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## The All-Party Parliamentary Group on Brain Tumours

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### A record of the minutes for the APPG Meeting

#### Wilson Room, Portcullis House

Tuesday 17<sup>th</sup> July 2018, 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.

**Sue Farrington Smith MBE** – Brain Tumour Research (Chaired meeting when Derek Thomas MP had to leave briefly to attend parliamentary votes)

#### Guest Speakers

**Dr Mike Batley** - Department of Health and Social Care

#### Attendees

The following Parliamentarians were in attendance.

1. Derek Thomas MP (Con, St Ives)
2. Peter Aldous MP (Con, Waveney)
3. Sarah Jones MP (Lab, Croydon Central)
4. Stephen Timms MP (Lab, East Ham)
5. Charles Walker MP (Con, Broxbourne)
6. Dr Julian Lewis MP (Con, New Forest East)

#### Apologies

The following Parliamentarians sent their apologies:

- Drew Hendry MP
- Emma Lewell-Buck MP
- Debbie Abrahams MP
- Baroness Masham of Ilton
- David Lidington MP
- Nicky Morgan MP
- Helen Hayes MP

## Minutes

**Derek Thomas** introduced the AGM and thanked Brain Tumour Research for providing the Secretariat to the Group, with support from The Brain Tumour Charity and PB Consulting. He also thanked Carrie Hume for her work as Head of Public Affairs at Brain Tumour Research before she leaves later that week. He welcomed her successor, Erika Murigi.

Derek went over the minutes from the last meeting. He said, that during the last meeting he agreed to write to Jessie Norman, Parliamentary Under Secretary of State for Transport, asking him if they would meet with young ambassadors who spoke at that meeting. Derek has done this but has not had a response yet.

**Derek Thomas** was then nominated, seconded, and stood unopposed as Chair of the All-Party Parliamentary Group. He then nominated the following parliamentarians as officers, which were also seconded and approved.

### **Current officers re-standing for election:**

Alistair Carmichael MP  
Kevin Brennan MP  
Lord Carlile of Berriew

### **New officers of the APPG:**

Jim Shannon MP  
Pauline Latham MP  
Baroness Masham of Ilton

### **Finance:**

The APPGBT has spent nothing and received no income since Derek has taken over. Brain Tumour Research has contributed benefits in-kind of between £12,001 and £13,500, PB Consulting £1,501 - £3,000, and the Brain Tumour Charity £1,501- £3,000. Derek signed the finance form and Brain Tumour Research agreed to publish this, as per the APPG rules.

### **APPGBT Inquiry into the economic and social impacts of brain tumours:**

Derek Thomas introduced the ongoing inquiry and what it aims to do, explaining that there has been five inquiry oral evidence sessions. The last session was with those who had lost loved ones or those with a brain tumour or a family member with a brain tumour. Derek acknowledged we can do much better, especially in terms of life chances. The report will be published in autumn 2018, and Derek said the focus for most of next year will be on making sure the recommendations gain traction.

**Sue Farrington Smith** added that the Inquiry launched a web forum first of all, with 213 responses and 10 written expert responses. 19 people gave evidence at evidence sessions. The inquiry also conducted a literature review of papers relating to the inquiry. Next steps include drafting the report in July and August and launching the report in November or December. In the meantime, the Inquiry Panel will work on developing the recommendations.

**Sarah Jones MP** explained she went to two sessions and both were educational and moving. She said hearing the lived experiences was telling and the report will be powerful.

An audience member with a brain tumour said that the 'together we will find a cure' slogan is hugely encouraging. Radiotherapy has helped her but she needs a level of optimism. Negative

prognoses are horrible, and thankfully the APPG's message is very different. She asked the APPG to please carry on with what they are doing. The quality of medical research in the UK is extraordinary, but hope helps too. She added that she knows what the side effects are when you take risky treatments and wants this to be available for everyone.

**Derek** said that he is given hope and confidence when people are optimistic about curing brain tumours. After 40 years of little progress, we are now seeing progress in terms of treatment availability.

