The All-Party Parliamentary Group
on Brain Tumours

A record of the minutes for the first General Meeting of this Parliament

Grand Committee Room, Westminster Hall

28th November 2017, 17:45 - 18:45

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Chair

Derek Thomas MP (Con, St Ives) was elected to Parliament for St Ives in May 2015. He was elected as the new Chair of the All-Party Parliamentary Group on Brain Tumours (APPGBT) on Monday 10th July 2017, following Rebecca Harris MP's promotion to Assistant Whip for the Government.

Guest Speakers

Dr Sheuli Porkess, Interim Executive Director Research, Medical and Innovation, The Association of the British Pharmaceutical Industry

Professor Silvia Marino, President of the British Neuro-Oncology Society and Director of the Brain Tumour Research Centre of Excellence, Queen Mary University of London

Dr David Jenkinson, Chief Scientific Officer, The Brain Tumour Charity

Dr Kieran Breen, Director of Research, Brain Tumour Research, and Member of the Committee for Advanced Therapies at the European Medicines Agency (EMA)

Mr Emlyn Samuel, Head of Policy Development, Cancer Research UK

Attendees

The following MPs were in attendance:

1. Derek Thomas MP
2. Peter Aldous MP
3. Mark Pawsey MP
4. Nicky Morgan MP

5. Albert Owen MP
6. Kit Malthouse MP
7. Jim Fitzpatrick MP
8. Iain Stewart MP
9. Henry Smith MP
10. Guy Opperman MP

Apologies

The following MPs gave their apologies:

- Steve Baker MP
- Rt Hon Tom Brake MP
- Rt Hon Alistair Carmichael MP
- Tracey Crouch MP
- Vicky Ford MP
- Jim Shannon MP

Minutes

Derek Thomas MP, Chair of the APPGBT, gave the welcoming words and highlighted the minutes of the previous meeting (10th July 2017). Mr Thomas said that this meeting was focusing on Brexit, one of the key priorities for the APPGBT. Other priorities for further meetings include the upcoming Task & Finish Group report and the impact of brain tumours on families. Mr Thomas said he believed that the Task & Finish Group report is due to be published before Christmas and so would be considered in due course along with a planned inquiry relating to the impact of brain tumours. Mr Thomas also outlined how it had been hoped that Steve Baker MP from the Department for Exiting the EU would be present to hear from the APPGBT together with Vicky Ford MP. However, both had given their apologies, and it is intended for the APPGBT to brief them with the results of the meeting. Mr Thomas introduced the topic of the current meeting "Securing brain tumour researchers' and patients' needs as we leave the European Union".

Dr Sheuli Porkess Interim Executive Director Research, Medical and Innovation for The Association of the British Pharmaceutical Industry, was the first guest speaker. She gave an overview of the priorities of the pharmaceutical industry and the Brexit Health Alliance on the Brexit process. Dr Porkess said that the pharmaceutical industry is used to dealing with uncertainty and risk. She said that the key priorities for the industry are to ensure that the UK secures regulatory alignment with the EU, that long term predictability in funding continues for UK projects and that collaboration in research is not affected. Alongside these key priorities Dr Porkess said that other key factors are ensuring that the best talent continues to be able to work in the UK and that trade continues to flow smoothly across the EU and UK borders. Dr Porkess highlighted that the industry was directly or indirectly responsible for 220,000 jobs in the UK and that supply chains were interlinked across the EU in very complex ways, with 2,600 final products made in the UK.

Dr Porkess said it was essential that regulatory alignment was prioritised to avoid disruption that would affect patients. Describing the system currently in place, with regulatory harmonisation

being coordinated by the European Medicines Agency (EMA), she stressed that the system was built for a free flow of goods and people, along with streamlined licensing of drugs. The current licensing system promotes innovation and there needs to be action taken to ensure that patients in the UK are not disadvantaged after Brexit.

Dr Porkess said that the UK played a significant part in EU research, highlighting that 20% of the EU-funded research was carried out within the UK with 80% of this research having co-authors located elsewhere within the EU. The UK also received €8.8 billion in research funding and was a key part of 23 of the 24 European Reference Networks and the Innovative Medicine Initiative (IMI). The IMI is particularly important for rare and less common diseases.

Professor Silvia Marino, **President of the British Neuro-Oncology Society and Director of the Brain Tumour Research Centre of Excellence at Queen Mary University of London**, described her journey as an EU national scientist working within the UK. Professor Marino studied in Italy and came to work in the UK, rising to the top of her profession and never feeling she was at a disadvantage for not being British. She says it is essential that this does not change following Brexit and knows other scientists feel the same. Professor Marino said that there are clear challenges caused by Brexit for people like herself and research more generally but that these are not insurmountable. Her biggest concern is the UK's ability to attract and retain staff if Brexit makes applications more difficult and individuals' situations more unstable.

