

Cancer52 Second Annual Briefing

Cancer52's second annual briefing at the House of Lords was attended by nearly 80 people who came to hear how the organisation is growing its membership and working towards its key aims.

The event, held in October 2012, attracted a mix of people representing Cancer52's charity members, partnership organisations from the UK and Europe, industry and government bodies and stakeholders in the rare and less common cancer community.

Speakers included Professor Sir Mike Richards CBE, Director of Domain One of the NHS National Commissioning Board and previously National Clinical Director for cancer, and consultant medical oncologist Dr James Larkin from the Royal Marsden Hospital, who detailed the issues and challenges in treating rare and less common cancers in the UK and promoting research into this area.

The briefing was led by Cancer52 chair Simon Davies, and introduced by the organisation's honorary president Baroness Delyth Morgan of Drefelin, who said: "No national cancer initiative should exist without rare and less common cancers having a view. I think that's a really great goal and I'm delighted to support that."



Honorary President Baroness Delyth Morgan



Professor Sir Mike Richards

Cancer52's membership has grown from 45 organisations to 61 in the past year, she added, showing those representing rarer cancers are increasingly coming together to make their voices heard.

Attendees next heard from Sir Mike Richards, who explained how many less common cancer organisations are facing the same challenges, emphasising the need for these groups to work together.

He highlighted the key problem of late diagnosis, an issue which has risen to the top of the agenda for cancer. Campaigns to highlight the symptoms of bowel cancer, for example, have increased awareness and led to more patients visiting their GP, with more people being referred to secondary care.

"I will acknowledge that we have started with the most common cancers in terms of trying to promote earlier diagnosis, he told delegates. "But we need to start somewhere and we need to learn from that.... We are now developing and rolling out a programme relating to blood in urine, because that is a common symptom for kidney cancer and bladder cancer, neither of which are in the common cancer league."



Dr James Larkin

Sir Mike also talked about the tasks of evaluating patient experience and measuring the quality of life of long-term cancer survivors, flagging up the patient reported outcome measures (PROMS) surveys, which have been trialled in breast, colorectal, prostate and non-Hodgkin's lymphoma cancer patients.

"We are trying to learn more about the quality of life of long-term survivors," he said. "Not just their experiences in the NHS but whether they have long-term symptoms or problems... We are going to be doing further PROMS work for bladder, ovarian, cervical and uterine cancer, and then we can think about other cancers in the future."

Dr James Larkin then spoke to attendees on service delivery, which he called a "critically important area, particularly for rare and less common cancers".

He highlighted the need to grow the number of patients with less common cancers entering clinical trials, and called for better training and infrastructure around patient care.

"I think research is critically important," he told delegates, "and without patients going into clinical trials I think it is going to be very difficult to make further progress." Around 10% of patients with melanoma enter clinical trials in the UK, he added, while the proportion of people with haematological malignancies like leukaemia or lymphoma entering trials is as much as 50% or more.



Simon Davies

Dr Larkin also spoke about the conflict between NHS plans to centralise teams looking after people with rare and less common cancers, and the need for people to have their care delivered as close as possible to home. "Ultimately I think that can be done in partnership and I very much like to think that this group, as it grows, will be a part of that discussion and lead that forward," he said.

Simon Davies then provided an update on the progress that has been made so far at Cancer52, highlighting the work that has been done to increase the organisation's profile, as well as its involvement in a constellation of symptoms group and a GP learning module.

Thanking the companies that have provided funding so far, he said that securing further finance was crucial to creating a "go-to organisation for anyone that has anything to do with rare and less common cancers."

Engaging with members and stakeholders is also essential in achieving the organisation's key aims, he added. "For those of you that are involved in policy, or the development of services or treatments, there are really rich rewards for communicating with this community of people that represent rare and less common cancers. It is a voice that previously hasn't been heard significantly and is becoming increasingly important."

For more information about Cancer52 please visit www.cancer52.org.uk