



All-Party Parliamentary Group on Brain Tumours

Neuropathology, focused ultrasound and APPGBT updates

Tuesday 20th February 5pm-6pm, Committee Room 15, Palace of Westminster

Agenda

Welcome from Chair, **Holly Mumby-Croft MP**.

Apologies received.

Matters arising from 14th November 2023 meeting.

Introduction of Speakers:

- Neuropathology, tissue storage and whole genome sequencing an overview - **Professor Kathreena Kurian**
- Focused Ultrasound - **Mr Kismet Hossain-Ibrahim**
- An update from Tessa Jowell Brain Cancer Mission - **Dr Nicky Huskens**
- An update on recent brain tumour meetings at Westminster - **Hugh Adams**

Discussion with APPG.

AOB and next meeting.

Speakers and Parliamentary Attendees

Speakers:

- Professor Kathreena Kurian, consultant neuropathologist and Professor of Neuropathology at the University of Bristol
- Mr Kismet Hossain-Ibrahim, research fellow at the University of Dundee
- Dr Nicky Huskens, Chief Executive Officer of the Tessa Jowell Brain Cancer Mission
- Hugh Adams, Head of Stakeholder Relations at Brain Tumour Research

Parliamentarians:

- Holly Mumby-Croft
- Lord Aberdare
- George Freeman MP
- Will Quince MP
- Ruth Cadbury MP

Apologies received:

- Lord, James, O'Shaughnessy
- Lord, Stuart Polak
- Lord, James, Bethell
- Daisy Cooper MP
- Peter Gibson MP
- Mark Pawsey MP
- John McDonnell MP
- Sarah Owen MP

Discussion Overview

Discussion centred around neuropathy, focused ultrasound and how the whole system can work together to translate research into readily available life-saving treatments for patients. Attendees also discussed Siobhain McDonagh MP's upcoming private members bill on brain tumours and on the APPG on Brain Tumour's recent engagement with Servier (the manufacturer of Vorasidenib which is showing early efficacy in low grade gliomas) and a meeting earlier that day that the APPGBT secretariat provider, Brain Tumour Research, held with the Minister for Health and Secondary Care, Andrew Stephenson MP.

Discussion Summary

Welcome from Chair, Holly Mumby-Croft MP

Holly Mumby-Croft MP (HMC), an officer of the APPGBT, welcomed attendees including former Minister for Health and Secondary Care, Will Quince MP, and former Minister for Science, Research and Innovation, George Freeman MP.

Private members bill tabled by Siobhain McDonagh MP

Siobhain McDonagh MP's (SM) parliamentary researcher shared SM's apologies for being unable to attend and updated attendees on the progress of her private member's bill on brain tumours. This bill aims to introduce legislation to increase clinical trial availability for brain tumour patients. The bill will call for the NHS to set targets to increase the number of people with brain tumours participating in clinical trials, for every medical oncologist to take at least one course on brain tumours and for regulators to expedite applications for brain tumour treatments. The bill will call for direct referral options from opticians to an MRI scan and will also focus on deploying the £40 million pledged for brain tumour research in 2018.

It was noted that while this type of bill is rarely taken up by the Government, it is an opportunity to highlight these asks in the public record.

Overview of neuropathology with Professor Kathreen Kurian

Professor Kathreen Kurian (KK) gave an overview of the field of neuropathology and the treatment pathway for brain tumours.

KK noted the challenges of treating brain tumours and that while different patients may have the same diagnosis, the abnormalities in the genome are unique. She further noted the difficulty in removing the whole tumour without harming the patient.

KK shared that not all surgeons are currently asking for consent to collect and store tissue with a recent national survey finding that less than 30% of brain tumour patients were asked by their surgeon. She highlighted the importance of tissue collection and storage to understand the genome sequencing of tumours and the efficacy of different treatments.

