



Minutes

APPGBC Bi-Monthly Officers' Meeting

Wednesday 27 April, 10.00am to 11.00am, Interview Room 2, Portcullis House

Attendees:

Amelia Chong (APPG on Breast Cancer) (AC); Jessica Faulkner (office of Sharon Hodgson MP) (JF); Andy Glyde (Breast Cancer Care) (AG); Francesca de Munnich (APPG on Breast Cancer) (FDM); Craig Tracey MP (CT); Philippa Whitford MP (PW).

Apologies:

Maria Caulfield MP; Jo Churchill MP; Sharon Hodgson MP.

1. Welcome and introductions

- AC explained that the new Bi-Monthly Officers' meetings would enable there to be regular contact with the officers to discuss breast cancer policy developments and upcoming APPG activity.

2. APPGBC Breast Cancer Prevention Debate

- CT apologised for not being able to attend the Breast Cancer Prevention Debate on Tuesday 26 April.
- PW suggested the debate could have been done as a bigger event with a larger audience including more MPs and big names – the Secretariat took this on board.
- PW said that from the debate it was clear we will have to accept money for prevention will come from money used for other areas, for example breast cancer research and treatment. A clear message is needed from politicians to articulate that alcohol, weight, smoking and exercise are four key factors that would make a big difference to public health. Core messaging is needed for schools, education, towns and so on.
- PW said that it would be good for a 90 minute Westminster Hall debate on breast cancer prevention to be held. She emphasised the need for a minister such as Jane Ellison to be involved and to get the message into the Department for Health.
- The Secretariat said that there was good engagement with the live tweeting of the debate.

ACTION:

- Secretariat to investigate timings for a Westminster Hall debate on breast cancer prevention.

3. Blog posts and information about officers



- AC said it would be good to have guest blog posts from officers of the APPGBC.
- AC suggested PW write a guest blog for the APPGBC site on her recent experience in Palestine performing breast cancer surgery on a number of Palestinian women.
- PW said it would be good to have more photos and information about the officers and members of the APPGBC on the website, explaining why they have got involved – the Secretariat agreed.

ACTION:

- Secretariat to update APPGBC website with information about officers and members.
- Secretariat to investigate the possibility of guest blog posts for APPGBC site including PW's trip to Palestine.

4. The APPGBC AGM

- AC said the APPGBC AGM will be held in the middle or end of July – before the summer recess but after the EU Referendum. AC asked what format the officers wanted for the AGM.
- PW responded by saying it would be good for the APPGBC to have a higher profile, more active members and a bigger audience. CT suggested that we go through the formalities of the AGM in a closed session, followed by an open session.
- PW also suggested refreshments and mingling at the start for members, peers and staff, as long as it was not too expensive. JF commented that it would be good for the event to specifically state it was open to staff and not just MP-only.
- CT said that the committee rooms are free to use and suggested that at the AGM there should be 5 minute speeches with lots of time for Q&A to open up the event.

ACTION:

- Secretariat to finalise date and book room for AGM.
- Format for AGM to be decided upon.

5. Breast Cancer Awareness Month Reception

- AC noted that the Breast Cancer Awareness Month (BCAM) reception will be held either on the 19th or 26th October. PW asked why it would not be held earlier in the month and AC explained that this was due to conference recess. AG also emphasised that many BCAM events are usually held earlier in the month.
- AC suggested there should be a theme. PW agreed and noted last time that the theme was metastatic breast cancer.

ACTION:

- Secretariat to finalise date and book room for BCAM reception.
- Theme to be decided upon for reception.



6. Activity with other cancer-related APPGs

- AC said that ministers respond well to joint activity with other APPGs. She said it was much easier to get prominent figures to attend and speak at events, for example Cally Palmer, when coordinating between the APPGs. This ensures that such individuals do not have to attend multiple events.
- PW agreed that the cancer-related APPGs working together is much more powerful and stated that so many issues are core to the groups, for instance cancer drugs.
- AC explained a one-day event on either 29th June or 4th July will be held by the APPGC on its Cancer Strategy Inquiry. Harpal Kumar and Simon Stevens have both been invited to attend. AC asked if any officers from the APPGBC would want to sit on the panel. PW and CT said they were both very interested. JF said she would talk to Sharon Hodgson MP about this.
- AC explained that, following a letter written to him after the joint APPG cancer strategy breakfast, Professor Ian Cumming, Chief Executive of Health Education England, had agreed to meet the cancer APPGs. The APPGC is coordinating this.

