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## The All-Party Parliamentary Group on Brain Tumours

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### **A record of the minutes for the All-Party Parliamentary Group on Brain Tumours Meeting Macmillan Room, Portcullis House - Tuesday 12<sup>th</sup> March 2019, 17:15 - 18:30**

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#### **Chair**

**Derek Thomas MP** (Con, St Ives) was elected to Parliament for St Ives in May 2015. He was elected as the new Chair of the All-Party Parliamentary Group on Brain Tumours (APPGBT) on Monday 10<sup>th</sup> July 2017, following Rebecca Harris' promotion to assistant Government Whip. He was re-elected into this role at the AGM on 17<sup>th</sup> July 2018.

#### **Guest Speakers**

- Dr Nicky Huskens – Director, Tessa Jowell Brain Cancer Mission
- Jess Mills – Tessa Jowell Brain Cancer Mission
- Vicky Ringer – Co-Founder & Trustee, Levi Star Children's Brain Tumour Charity

#### **Attendees**

The following Parliamentarians were in attendance.

- Derek Thomas MP (Con, St Ives)
- Dr Julian Lewis MP (Con, New Forest East)
- Jim Shannon MP (DUP, Strangford)
- Virendra Sharma MP (Lab, Ealing Southall)
- Charles Walker MP (Con, Broxbourne)
- Lord Brooke of Alverthorpe

#### **Apologies**

The following Parliamentarians sent their apologies:

- Jacob Rees-Mogg MP (Con, North East Somerset)
- Baroness Morgan of Drefelin
- Baroness Masham of Ilton
- Baroness Finlay of Llandaff
- Rt Hon. Lord O'Shaughnessy

## Minutes

**Derek Thomas MP, Chair of the APPGBT**, began the meeting by saying he was encouraged by the response of Parliamentarians to Brain Tumour Awareness Month. Following that, **Sue Farrington-Smith MBE, Chief Executive of Brain Tumour Research**, gave a brief history of the brain tumour community's campaigning journey so far.

**Jess Mills**, daughter of Baroness Tessa Jowell, was the first speaker to present her thoughts. She explained that nothing could prepare patients and families for the hopelessness one feels at the time of a brain tumour diagnosis. She felt fortunate that her family were inundated with offers for help. However, this help revealed the stark contrast between what sort of treatment they were initially offered and what Baroness Jowell received. Ms Mills said she felt people were having their fate written by virtue of their background and privilege. She explained how the Tessa Jowell Brain Cancer Mission (TJBCM) was set up to eradicate this gap. To do this, Ms Mills explained how the TJBCM were targeting five key areas which needed to be addressed; research, data, patient experience, training and clinical trials.

**Dr Nicky Huskens, Director of the Tessa Jowell Brain Cancer Mission**, was next to speak. She firstly paid tribute to Lord O'Shaughnessy, who had been instrumental in the creation of the TJBCM and revealed he was in the process of joining the TJBCM's Joint Strategy Board, which is made up of brain tumour charities and the clinical community. Dr. Huskens then gave a brief overview of the four strategic programmes within the mission. She went on to highlight the key aims of the patient strategic programme. She explained how they are encouraging adoption of the 'Cambridge Model' to ensure patients are being treated by specialised neuro-surgeons and are discussed in a pre-operative multi-disciplinary team (MDT). She explained the programme is also investigating initiatives to encourage timely diagnosis for adults to follow in the footsteps of paediatric initiatives like HeadSmart. TJBCM also has a strategic programme to enhance the training of medical professionals. She explained that there currently are not enough specialised neuro-oncologists (both clinical and medical) to treat patients with brain tumours. As a result, the TJBCM is setting up a clinical fellowship for newly qualified oncologists to further specialise for a full year in brain tumour treatment. In the treatment and trial strategic programme, the mission is focused on further supporting the Tessa Jowell BRAIN-MATRIX, a novel clinical trial which offers targeted treatment and non-standard treatment for brain tumour patients. Dr Huskens explained that the fourth strategic programme is focused on research. Its aim is to work with experts from adjacent scientific fields to bring new ideas, scientific methods and scientists to the brain tumour community. She concluded by explaining the TJBCM was not a fundraising body, or a charity, but rather a convening body, which sought to bring different organisations together to create a unified voice and combat brain tumours. Brain Tumour Research, The Brain Tumour Charity, Braintrust, Brain Tumour Support and Cancer Research UK are all jointly working on the initiatives within the mission.

Following Dr Huskens' remarks, the floor was opened for questions and an attendee asked how patients were meant to access new initiatives. Ms Mills responded by saying that the BRAIN-MATRIX is still being set up and that the training programme is still in development. Patients will eventually have access to 10 different hospitals across the UK that will be participating in the trial. This is also where the fellowships for clinicians will be hosted. Another member of the audience inquired whether the TJBCM was aware of the work in children's neurosurgery, particularly a group called Brainbow. Ms Mills and Dr Huskens both acknowledged paediatricians had done a lot of good work and adult treatment services must learn from them.

