



## The All-Party Parliamentary Group on Brain Tumours

### Briefing to Parliamentarians - July 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.

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

*Pathway to a cure – breaking down the barriers*

### Agenda

- Welcome from Chair, Derek Thomas MP
- Apologies received
- Introduction of speakers
- Matters arising from meeting held 2<sup>nd</sup> March
- APPGBT inquiry – Hugh Adams, Brain Tumour Research
- The role of the National Cancer Research Institute (NCRI) – Dr Iain Frame, CEO, NCRI
- My own brain tumour story – Tom Parker, singer and patient
- Group discussion and questions to speakers
- 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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## APPGBT inquiry

Since the landmark 2016 Petitions committee report into funding for brain tumour research<sup>1</sup>, there has been another report into brain tumour research from the Department of Health and Social Care (DHSC)<sup>2</sup>, oral evidence sessions from the Petitions Committee<sup>3</sup>, a £40 million funding announcement from the National Institute for Health Research (NIHR) and Westminster Hall debates<sup>4</sup>. 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.

### References

1. <https://publications.parliament.uk/pa/cm201516/cmselect/cmcompetitions/554/554.pdf>
2. <https://www.gov.uk/government/publications/brain-tumour-research-task-and-finish-working-group-report>
3. <https://committees.parliament.uk/oralevidence/2273/pdf/> and <https://committees.parliament.uk/oralevidence/2274/pdf/>
4. <https://hansard.parliament.uk/commons/2020-12-07/debates/5A3AD7FE-2CEB-4B07-896B-FA5D292A07E9/ChildhoodCancersResearch>

On Tuesday 13<sup>th</sup> July, the APPGBT will launch an inquiry provisionally titled **Pathway to a cure – breaking down the barriers** with the aim of providing clear recommendations and an action plan to address these barriers.

The inquiry will seek to move from ‘talk to action’ and focus on solutions rather than problems, whilst acknowledging that the complexity of brain tumours means it continues to be very difficult for researchers to access funds that have been allocated for ‘general research’ into cancers and that there has been a failure to ring-fence funding for research into brain tumours.

We will find out what researchers still see as barriers to progress and what they would do about it.

The scope of the inquiry will include the roles of the NIHR, UK Research and Innovation (UKRI) and devolved nations’ departments of health in providing financial support and structural underpinning. Challenges will be made as to why brain tumours continue to be given a lack of priority when it comes to funding allocation and why there is a lack of representation of brain tumour experts when such applications are being considered. Is it still true that too many grant-making bodies will only fund ‘no-risk’ applications where they can be guaranteed a successful outcome, leading to a lack of innovation in some institutions? Is there still an insistence on lots of ‘pilot data’ before agreeing to fund any research, when the data is not available? What can be done to change a lack of flexibility within funding streams to fund research outside of narrow priorities and a bias towards the Russell Group of Universities which leads to a lack of recognition and prejudice against other Universities for their research, being regarded as not having the same level of prestige?

We will identify where progress has been made post the 2016 report and where it hasn’t.

Other areas for consideration alongside the funding for early-stage research will be the quality and size of the workforce, the opportunities presented by the repurposing of drugs and novel drug delivery, access to clinical trials, and the current scientific and research landscape.

What most certainly hasn’t changed in the time elapsed since the Petitions Committee report of 2016 is that brain tumours remain the biggest cancer killer of children and adults under the age of 40. This is a situation the APPGBT is not prepared to tolerate and the inquiry is announced to aid in the development of a pathway to a cure.

The format of the inquiry will be two evidence sessions per term for the duration of the 2021/22 parliament, meaning six sessions in all ending summer 2022. We will cast the net wide for written evidence to ensure completeness, with invitations for key stakeholders being given to provide oral evidence to the panel. The inquiry report will be written during Autumn 2022 and released early 2023.

The inquiry panel will be comprised of:

- Derek Thomas MP (Chair)
- Three elected representatives who are supporters of the APPGBT
- Sue Farrington Smith MBE – Brain Tumour Research Chief Executive
- Representative from another brain tumour research funding charity
- A senior clinician or scientist
- An industry representative
- An academic from an allied neuroscience

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## The role of the NCRI

The NCRI helps deliver better outcomes for all those affected by cancer throughout the UK and beyond. Identifying gaps in cancer research and addressing them. Looking out for unnecessary, expensive duplication of effort and guarding against it. They tirelessly search for new ways and means to accelerate the progress of cancer research. Dr Iain Frame joined the NCRI as its CEO in August 2018. Iain is a strong advocate of getting results by developing partnerships and using innovative approaches to support the research community. The charity Brain Tumour Research, which provides the APPG secretariat, is a partner of the NCRI. Iain will be presenting on what funding lessons the NCRI has learned and which of these could be applied to brain tumours as we search for greater central funding.

## My own brain tumour story

Tom Parker is an English singer best known for being a member of the British-Irish boy band The Wanted. On 12<sup>th</sup> October 2020, he announced in the media that he had been diagnosed with an inoperable stage 4 glioblastoma. View Tom’s story at: <https://www.ok.co.uk/celebrity-news/tom-parker-brain-tumour-kelsey-22820686>. A glioblastoma is the most commonly diagnosed malignant brain tumour. Brain tumours are graded 1 - 4 with 4 being the most malignant. At this 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 talk will be filmed by Channel 4 TV for possible inclusion in a 90-minute film on Tom to be screened as part of the *Stand Up To Cancer* series. Should any meeting attendees have a strong wish not to be recorded please can they advise before the meeting starts.

## 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)