



The All-Party Parliamentary Group on Brain Tumours

Minutes of the Annual General Meeting of the All-Party Parliamentary Group on Brain Tumours

The Wilson Room, Portcullis House - Tuesday 16th July 2019, 17:30 - 18:45

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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 Chair of the All-Party Parliamentary Group on Brain Tumours (APPGBT) on Monday 10th July 2017. He was re-elected into this role at the Annual General Meeting of the APPGBT on 16th July 2019.

Guest Speakers

- Mr Ashan Jayasekera, Neurosurgeon & Researcher, University of Newcastle
- Sue Wood, Dietician, Matthew's Friends
- Emma Williams MBE, Chief Executive, Matthew's Friends
- Dr Neil Bindemann, Patient Speaker
- Andrew Scarborough, Patient Speaker

Attendees

The following Parliamentarians were in attendance.

- Derek Thomas MP (Con, St Ives)
- Lee Rowley MP (Con, North East Derbyshire)
- Marcus Jones MP (Con, Nuneaton)
- Peter Aldous MP (Con, Waveney)
- Rt Hon. Nicky Morgan MP (Con, Loughborough)
- Yasmin Qureshi MP (Lab, Bolton South East)
- Jim Shannon MP (DUP, Strangford)
- Mark Pawsey MP (Con, Rugby)
- Dr Philip Lee MP (Con, Bracknell)
- Charles Walker MP (Con, Broxbourne)
- Kevin Brennan MP (Lab, Cardiff West)

Apologies

The following Parliamentarians sent their apologies:

- Baroness Walmsley
- Richard Benyon MP (Con, Newbury)
- Kerry McCarthy MP (Lab, Bristol East)
- Emma Lewell-Buck MP (Lab, South Shields)
- Tracey Crouch MP (Con, Chatham & Aylesford)
- Pauline Latham MP (Con, Mid-Derbyshire)

Minutes

Derek Thomas MP (Con, St Ives) began the APPGBT's Annual General Meeting by conducting formalities of the Annual General Meeting.

Derek Thomas MP was 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:

- Rt Hon. Alistair Carmichael MP
- Kevin Brennan MP
- Jim Shannon MP
- Pauline Latham MP
- Baroness Masham of Ilton
- Lord Carlile of Berriew

New officers of the APPG:

- Lee Rowley MP
- Yasmin Qureshi MP
- Helen Hayes MP

Finance:

The APPGBT has spent nothing and received no income. Brain Tumour Research has contributed benefits-in-kind of between £10,501 and £12,000, PB Consulting £1,501 - £3,000, and the Brain Tumour Charity £0 - £500. Derek Thomas MP signed the finance form and Brain Tumour Research agreed to publish this, as per the APPG rules.

After the AGM formalities were completed, it was revealed that several attendees had attended a meeting with Seema Kennedy MP, Parliamentary-Under-Secretary of State for Health, earlier that day. Attendees gave an overview of the meeting saying Ms Kennedy had been sympathetic and receptive to their arguments and proposals. Another attendee revealed Ms Kennedy had suggested that if brain tumour researchers wanted to see improvements in their research, they should approach the European Medicines Agency (EMA) rather than the UK-based, Medicines and Healthcare products Regulatory Agency (MHRA). Derek Thomas MP then explained how the meeting had been especially useful considering there were relevant civil servants also present.

Following the update from the meeting with the Health Minister, the meeting turned its attention toward the first speaker, **Mr Ashan Jayasekera, Neurosurgical Trainee & Researcher, University of Newcastle**. Mr Jayasekera explained to the audience his specific area of research – improving ways brain tumours can be treated surgically. His particular area of interest is gliomas – a type of tumour that is notoriously difficult to treat. He explained how glioma's often caused patients to have seizures. Traditionally, an effective way of treating seizures in patients with gliomas is to remove the tumour and some of the surrounding brain tissue. However, it is often difficult to know which bits of the surrounding brain tissue need removing to improve seizure control for patients. The standard way of doing this is using an invasive technique called electrocorticography, however, this is not especially effective and carries risks.

