

Cross Party Group on Brain Tumours

8 October, 13:00, Committee Room 3

Scottish Parliament

Topic: Inaugural Meeting of the Cross-Party Group on Brain Tumours

Minutes

Present

MSPs

Finlay Carson MSP, Deputy Co-Convenor (convened the meeting)

Colin Smyth MSP, Deputy Co-Convenor

Ben Macpherson MSP, Deputy Co-Convenor

Alexander Stewart MSP

Rachel Hamilton MSP

Invited Guests

Minister for Public Health and Women's Health, Jenni Minto MSP

Guest Speaker: Prof Steve Pollard, University of Edinburgh

Guest Speaker: Dr Joanne Birch, University of Glasgow

Guest Speaker: Theo Burrell, Individual

Guest Speaker: Nadia Majid, Individual

Non-MSP Group Members

Gillian Hailstones, Beatson Cancer Charity

Andrew Wright, Tessa Jowell Brain Cancer Mission

Phelim O'Toole, Edinburgh Headway Group

Hester Lee, The Neurological Alliance of Scotland

Caroline Lauder, Scottish Government

Carol Cochrane, BrainsTrust

Thomas Brayford, Brain Tumour Research

Evan Smyth, Brain Tumour Research (minutes)

Other Attendees

Jill Rennie, Individual

Apologies

Beatrice Wishart MSP, Convener

Jackie Baillie MSP

Liam MacLua-Hodgson, The Brain Tumour Charity

Sorcha Hume, Cancer Research UK

1. Welcome by Finlay Carson MSP

Finlay Carson MSP welcomed everyone to the inaugural meeting of the Cross-Party Group on Brain Tumours and read a statement from Convener of the Group, Beatrice Wishart MSP:

I am pleased that the first meeting of the Brain Tumours Cross Party Group is taking place today but sorry I am unable to attend.

I am very grateful to Finlay Carson for agreeing to chair the meeting and to Brain Tumour Research for providing the secretariat to the group.

The formation of this CPG is about working together so that improvements can be made in research, diagnosis and treatment for the various types of brain tumours that affect too many, predominantly, young people.

Brain Tumour Research recently highlighted the work of scientists in the Centre of Excellence at the University of Plymouth on finding a new way of addressing meningiomas that could mean future patients avoid invasive surgery and/or radiotherapy, treatment which my daughter Louise has undergone.

I spoke recently with a constituent who has been diagnosed with an inoperable brain tumour and told him about the newly-formed CPG. He was encouraged to learn of it and said it gave him hope for the future.

The collaboration of Brain Tumour Research with the Beatson Cancer Charity offers further hope through a Scottish Centre of Excellence.

It is up to those of us in this Cross Party Group to work together and help to turn hope for everyone living with brain tumours, and those who will follow, into positive outcomes.

Finally, I would like to send good wishes to Theo Burrell, patron of Brain Tumour Research. Theo and her family are in my thoughts following her recent announcement that she is undergoing further treatment for her brain tumour regrowth and I wish her well.

2. Statement from Jenni Minto, Minister for Public Health and Women's Health

The Minister thanked Beatrice Wishart MSP for her hard work in furthering the debate and pushing to establish the Cross-Party Group on Brain Tumours. The Minister recognised the difficulty that health professionals face in recognising the symptoms of brain tumours and expressed concern about the current survival rate figures.

The Minister highlighted the work being done through the 10-year Cancer Strategy in Scotland. The Minister emphasised the importance of early diagnosis, raising awareness and supporting local health boards across Scotland. The Minister emphasised the importance of research in creating better treatment outcomes for patients and advised Professor Pollard to send a funding proposal to the Chief Scientist Office. The Minister also highlighted the need for clinical trials and treatments to be equally accessible for all patients.

In answering questions from MSP and invited guests, the Minister outlined the need for consistent and equitable access across health boards, the potential of Artificial Intelligence (AI) in health, and the provision of training to GPs on brain tumour symptoms.

