



## The All-Party Parliamentary Group on Brain Tumours

### Briefing to Parliamentarians – December 2021

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

### *Why we need a cure*

#### Agenda

- Welcome from Chair, **Derek Thomas MP**
- Apologies received
- Introduction of speakers
- Matters arising from meeting held on 13<sup>th</sup> July
- Why we need a Cure – **Tom Parker, Dave Bolton** and others
- Tessa Jowell Brain Cancer Mission – latest news from **Dr Nicky Huskens**
- *Pathway to a Cure* the APPGBT inquiry – an update from **Sue Farrington Smith MBE**
- 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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## Why we need a cure

**Tom Parker** is a singer best known for being a member of the British-Irish boy band, The Wanted. The band has been certified for 600,000 albums and two million singles in the UK. Their nominations include 14 World Music Awards, two Brit Awards, an American Music Award, and an MTV Video Music Award. On 12<sup>th</sup> October 2020, Tom announced in the media that he had been diagnosed with an inoperable grade 4 glioblastoma multiforme (GBM). [www.ok.co.uk/celebrity-news/tom-parker-brain-tumour-kelsey-22820686](http://www.ok.co.uk/celebrity-news/tom-parker-brain-tumour-kelsey-22820686). A GBM is the most commonly diagnosed malignant brain tumour. Brain tumours are classified from grades 1 - 4, with 4 being the most malignant.

A 90-minute film on Tom as part of the *Stand Up To Cancer* series was recently screened on Channel 4.

At this APPGBT meeting, Tom will talk about his brain tumour journey so far and share with attendees what he has learnt, his hopes, his fears and his aspirations.

Tom's 'brain tumour brother' is international keynote and motivational speaker **Dave Bolton**.

Dave served in Air Ops Iraq, survived being crushed by an articulated lorry and went on to become a World Champion kick boxer as well as a Detective Sergeant tackling serious and organised crime.

In 2014, Dave suffered a 15-minute nocturnal seizure at home. He stopped breathing, dislocated his right shoulder, and bit through his tongue. It was confirmed that Dave had a tennis ball-sized tumour located in the frontal lobe of his brain. He underwent a life-saving craniotomy and de-bulking brain operation at The Walton Centre for Neurology, Liverpool. Histology showed that the tumour was an astrocytoma grade 2, with a life prognosis of five years. In 2015, Dave again attended The Walton Centre to be given the results of a routine MRI brain scan. There was regrowth of Dave's tumour. Dave spent a total of 14 days in hospital after his second brain surgery within 14-months. His tumour had progressed to become a GBM. His life prognosis was three months without treatment and six to eight months with treatment.

In 2015, Dave was classed as having terminal cancer. In 2021, he remains a passionate campaigner, looking to understand and improve the options and opportunities there are for brain tumour patients.

Tom and Dave will be joined by other members of the brain tumour community to give personal and poignant insights into what it means to be a UK brain tumour patient in 2021. Other speakers will contribute their experiences, including issues such as the need to self-fund and travel overseas to access the most innovative therapies that provide the hope that currently the NHS is often unable to do.

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## Update on Tessa Jowell Centres of Excellence

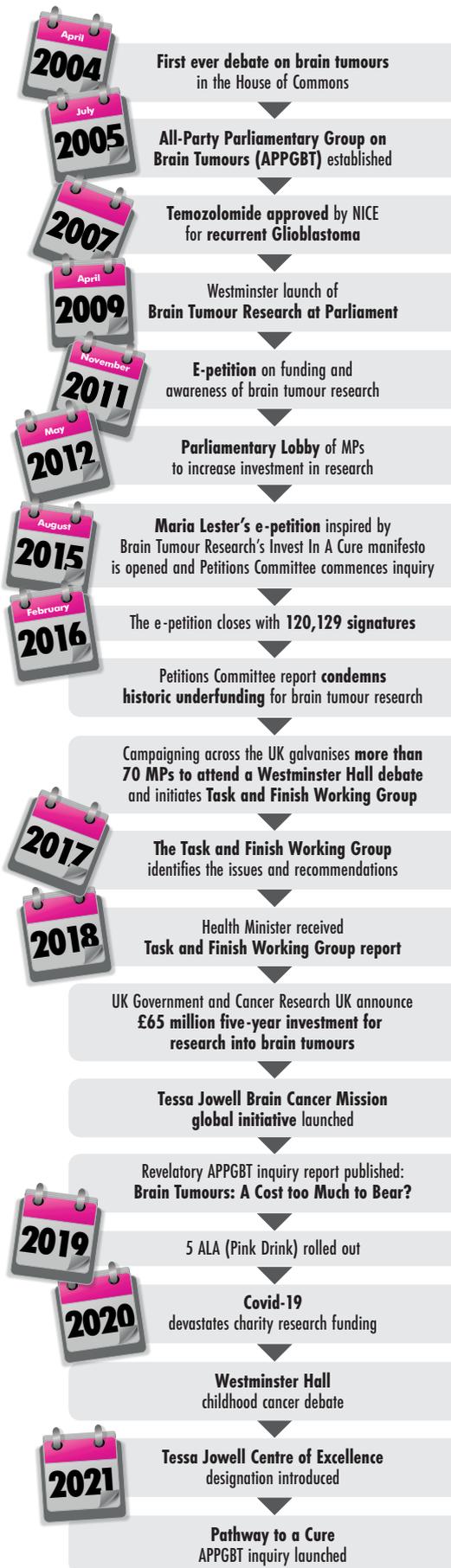
At the meeting of the APPGBT on 2nd March 2021, the Tessa Jowell Brain Cancer Mission (TJBCM) launched the Tessa Jowell Centres of Excellence Programme and announced the first nine centres obtaining that designation. This was the result of a one-and-a-half-year process of defining standards of excellence and measuring centres against these standards through an intensive application process, including virtual site visits, feedback from more than 1,000 patients and in-depth analysis of every aspect of the centres' services.

The elements which centres were measured against were:

- Excellent treatment in surgery, pathology, imaging and chemo and radiotherapy
- Emphasis on patient quality of life throughout the journey
- Offer clinical trial opportunities
- Offer good training and development for staff
- Site for excellence and innovation in brain tumour research

**Dr Nicky Huskens** is the Director of the TJBCM and she will provide an update to the APPGBT at this meeting in order to:

- Explain how Centres of Excellence have supported fellow centres in enhancing their services
- Highlight the positive improvements made by centres that have not yet received designation and how close they are to becoming designated early next year
- Provide an update about the new centres that applied over the summer to be part of the network of centres
- Announce the launch of the upcoming Academy to share brain tumour best practice and close any gaps identified during the designation assessment



## Pathway to a Cure inquiry update

The Pathway to a Cure – breaking down the barriers inquiry was launched at the APPGBT meeting on 13<sup>th</sup> July 2021.

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, oral evidence sessions from the Petitions Committee, a £40 million funding announcement from the National Institute for Health Research 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 will outline the framework for the inquiry and the route to it providing clear recommendations and an action plan to understand where we are now and where we need to get to if we are to change the starkest of facts – that brain tumours continue to kill more children and adults under the age of 40 than any other cancer.

Next steps:

- August to December 2021 – Literature review
- January to February 2022 – Call for written evidence
- March to June 2022 – Oral evidence sessions and updates to APPG
- July to September 2022 – Analysis of evidence
- October to November 2022 – Draft report
- December 2022 – Launch report

## 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](http://www.braintumourresearch.org/campaigning/appg-on-brain-tumours)