

Cross-Party Group on Brain Tumours

Thursday 12th February 2026. 10:00 – 11:00

Present

MSPs

Beatrice Wishart MSP (Convener)
Finlay Carson MSP

Non-MSP Group Members

Andy Wright – Tessa Jowell Brain Cancer Mission
David Garcia Jurado – The Brain Cancer Charity
Helen Smith – Beatrice Wishart MSP Staff
Jana Abdal Rahman – Brain Tumour Research
Dr Joanna Birch – University of Glasgow (researcher at Brain Tumour Research Centre of Excellence)
Katherine Dew – Brain Tumour Research (secretariat)
Peter Carroll - Neurochase
Liam Mac Lua-Hodgson – The Brain Tumour Charity
Dr Louise Dutton - University of Glasgow (researcher at Brain Tumour Research Centre of Excellence)
Gillian Hailstone – Beatson Cancer Centre
Dr Sarah Kingdon - The Beatson and Edinburgh Cancer centre
William Coulter – Beatrice Wishart MSP Staff

Supporters

Aimee Woodgate
Ashley McWilliams
Dawn Kennedy
Jill Rennie
Nadia Majid
Sarah Bainbridge
Susie Goodburn

Apologies

Apologies sent via email to Secretariat:

1. Archie Goodburn
2. Charlie Maynard MP
3. Foyso Choudhury MSP
4. Jackie Baillie MSP
5. Jackson Carlaw MSP
6. Laura Hadley-Stove

7. Liam Vincent-Kilbride
8. Molly Fenton
9. Dr Sheelagh Harwell
10. Dr Sorcha Hume
11. Claire Cordiner
12. Hester Lee

Agenda item 1 – AGM proceedings

Beatrice Wishart MSP explained that, in line with procedure, the Group was required to re-elect its Convener, Deputy Convener, and Secretariat. She was re-elected as Convener, seconded by Finlay Carson MSP. Finlay Carson MSP was then re-elected as Deputy Convener, seconded by Beatrice Wishart MSP. The Secretariat, Brain Tumour Research, was also re-selected by those in attendance.

Agenda item 2 - Updates on current priorities

The Convener moved onto actions from the last meeting. The CPG wrote to the Cabinet Secretary for Health and Social Care, Neil Gray MSP, about genomic testing, and received a response. The Convener shared this update with the Group.

The CPG agreed to write to the Scottish Medicines Consortium about access for Scottish patients to Vorasednib. The decision for this appraisal in Scotland will be on the 9th of March 2026. The decision for England will be in April.

The Brain Tumour Charity were invited next to speak on their report, which was published at the end of last year. Liam Mac Lua-Hodgson outlined that the report found new brain tumour diagnoses alone in 2025 will create a financial burden of £18.7 billion across the United Kingdom, driven by low survival, long-term effects of a brain tumour, and wider losses from reduced earnings, ongoing care needs, and premature death.

On average, each brain tumour diagnosis is associated with a financial burden of more than £1.4 million. The £18.7 billion burden brings together personal finance costs (£5.17 billion) and the monetary value of lost health and life (£13.5 billion). The greatest financial costs extend far beyond healthcare, falling instead on lost income, reduced economic prosperity, and long-term financial insecurity. In Scotland, the burden of illness totals just over £1.6 billion.

Within the report, personal stories of the financial impact of a brain tumour are shared. Community members describe the challenges of having to stop work due to symptoms, as well as more hidden costs such as travel requirements related to treatment and appointments, home adaptations, and greater care needs.

For children and young people, a brain tumour diagnosis can disrupt their education and future opportunities. It has been found that those affected are more than twice as likely to finish school without any formal qualifications.

To change this, a fairer, smarter, and more resilient health system is needed, along with a national approach to tackle brain tumours in diagnosis, care, treatment, and research.

Discussion:

Nadia Majid, a supporter and regular attendee to the Group, asked whether comparative data against other cancers is available.

Liam responded that some comparative data and a breakdown of specific costs could be found in the report by Young Lives vs Cancer and noted that it would be useful to check whether comparable data existed elsewhere.

Katherine responded that she will support Liam in identifying comparative data through the Brain Tumour Research manifesto which will be published in March. She also highlighted the recent announcement by the UK Government of a fund for NHS England to support families of children and young people with cancer to cover travel costs to and from appointments suggesting this could be a helpful starting point for further analysis.

Gillian Hailstone from the Beatson Cancer Charity enquired about the model used in the report to find the costs and its availability. Liam clarified that the general model was publicly available, but that the more detailed version was not currently in the public domain. Gillian added that she would like to see other cancer fields adopt a similar modelling approach, as it could improve understanding of financial and societal burden across conditions.

David Garcia Juardo pointed out that, particularly in relation to brain tumours, most cases are cancers but some are non-cancerous, and that any analysis must factor in the impact of non-cancerous tumours as well. He stressed that these can still have a profound effect on individuals' lives and often involve additional complications, reinforcing the overall impact of brain tumours as a condition group.

