

# All-Party Parliamentary Group on Brain Tumours

Minutes of the APPG on Brain Tumours held at 09:00 on 29/03/2022 via Zoom link

## PRESENT

- **Parliamentarians** - Derek Thomas MP, Greg Smith MP, Holly Mumby-Croft MP, Hilary Benn MP, Lord Polak, Lord Carlile of Berriew.
- **Invitees**- Jamie Lederhose, Kate Roberts (The Brain Tumour Charity)
- **Secretariat** – Sue Farrington-Smith (Brain Tumour Research), Hugh Adams (Brain Tumour Research), Karen Noble (Brain Tumour Research).
- **Support** – Callum Graham Robertson (HCC), Roxana Diba (HCC)

## PROCEEDINGS

### 1. WELCOME

Derek Thomas MP welcomed parliamentary colleagues and guests to the meeting and introduced the speakers.

### 2. PATHWAY TO CURE INQUIRY UPDATE

Sue Farrington Smith spoke of the failings of the government in funding research, and how the voluntary sector has been left to fill these gaps in funding. She went on to compare funding between different types of cancers and how Cancer Research UK's commitment to making lung cancer a priority leveraged funding from other areas. She then summarised the milestones made by the APPG since 2005.

Sue provided an update on the 'Pathway to a Cure' inquiry. Sue stated that the NCRI had reported that every large Brain Tumour clinical trial in the last 5 years has failed to improve outcomes. She said that elements that needed changing are the integration between scientists and clinicians, better translational research training for scientists and better utilisation of the Cancer Research UK experimental cancer medicine sector. She continued that the report highlighted that funding models were not fit for purpose, there was a lack of feedback for unsuccessful research applications and a lack of funding available for pre-clinical research. Further to this, there were issues reported in the barriers to careers in research, due to short-term contracts, lack of stability and a lack of funding.

Sue finished her update by outlining the next steps, namely the publishing of their position paper on the challenges faced in brain tumour research.

Hilary Benn MP asked what conclusions should be drawn from the fact that every large clinical trial has failed in the past 5 years and what would funders draw from that. He also asked for the status of the £30m that was left from the promised £40m by the government. Hilary said that perhaps the aetiology of brain tumours needed to be looked at, if looking for treatments has failed.

Garth Cruickshank responded to Hilary by saying that he was unsurprised by the failures of the clinical trials especially considering the complexity of certain brain tumours. Garth said that the influence of pharmaceutical companies meant that some trials were less well conceived than they could be. He continued, that a lot of benefits come out of these clinical trials, just not the ones specifically hoped for. For instance, one trial found a good method to control swelling. However, this finding was hard to put into clinical practice, as NICE were looking at it from a survival rate perspective, rather than one of improving quality of life.

Lord Polak also asked for the status of the £30m, to which Sue responded that Secretary of State for Health and Social Care Sajid Javid was using out of date statistics.

### 3. PARLIAMENTARY QUESTIONS UPDATE

Lord Carlile of Berriew said that as someone with no scientific expertise, the medical jargon in the House of Parliament needed to be simplified. He also said parliamentarians need some consistent conclusions and PQs that are phrased in a way that does not allow for evasive answers.

Hugh Adams responded to this with the details of recent PQs and their answers, thanking the panel members for their support. He said that in the last 18 months, 58 questions had been tabled, 17 on the government funding levels, 9 on supporting research, 13 on treatment and support and 1 on diagnosis. Hugh continued that as Jeremy Hunt recently disclosed that his mother had died from a brain tumour, the group were keen to engage with him. Hunt recently stated that they needed to find out as much about brain tumours as we do about other cancers. Hugh also said that conversations with Sajid Javid would be taken forward via a letter and other means as required.

Lord Polak stated that Sajid Javid should be invited to attend a meeting of the APPG for Brain Tumours.

### 4. CLOSING THE GAPS IN NHS BRAIN TUMOUR CARE

Jamie Lederhose began by describing the functions of The Brain Tumour Charity - funding research by investing £38m in the last five years, providing specialist support and information and campaigning to raise awareness of the signs and symptoms of brain cancers. Jamie continued that the results of the 1500 care surveys that have been completed over the past year have been used to inform their services. Jamie also highlighted to the members of the meeting that the respondents of the survey did not reflect the population as a whole, as the majority were white and more women responded than men. He said that the charity was developing a brain tumour-specific holistic needs tool, and submitting patient experience data for various consultations to ensure that this evidence is captured.

Kate Roberts from The Brain Tumour Charity followed up with some of the findings from their surveys. Kate said that only 79% of brain tumour patients had a clinical nurse specialist (CNS), despite the NHS long term plan recommending that every patient should have a named CNS. Additionally, only 59% of patients found that they could ask their CNS 'anything they felt like'. Kate said that this reflected the overworked and overstretched work burdens of CNSs. She continued that there was a 30%-point range in access across regions.

Kate also stated that they had found that holistic needs assessments, and the resulting care plan, had only been offered to 40% of patients in their survey, and only 21% of patients found that their care plan was working well, with a 48%-point range across the UK.

Only 42% of survey respondents had been informed of research participation, and only 35% were involved in some form of research. Again, a considerable range was found across the UK at a 37%-point difference between regions.

Heather Dearie agreed that she found that as a volunteer with Brain Tumour Support, a lot of patients felt they were "spinning in the wind", and more nurses are needed. Jamie agreed and said that it was a long-term problem with a long-term solution. He continued that they needed to see the government give the NHS the investment required to grow the workforce, but in the meantime, charities are doing a lot to provide the needed support.

Sue asked how much of the £38m has been invested into UK research. Jamie replied that about one third had been spent in the UK and the rest internationally, as they want to fund the best research wherever it is.

*5. CLOSE OF MEETING AND AOB*

Derek Thomas MP formally closed the meeting and thanked all supporters of the APPG.