



## The All-Party Parliamentary Group on Brain Tumours

### Briefing to Parliamentarians - May 2021

This Briefing was produced and funded by Brain Tumour Research. This is not an official publication of the House of Commons or the House of Lords. It has not been approved by either House or its committees. All-Party Parliamentary Groups are informal groups of Members of both Houses with a common interest in particular issues. The views expressed in this report are those of the Group.

## AGM – A Review of the Year and Next Steps

### Annual General Meeting (AGM)

#### Agenda

- Welcome from Chair, Derek Thomas MP
- Apologies received
- Election of Chair and Officers
- Confirmation of the name and purpose statement of the Group
- Income and Expenditure
- Update from the Secretariat

Since our last Annual General meeting in February 2020, the APPG has held three virtual meetings and several closed meetings with topics including:

- The launch of the Tessa Jowell Brain Cancer Mission (TJBCM) designated Centres of Excellence for patient care
- Updates on the £40 million made available for allocation to brain tumour researchers through the National Institute for Health Research (NIHR) in 2018 including suggestions from Consultant Neuropathologist, Dr Kathreena Kurian to identify and remove boundaries to better allocation and a meeting with Health Minister, Lord Bethell on the subject
- Explored discovery science funding avenues with the Medical Research Council (MRC)
- Met with surgeons and clinicians to look at better drug delivery projects
- Contributed to a Westminster Hall debate on childhood cancer and particular DIPG brain tumours
- Discussed issues surrounding UK access to US-based trials with a Pharma company
- Investigated the reasons why patients self-fund treatment abroad and why such treatments aren't available in the UK
- Heard about the SAFER (seizure activity before and after radiosurgery) study and the work the DVLA are doing to enable the swifter return of driving licences to patients
- The International Brain Tumour Alliance (IBTA) presented their Brain Tumour Patients' Charter of Rights

### 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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## The Translational Pipeline

The brain tumour research pipeline needs adequate funding throughout – funding at the discovery end is needed to evidence the quality required for NIHR clinical research funding.

Professor Silvia Marino, Professor of Neuropathology at Barts and The London School of Medicine and Dentistry, Queen Mary University of London, will explain how – whilst the last 20 years has seen a revolution in our understanding of how cancer develops – options for treating brain tumours are very limited and they remain one of the deadliest forms of cancer. Substantial effort is required to change this situation. Research of the type Silvia conducts is at the forefront of finding new and more effective ways to treat patients with a brain tumour.

Basic research (also known as discovery science) and pre-clinical translational research is a crucial step in drug development since it lies at the very start of the process. If this research doesn't happen, there will be no new discoveries progressing to drug discovery, drastically restricting the pipeline of future new treatments.

This research is costly and risky but without new discoveries, the outlook for patients with brain tumours is very bleak. Whilst high risk, where successful, discovery science can lead to significant progress, new ways of thinking and new treatment strategies. It is this investment in discovery science that can, in time, deliver huge improvements in patient survival.

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## Brain Tumour Research Petition and Report

The Realf family's 2015 petition gained more than 120,000 signatures, becoming the first to prompt an inquiry by the new House of Commons Petitions Committee and leading to the publication of a landmark report. This was followed by the April 2016 Westminster Hall debate attended by more than 70 MPs, all of whom were in agreement that more needed to be done.

The House of Commons Petitions Committee declared that *"successive Governments have failed brain tumour patients and their families for decades."* Its March 2016 report *Funding for research into brain tumours* quoted the most recently reported investment in brain tumour research (2014) as 1.5% (£7.7 million) of the £498 million national spend on research into cancer and led to the establishment of a dedicated DHSC Task and Finish Working Group on Brain Tumour Research. Two years later, in May 2018, when the report of the DHSC Task and Finish Working Group on Brain Tumour Research was published, the Government committed to a £20 million funding boost, with Cancer Research UK (CRUK) committing to a further £25 million over five years. Another £20 million was added on the tragic death of Baroness Tessa Jowell from a brain tumour in May 2018.

During the year and at a meeting with Lord Bethell in December 2020 the APPG learned that only £9 million of the promised Government money has been spent and the COVID-19 pandemic has seen CRUK warning of a £150 million downturn in its research spending.

The charity Brain Tumour Research launched a petition on their website in August 2020 which gained 112,260 signatures calling for an increase in the national investment for brain tumour research. Susan Castle Smith, Head of PR and Communications at Brain Tumour Research will share the views of the brain tumour community and the path to the resultant levelling up report which calls for the Government to create a legacy for the brain tumour community and make the UK a world leader in finding curative therapies for brain tumours. The report explains why it is time for the Government to introduce a dedicated Levelling Up Brain Tumour Research Fund of £105 million and to increase the ongoing national investment in brain tumour research to £35 million a year so that we can stop the devastation of this awful disease – *all members should have received a copy of this report.*

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## Next Steps

The APPG will work to respond to the calls from the brain tumour community and to reflect the concerns expressed in the Levelling Up report. The report will be delivered to Prime Minister Boris Johnson by Derek Thomas MP as agreed at PMQs in March.

We will continue to meet with UK based scientists and clinicians to learn of advances and opportunities and seek to remove barriers to improving options and outcomes for brain tumour patients.

Translational research is a multi-stage process taking innovations from the scientist's bench to the patient's bedside. The component parts of the process are interdependent yet funding for these parts is currently independent. Government funding for basic research and discovery science into brain tumours is allocated by the Medical Research Council (MRC) which is part of UK Research and Innovation (UKRI). Funding for the UKRI is distributed by the Department for Business, Energy and Industrial Strategy (BEIS). Government funding for clinical trials is allocated by the National Institute for Health Research (NIHR); funding for which is distributed by the Department of Health and Social Care (DHSC). The APPG will continue to meet and talk with representatives of both bodies and ministers responsible so we can improve this two-step independent model of research funding to deliver what is required for brain tumour patients, and to ensure that both funding streams for brain tumour research are working effectively collegially and interdependently.

A joined-up approach to research funding and the whole translational research pipeline is required to deliver results in this area and make a difference for those diagnosed with a brain tumour.

## Brain Tumour Research Member Charities