Professor Marino said that, due to charities' investments in brain tumour research, the research effort is beginning to reach a critical mass with a significant increase in applications to a range of funders. However, there is significant uncertainty over how the applications to EU sources and those with a European collaborative element will be treated. Added to this is the key issue of collaboration, essential for research success and innovation. There is a concern that collaboration between countries, so essential to the exchange of ideas, may suffer from a range of unintended obstacles which could develop as a result of leaving the EU. Professor Marino also raised the issue of access to pan-European clinical trials and whether new pathways to engaging in clinical trials can be defined as soon as possible.

Dr David Jenkinson, Chief Scientific Officer of The Brain Tumour Charity, began by saying that while there has been a great deal of progress in the money raised by charities for brain tumour research projects, the majority are still collaborative in both money and skills. He added that while this is true of all cancers, it is particularly true of brain tumours where the 150 subcategories and paediatric tumours make collaboration essential on research, clinical trials and funding. Dr Jenkinson used the AspECT trial of paediatric brain tumours as an example of where an absence of barriers for patients and research are essential.

Dr Jenkinson agreed with the previous two speakers and raised the issue of visas for researchers, asking whether it was possible to guarantee tier 1 visas for EU national scientists to give some comfort and security for those already here. He added that people needed to feel secure in where they are living or where they were considering moving. Dr Jenkinson also stated that the UK benefited significantly from EU research funding, netting over €8 billion from €5 billion contributions, and that there was a clear need for alignment of regulation for the UK to continue to benefit from the EU's ability to develop innovative and novel treatments. He raised the issue of confusion over regulation following our departure from the EMA and whether approval for drugs would slow down. A key point raised by Dr Jenkinson was over access to the European Reference Network scheme as it is currently only open to member states.

Dr Kieran Breen, Director of Research for Brain Tumour Research and Member of the Committee for Advanced Therapies at the European Medicines Agency, began by explaining his role on the Committee for Advanced Therapies. The committee is made up of representatives of 28 member states in addition to co-opted experts and assesses applications for marketing authorisation from a range of different medicines and treatments including gene and cell-based therapies. Dr Breen said that the committee has at least five potential brain tumour therapies in the pipeline and that the committee works to help them reach patients quickly. The UK plays a big role in the process, with the Medicines and Health Products Regulatory Agency taking on 20% of the case load for product assessment. He said that the application process is centralised and there is a serious issue for the UK's involvement in this if it is outside the EMA.

Dr Breen said that these issues could see a loss of income for the MHRA but more importantly a delay in access for British patients to promising and innovative treatments. He continued to say that if there is a clean break with the EMA, companies will have to apply to two different bodies and through two potentially different schemes for product approval. This is likely to slow down patient access within the UK by between 6 and 12 months. This is due to the population difference between the UK and the rest of the EU where applications to the EMA for approval will have access to a market of over 500 million people while those to the MHRA will target only 65 million. He concluded by saying that there is scope for a major impact on the availability of new therapies in the UK as a result of the UK leaving the EU.

Mr Emlyn Samuel, Head of Policy Development, Cancer Research UK started by saying that he agreed the analysis of the other speakers and agreed with their views on the issues facing research in the UK. Mr Samuel summarised the work that Cancer Research UK had been undertaking since the referendum result, most notably to establish the charity's policies towards Brexit. Mr Samuel said the review focused on understanding what the UK added to the EU and looked to provide the Government and the life science sector with a full understanding of the current situation before policies could be made. He said they found that the UK made a significant contribution to science within the EU through intellectual leadership, participation in clinical trials, through advisory bodies, the funding of world class research centres and providing a training ground for science workforces.

Mr Samuel said that the report from this review was widely praised and raised important questions for the Brexit process. He said Cancer Research UK then began to formulate its position which contained similar priorities to the other speakers. Furthermore, mobility for researchers was crucial to attract and retain the best talent and that regulatory alignment was essential to build on the excellent record in clinical trials. Mr Samuel said that a quarter of the clinical trials funded by his charity had EU collaboration and that this was particularly true for less common cancers such as brain tumours. He ended by saying that the Government's response to addressing concerns expressed by Cancer Research UK so far was encouraging.

Questions

Following the presentations there was a short period for questions from the audience. Kathy Oliver, representing the International Brain Tumour Alliance, raised the issue of how important the patient voice is on EU-platforms and the EU Reference Network, and asked whether the

UK’s involvement should be protected and money ring-fenced to this end. This was acknowledged as an important consideration by the panel. Albert Owen MP asked whether the APPGBT would make a submission to the Business, Energy and Industrial Strategy Committee inquiry on Brexit and the implications for UK business: Pharmaceuticals inquiry. The APPGBT agreed that it would endeavour to do this.

The meeting closed at 18:45.

Next meeting to be confirmed.