



## All-Party Parliamentary Group on Brain Tumours

Minutes of the virtual meeting held at 09:00 on 10<sup>th</sup> November 2020 via Zoom link

### PRESENT

- **Parliamentarians** – Derek Thomas MP, Ruth Cadbury MP, Hillary Benn MP, Ben Lake MP, Lord Randall, John McDonnell MP, Seema Malhotra MP, Sir Charles Walker MP, Sir Jeffrey Donaldson MP, Greg Smith MP, Baroness Masham
- **Secretariat** –Brain Tumour Research: Sue Farrington-Smith MBE, Hugh Adams
- **Speakers** – Dr Kathreena Kurian, Dr Nicola Rosenfelder, Kathy Oliver
- **Support** – PB Consulting; Dan Jones Ben Rowden, Peter Hand

### APOLOGIES

- Paul Bristow MP, Jayne Hunt MP, Peter Aldous MP, Stephen Timms MP, Rushanara Ali MP, Lord Carlile, Elliott Coburn MP, David Simmonds MP, Lord O'Shaughnessy, Jim Shannon MP, Chris Bryant MP

### PROCEEDINGS

#### 1. WELCOME

Derek Thomas MP welcomed parliamentary colleagues and guests to the second virtual 2020 meeting of the All-Party Parliamentary Group on Brain Tumours. The Secretariat provided an update on outcomes from the previous meeting, including a discussion into NIHR funding and working with the AMRC.

#### 2. PRESENTATION BY DR KATHREENA KURIAN

Consultant Neuropathologist, Dr Kurian, spoke to the issue of funding and the structural problems that researchers face in accessing funding. She highlighted that it is difficult to ascertain pure brain tumour research funding from generic funding for infrastructure and identified the problem as being “competing with different tumour types, targeted calls and rejection panels”. Broadly, Dr Kurian highlighted three areas for policy change:

- 1) **Experts** – in a uniquely complex area, brain tumour research proposals aren't considered by a panel that contains a brain tumour expert. The proposed solution is the establishment of a pool of brain tumour grant panellists of different seniority grades, balanced genders, ethnicity and sexuality if possible, to represent the full range of expertise and new grant ideas, rather than ‘established experts’ drawn from a wider expertise pool
- 2) **Process** – even if deemed fundable a brain tumour research application will then be ranked against all other fundable projects with no fast tracking to the money being made available. A proposed solution is to change the system so that if a brain tumour grant is deemed fundable by a panel, it is automatically funded during a highlighted brain tumour funding round (such as the one announced last month).
- 3) **The rejection of proposals** can lead to the brightest minds being lost to brain tumour research. It takes researchers a significant amount of time and scientific rigour to write these applications, which could be seen as poor use of valuable research time if they are to be rejected in manner leading to dejection. Dr Kurian mentioned at the APPG that she had a funding proposal rejected by the NIHR, and that news of this was relayed in two lines of curt

text. This could be mitigated by the creation of a register of 'priority' previously rejected brain tumour researchers who can be targeted with grant workshops, grant writing skills so they are not lost to the field

Mike Batley, from the NIHR, responded to this section by reminding the group that the NIHR provides a range of support measures, including support for researchers who are writing their grants. This in addition to the work of the Tessa Jowell Brain Cancer Mission in this area. He agreed that more could be done.

Mike then underscored that the £6 million figure cited is for NIHR programmes, and does not include spend on infrastructure which cannot be allocated to specific cancer sites.

### *3. PRESENTATION BY DR NICOLA ROSENFELDER*

Dr Rosenfelder gave a presentation on the SAFER study. SAFER stands for Seizure Activity Before and After Radiosurgery.

The study is trying to look at the patient experience after treatment for secondary brain tumours. The presentation covered brain metastases, seizure risk and the DVLA.

Dr Rosenfeld explained that whilst 3,375 people are diagnosed each year with primary brain cancer, some 16,000 patients are diagnosed with secondary brain cancer (brain metastasis) from other primary sites.

She explained that the DVLA guidelines are very clear; anyone with a brain metastasis must immediately notify the DVLA and the driving ban is in place for two years unless, after one year the patient can show there is no risk of seizure. The risk limit for a seizure is anything above 20%; anyone above this risk cannot drive.

