

# **Cross Party Group on Brain Tumours**

**20 February, 13:00, Committee Room 2**

**Scottish Parliament**

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

## **Minutes**

### **Present**

#### **MSPs**

Beatrice Wishart MSP, Convener

Finlay Carson MSP, Deputy Co-Convener

Colin Smyth MSP, Deputy Co-Convener

Ben Macpherson MSP, Deputy Co-Convener

Alexander Stewart MSP

#### **Invited Guests**

Guest Speaker: Prof Anthony Chalmers , University of Glasgow

Guest Speaker: Liam MacLua-Hodgson, The Brain Tumour Charity

Guest Speaker: Alastair Ross, Association of British Insurers

Guest Speaker: Thomas Brayford, Brain Tumour Research

#### **Non-MSP Group Members**

Gillian Hailstones, Beatson Cancer Charity

Evan Smyth, Brain Tumour Research (minutes)

#### **Other Attendees**

#### **Apologies**

### **1. Welcome and Formalities**

Beatrice Wishart MSP opened the meeting and welcomed attendees. The minutes from the previous meeting were approved, and there were no matters arising.

## **2. Proton Beam Therapy – Professor Anthony Chalmers**

Prof Chalmers introduced himself as Chair of Clinical Oncology at the University of Glasgow and Co-Chair of the Scottish Brain Tumour Research Centre of Excellence. He explained the challenges of treating glioblastoma due to the tumour's location, which makes surgery and radiotherapy difficult, and the blood-brain barrier, which hinders drug delivery. He highlighted the chronic underfunding of brain tumour research and the difficulty in securing commercial investment due to its high-risk, low-reward nature. He stressed the need for investment in research infrastructure.

On a positive note, Prof Chalmers spoke about advancements in brain tumour research, particularly in developing imaging tools. He noted that the Scottish Brain Tumour Research Centre of Excellence brings together expertise from Glasgow, which focuses on clinical trials, and Edinburgh, which specialises in discovery research. He thanked Brain Tumour Research and Beatson Cancer Charity for funding £2.4 million over five years, which enabled the centre's launch.

Prof Chalmers then discussed Proton Beam Therapy, explaining that traditional radiotherapy damages healthy brain tissue, which can impair cognitive function. Proton Beam Therapy, however, allows for targeted radiation, minimising damage to healthy brain tissue.

Prof Chalmers noted that both UK hospitals offering Proton Beam Therapy are in England, meaning Scottish patients must travel. He highlighted the APPROACH clinical trial, which studies the neurocognitive effects of Proton Beam Therapy compared to traditional radiotherapy. However, Scottish patients have been denied access due to excess treatment costs of approximately £100,000 per patient.

Prof Chalmers mentioned that the Welsh Government has created a dedicated fund, overseen by an advisory board, to cover excess treatment costs.

Beatrice Wishart MSP thanked Prof Chalmers for his presentation and opened the floor to questions.

Finlay Carson MSP asked if patients referred by a GP to an English specialist for a non-brain tumour issue would have their expenses, including medical expenses. Prof Chalmers clarified that because the trial is not an NHS-approved treatment, this would not be possible.

Colin Smyth MSP suggested that the Cross-Party Group should write to the relevant ministers, as this was a reasonable financial request. Beatrice Wishart MSP and all members agreed.

Finlay Carson MSP asked about the current budget for excess treatment costs in Scotland. Prof Chalmers stated that Scotland's budget is £100,000 and is held within the Chief Scientist's Office, which lacks sufficient funds.

A representative from Cancer Research UK (CRUK) stated that they have been liaising with the Welsh Government on excess treatment cost funding and offered to support a Scottish effort.

Finlay Carson MSP asked about the role of private investment in Proton Beam Therapy. Prof Chalmers responded that improved infrastructure would encourage industry involvement in UK clinical trials.

### **3. Presentation from The Brain Tumour Charity**

Liam Mac Lua-Hodgson, Policy and Campaigns Officer at The Brain Tumour Charity, introduced the organisation's focus on early and faster diagnosis. He explained that their policies in Scotland are guided by the Scottish Steering Committee, which prioritises raising awareness, developing diagnostic tools, and improving diagnostic pathways for brain tumour patients.