Another guest said a member of her support group's husband has terminal glioblastoma and has been trying to get Avastin. But to his distress, it isn't funded as it isn't commercially viable for glioblastoma. They are using every penny they can to buy the drug to spend more time together. But they were very stressed and have had to look hard to find someone to prescribe it. She said it felt like the patient is just a statistic to pharmaceutical companies.

It was agreed that if there were more clinical trials conducted, more treatments could become available.

Tina Mitchell Skinner, the founder of Brain Tumour Support, added to the previous comments about the importance of patient positivity. Brain Tumour Support's slogan is 'together we are stronger'.

Following on, Kathy Oliver of the International Brain Tumour Alliance also wanted to inject hope. She noted that the world is coming together around this disease. Everyone has a desire and understanding that it will take a worldwide effort to beat brain tumours.

Another guest said that they are doing work with carers to support people and families with brain tumours.

Prof. Keyoumars Ashkan from King's College Hospital said that an improvement in patient positivity is one of the biggest advancements in brain tumour care over the past ten years.

Derek thanked guests for their contributions.

**Dr Mike Batley**, Deputy Director of Research Programmes at the Department for Health and Social Care, said that the report of the Task and Finish Working Group published on 22<sup>nd</sup> February 2018 has resulted in swift progress. The report was very helpful and drove home the message that funding is needed. Funders are ready to put money in and the Department is keen to receive funding applications. The report was good in setting out the barriers which need to be overcome if cures are to be found. The publication was accompanied by Jeremy Hunt's announcement that £20m would be invested into brain tumour research - this is now being doubled. He stressed that they are only funding the highest quality research.

Also, Cancer Research UK (CRUK) announced £25m of funding over 5 years supporting two new specialised research centres. In April 2018, the National Institute of Health Research (NIHR) published a 'Highlight Notice'. This is a call for research into brain tumours, encouraging collaborative applications that demonstrate how they have built on recent initiatives in this area. This funding is available right across the NIHR programmes, including translational through to clinical trials.

In May 2018, £40m would be invested into research as part of the Tessa Jowell Brain Tumour Mission. It reflected growing optimism that new research proposals of high quality are being developed.

The Task and Finish Working Group recommendations are being considered and embraced within the Tessa Jowell Brain Cancer Mission, which aims to unify efforts and resources on brain tumours. It is championed by Lord O'Shaughnessy. Good progress has been made – there was a meeting in June 2018 at which Prof. Richard Gilbertson was appointed as Interim Chair, although Lord O'Shaughnessy is keen to stay involved to drive it forward long term.

Prof. Gilbertson will move this towards a long term stable structure. The aim is to have the final structure for this in early 2019 and in the meantime, there is agreement that activity will be based around:

- Research & Development;
- Patient experience;
- Data issues;
- Funding

The next meeting is at the end of July 2018.

The key message is - there is strong momentum behind progress and they are keen to keep this going.

Questions for Dr Batley:

1. **Where are the CRUK research centres going to be?** - Cambridge and Edinburgh.
2. **Do you know what type of brain tumours will be researched?** – The funding is for high quality proposals so it depends on what brain tumours the proposals that come in are focused on. They will wait for the proposals then we will know what will be funded.
3. **Does NIHR funding include research into neuroscience and rehab? As survivors then are left with brain injury. This is always hard to raise as an agenda for research.** – The brain cancer mission's coverage is still in development, and Dr Batley didn't know if this will include survival. Survival is probably up for research at the moment, and Dr Batley said they are certainly open to it. Derek added that the Inquiry report recommendations will look at this.
4. One guest with a brain tumour asked, **with regards to the centres of research, my immunotherapy is based at University College London Hospital (UCLH), although Cambridge Addenbrookes is your centre. Can you comment on possibly investing time in UCLH?** – Mike answered that the research centres are funded by CRUK. These research funding programmes are open to researchers anywhere so if people in UCLH have proposals they are more than welcome to put their ideas forward. The guest replied to ask **do you take the point that my immunotherapy is only available at UCLH?** – Yes, Dr Batley said.
5. **With regards to the National Institute of Health & Care Excellence (NICE) recommendations on urgent research topics published last week, is the timing of this publication aligned enough to be taken on board when deciding research projects?** – Dr Batley said that some research projects have fed into the guidelines and they should have some influence, but only pre-existing data can do this. A lot of possible topics could be researched as it is a massive disease. Economic work about the cost to the patient has been done and this was great. The most important prognostic factor for survival was being married as it means people are interested in you and your outcome. We shouldn't underestimate this – we need to surround people with support. Brain