Another attendee said she felt part of the issue was getting GPs to refer patients to specialists. Ms Mills acknowledged this issue and said the TJBCM is awaiting the outcome of research into this and will be committed to support the set-up of a similar campaign as HeadSmart in adults as a way of dealing with this issue. Prof. David Walker, who initiated HeadSmart, was in attendance and he reiterated how the blood-brain barrier is an issue and said the TJBCM should focus on drug delivery as it was an area which was currently lacking. Kathy Oliver, from the International Brain Tumour Alliance, was next to speak and asked what the TJBCM was doing to interact with other global initiatives. Ms Mills replied saying she was a UK Ambassador to the Eliminate Cancer Initiative and that she was keen to provide data for the BRAIN MATRIX.

Two final questions were then fielded from members of the audience. Firstly, an attendee asked how the TJBCM intended to involve the wider research community. Dr Huskens said it was an important question and welcomed different ways of thinking. Finally, a question was asked about how the TJBCM was implementing the £65 million worth of government funding. Both Ms Mills and Dr Huskens explained how the TJBCM is not the custodian of the funding. Applications still needed to be made through formal channels and they are encouraging high-quality applications to be submitted to the National Institute for Health Research (NIHR). Spending will then be tracked through the NIHR. Dr Huskens also confirmed that the TJBCM website is due to be live in the near future.

**Vicky Ringer, co-founder and trustee of Levi's Star Children's Brain Tumour Charity**, was the final guest speaker. She revealed she had lost her son, Levi, to a brain tumour when he was six years old. Since then, she has set up a charity in his name and is also conducting doctoral educational research at the University of Leeds, focusing on how children with brain tumours are supported within education. Given her professional background as a Special Educational Needs teacher, Ms Ringer saw there was no specialised programme or pathway of intervention for children returning to school after having a brain tumour. These children may return to school suffering from cognitive difficulties, short-term memory, fatigue and/or physical impairments etc.

She explained there was a different level of support for children suffering from brain tumours, depending on the school. She also revealed special needs systems were incredibly difficult to navigate. Her charity helps guide parents through that pathway and advises school about the areas of support a brain tumour survivor may need. Levi's Star Children's Brain Tumour Charity also runs a specialist educational outreach service for paediatric brain tumour survivors. Ms Ringer argued not enough was being done to recognise the long-term cognitive, social and emotional and physical difficulties for children who have had brain tumours and the huge impact it had on their education.

In order to tackle this problem, Ms Ringer revealed she was undertaking qualitative research to get a more detailed understanding of children's experiences at school. Her work in schools with brain tumour survivors has shown teachers and SENCO's need to be trained so they are better equipped at dealing with this issue and suggested the need for a pathway of support they could access. This was particularly important to teaching assistants, who often work with some of the most vulnerable children. Otherwise, this vulnerable group of children would be in danger of falling even further behind their peers.

Questions were once again opened to the floor and an attendee asked what support was available to the peers and siblings of children with brain tumours. Ms Ringer said there wasn't any at the moment, but she hoped this support would be part of a proposed pathway. Then, Prof. David Walker thanked Ms Ringer for the work she was doing and spoke about how the educational outreach service Levi's Star is providing was 'value for money' and a much-needed service. He added that investment in this kind of work that may produce faster results than long-term improvement strategies like scientific research and, therefore, asked those from the TJBCM how they suggested striking the correct balance so as to deliver long and short-term initiatives. Ms Mills responded saying the TJBCM was a multi-dimensional convening organisation and while there was some low-hanging fruit, they will also plant trees for the future.

With the meeting drawing to a close, **Derek Thomas MP** made some final comments. Following research during the meeting, he was able to share that the NIHR had, so far this reporting year, received twenty applications for funding, two had been accepted at this point. He referenced the Long-Term NHS Plan as a step in the right direction but also said he was worried about the upcoming Social Care Green Paper being too focused on older people. Consequently, he said it was essential that the APPGBT had the right influence on this paper and vowed to continue to beat the drum of the brain tumour agenda. He also said he felt not every child with Special Educational Needs was accessing the support they needed. He thanked everyone for coming and said the next meeting would be in May 2019.

### **Actions Arising**

- In response to an earlier question, the APPGBT to explore whether a child with a brain tumour is considered to be left with an Acquired Brain Injury;
- Co-ordinate meeting with Education Ministers, Vicky Ringer and Sue Farrington Smith to discuss findings;
- Seek clarity on the NIHR application process and why research funding applications may not be successful;
- Review the upcoming Social Care Green Paper and identify whether or not this addresses how to properly support and care for children. If necessary, consider plans to take forward.