



The All-Party Parliamentary Group on Brain Tumours

Briefing to Parliamentarians – March 2022

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Virtual Meeting of The All-Party Parliamentary Group on Brain Tumours

Pathway to a Cure inquiry update

Agenda

- Welcome from Chair, **Derek Thomas MP**
- Apologies received
- Introduction of speakers
- Matters arising from meeting held on 17th December 2021
- Pathway to a Cure inquiry update – **Sue Farrington Smith MBE**, Brain Tumour Research
- Parliamentary Questions update – **Hugh Adams**, Brain Tumour Research
- *Closing the gaps in NHS brain tumour care* - **Jamie Lederhose and Kate Roberts**, *The Brain Tumour Charity*
- AOB
- Next meeting

APPG on Brain Tumours Objectives

To raise awareness of the issues facing the brain tumour community in order to improve research, diagnosis, information, support, treatment and care outcomes.

Secretariat

The charity Brain Tumour Research, supported by Health Comms Consulting, provides the Secretariat for the All-Party Parliamentary Group with contributions from its Member Charities.



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Pathway to a Cure inquiry update

The Pathway to a Cure – breaking down the barriers inquiry was launched at the 13th July 2021 meeting of the APPGBT.

The context of this inquiry is that since the landmark 2016 Petitions committee report into funding for brain tumour research, there has been another report into brain tumour research from the Department of Health and Social Care (DHSC), oral evidence sessions from the Petitions Committee, a £40 million funding announcement from the National Institute for Health Research (NIHR) and Westminster Hall debates. Many Parliamentary Questions have been asked and comments made in debates, but funding issues for vital brain tumour research continue to be raised and barriers continue to be identified.

This inquiry aims to bring clarity to the lack of progress by scrutinising commitments made in recent years and assessing progress, as well as seeking evidence from patient, researcher, and clinician experts. This evidence will form the basis of a report with key recommendations for Government.

At today's meeting, Sue Farrington Smith MBE, Chief Executive of Brain Tumour Research and inquiry panel member, will provide an update on the inquiry following written evidence collation from those involved in clinical and lab-based research and oral evidence sessions involving funders, clinicians and scientists.

Parliamentary Questions

Parliamentary Questions are a vital piece of the political 'toolkit' for Brain Tumour Research, our campaigners and our supporters at Westminster. Fifty-eight brain tumour related Parliamentary Questions have been asked since 17th September 2020, with the majority enquiring about Government funding levels. They are also a key way for the APPGBT inquiry to gather information regarding Government funding. Hugh Adams from Brain Tumour Research will report to the APPGBT on the last 18 months of questions and answers at Westminster and focus on what has happened in early 2022 as we try to unpick what the current funding situation is both at Westminster and across the devolved nations.

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Closing the gaps in NHS brain tumour care

In late 2020, The Brain Tumour Charity launched the *Improving Brain Tumour Care surveys* to help gather evidence of patients and carer's experiences of NHS treatment and care across the UK.

Capturing the experiences of just under 1,500 people affected by brain tumours across the UK, the results have already been used to help improve care at a local level, as part of the expert-led assessments of NHS hospital centres applying to become Tessa Jowell Centres of Excellence – a programme led by the Tessa Jowell Brain Cancer Mission, which Dr Nicky Huskens kindly updated on at the December APPGBT meeting.

At this APPGBT meeting, The Brain Tumour Charity – which has invested around £38 million in world-class research (£12.2m in the UK and £25.8m internationally) in the last five years and provides a wide range of support and information services – will present some of the latest national results from the surveys, which identify some significant gaps and variations in NHS care. In particular, the survey has identified key issues in access to Clinical Nurse Specialists, the provision of Holistic Needs Assessments to help identify patients' unique care needs in research participation.



This meeting is being held at the end of **#BrainTumourAwarenessMonth** which has seen brain tumour charities, hospices and other charities that fund research into brain tumours across the UK engage in awareness raising activities.

Brain Tumour Research Member Charities



The social media hashtag for the meeting is **#APPGBT**. This Briefing and the Minutes of the meeting will be available at: www.braintumourresearch.org/campaigning/appg-on-brain-tumours