Mr Mac Lua-Hodgson stated that early and faster diagnosis improves quality of life, prevents disability, and enhances treatment tolerance. However, brain tumours are difficult to diagnose due to vague, non-specific symptoms. He highlighted the disparity between Scotland and England, where emergency presentation rates are over 70% in Scotland compared to 45% in England. While data on the cause is limited, it indicates less effective referral pathways in Scotland.

Mr Mac Lua-Hodgson outlined key policy goals, including giving GPs direct access to CT imaging, a commitment included in the Scottish Cancer Plan that requires further action.

The Brain Tumour Charity's next steps include launching a new report in March, piloting a programme to improve primary care knowledge, and advocating for brain tumours to be included in optimal timing pathway trials.

Beatrice Wishart MSP thanked Mr Mac Lua-Hodgson for his presentation and acknowledged the importance of non-specific symptoms, sharing her personal experience with her daughter's emergency presentation.

Finlay Carson MSP asked whether patients are self-referring to A&E due to difficulties obtaining a diagnosis through their GP. Mr Mac Lua-Hodgson said there is no detailed data yet, but it is likely a mix of both scenarios.

Theo Burrell, brain tumour patient and Patron of Brain Tumour Research, shared that she saw five different GPs before presenting herself at A&E, despite having textbook symptoms. She stressed the need for improved GP training.

Alexander Stewart MSP stated that current GP training is inadequate and that charities are shouldering too much of the burden. He urged the government to prioritise brain tumours.

Alexander Stewart MSP suggested that the CPG could push GP training up the agenda and Beatrice Wishart MSP agreed, suggesting a letter on this point to the Scottish Government.

A representative from CRUK offered to work with Mr Mac Lua-Hodgson on improving GP training, citing previous successes in breast cancer awareness.

#### **4. Travel Insurance for Patients with Brain Tumours**

Alastair Ross, Head of Public Policy at the Association of British Insurers, explained that travel insurance primarily covers medical expenses, with £290 million of last year's £501 million in claims being healthcare-related.

Mr Ross noted that insurance costs are based on risk assessment, including destination and healthcare costs in that country. He advised patients to seek specialist travel insurance providers rather than mainstream insurers.

Beatrice Wishart MSP thanked Mr Ross and invited questions.

Prof Chalmers asked whether patients undergoing treatment could obtain insurance. Mr Ross said it depends on individual circumstances, but patients with a doctor's note and scheduled treatment should qualify.

Finlay Carson MSP asked for clarification on whether mainstream insurers should be avoided. Mr Ross confirmed that specialist providers offer more suitable options.

Theo Burrell shared that her short trip to Europe cost over £300 in insurance, despite her condition being stable. Mr Ross said insurers base costs on risk models.

Gillian Hailstone, CEO of Beatson Cancer Charity, suggested that charities and industry partners create a fund to support brain tumour patients with travel insurance costs.

Ben Macpherson MSP raised concerns about the cost difference between benign and cancerous brain tumours. Mr Ross explained that stable conditions should allow for an accurate quote but acknowledged the high cost.

Prof Chalmers suggested that insurers allow more detailed medical assessments to improve pricing accuracy.

#### **5. Brain Tumour Awareness Month – March 2025**

Thomas Brayford, Policy and Public Affairs Manager at Brain Tumour Research, outlined upcoming initiatives, including 'Wear a Hat Day' and a Westminster private member's

bill led by Scott Arthur MP. The bill seeks to improve rare cancer research funding, review orphan drug regulations, and enhance data sharing.

Mr Brayford encouraged attendees to contact their Westminster MPs for support.

## **6. Any Other Business (AOB)**

Finlay Carson MSP thanked Beatrice Wishart MSP and Brain Tumour Research for their work in making the Cross-Party Group effective.

Beatrice Wishart MSP thanked attendees and confirmed that the group would write to the relevant minister regarding Proton Beam Therapy treatment costs.

Meeting adjourned.