Palliative Medicine, Chair of the APPM

chair@appm.org.uk

Guidance for executive committee members

1. Attendance: Attend 50% of the meetings in one year (staying at each meeting for >75% of the meeting time). Co-opted members who are representing a group eg TFSL or CSAC can, at the chairs discretion send another representative or written information.
2. Meetings:
 - a. Study day (London):
 - i. June meeting outside London
 - ii. Nov (Thurs) meeting in London
 - b. Study day (Birmingham)
 - i. June meeting in London
 - ii. Nov (Thurs)meeting in Birmingham
3. Commitment: Two face to face meetings per year and two teleconferences per year (minimum). Take up of specific role within the executive which will be reviewed usually every 3 years.
4. Costs:
 - a. Meetings –travel costs and lunch (provided or refunded).
 - b. Study day-executive committee members have access to the very early bird rates. Study or research day is only free if the individual is presenting (not including chairing session)

If not able to meet minimal attendance requirements and/or take forward the specific role then the executive member should step down enabling another individual who may have more time to commit to the executive role.

Expressions of interest for APPM Executive committee

Positions and roles on the executive vary depending on current standing executive members. The executive committee strives to maintain a diverse representation of doctors across the field and UK.

The written statements below, on your background and reason for joining the exec committee, will be shared with the APPM members as part of the voting process to enable them to have an informed choice on who will represent them.

Date of application					
Name					
Current role					
Place of work(s)					
Region	England	N.Ireland	Wales	Scotland	
Email contact					
Circle which executive role(s) you may wish to be involved in					
Study day	Trainee	Education	Resources	GP and/or Hospice doctor development	
Research	Website	Guideline development	Other (please state)		
What group would you be representing (circle)					
General Paediatrician			Hospice doctor		GP
Nurse			Allied Health professional		
Briefly outline your relevant background and the reason you have expressed an interest in a particular role(s).					
Briefly outline why you would like to join the executive (include previous experience and skills and/or desire to develop new skills)					