The All-Party Parliamentary Group on Brain Tumours

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Tumour Surgery, Vorasidenib, Siobhain McDonagh and updates

Tuesday 14th November 5pm-6pm, Committee Room 15, Palace of Westminster

Agenda

Welcome from Chair, **Derek Thomas MP.**

Apologies received.

Matters arising from July meeting.

Introduction of Speakers:

- A holistic overview of the diagnosis, investigation, and treatment of patients with brain tumours, **Consultant Neurosurgeon Peter Whitfield.**
- Vorasidenib, **Connor and Dawn Emerton.**
- Campaigning to improve outcomes, **Siobhain McDonagh MP.**
- An update from the Tessa Jowell Brain Cancer Mission, **Dr Nicky Huskens.**

Discussion with APPG.

AOB and next meeting.

Speakers and Parliamentary Attendees

Speakers:

- Peter Whitfield
- Connor Emerton
- Siobhain McDonagh MP
- Dr Nicky Huskens

Parliamentarians:

- Helen Hayes MP
- Daisy Cooper MP
- John McDonnell MP
- Greg Smith MP
- Holly Mumby-Croft MP
- Siobhain McDonagh MP
- Philip Hollobone MP
- Caroline Ansell MP

Discussion Overview

The meeting brought together families, advocates, clinicians, parliamentarians, and key stakeholders from across the brain tumour space. Participants discussed the importance of clinical trials, incentivising both clinicians to run trials and pharmaceutical companies to expand existing trials. Discussion also centred around the ground-breaking drug Vorasidenib, and how the Government can incentivise pharmaceutical companies to invest and expand into the UK market.

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Discussion Summary

Welcome from Chair, Derek Thomas MP

Chair of the APPG, Derek Thomas MP (DT) welcomed attendees and emphasised the cross-party interest in brain tumours by welcoming parliamentarians from across the House.

Overview of the diagnosis, investigation, and treatment of patients with brain tumours, Consultant Neurosurgeon Peter Whitfield

Peter Whitfield (PW) gave a presentation covering the clinical biology of brain tumours, research within the sector, and current treatment options.

There are three types of brain tumours: intrinsic that sit within the brain tissue, benign that sit in layers around the brain, and metastatic which is cancer spread from other parts of the body to the brain. The symptoms of brain tumours are raised intercranial pressure, for instance headaches, drowsiness, nausea; parts of the brain incorrectly functioning; and seizures. MRI scans are key to the diagnosis of brain tumours.

Research on brain tumours is particularly complicated, given the difficulty of the blood brain barrier and the difficulty in getting drugs into the brain. Moreover, every cell has genes and particular genes give a marker which is key to diagnosing brain tumours. In research, it is key to ensure the same markers are compared, which is challenging given there are over 100 types of brain tumours.

There are several clinical research strategies looking at diagnostics, including advances in the MRI scanner, use of imaging and liquid biopsies, and interoperative strategies that include examples such as keeping patients awake to minimise collateral damage, use of imaging during operations and rapid diagnostic tests to use once the tumour has been inspected.

Positive trials for brain tumours are rare and clinicians are reluctant to run trials due to the increasing administration and scrutiny. There needs to be more incentives for clinicians to run trials.

Current treatments include:

- Open surgery
  - Patients drink a liquid which lights up the tumour, showing the tumour boundaries. Surgeons use a SIMS machine to navigate the brain, often a challenging task given that once open the brain shrinks and moves off target. During surgery patients are awake.
  - There is an opportunity for surgeons to administer drugs during surgery, but this would require a rapid diagnostic test to determine which drug is suitable, something not yet available.
- Radiotherapy
  - Radiotherapy is the standard, most effective treatment and protocols have improved; however, these improvements are not widespread across the country.
  - Often radiotherapy is used in conjunction with chemotherapy as radiotherapy tools are often too precise, focusing on a small volume of tissue. The brain tends to be

well protected from chemotherapy whereas radiotherapy can cause other debilitating problems.

- Drugs such as Vorasidenib
  - Trials have found that the progression through survival by patients taking Vorasidenib is substantially better than standard treatments.
- Physical treatments:
  - Tumour treating fields – recommended use of 18 hours a day and shows marginal increase over standard treatments. Due to its cost, NICE has not approved the treatment on a QALY basis. There is an international trial, TRIDENT, researching the timing of this treatment compared to chemotherapy.
  - Spinning magnetic fields – there is emerging evidence that this could be a promising treatment.
  - Cooking the tumour from within – this treatment has been experimented on mice but has not yet been trialled on humans.

Other emerging treatments include gene therapy and vaccines, however the efficacy of these is yet to be proved.

PW emphasised the need to facilitate living beyond a brain tumour by improving assessments of treatments, the use of precision medicine, and improving research and clinical trials.

When asked by DT if he was optimistic about the future of research into brain tumours, PW responded that he was, but that treatment companies need to be incentivised to expand clinical trials.

PW recommended the APPG speak with the British Neuropathological Society.

Vorasidenib, Connor and Dawn Emerton

Connor Emerton (CE) shared his brother's struggle with grade two glioblastoma.

He outlined the promising results of Servier's phase 3 clinicial trial for the drug Vorasidenib. Vorasidenib is the first drug to permeate the blood brain barrier. In America Vorasidenib is available through managed access however there is no way to access it in the UK. Despite initial statements, Servier have not made any applications to the MHRA early access scheme.

CE has been working with Daisy Cooper MP (DC) to positively engage with Servier to ask when Vorasidenib may become available to patients through managed access and urged other parliamentarians in attendance to engage and persuade Servier to expand into the UK market.

DC noted challenges around the UK's commercial market following Brexit, and the tone of conversations between the UK Government and pharmaceutical companies. DC suggested that companies are reluctant to spend money on MHRA applications with regulatory changes on the horizon that would mean any drug adopted by the FDA would be automatically adopted by the MHRA.

Siobhain McDonagh MP (SM) noted that she is due to meet with Servier shortly and welcomed others to attend. DT suggested that those with an interest in or information related to Servier meet to establish the key issues and solutions ahead of meeting with Servier and ministers.

Campaigning to improve outcomes, Siobhain McDonagh MP

SM emphasised the importance of increasing clinicial trials and incentivising clinicians to run trials. She further suggested that pharmaceutical companies should be incentivised to widen their clinical trials and expand into the UK market.

An update from the Tessa Jowell Brain Cancer Mission, Dr Nicky Huskens

Dr Nicky Huskens (NH) outlined the Tessa Jowell Brain Cancer Mission's current programmes which cover research, an examination of hospital services and treatment centres to identify gaps in service delivery and access to clinical trials, fellowships in oncology and encouraging clinical trial principal investigators, and engagement with the National Institute for Health and Care Research (NIHR) calling for funding backed by NIHR for clinicial trials on brain tumours.

DT thanked attendees for their time and closed the meeting.

Meeting Outputs

- The APPG agreed to engage with the British Neuropathological Society
- The APPG agreed to work with OurBrainBank on the group's recommendation around correctly storing brain tumour tissue.
- The APPG agreed to facilitate a discussion on engagement with Servier to identify the barriers to their expansion into the UK market.
- The APPG agreed to hold more regular, shorter APPG meetings.

Contact

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