3. Statements from Professor Steve Pollard and Dr Joanna Birch

Professor Pollard provided an overview of the scientific challenges facing the research of brain tumours. He highlighted that the late detection of brain tumours is a major issue. Professor Pollard also noted that treatments providing breakthroughs in other forms of cancer are unable to be used when operating on the brain. This is because the brain, unlike other organs, cannot withstand the same level of detrimental treatment.

Professor Pollard then outlined the work being done at the Scottish Brain Tumour Research Centre of Excellence. Funding has allowed the researchers to conduct research with the aim of de-risking the subject area of brain tumours, to allow industry partners to take the research forward.

Professor Pollard told the group that the Centre of Excellence is looking to grow capacity through training new PhD students, but needed more integration across academia, Government and industry to build the critical mass of research in Scotland. This is in the hope that, in turn, it would convince other researchers to pivot their work towards the issue of brain tumours.

Dr Joanna Birch then addressed the Group, expressing that Scotland was well placed to combat the disease, with a wide range of academic and clinical expertise, to conduct world-leading research on brain tumours. Dr Birch noted that there are over 80 researchers in Scotland across the whole career range.

In answering questions from MSPs and invited guests, Professor Pollard and Dr Birch expressed that the research community has positive momentum. However, they highlighted that other disease areas such as breast and lung cancer have seen rapid improvements in patient outcomes due to the increased funding being placed in research. Prof Pollard also outlined how researchers are attempting to adapt immunotherapy treatments, to allow them to be suitable for use on the brain.

4. Statements from campaigners

The group then heard from Theo Burrell, a patron of Brain Tumour Research. Ms Burrell shared her lived experience after being diagnosed with a glioblastoma in 2022 at the age of 35. Ms Burrell expressed the difficulty of being diagnosed, as despite suffering from textbook brain tumour symptoms, it took 6 months for a diagnosis. Ms Burrell expressed the need for better treatment options, earlier diagnosis, but most importantly to find a cure.

The group then heard from Nadia Majid, who lost her four-year-old son Rayhan in 2018 just four months after his diagnosis. Ms Majid highlighted the frustrating treatment process that brain tumour patients go through. In order to secure a proper diagnosis, Ms Majid revealed that after being turned away as an overly worried mother, she had to exaggerate her son's symptoms in order for him to be scheduled for an appropriate scan. At every stage of Rayhan's treatment process, healthcare professionals were unable to explain the cause of Rayhan's symptoms, or the likelihood of success.

3 weeks after his first surgery, new scans showed that the tumour had grown back to its original size, with two more tumours now also present. Following this, Rayhan completed 30 different sessions of radiotherapy, but follow-up scans showed that this treatment had failed to improve his condition. All throughout this process, healthcare professionals still could not explain the changing in his physical condition. The lack of understanding in the research of brain tumours had left her son defenceless against this disease, with inadequate treatment being the only option. Ms Majid emphasised the need to invest into research to ultimately give healthcare professionals the tools to fight brain tumours and improve real outcomes for patients.

Jill Rennie, who lost her husband last year to a glioblastoma, reiterated the sentiments expressed by Ms Burrell and Ms Majid. She also expressed concern about the difficulty and expense involved in obtaining travel insurance whilst having a brain tumour.

5. Statement from the Secretariat

Thomas Brayford, of Brain Tumour Research, thanked members for their contributions and praised the efforts of those involved with setting up the Cross-Party Group on Brain Tumours. Mr Brayford noted that it is important to have brain tumours as an issue increasingly present in politics, but that it is even more important to act on these discussions.

Mr Brayford expressed that the best results for brain tumours patients will come from collaboration between the Government, industry, academia and third sector. This will allow those in charge of the research process to integrate patient voices and lived experience into their work, driving real outcomes for patients and their loved ones.

6. AOB

Finlay Carson MSP asked if there was any other business to be attended to within the meeting.

Ben Macpherson MSP raised questions pertaining to how the Cross-Party Group would be able to help brain tumour patients with the indirect costs of their condition, namely the increased cost of travel and health insurance.

Ms Burrell and Ms Majid expressed a desire to focus the scope of the next meeting on early diagnosis and the issues that arise from living with a brain tumour.

Members agreed to schedule the next meeting for early 2025.

Finlay Carson MSP thanked members for their contributions and drew the meeting to a close.