

## Cancer52 All Member Update 2nd December 2016

## Dear All

I hope you are all well and enjoying a busy run up to Christmas ... and I look forward to seeing many of you at Britain Against Cancer next week.

And for those of you involved in either the Cancer52 board or the Policy and Public Affairs Steering Group - **Monday 12th December** is the next meeting. If further info on venue/timings etc is needed please email <a href="mailto:annette.parry@cancer52.org.uk">annette.parry@cancer52.org.uk</a>.

## Updates follow ....

- reminder about Britain Against Cancer next week (6th December)
  - Cancer52 is now a stakeholder organisation for the All Party Parliamentary Group on Cancer and as such was invited to organise a BAC talk in the afternoon of the conference.
  - the session is called An insight into patient experience for those with rare and less common cancers and speakers include Neil Churchill, Director of Patient Experience, NHS England, Emma Moore, Quality Health, and Colleen Fletcher, MP. More details here.
  - find us on the <u>Orchid</u> stand, with thanks to board member Orchid CEO Rebecca Porta.
- help needed in producing our consultation response on commissioning policies, specifically the NHS England consultation on Individual Funding Requests
  - Kate Morgan of Myeloma UK is leading on this and her request for information and help is <a href="here">here</a>. We would be very grateful for a response to this, with a deadline of <a href="mid-December">mid-December</a> for feedback to Kate (the consultation itself shuts mid Jan).
- an opportunity to apply for a bursary to the NICE 2017 conference
  - the conference is May 2017 but the patient bursary scheme is opening now and closes on Thursday 5th Jan 2017 with nothing being considered after that.

- opportunity to apply for the role of Patient & Public member of the Specialist Cancer Surgery Clinical Reference Group
  - The Specialist Cancer Surgery CRG is looking for a patient and public voice (PPV) representative to join their CRG to act as a champion for patients and their interests. PPV members are expected to use their skills and experience as patients, carers, members of the public or organisational representatives to constructively challenge, influence and help the CRG develop strategies in respect of its work programme. PPV members assist the CRG in understanding the diverse perspectives of patients, carers and the public relevant to the work of the group and provide a consumer viewpoint in all group activities.
  - Clinical Reference Groups (CRGs) are established to provide specialty-specific clinical advice and leadership for Specialised Commissioning. They sit under six National Programme of Care (NPoC) Boards, to which they are responsible, and form working groups which cover all of the major clinical areas within the Specialised Commissioning portfolio (with the exception of the very rare conditions). The role of the CRGs is to lead the development of clinical commissioning policy, service specifications and quality dashboards, advise on service reviews, conduct horizon scanning and advise on innovation, identify and explore opportunities to reduce clinical variation in healthcare and to deliver value.
  - The Specialist Cancer Surgery CRG sits under the National Programme of Care for Cancer and covers a wide range of oncological surgical specialities including anal cancer, brain, gynaecology, head and neck cancer, oesophagogastric cancer, thoracic surgery (lung) and urology.
  - the application pack is <a href="here">here</a>, any queries to Rupinder Dev at NHSE rupinder.dev@nhs.net
- · welcome to new member
  - It's On The Ball is a Norwich based charity, which aims to raise awareness of Testicular Cancer, provide support to those



- affected and their families; and to raise funds to enable those aims. The charity achieves its aims by giving talks and presentations in schools, colleges, and to clubs, sports teams, and business groups, as well as conducting awareness campaigns in the press and social media.
- Support to patients includes a buddy system for those recently diagnosed, a support pack for patients undergoing treatment, and financial aid if required on a case by case basis. <a href="https://www.itsontheball.org">www.itsontheball.org</a>
- publicising some of the great work going on out there .... a <u>video</u> that launched The Swallows charity recent conference, and news that Solving Kids Cancer's appeal against <u>NICE's decision</u> has been upheld.

our thanks to Cancer52 member
 Toby Freeman of the Robin Cancer
 Trust who ran a great social media workshop for us in November. The resultant tweets to report on the session provoked a positive storm of commentary and feedback.



• finally Cancer52 recently asked its members if they'd done any work on patient experience and the role of the CNS, and it was summarised and <u>a report</u> then supplied to the Cancer Patient Experience Advisory Group. With thanks to The Brain Tumour Charity and Pancreatic Cancer UK for their work on this.

Regards,

Jane

CEO

Cancer52







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Our mailing address is: info@cancer52.org.uk

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