



Briefing to Parliamentarians

November 2020

Reducing the social and economic burden of brain tumours

Facilitate increased investment for research into brain tumours

At our July meeting Mike Batley, Deputy Director of Research Programmes at the Department of Health and Social Care (DHSC), who is accountable for the National Institute for Health Research (NIHR) research programmes at DHSC, told the APPG that just £6 million of the proposed £40 million of money set aside by the NIHR in 2018 for brain tumour research over the following five years had actually been allocated. Derek Thomas MP, Chair of the APPG, Lord O'Shaughnessy the Health Minister in 2018, and brain tumour scientist Dr Kathreena Kurian have since met, and the November APPG will allow Dr Kurian to present on a new pathway for effective and successful applications by brain tumour scientists in a drive to get more of the £40 million allocated for its original purpose.

Ensure a swift return to independence for brain tumour patients

In early 2018, the APPG launched its first-ever Inquiry. Evidence was compiled and published in a report entitled *Brain Tumours – a cost too much to bear?*

Central to this report were issues faced by brain tumour patients around the loss of their driving licence and the return of licences, post clinical approval, in a timely fashion. Many submissions to the Inquiry complained that it took an unduly long time, sometimes more than three months, for driving licences to be returned after clinicians had declared patients fit to drive again. For those brain tumour patients who rely on a car for transport, these delays can result in unnecessary social isolation, reduced quality of life and financial loss.

In the APPG meeting on the 10th November there will be two updates relevant to this area:

Dr Nicola Rosenfelder, Consultant Clinical Oncologist, Neuro-oncology Unit at The Royal Marsden NHS Foundation will outline the SAFER Study (short for Seizure Activity beFore and affEr Radiotherapy).

This is the first prospective study to determine the frequency and risk of seizures post-stereotactic surgery (SRS) and to design a risk-stratification system to allow identification of patients at low and high risk. This will enable us to understand better the risk of seizures in patients and thereby predict long-term seizure-free status which in turn will help inform future driving guidelines and, ultimately, allow those at lower risk of post-SRS seizures to return to driving sooner if appropriate.

Emeritus Professor of Neuro Surgery Garth Cruickshank will then update on the revision of the Driver and Vehicle Licensing Agency (DVLA) Brain Tumour Driving regulations, which we as an APPG are keen to push through as soon as possible as they will make a considerable difference for brain tumour patients given medical permission to drive again, to have their driving licence returned as soon as possible.



Identify ways to improve patient experience

Launched in July, *The Brain Tumour Patients’ Charter of Rights* is intended to address brain tumour inequalities across countries. It is also meant to stimulate debate and discussion. The Charter goals are shared by healthcare professionals, patients, caregivers or advocates. The Charter can provide everyone with an aspirational framework for improving healthcare systems and communications – goals which we hope will help reduce inequalities from country to country and support better outcomes. How is this of relevance to UK brain tumour patients? Kathy Oliver, Co-Director and Chair of The International Brain Tumour Alliance (IBTA), one of the driving forces behind the Charter, will explain.



Increase the number of patients involved in clinical trials

A closed meeting held in October was an opportunity for the Chair of the APPG, Derek Thomas MP, and Vice Chair, Lord Carlile of Berriew, to be informed of and discuss issues surrounding facilitating UK based clinical trials for potential therapeutics for ultra-orphan diseases such as DIPG, giving UK families of DIPG patients some hope without huge personal financial cost. DIPG is an aggressive, high-grade (fast-growing) form of childhood brain cancer with an average life expectancy of 10-12 months from diagnosis.

Hugh Adams, Head of Stakeholder Relations at Brain Tumour Research, will explain the background to the meeting with Midatech, the discussions held and the actions arising that will be taken forward by the APPG.

APPG on Brain Tumour's 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 PB Consulting provides the Secretariat for the All-Party Parliamentary Group with contributions from its member and other Charities.

Brain Tumour Research Member Charities



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Research**

Together we will find a cure

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www.braintumourresearch.org | Tel: 01908 867200 | campaigning@braintumourresearch.org
Brain Tumour Research, Suite 37, Shenley Pavilions, Chalkdell Drive, Shenley Wood, Milton Keynes MK5 6LB
Registered charity number 1153487 (England and Wales) SC046840 (Scotland). Company limited by guarantee number 08570737.