Dr Rosenfelder explained that secondary brain cancer patients are increasing; more patients are living longer with cancers due to better treatments; this means increased risk of secondary brain cancer. In addition, more patients are now living longer with secondary brain cancer and MRI scans have improved meaning that cancers are identified much earlier.

However, all patients are considered to be at equal risk of seizures, regardless of symptoms. The implications of this is enormous; an immediate driving ban, increased anxiety, loss of work/independence, a drastic loss of quality of life. It is described as a 'constant reminder' of their brain tumour.

This is also a problem for research studies; people do not want to participate in case they find a tiny tumour which would result in a driving ban. Dr Rosenfelder explained that the 20% risk rule is outdated and this is why the SAFER study was introduced, in order to determine which factors are important in determining seizure risk. This would help develop a risk stratification system, this could ultimately shift DVLA policy and improve quality of life for many patients.

In addition, Dr Rosenfelder explained that the one to two year time frame limit is sensible, but not evidence based, and that the SAFER study would help address this matter.

The ultimate aim of the SAFER study is to help the DVLA develop better, more evidence based guidelines which will balance safety with quality of life for patients.

Dr Rosenfelder explained that the DVLA have so far not responded to the study.

#### *4. UPDATE BY SUE FARRINGTON SMITH MBE ON BEHALF OF EMERITUS PROFESSOR GARTH CRUICKSHANK*

The 2018 APPGBT Inquiry into the economic and social impacts of a brain tumour heard that following a brain tumour diagnosis, many patients are required to surrender temporarily their driving licence whilst they undergo further diagnostics and treatment. The majority of patients understand the need to do this on the grounds of safety and so surrender their licence entirely willingly.

However, 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.

The APPGBT believed that these delays in returning driving licences are due to a lack of resource in the Drivers' Medical Group (the part of the DVLA which considers whether drivers with a medical condition are safe to drive). The Inquiry heard that the DVLA has significantly improved the Drivers' Medical Group in recent years, by adding more specialist medical staff and improved computer systems. Nevertheless, waiting times for those awaiting the return of their driving licence still seem unacceptably long.

Emeritus Professor of Neuro-Surgery Garth Cruickshank who was Chair of DVLA neurology panel 2015-2019, can't now be with us today.

He told us that he has been working with Jeremy Rees, Neuro-oncology advisor on the Driver's Medical Panel for the DVLA and with the Drivers Medical group of the DVLA to improve the situation. They have just completed a revision of the DVLA regulations with respect to brain tumours, which they expect to be incorporated into the Assessing Fitness to Drive – guidance for medical professionals, before Christmas this year.

It is expected that the new regulations will help to get more people driving earlier and make assessments fairer and up to date with current molecular tumour typing etc. Although some patients will still need to stop driving because of their risk.

#### *5. PRESENTATION BY KATHY OLIVER*

Kathy Oliver Co-Director and Chair of The International Brain Tumour Alliance (IBTA) presented on the work the IBTA is doing to develop the Brain Tumour Patients' Charter of Rights. 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.

#### *6. PRESENTATION BY HUGH ADAMS*

Hugh Adams, Head of Stakeholder Relations at Brain Tumour Research explained that a closed meeting held in October was an opportunity for the Chair of the APPG, 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.

The background to the meeting with Midatech Pharma, a UK based company conducting a US based DIPG trial, the discussions held and the actions arising that will be taken forward by the APPG were presented. Information was also provided by Kathy Oliver regarding other worldwide studies and clinical trials into DIPG.



## *7. AGREED OUTCOMES*

- APPG to secure a meeting between Derek Thomas MP, Hillary Benn MP, Dr Rosenfelder and a Transport Minister to present on the SAFER study.
- APPG members to table parliamentary questions relating to the three areas of change set out by Dr Kurian on NIHR funding.
- APPG to meet with the Tessa Jowell Brain Cancer Mission.
- Secretariat to meet with Derek Thomas MP to finalise clear outcomes and timelines from the meeting
- APPG to write to parliamentarians in attendance, to ask for assistance in tangible key areas of work identified by the group.

## *8. CLOSE OF MEETING*

Derek Thomas MP formally closed the meeting.