Beatrice Wishart MSP shared that her own daughter was diagnosed with a non-cancerous brain tumour which affected her life, underlining the importance of recognising non-malignant cases in research and policy discussions.

Liam also asked about the travel funds available to support young people and whether such support extended to Scotland. Katherine responded that she will follow up with the Convener of the Group to find out more detail on this announcement. Following the meeting, the Convener's office confirmed that the announcement does not apply, as it relates to the UK Government and health is a devolved matter. Gillian concluded by reiterating that the impact of non-malignant brain tumours is significant and that greater awareness of this issue is needed.

Agenda item 3 - CPG report and next steps for CPG post election

Beatrice Wishart MSP outlined that a legacy report for the Group is being prepared by the Secretariat and the Convener's office. Once it has been finalised a copy will be circulated amongst supporters and members of the group.

Beatrice reassured attendees that after the election and once Holyrood starts its new Parliamentary session, incoming MSPs will work hard with Brain Tumour Research to restart the group.

Finlay Carson MSP raised the point that it is a priority for him and his colleagues to restart the Group.

Agenda item 4 – Brain Tumour Research Manifesto Launch event on 18 March

Katherine invited attendees to a drop-in at the Scottish Parliament on 18th March between 1.00pm and 3.30pm in Committee Room 4 for the launch of Brain Tumour Research's 'Plan for Scotland' ahead of the Scottish Parliament election. Brain Tumour Research envisage the Plan as a toolkit for the future Scottish Government. The aim was for incoming Members of the Scottish Parliament to better understand the experiences of patients and their loved ones, and to demonstrate the impact and effectiveness of the CPG's work.

Personal invitations would be sent out for the launch and anyone facing treatment or logistical challenges impacting their attendance was encouraged to contact Katherine directly so that support could be arranged.

Dr Scott Arthur MP, sponsor of the Rare Cancers Bill, is scheduled to be in attendance, and some of the traditional Brain Tumour Awareness Month hats will be available for attendees to wear. Beatrice Wishart MSP commented that the launch was a positive way to conclude the session. Dr Jo Birch from the Scottish Brain Tumour Research Centre of Excellence is also due to attend.

Agenda item 5 - AOB

Sarah Brainbridge from Brain Cancer Justice thanked the group for the invitation to both this meeting and the previous one. She noted that the National Cancer Plan currently applies only to England, and expressed support for extending it to other nations. The issue of a "postcode lottery" was highlighted as a recurring concern, alongside support for the progress being made in England and hopes that similar developments will follow in Scotland.

She also spoke about a major campaign focused on tissue freezing, which is considered vital for the future of brain tumour research. She highlighted that there are many exciting developments in this area and stressed the importance of bringing together voices from all nations so efforts remain aligned and connected. She added that she looks forward to 18th March and to seeing what emerges from the next CPG.

Katherine noted that related work on tissue freezing is also being undertaken by the group's sister body in Westminster, the APPG on brain tumours, with the aim that progress made there will apply across the United Kingdom.

Discussion:

Susie Goodburn highlighted a petition to the UK Government on raising brain cancer awareness which is open until the first week of March. The goal is to reach 100,000 signatures to secure a debate in the UK Parliament; it currently stands at around 50,000, so further promotion is needed.

Sarah Brainbridge noted that parliamentary activity is helping to amplify awareness, including debates and questions being raised. She described this as another tool to strengthen the collective voice of the patient community and encouraged anyone with ideas to share them.

Beatrice Wishart MSP urged everyone on the call to share the petition on social media and said she was happy to support.

Nadia Majid added that while she has shared the petition widely on social media, messaging platforms such as WhatsApp can be more effective, as people are often more responsive to direct messages from personal contacts. She encouraged members to share it through their own networks to create a knock-on effect.

Liam provided an update on actions from the Scottish steering group and the advocacy group at The Brain Tumour Charity, focusing on improving diagnostic pathways through engagement with health boards and data gathering. He noted that emergency-setting diagnoses are significantly higher in Scotland than in England and Northern Ireland and therefore work is underway to find out why and how this can be improved.

Finlay Carson MSP thanked Beatrice for her leadership, noting that the CPG has worked well and that its progress reflects strong collaboration between MSPs, researchers, and patient advocates. He said the group's achievements are largely due to Beatrice's determination, particularly in pushing for letters to ministers and stakeholders.

The Convener thanked Finlay for his support, including chairing meeting when required, other MSPs for their contributions, and health ministers for their engagement in responding to correspondence, questions, and attending meetings. These sentiments were echoed by Katherine on behalf of Brain Tumour Research. The Convener expressed appreciation to Brain Tumour Research for providing the Secretariat, thanked her office staff Helen and Will, and thanked everyone who has supported and grown the community, expressing hope that this momentum will continue into the next Session.

Agenda item 6 - Date of Next Meeting

The next meeting of the Cross-Party Group will be after the new Scottish Parliamentary Session starts and the Cross Party Group has been re-established. The Secretariat will inform members in due course.