

MEMBERS UPDATE

1 May 2018

Dear all

Last week, we held a very successful All Members Meeting attended by around 25 members, who heard presentations from the following speakers:

- Rebecca Rennison, Target Ovarian Cancer - update on Policy and Public Affairs Steering Group
- Sarah McDonald, Sarcoma UK - update on Access to Data Working Group
- Susan Oliver, Psedomyxoma Survivor - challenges of running a charity for an extremely rare cancer
- Jenna Dilkes and Chloe Kastoryano, NICE - Introduction to new NICE systems and overview on what's working and what's not for rare or less common cancers within NICE

All presentations can be found in the [Members Area](#) of the Cancer52 website (password [Cancer52members](#)).

In this bulletin, we are sharing the following with members:

- [Westminster Hall debate on NHS Cancer Targets](#)
- [NICE Adjusted TA - technical report example](#)
- [National Lymphoedema Partnership commissioning guidance document](#)
- [Cancer Drugs Fund - 2017-18 Q3 Activity Report](#)
- [Launch of Testicular Cancer Network and National Germ Cell Group](#)
- [Merkel Cell Cancer survey](#)
- [Leukaemia Care's Watch Wait Worry campaign](#)

Best wishes

Jane Lyons
CEO
Cancer52

Westminster Hall debate on NHS Cancer Targets

John Baron MP has tabled a Westminster Hall debate on **NHS Cancer Targets** on **Tuesday 1 May, from 2:30 - 4:00pm**.

John will be using the debate to talk about continued delays in the release of transformation funding and the link to the 62-day wait target, following on from his meeting with the Prime Minister in March. You can find the press release following from this meeting [here](#)

John is keen for other MPs to be encouraged to speak in the debate on the wider issues of cancer targets and outcomes. You can find the contact details for your MP [here](#).

NICE Adjusted TA - technical report example

As part of the consultation on the updated technology appraisal process guide (adjusted TA) NICE is in the process of developing a 'technical report'. This document would go out for targeted consultation prior to the first committee meeting, and would replace the PMB.

Cancer52 members are being invited to comment on an example version of the technical report. Please find attached an [example of this report](#) together with a [comments table](#) in which to collate any comments.

Please return any comments to [Gavin Kenny](#), Assistant Project Manager, Planning and Operations, Technology Appraisals by **5pm on Friday 11 May**, [copying us in](#) for information as Cancer52 will also be responding generally regarding rare and less common cancers.

National Lymphoedema Partnership commissioning guidance document

Cancer52 member, Lymphoedema Support Network is pleased to share the National Lymphoedema Partnership [commissioning guidance document](#). It is aimed at educating Commissioners in the hopes of reducing the geographical and condition cause inequality in the treatment of lymphoedema across the UK. The first 15/16 pages are the pertinent parts.

They are seeking support from organisations who feel that they would like to add their voice to theirs. The document will be soft launched over the summer and then will be formally launched in October at a Parliamentary reception.

If you would like to write a supporting statement and/or allow us to use your logo on the document please do get in touch with [Karen Friett](#), Chief Executive LSN.

Cancer Drugs Fund third quarterly activity report

On a quarterly basis, NHS England is committed to providing an indication of activity and the current CDF expenditure.

We are pleased to share the third quarterly activity report for the Cancer Drugs Fund for the period July-December 2017, which is available [here](#).

Testicular Cancer Network and National Germ Cell Group

Following the recent Germ Cell Conference on 23 April, the [Testicular Cancer Network](#) has been formally launched.

Also, from the conference, the [National Germ Cell Group](#) will become an entity.

Merkel Cell Carcinoma (MCC) survey

Cancer52 member, the NET Patient Foundation is a National UK organisation that supports the neuroendocrine cancer community. They have recently put together some new information for patients regarding Merkel Cell Carcinoma (MCC), to support a perceived unmet need within this community.

It is vital they understand the needs of this community and the ways in which they can best support patients and their loved ones, so have also compiled a short [survey](#).

They are asking for Cancer52 members' help to ensure this survey gets disseminated to as many MCC patients as possible.

Leukaemia Care's 'Watch Wait Worry' campaign

It is estimated that there are currently around 13,000 Chronic Lymphocytic Leukaemia (CLL) patients living on Watch and Wait in the UK instead of being treated. The length of time a patient is on Watch and Wait before requiring treatment is a significant uncertainty. For many patients there is a substantial emotional and physical burden that comes with watching and waiting, or rather, worrying. Leukaemia Care reveals, in its latest report, that over half of CLL patients on Watch and Wait report feeling more depressed or anxious following diagnosis. However, there is a significant lack in provision of both information and support to help these patients come to terms with their diagnosis and adjust to living with an incurable cancer. Therefore, a new guidance

document for patients has been launched, Living Well with Watch and Wait. This guide uses the experience of CLL patients to provide helpful advice and point towards the resources that can help patients during their CLL journey.

Download the 'Watch and Wait Worry' report and 'Living Well with Watch and Wait' [here](#).

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