



All-Party Parliamentary Group on Brain Tumours

Minutes of the virtual meeting held at 09:00 on 07/12/2021 via Zoom link

PRESENT

- **Parliamentarians** – Holly Mumby-Croft MP, Lord Carlile, Nadia Whittome MP, Ben Lake MP, Greg Smith MP, Derek Thomas MP, Lord Polak, Hilary Benn MP, Gavin Robinson MP, Lord Carlile of Berriew, Andrew Stephenson MP, Hannah Bardell MP
- **Secretariat** – Sue Farrington Smith (Brain Tumour Research), Hugh Adams (Brain Tumour Research)
- **Support** – Emma Lagerstedt (HCC), Annie Collings (HCC)

APOLOGIES

- Ruth Cadbury MP (sent a representative), Jane Hunt MP (who sent a representative), Baroness Morgan, Emma Lewell-Buck MP, Karen Bradley MP, Siobhan Baillie MP, Lord O'Shaughnessy, Paul Bristow MP

PROCEEDINGS

1. WELCOME

Derek Thomas MP welcomed parliamentary colleagues and guests to the virtual 2021 meeting of the All-Party Parliamentary Group on Brain Tumours.

2. SECRETARIAT PROVIDED AN UPDATE ON WORK OF APPG SINCE 13th JULY 2021

The Secretariat updated attendees on the Channel 4 filming that took place with Derek Thomas, Holly Mumby Croft and Lord Polak alongside patients Tom Parker and Dave Bolton and campaigner Maria Realf – all of whom were at this meeting. Video clips made by Derek Thomas in his role as Chair that were used to open conferences held by the Children's Brain Tumour Drug Delivery Consortium (CBTDDC) and the SUCCESS Charity were also mentioned.

3. UPDATE FROM PATIENTS ON THEIR TREATMENT EXPERIENCE

Tom Parker told his story of being diagnosed with a glioblastoma multiforme (GBM) and gave an update on his experience of receiving chemotherapy treatment for his brain tumour, stressing the severe side effects of his treatment regimen. Dave Bolton added to Tom's experience and outlined the difficulties he faced when accessing funding for treatment. Dave said there are many factors which have led to his long-term survival of cancer and these include both conventional medical treatments and holistic treatment.

Dave and Tom agreed the impact on their families is one of the most overlooked impacts of receiving a brain tumour diagnosis.

Charlie Sharpe spoke of his experience with a brain tumour and said for those in recovery the impact of a brain tumour on a patient's mental health can be a serious issue. Charlie said he experienced intense fatigue which impacted his recovery and quality of life.

Holly Roberts told the group of her son Larsen's experience being treated for a brain tumour and the severe side effects of treatment and said there was no child friendly treatment for brain tumours. Holly also noted that the element of hope among medical staff and reluctance to give a bad diagnosis can lead to disappointment for patients.



Nicki Hopkins noted the challenges she faced finding innovative treatments on the NHS for her husband. Nicki said she resorted to setting up a GoFundMe which allowed her husband to find alternative treatment options abroad and expressed her frustration at the difficulty in finding treatments available in the UK for brain tumours patients.

Professor David Walker said widespread complications of therapy can theoretically be avoided if there is a priority to develop novel treatment techniques straight to the brain and highlighted the importance of research in this area.

Charlie Sharpe said there is limited data on the effects treatments for brain tumours can have on the brain and the long term impact for patients in remission.

Holly Roberts asked Professor Walker how doctors can access research in a timely fashion. Professor Walker said the process of research is time consuming and in childhood cancers is sometimes limited. In adults there have not been any new drugs to treat glioblastoma in the last twenty years.

Professor Walker noted that there are a number of restrictions on research and that a focus area needs to be on collaboration and ensuring funding schemes are able to fund appropriate research. Professor Walker said he has submitted credible funding applications as an experienced researcher in the field which have been turned down with very little information regarding why, and noted that there is a need for more transparency in funding decisions.

Tom Parker raised the possibility of CBD treatments providing relief for patients suffering from brain tumours and Derek Thomas MP said the group would consider a meeting to discuss CBD treatments.

Professor David Walker said cancers in adults receive separate funding and grants from universities. There are less incentives for research into childhood cancers, which reduces the amount of research in the area.

Professor Oliver Hanemann said the streamlining of treatment is happening to some extent but that there is more to be done on this issue.

4. UPDATE ON TESSA JOWELL CENTRES OF EXCELLENCE

Dr Nicky Huskens, Tessa Jowell Brain Cancer Mission, provided an update on the Mission's work. The Centre received 20 applications to gain 'Centre of Excellence' status, nine centres gained this recognition, and 8 new centres applied this month, with applications open again in the New Year.

Dr Huskens also noted the benefit for hospitals which have not gained 'Centre of Excellence' status, noting that in the last nine months every hospital that has not received Centre for Excellence designation has accepted their feedback and hospitals are working more collaboratively to share areas of best practice.

On a national level there is more innovation and participating centres have identified common issues which can be resolved. An academy for Brain Tumour specialists has been set up with webinars, workshops and mentorship opportunities.

5. PATHWAY TO A CURE INQUIRY UPDATE

Sue Farrington Smith MBE provided an update on the inquiry. Following a review of the literature (reports, inquiry transcripts) questions for researchers, clinicians and funders have now been drafted and these will revolve around the design of the service, funding models, and progress on Government commitments regarding research. Industry will be asked what



needs to be done to improve access to clinical trials and how to access more support from the Government.

The timeline can be reviewed below:

- 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

Professor David Walker suggested including the UK Research Institutes as one of the groups to be questioned. Professor Walker also suggested questioning universities and charities which fund grants for research. Sue confirmed that these are included in those feeding into the inquiry and will be asked to provide written evidence

7. CLOSE OF MEETING AND AOB

Derek Thomas MP formally closed the meeting at 10:35 and thanked all supporters of the APPG.

8. ACTIONS ARISING

- Consider a meeting to discuss CBD treatments
- Call for written inquiry evidence