tumours threaten your life and your abilities, so the abilities are a really important part. Scientists can offer the world through science, but patients want something to make their life better right now.

6. An attendee asked whether the group are looking at how to **help people live with their disability right now?** Prof. Gilbertson said he didn't have the bandwidth to discuss this. Disability and cure are both important. **Sarah Jones MP** said she is on a steering group with Tessa Jowell's daughter and she is thinking about this side of things as well.

Dr Mike Batley said that all three of the public, patient and carer are at the heart of everything NIHR does.

A guest said he was on the committee who formulated the NICE guidelines and one key feature is: what is evidence based? NICE go to great length to find evidence-based aspects that lead to a recommendation. Evidence can be weak or strong, and formulation of themes sometimes relies on weak evidence. Some research looks at the mechanism of how brain tumours arise and how to model this. NICE guidelines will never address this as it looks at diagnosis and treatment based on past research on which there is existing evidence. So not all research will be covered in NICE.

Dr Helen Spoudeas added that guidelines are just part of the picture based on evidence. Rehab and quality of life are covered.

**Peter Realf**, added that, in 2016, the petitions committee produced a brain tumour report containing a considerable number of conclusions and recommendations. How does this fit into the current arrangement? It seems to have been forgotten about. **Sue Farrington Smith** answered that she is working on ensuring the current work covers this and nothing is forgotten. She encouraged him to ask her again at the end of August 2018.

A guest had one more question about NIHR funding: if it covers everything from fundamental research all the way through, it must cover how to get drugs into the brain through delivery. Is there something in NIHR that has this covered or will it be picked up by CRUK? Answer: NIHR doesn't do basic science. The programmes chosen aren't always the easiest to navigate but NIHR has broad coverage. Work goes on behind the scenes to choose the correct programme.

**Prof. David Walker** and his colleague **Dr Emma Campbell** highlighted how research to develop better ways of getting drugs into the brain does not clearly fit into the remit of current funding calls. They mentioned that you can read more about the drug delivery challenge in this blog from the Children's Brain Tumour Drug Delivery Consortium (CBTDDC) - <http://www.cbtddc.org/news/blog-bbb.aspx>

**Sue Farrington Smith** added that she organised the very first House of Commons reception in 2004 and found it amazing that things have moved on so much that we have broadened the scope and are now arguing about what should or shouldn't be worked on. The charity Brain Tumour Research focuses on research and research funding, and it is exciting that nationally investment is now on the path to having £30m per annum going into brain tumour research from roughly £1m in 2002. Sue said this is still not enough though. In the past, researchers have applied to CRUK and have had their proposals knocked back. Work needs to be done to give researchers the confidence to apply, as it can now work. It's a snowball effect. We're in a fantastic moment now and it is great that we can also think about the other things we need to get right. Sue added that 70 children per year still die from brain tumours, although generally, outcomes for children are better. The adult situation isn't as good - we still have learnings and need to keep building on momentum.

**Prof. Walker** said that good proposals will be considered but it's hard to get on the consideration table if you don't meet the pre-planned headings. Drug delivery is a huge problem in brain tumours which doesn't apply to other tumours because of the blood-brain barrier. This has been raised in Europe and with Prof. Gilbertson, and proposals are being put together to address this hoping it will be noticed. But it needs a heading. 70% of prescriptions are spent on drugs that don't enter the brain. We need to address this imbalance within our thinking.

**Kathy Oliver** added that even though large sums of money are available, it's also available in other countries like Australia and the USA. We need to avoid duplication in research and support efforts. There is no need to reinvent the wheel, just to build on what is already there. One way of doing this could be to support international conferences. Better efforts are needed to reduce duplication.