Given this, Mr Jayasekera explained there was a clear need for a more effective, non-invasive procedure and this is what he and his team are committed to researching. While they had made significant progress in the field, they were inhibited by a lack of funding and human resources. Questions were then taken from the meeting attendees and Mr Jayasekera answered on the specificities of the work he is leading. One attendee said that it was encouraging to see he had been able to raise money from a neuroscience charity.

Sue Wood, Registered Dietitian, Matthew's Friends, was the meeting's next speaker and proceeded to give an insight into the overlay between ketogenic diets and brain tumours. She explained that ketogenic diets essentially mimic fasting – with the low carbohydrate intake leading to adaptive biochemical changes

so that fat becomes the dominant fuel source in the body. Ms Wood explained how this ketogenic fuel-switch had been used to treat epilepsy since the 1920s but was only recently being explored for its therapeutic potential in a wide range of neurological conditions, including brain tumours. She explained that ketogenic adaption leads to a cascade of biochemical changes in the brain; enhancing energy capacity, modifying gene expression, influencing neurotransmitter pathways and antioxidant status. Also, the gut microbiome is markedly affected and that this may account for some of the effects such as improved regulation of inflammation, yet to be further explored.

Ms Wood said, based on pre-clinical (laboratory-based) studies which had been undertaken within this field, it had been established that many of the biochemical pathways influenced by ketogenic metabolism were also known to be important for malignant brain tumour progression and that ketogenic diets may enhance the effect of standard chemo-radiation therapy. However, clinical (patient-based) studies were limited and as such there was not the evidence for supporting this approach within current neuro-oncology practice. With that said, it was clear there was an argument for clinically supported ketogenic diet therapy as an option for those with drug-resistant seizures, fatigue and impaired quality of life in association with their brain tumour.

The APPG then heard from two patient speakers, **Dr Neil Bindemann** and **Andrew Scarborough** – individuals who had explored the benefits of ketogenic diets because of their expertise in the brain tumour/neurosurgical field. Their understanding of their own condition meant they were both inclined to adopt ketogenic diets, despite the fact no healthcare professional had suggested the diet to them. Dr Bindemann said if healthcare professionals were to give people the opportunity to try ketogenic diets, it would allow for a wider research base around metabolism and tumour growth. Mr Scarborough agreed, saying it was important to raise awareness of the benefits of ketogenic diets, or metabolic diets as he would prefer them called, given how much it had improved his own quality of life.

Questions were taken from the floor and one attendee asked if the Tessa Jowell Brain Cancer Mission had been in discussion with those involved in ketogenic diets. Ms Wood said they were not currently working closely with them and this would be difficult given their treatment was not clinically approved. Another attendee asked if ketogenic diets could work in tandem with other treatments – specifically chemotherapy – to which Ms Wood replied yes and they had already seen effective examples of this happening.

Yasmin Qureshi MP asked what the speakers would like to see from the NHS and government to support their initiatives. **Emma Williams MBE, Chief Executive, Matthew's Friends**, responded saying the difficulty was that without clinical evidence, it was extremely difficult to secure funding. Further studies (both preclinical and clinical) are urgently needed. After some final remarks from Derek Thomas MP, the meeting drew to a close.

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

Name of group: *All-Party Parliamentary Group on Brain Tumours*

Period covered by this statement: *17th July 2018 – 15th July 2019*

	£
A. Balance brought forward from previous year:	0
B. Income received during the year:	
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
TOTAL income	0

C. Expenditure during the year:

i. Employment costs (salaries, NI, pensions costs)	0
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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	<i>Brain Tumour Research:</i> <i>£10,501 - £12,000</i> <i>PB Consulting:</i> <i>£1,501 - £3,000</i> <i>The Brain Tumour Charity:</i> <i>£0 - £1,500</i>
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Signed by Chair of Group:

Date: 16/07/19