



Briefing to Parliamentarians

March 2019

With more funding for research into brain tumours – are advances being made?

In the three years since a Parliamentary e-petition, signed by over 120,000 people, called for more funding for research into brain tumours, there have been various Parliamentary reports, a Westminster Hall debate, a Department of Health & Social Care (DHSC) Working Group, an Inquiry into the costs of brain tumours and the establishment of the Tessa Jowell Brain Cancer Mission.

This political activity has already secured commitments for an uplift in Government and charity investment towards tackling brain tumours, totalling £65 million. The brain tumour community is now coming together to decide how best to utilise this much-needed funding to drive progress in important areas such as patient experience, standard of care, access to innovative clinical trials, developing the brain tumour workforce and facilitating ground-breaking research.

This meeting of the All-Party Parliamentary Group on Brain Tumours (APPGBT) will hear updates on these efforts and the latest developments in brain tumour politics and policy.

The meeting will also consider how a brain tumour diagnosis affects children and young people, specifically their education. This was identified as a serious issue in the APPGBT's 2018 Inquiry into the economic and social impacts of brain tumours.

Health Secretary questioned about progress

In January 2019, the House of Commons Petitions Committee questioned the Secretary of State for Health & Social Care, Matt Hancock MP, about what the Government was doing to advance research into brain tumours and how this might be impacted by Brexit.

Members of the Committee focused their questions around the allocation of Government funding for research into brain tumours, how the DHSC is working to develop the infrastructure and grow the workforce required to facilitate more research and what is being done to improve diagnosis rates. Matt Hancock MP referred to the establishment of the Tessa Jowell Brain Cancer Mission and the progress being made. The Petitions Committee also committed to monitoring developments.

Tessa Jowell Brain Cancer Mission

In February 2018, the Tessa Jowell Brain Cancer Mission (TJBCM) was formed, embracing the key recommendations of the DHSC Task and Finish Working Group. Developed with the input of Baroness Tessa Jowell, the TJBCM seeks to unify efforts and resources with a focus on progressing clinical trials, improving patient experience and enhancing the application of data.

The TJBCM is Chaired by Professor Richard Gilbertson and serves as a national convening body, uniting professional, patient, charity and Government groups to share information and work together to eradicate brain tumours.

The TJBCM Steering Group comprises:

- Prof Richard Gilbertson (*Chair, TJBCM*)
- Dr Nicky Huskens (*Director, TJBCM*)
- Sarah Jones MP
- David Fitzgerald (*NHS*)
- Dr Helen Campbell (*DHSC / National Institute for Health Research*)
- Prof Colin Watts (*University of Birmingham*)
- Dr Sarah Jefferies (*Cambridge University Hospitals*)
- Prof Steve Pollard (*The University of Edinburgh*)
- Sarah Lindsell (*The Brain Tumour Charity*)
- Sue Farrington Smith MBE (*Brain Tumour Research*)
- Will Jones (*brainstrust*)

The TJBCM has arranged its work under four Strategic Programmes:

- **New Roads in Research**

Engage world-leading neuro-, developmental and systems biologists to spend time working on brain tumours, bringing in bright minds and ideas to cure brain tumours.

- **New Roads in Treatment and Trials**

Support and further enhance the first UK adaptive trial for brain cancers: BRAIN MATRIX.

- **New Roads in Training**

Design and obtain funding for up to nine annual fellowships enabling newly qualified medical and clinical oncologists to specialise for a year in brain tumours.

- **New Roads for Patients**

Elevate the minimum standard of care for patients across the UK by implementing an integrated approach for managing patients. Ensure that as many patients as possible have access to a dedicated outpatient brain tumour clinic and are being operated on by surgeons who spend more than 50% of their time on neuro-oncology activities.

Now that the TJBCM has been formally established, it will work throughout 2019, putting patients first and sharing insights, knowledge and resources with the brain tumour community and progress a detailed plan of action to improve outcomes for brain tumour patients and their families.

Supporting paediatric brain tumour survivors in education

The APPGBT's 2018 Inquiry *Brain Tumours – A cost too much to bear?* collected evidence of how younger patients face a unique survivorship burden after brain tumour treatment, particularly how this can affect their school-life.

Vicky Ringer, co-founder and Trustee of the children's brain tumour charity Levi's Star, is a doctoral researcher at the University of Leeds. Vicky is studying how paediatric brain tumour survivors are supported within education and will address the meeting about her findings.

Children spend at least 30 hours a week at school and therefore time at school is a major influencing element on a child's rehabilitation following treatment for a brain tumour.

The support given at school can have a substantial impact upon paediatric brain tumour survivors and should help to ensure they reach their potential. This is especially important considering that young people can experience difficulty in areas such as cognition and learning, social skills and behaviour/emotional regulation. Physical difficulties can also be experienced as a result of a brain tumour and its treatment.

Understanding the 'human experience' of young people affected by brain tumours as they return to school is vital and Vicky will outline how we could improve educational practice in this respect.

The Secretariat of the APPG on Brain Tumours is provided by:



**Brain Tumour
Research**

Together we will find a cure

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The Brain Tumour Research charity, supported by The Brain Tumour Charity and PB Consulting, provides the Secretariat for the All-Party Parliamentary Group on Brain Tumours.

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