**Peter Realf** said that £20m on funding is being doubled, but asked if there is a sense that this could be increased further? Mike answered that it's dependent on the proposals that come in. They need high quality proposals, in which case it could go over £40m. The Tessa Jowell Brain Cancer Mission will get rid of barriers stopping proposals coming through, and money is there for proposals that come in. The Task and Finish Working Group work focuses on encouraging proposals to come in. Funding announcements and sending out the message also help to encourage.

**Prof. Walker** pointed out that one thing identified by the task and finish working group is that funding announcements are a massive step forward – brain tumour research is now a full career choice.

**Sue Farrington Smith** said that oncologists don't get trained in neuro-oncology and that they are working on this. It's about trying to get doctors interested in neuro-oncology from an early stage. More funding leads to more research and so on. CRUK did something similar for lung cancer, which is now right up there in terms of research funding.

A guest asked if we can home grow more research? We need the scientists with experience and will. Can we offer scholarships etc. to help people stay in the field?

Another guest was moved by the theme of doing things together. Funding schemes tend to not encourage collaboration and usually, it is industry developing things based on academia. Could be more successful if interactions are encouraged.

Dr Batley said that some NIHR programmes are focused on bringing on promising ideas. NIHR does provide a platform for research to come in within the NHS.

Another guest asked how much of the first tranche of the £20m has been allocated already? Dr Batley answered that it is not allocated as such but some has already been spent. The Royal Marsden Hospital is already doing some work. The funding call was in April 2018 so panels will be meeting in the coming months to discuss.

**Peter Realf** said that, in terms of the number of categories, the Task and Finish Working Group looked at 8 areas and now there are only 4? Mike answered that there are 4 key broad headings which aim to take on all task and finish working group recommendations.

**Sue Farrington Smith** laid out the following plans for the year ahead:

- Taking the inquiry report recommendations forward.
- Following the Tessa Jowell Brain Cancer mission actions and progress.
- Following up on today's questions.
- Working with other cancer APPGs on drug discovery, innovation and trials. Looking into NHS patient data cancer strategy.
- Looking at issues coming up across the year.

Sue Farrington Smith pointed to the handout given and asked for any further suggestions to be sent to [appg@braintumourresearch.org](mailto:appg@braintumourresearch.org) .

No other business.

**The meeting closed.**

**Template for income and expenditure statement for All-Party Parliamentary Groups**

Name of group:.....BRAIN TUMOURS.....

Period covered by this statement: .....10.07.2017 to 16.07.2018.....

	£
<b>A. Balance brought forward from previous year:</b>	0
<b>B. Income received during the year:</b>	
i. Membership subscriptions (parliamentarians)	0
ii. Monetary donations (including external subscriptions and sponsorship)	0
iii. Trading income	0
iv. Interest received	0
v. Other (please explain)	0
<b>TOTAL income</b>	<b>0</b>

**C. Expenditure during the year:**

i. Employment costs (salaries, NI, pensions costs )	0
ii. Costs of contractors and freelance staff	0

iii. Visits and events (UK)

0

iv. Visits and events (abroad)

0

v. Cost of generating income

0

vi. Office and communications costs

0

vii. Other (please explain)

0

**TOTAL expenditure**

0

**D. Balance carried forward ( A+ total B-  
total C)**

0

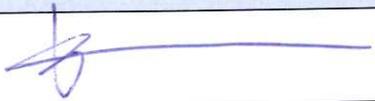
**E. Value of benefits in kind received from  
each source during the reporting year (in  
bands of up to £1,500; £1,501-£3,000;  
£3,001 to £4,500; £4,501 to £6,000 etc )**

**Please itemise according to the source and  
band**

*Brain Tumour Research –  
£12,001 – 13,500*

*PB Consulting –  
£1,501 – 3,000*

*The Brain Tumour Charity –  
£1,501 – 3,000*

  
**Signed by Chair of Group:**

**Derek Thomas MP**

**Date:** 17/07/18