KK continued that as part of the 'Closing the gap: a roadmap for equitable access to genomic testing' report conducted in partnership with Tessa Jowell Brain Cancer Mission, she has spoken to key stakeholders across the country to understand the obstacles in the pathway and why patient tissue is not being sent for genome testing. Responses pointed to the long travel distances for the tissue to reach the laboratory, a lack of system interoperability, staff availability and training, and delays in results. An adult patient would ideally start treatment

within six weeks of diagnosis and some tissue results are taking up to four months to receive. Patients and clinicians have become disillusioned by the long delays and have stopped asking or requesting for tissue storage.

The report makes five recommendations:

1. Establish a hub and spoke model of whole genome sequencing (WGS) with centralised Genomic Tumour Advisory Board (GTAB) oversight.
2. Fund central and local coordinators to support the WGS pathway to ensure tissues are transported effectively and efficiently.
3. Establish a National Brain Tumour Precision Medicine Board.
4. Invest in training for NHS professionals involved in the WGS.
5. Establish funded WGS pathways in Scotland, Wales and Northern Ireland.

Focused ultrasound with Kismet Hossain-Ibrahim

Kismet Hossain-Ibrahim (KHI) spoke on using MR-guided ultrasound for brain tumours. He noted that there is a wealth and breadth of research around focused ultrasound and it is currently used to treat essential tremors. There are currently three centres in England providing the equipment to treat essential tremors that could be used additionally to treat brain tumours.

KHI explained that focused ultrasound treatment is an effective treatment in penetrating the blood brain barrier and can target both the tumour and the blood vessels that feed the tumour. KHI explained that 5-ALA (5-Aminolevulinic Acid), a drink taken prior to surgery, causes the tumour cells to glow pink under UV light and allows the surgeon to decipher tumour cells from healthy cells to ensure the removal of more of the tumour and less damage to healthy tissue. Sonodynamic therapy (SDT) uses the energy of focused ultrasound to activate 5-ALA to selectively kill the tumour cells.

KHI emphasised that despite the potential efficacy and safety of SDT for treating brain tumours, there is not a large enough evidence base to fulfil the approval requirements set out by the MHRA. Despite the small patient population, KHI noted that this life-saving treatment had been fast tracked by the FDA but that the MHRA would not follow suit.

George Freeman MP (GF) agreed to meet with KHI to understand the key barriers preventing the repurposing of focused ultrasound for brain tumour patients. The APPGBT agreed to facilitate engagement.

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

Dr Nicky Huskens (NH) drew attention to Tessa Jowell Brain Cancer Mission's report, 'Closing the gap', that has been produced in collaboration with forty-one healthcare professionals, charity stakeholders, NHS England, Genomics England and the NIHR. The report presents cost-effective recommendations including around increasing genomic testing and access to precision-led trials. Tessa Jowell Brain Cancer Mission plans to host a roundtable to discuss the report's recommendations and will work with researchers and the charity sector to identify opportunities to deploy the £40 million pledged by the Government in 2018.

NH noted the Mission's work to understand accessibility to brain tumour treatments across the country and what innovative treatments are currently available. They will be working with hospitals across the country to collect and collate data on the number of patients treated and how they are treated.



An update on recent APPGBT activities

Hugh Adams (HA) updated attendees on the APPGBT's recent activities and meetings with Servier to address the barriers in market access for their drug, Vorasidenib.

HA noted the APPGBT's ongoing engagement with The British Neuropathological Society as advised in the actions of the November meeting and this was illustrated by the Chair of the British Neuropathological Society Clinical Practice Committee (KK) presenting to this meeting. British Neuro-Oncology Society. HA also reported on recent engagement with the Minister for Health and Secondary Care, Andrew Stephenson MP.

HMC thanked attendees for their time and closed the meeting.

Meeting Outputs

- The APPGBT agreed to hold an AGM in May.
- The APPGBT agreed to seek out opportunities to input into the upcoming party manifestos.
- George Freeman MP agreed to meet with Kismet Hossain-Ibrahim to understand the key barriers preventing the repurposing of focused ultrasound for brain tumour patients. The APPGBT agreed to facilitate engagement.
- The secretariat to engage with former ministers Freeman and Quince to discuss opportunities and barriers to progress learnt during their times in office.

Contact

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