ACTION:

- Secretariat to let the APPGC know that officers are interested in taking part in Cancer Strategy Inquiry.

7. Update on the Cancer Drugs Fund

- AC said she appreciated the CDF is an English system but quickly outlined changes to the system. She explained although it will continue to have the same name, the CDF will change on 1st July and will move from being under the jurisdiction of NHS England to NICE.
- All new licensed cancer drugs will first be referred to NICE for appraisal. Cancer drugs on the old CDF will be reconsidered by NICE under new criteria in the summer.
- AC explained that Breast Cancer Now is not convinced by the new system and concerned that drugs won't be approved.
- PW said that the PACE system worked well in Scotland and that dialogue is being opened with big pharmaceutical companies. PW emphasised that pharmaceuticals are waking up to the fact that there is a deal to be done.
- CT asked how the assessment system differs in Scotland and PW explained that effectiveness, rather than cost is given the greatest weighting. PW also said that it is a new drugs and rare diseases fund, rather than a cancer drugs fund and that it is proportionally much bigger in Scotland than the CDF in England is. Furthermore, there is more real-time discussion for companies to drop the prices of drugs and more flexibility and negotiation.
- AC said she would update the officers on the new CDF system after the EU Referendum.
- PW said it would be good for there to be a session for the APPGBC to have an in-depth look at the new CDF.

ACTION:



- AC to update APPG officers on CDF in the summer.

8. Update on secondary breast cancer

- AG explained there is an issue of data collection and publication of data on secondary breast cancer in England. The National Cancer Registration and Analysis Service (NCRAS) have been asked what the barriers are and why data isn't being collected.
- Breast Cancer Care have launched the 'Who's Counting?' campaign to get campaigners to contact their local Hospital Trust to ask if they are collecting the number of people diagnosed with secondary breast cancer.
- AG explained Breast Cancer Care are conducting the largest ever UK-wide survey of those with secondary breast cancer. They are trying to find out what are patients' needs. Results are expected over the summer. They are having difficulty receiving responses from women in Wales and Scotland. So far, Breast Cancer Care have heard back from around 30 Trusts. The next step will be to make Freedom of Information (FOI) requests to Trusts that do not respond.
- The survey is particularly looking at clinical nurse specialists, key workers or whatever equivalent model is in place. The work is examining what provision and access there is for patients, if they don't receive it then why and what are the benefits of the different models. The aim is to increase the numbers of specialist nurses, so that everyone has access to one. These are the main areas of work for Breast Cancer Care over the next 12 months.
- PW asked if there is data in Scotland. To her knowledge, there is already data on 75 to 80 per cent of those who go to hospital. AG said that the Scottish Cancer Strategy stated that 4000 people in Scotland have secondary breast cancer.
- PW suggested that Breast Cancer Care look at the three different networks in Scotland. Data has been looked at against the QPIs and it is clear from the methodology that Scotland is further on at collecting data.

9. The year ahead for the APPGBC

- AC asked the officers present what they wanted the APPG to achieve in the year ahead. AC said that it would be good for the APPG to have a more outward-facing profile and raised the issue of whether to bring more patient voices in.
- AC and AG agreed that a theme along the lines of 'The future of breast cancer: where do we go next?' might be good.
- PW said something on prevention would make sense. This would stop people going through the physical and mental trauma of breast cancer in the first place. She particularly emphasised the need to interact with young people. AG said Breast Cancer Care have specific services for younger women.
- CT suggested it would be good to do something out of parliament, for example in hospitals and schools. This would raise the profile of the APPGBC and engage others outside of parliament. It is often intimidating for people to come to parliament, so it would be good to do more outreach.



- AC suggested doing something with the Institute of Cancer Research (ICR) in South Kensington. Through the Service Pledge, Breast Cancer Now does a lot of work with local hospitals that we could liaise with.
- PW proposed doing something around survivorship. Survivors could be asked what was and was not good about their experience and what is life like for them now.
- PW also raised the issue of whether the APPG wanted to have an impact on policy or simply act as a high-profile group raising awareness.

ACTION:

- Secretariat to look into doing something with the Institute of Cancer Research (ICR) in South Kensington.

Secretariat
April 2016