

MEMBERS UPDATE

8 December 2017

Dear <<First Name>>

This bulletin reports on a very busy few weeks since we last communicated with members.

In this bulletin, you will find reports and information on the following topics:

- [Cancer52 parliamentary reception](#)
- [Cancer52 at Britain Against Cancer conference](#)
- [NICE Increasing Capacity within Technology Appraisals Consultation](#) - Cancer52 response
- [East of England Cancer Alliance](#) partnership opportunity
- [Summary of use MY data workshop](#)
- [ICPV VOICE 2018 course](#)
- [#myCNSmatters campaign](#) by Leukaemia Care
- Media request from [Tokyo Broadcasting Service](#)

Ingrid and I would like to take this opportunity to wish our members a happy Christmas and New Year.

Best wishes

Jane

Jane Lyons
CEO
[Cancer52](#)

News and Information

Cancer52 Parliamentary Reception

On 22 November, Cancer52, in partnership with Novartis, held a reception at the House of Commons.



The reception, hosted by John Baron MP, chair of the APPG on Cancer, was very well attended, with 22 patient

East of England Cancer Alliance

East of England Cancer Alliance  Following our involvement in the 'Delivering Transformation in

Cancer Outcomes Learning Event' in November, we have been contacted by the East of England Cancer Alliance who are very interested in the information we provided about Cancer52 and are keen to explore more closely, partnership working with us.

We are working with the alliance to help them better understand our organisation. To this end, we have been asked to complete the attached [document](#) to enable the alliance map where we deliver our services and highlight our impact within the East of England. In addition the table shows the

representatives, 32 member charities and 19 MPs supporting the event.

Steve Brine MP, minister with responsibility for cancer, recorded a video message of support which was shown at the event and can be viewed [here](#).

I would like to thank our three excellent patient speakers - Susan Oliver from [Pseudomyxoma Survivor](#), Roger Brown, from [WMUK](#) and Cancer52's own Ingrid Copperman.

We are now busy following up with the MPs who attended to ensure that rare and less common cancers is high on their agenda.

Photos and videos of the event can be viewed and downloaded [here](#).

Cancer52 at Britain Against Cancer conference 2017



Cancer52 had a strong presence at the annual Britain Against Cancer conference held in Westminster on 5 December.

Rare and less common cancers were high on the agenda and received mentions from many of the key speakers at the event, including John Baron MP, Chair of the APPG on Cancer and Jeremy Hunt, Secretary of State for Health.

We ran 2 well-attended breakout sessions entitled "[Rare and less common cancers: The patient perspective on Strategy delivery](#)" during which five patients told the audience about their cancer journey. We were honoured to have Professor Chris Harrison, National Clinical Director for Cancer, to speak and summarise the talks.

Our thanks to the patient speakers: Lyn Freeman, [NET Patient Foundation](#); Lesley Goodburn, [Pancreatic Cancer UK](#); Susan Oliver, [Pseudomyxoma Survivor](#); Roger Brown, [WMUK](#); Ingrid Copperman, Cancer52 and to Professor Harrison for his input. Also to Rebecca Porta of [Orchid Male Cancer](#) for allowing Cancer52 to 'perch' on their stand.

geographical areas in which the East of England Cancer Alliance operates, as well as its current system partners. They are keen to maximise voluntary sector impact in these areas by forming more system partnerships throughout the region. Please take a look at their [website](#) to find their current system partners listed.

We are therefore asking our members to help us complete the table. They originally asked for the completed table to be returned by 15 December but we have suggested that early January is a more likely and practical deadline, say Monday 8 January 2018. Please do [copy us in](#) on responses.

use MY data workshop summary

Following the use MY data workshop held on 12 October, we are pleased to share the [summary](#) of the [Commercial uses of patient data](#) workshop, which can also be found on the [use MY data website](#).

ICPV VOICE Course 2018



Vision On Information, Confidence & Engagement

ICPV are planning the next [VOICE Science for Advocates](#) (Vision on Information, Confidence and Engagement), a Science Course for patient advocates. VOICE is unique, the only course of this type in the UK and more information can be found in the [course flyer](#).

VOICE 2018 will be held once again at Barts Cancer Institute from 3-7 September. If you would like more information or are interested in registering someone for this unique and innovative course please contact [ICPV](#) directly.

#myCNSmatters campaign by Leukaemia Care

Leukaemia Care

YOUR Blood Cancer Charity

Leukaemia Care has launched its [#myCNSmatters](#) campaign and a new report entitled '[My CNS Matters: The invaluable role of a Clinical Nurse Specialist](#)'.

This report highlights the value that CNS access adds to the experience of leukaemia patients, including findings relating to 'watch and wait', provision of information and support, and patient involvement in their own care.

You can access the report and find out

NICE Increasing Capacity within Technology Appraisals Consultation

NICE National Institute for Health and Care Excellence

In November 2017 Cancer52 responded to the NICE Centre for Health Technology Evaluation consultation entitled "**Increasing capacity within Technology Appraisals**".

Whilst we of course share the desire for earlier and faster appraisal for new medicines our response focused on the seeming drop in levels of patient engagement in the HTA process and in the consultation process itself.

There will we understand be a second round of consultation in January 2018, and a speaker from NICE invited to our All Member Meeting on 24 January 2018 to explain the process.

Cancer52's full response can be read [here](#).



more about the #myCNSmatters campaign [here](#).

Tokyo Broadcasting Service

We have been contacted by Tokyo Broadcasting Service which is searching for a case study to feature in a news report. TBS is one of the major national TV networks in Japan which is making a news report about state funding for new drugs. Currently in Japan, there is no restriction on doctors prescribing approved drugs to their patients, with the health insurance system paying for treatment regardless of cost. Unfortunately this is becoming financially unsustainable and they are considering implementing a system similar to NICE to address this.

They would like to illustrate some of the issues and anomalies which NICE has created in England and are looking for an illustrative 'case study' of a patient who is being denied (or may be in the future) access to a drug which could improve their condition or their quality of life, on the basis of cost-effectiveness. The same drug may already be available to patients in other countries - or for a different condition.

If you have a case study which fits this profile, please email [Jason Priestly](#) at TBS directly.

Dates for your diary - 2018



24 January 2018 - Cancer52 All Member Meeting - 11am-1pm - London

25 April 2018 - Cancer52 All Member Meeting - 11am-1pm - London

11 July 2018 - Cancer52 All Member Meeting - 11am-1pm - London

17 October 2018 - Cancer52 All Stakeholder Briefing - House of Lords

www.cancer52.org.uk

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