



MEMBERS UPDATE

18 December 2018

Dear all

It was great to see some of you at the Britain Against Cancer conference on 4 December.

Thank you to those of you - or your patients - who were caught on camera for our film aimed at capturing the patient voice regarding ambition for the NHS Long Term Plan. Photographs from the day can be found in the [Members' Area](#) of our website (password: *Cancer52members*).



Cancer Minister Steve Brine MP and Cancer52 CEO Jane Lyons

News and Dates for your Diary

- [Genomics event](#) - 7 January - late alert!
- [All Members meeting](#) - 23 January
- [Cancer Research UK ACE Workshop](#) - 31 January
- Financial position of the [Cancer Drugs Fund](#)
- [Consultation on NICE Principles](#) - closes 11 February
- [ABPI and DHSC 2019 Voluntary Scheme for Branded Medicines](#)

Looking ahead to 2019

- Get Data Out
- PHE conference or event 2019
- CRUK 5th Biennial Early Diagnosis Research Conference
- [The NHS Long Term Plan](#)

Collaborating to personalise cancer care through genomic medicine

NHS England, in partnership with Macmillan Cancer Support and Health Education England, has asked us to invite members of Cancer52 to attend a stakeholder summit from 12.00-4.30pm on Monday 7 January 2019 at [Ambassador Hotel, Bloomsbury, London](#). Apologies for late notification, see deadlines below.

This event will be the start of a journey to help to set out the future direction for collaboration and activity across the charitable sector in this important area of future cancer care.

This is a great opportunity for charities to contribute in shaping the future direction of

this work.

Please register to attend by emailing [Tessa Pearson](#) by **Wednesday 19 December** stating your full name, organisation and whether you have any dietary requirements.

If you have any further questions, please contact Dany Bell at Macmillan Cancer Support DaBell@macmillan.org.uk or 07455 725053.

All Members Meeting

Wednesday 23 January 2019 - 11am-1pm

We look forward to seeing member charities at the first All Members meeting of 2019, which is taking place on 23 January, from 11am to 1pm, at [St Anne's Soho](#), 55 Dean Street, London W1.

We are delighted to welcome our speakers. Confirmed are David Fitzgerald, National Cancer Programme Director of NHS England, our the keynote speaker, presenting on the topic of 'the NHS LTP and what it means for people with rare and less common cancers'. And Paul Catchpole from the ABPI on the new **2019 Voluntary Scheme for Branded Medicines Pricing and Access** (see [below](#) for more information).

Please register your attendance [here](#).

Cancer Research UK Accelerate, Coordinate, Evaluate (ACE) Workshop

Thursday 31 January 2019

We are delighted that Cancer Research UK are running an ACE workshop to which members of Cancer52, especially those within an interest in pancreatic, non-Hodgkin's Lymphoma, stomach, oesophageal, and ovarian cancers, are invited. This is a great opportunity to contribute to the development of what we all hope will prove to be a great asset for rare and less common cancers.

The session has the following aims:

- To consider the potential for Multidisciplinary Diagnostic Centres (MDC) as an approach for diagnosing less common and rare cancers with a broad symptoms signature and low/varying predictive value
- To understand the typical presentation of these cancer types and identify barriers to earlier diagnosis and treatment, with a view to enhancing referrals into MDCs.

The outline running order is as follows:

- **MDC data:** Review MDC evaluation data with a focus on diagnoses of hard to detect cancers, including pancreatic, non-Hodgkin's Lymphoma, stomach, oesophageal, and ovarian cancers; including national figures
- **Discussion:** What is the symptom signature for these hard to detect cancers and what are the known barriers to earlier diagnosis?
- **Moving forwards:** Develop a plan of action for 2019/20

The workshop will be held at Cancer Research UK, Angel Building, 407 St John Street, London EC1V 4AD on Thursday 31 January 2019, from 11am to 2pm.

If you would like to attend please register your attendance [here](#). It is likely that because of space limitations there will be a cap on numbers so please register your interest early.

Cancer Drugs Fund

We are sharing an [update](#) from the Cancer Drugs Fund on its financial position.

Currently NHS England does not anticipate the Cancer Drugs Fund will exceed its fixed £340m budget in the financial year 2018/19. There's also a link through to the current [Cancer Drugs Fund list](#).

Consultation on NICE Principles

Members are invited to comment on the consultation of a new version of the principles that guide the development of NICE guidance and standards. The consultation will run until 11 February 2019.

The document brings together existing statements of the way NICE practice, in particular the principles set out in its [Social Values Judgements document](#). It also links to, and is consistent with, the legislation that establishes NICE in its current form, the NICE charter, and other legal, ethical and technical considerations that relate to decisions about how to allocate fixed resources in health and social care. It may be of interest to anyone involved in developing NICE's guidance and standards and who would like to know more about how NICE goes about its work.

The consultation details can be found [here](#).

In the interim Cancer52 has been invited to join a NICE workshop in January to help NICE shape patient involvement in developing health technology guidance. The aim is to work with us to identify new, improved and more standardised approaches to patient involvement, and to then help prioritise these into options for consideration.

2019 Voluntary Scheme for Branded Medicines from the Association of the British Pharmaceutical Industry (ABPI) & the Department for Health and Social Care (DHSC)

The new 2019 Voluntary Scheme for Branded Medicines Pricing and Access (Voluntary Scheme) is a non-contractual voluntary agreement between DHSC and ABPI - that provides stability and predictability for all parties in terms of the UK's branded medicines expenditure and the medicines pricing and access environment for the period 2019-2023

NHS England is also a party to the agreement. The scheme aims to achieve a balance between patient access, affordability and supporting the development of innovative new medicines, including support for small companies

The slides from the recent briefing with DHSC and ABPI on the 2019 Voluntary Scheme can be found in the [Members Area](#) of our website (password: *Cancer52members*).

Looking ahead to 2019

We're already very excited here about what we will all be able to achieve in 2019.

Further details will follow early in the New Year when we hope to be announcing some very good news regarding access to data including:

- more cancer data to be available through PHE's **Get Data Out** programme
- a one day **PHE event 2019** focused on rare and less common cancers
- And some substantial savings for a couple of places on the CRUK 5th Biennial Early Diagnosis Research Conference in Birmingham in February. Further details to follow but help with poster judging also likely to be requested

The NHS Long Term Plan

At the time of writing we still await the publication of the NHS Long Term Plan. There is a Cancer52 intention to respond once we have seen it, but we will be reiterating our top priorities for the LTP - see below - and using it as an opportunity to highlight the patient voice through our upcoming film on the topic.

- Priority 1: Establish a Rare and Less Common Cancer Task and Finish Group
- Priority 2: Create a high level system target that incentivises the reduction of deaths from rare and less common cancers
- Priority 3: Drive access to specialist expertise, treatment and support that improves outcomes for people with rare and less common cancers by providing Cancer Alliances with a ring-fenced fund and ensuring Cancer Alliances drive change

And finally...

Merry Christmas and a Happy New Year

Thanks so much to all our members, supporters, partners, board members (in particular



our Chair Jonathan Pearce), steering group members, patient speakers, the team at NHS England who have worked so hard this year to pull together the cancer community input to the NHS Long Term Plan, our Cancer Minister, Steve Brine MP and both the retiring chair of the APPGC, John Baron MP and the incoming chair, Nic Dakin MP.

Best wishes

Jane Lyons

Ingrid Copperman

www.cancer52.org.uk

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