Cross-Party Group on Brain Tumours

Tuesday 25th November 2026. 18:00 - 20:00

Present

MSPs

Alexander Stewart MSP
Beatrice Wishart MSP (Convener)
Finlay Carson MSP

Invited guests

Speakers
Dr Louise Dutton - University of Glasgow
Olivia Clarke - Office of Dr Scott Arthur MP
Sharon Kane - Neurochase

Non-MSP Group Members
Andy Wright – Tessa Jowell Brain Cancer Mission
Elaine Murray – Brain Tumour Research
Helen Smith – Beatrice Wishart MSP Staff
Jana Abdal Rahman – Brain Tumour Research
Dr Joanna Birch – Glasgow University
Katherine Dew – Brain Tumour Research (secretariat)
Peter Carroll - Neurochase
Dr Sarah Kingdon - The Beatson and Edinburgh Cancer centre
Theo Burrell - Brain Tumour Research Patron and brain tumour patient
William Coulter – Beatrice Wishart MSP Staff

Supporters
Aimee Woodgate
Archie Goodburn
Claire Cordiner
Dawn Kennedy
Georgie Maynard
Hannah King-Page
Jeff Goodburn
Jill Rennie
Liam Vincent-Kilbride
Nadia Majid
Nicola Nuttall
Sarah Bainbridge
Susie Goodburn

Apologies

Apologies sent via email to Secretariat:

1. Ashley McWilliams
2. Charlie Maynard MP
3. Foysol Choudhury MSP
4. Jackie Ballie MSP
5. Jackson Carlaw MSP
6. Laura Hadley-Stove
7. Liam Vincent-Kilbride
8. Molly Fenton
9. Dr Sheelagh Harwell
10. Dr Sorcha Hume

Agenda item 1 - Welcome and Introductions

Beatrice Wishart MSP, convener of the group, welcomed attendees and noted that this is the final in-person meeting of the parliamentary session. She also welcomed Katherine Dew, the new secretariat, who has organised the meeting, the meeting's agenda and attendance.

Agenda item 2 - Dr Louise Dutton from University of Glasgow

Dr Louise Dutton introduced herself as working in the School of Cancer Sciences, in the research group led by Dr Joanna Birch. She began by outlining the challenges associated with treating Glioblastoma (GBM):

- The cancer cells can invade normal brain tissue
- Radiotherapy is often not effective
- The blood–brain barrier makes it difficult for treatments to reach the tumour site

Dr Dutton explained that these factors contributed to tumour recurrence and severe side-effects, and that survival rates remain extremely poor, with a median survival of 12–15 months following diagnosis. She highlighted the need for bespoke therapies, capacity building, collaboration, and for “derisking” research to encourage participation from industry and private investors.

Dr Dutton also spoke about the Scottish Brain Tumour Research Centre of Excellence, which brings together leading scientific experts from:

- the University of Edinburgh
- the University of Glasgow
- Cancer Research UK – Scotland Centre
- Cancer Research UK – Scotland Institute

She explained that through combined efforts across Edinburgh and Glasgow, Scotland is now uniquely positioned to cover the entire translational pipeline - from discovery research, to therapeutic development, and through to clinical translation. The overarching goal is to “derisk” brain tumour research in order to attract industrial funding and talent, and to bridge the "Translational Gap" where many discoveries are often lost.

Dr Dutton went on to describe the breadth of expertise and techniques available at the University of Glasgow, making it an ideal environment for translational GBM research.

These included:

- Numerous patient-derived cell lines that can be grown in 2D or 3D, with 3D cultures more closely resembling brain tumour structure
- An irradiation system allowing researchers to incorporate radiotherapy into experimental models
- In vivo models, as well as a small-animal radiation research platform for pre-clinical studies

She linked these strengths to the work of the laboratory group led by Dr Joanna Birch, which uses these techniques with the overarching aim of developing novel therapeutics for brain tumours.

Dr Dutton also described her career path. She completed a BSc in Biomedical Sciences at Keele University, followed by an MSc in Bioscience Research Training at Keele, during which she spent two semesters at the German Cancer Research Centre. She went on to complete a PhD in Medicine at Queen’s University Belfast and now works as a Research Assistant in Dr Birch’s team at the University of Glasgow.

She also provided an overview of the wider research team:

- Dr Joanna Birch – Principal Investigator and UKRI Future Leaders Fellow
- Sama Alsharif – PhD student researching ATR’s role in regulating migration and invasion in Glioblastoma cells and DIPG
- Josette Deanne Misquitta – PhD student researching exosomes and ASO technology to target glioblastoma cells
- Eliot Mason MBChB – paediatric doctor studying how childhood brain tumours interact with the immune system
- Dr Luis Pardo – Research Associate developing pre-clinical GBM models that incorporate the tumour microenvironment to study interactions between cancer and brain-resident cells

The team’s promising in vitro findings justified progressing to an in vivo study, in which patient-derived GBM cells were implanted into mice. After several weeks, MRI scans were performed to confirm tumour presence, and the mice were then placed on different treatment regimens, including radiotherapy, drug treatment, and combination therapy.

To conclude, Dr Dutton outlined her next steps:

- Writing up the BH3 project for publication
- Establishing DIPG lines in the lab to begin ATR research in DIPG

- Developing medulloblastoma models, including neurospheres and in vivo systems
- Applying for post-doctoral fellowships

Discussion:

The group's convener opened the floor to questions following the presentation. Sharon Kane asked about translating the research into clinical practice, specifically whether there may be challenges in administering the treatment before radiotherapy.

Dr Dutton responded that pre-clinical work didn't see a difference with administering before and after radiotherapy.

Archie Goodburn thanked the team for their research, including their work on low-grade gliomas. He asked what features makes a low-grade glioma look like in comparison to a healthy cell and whether data on this topic is limited.

Dr Joanna Birch responded that developing accurate models is challenging, as it is harder to fully understand what these cells "look like" biologically. However, the Brain Tumour Research Centre of Excellence has strengthened collaborations significantly, connecting their lab with many other groups who have been extremely generous in sharing data.

Finlay Carson MSP asked about the differing characteristics of brain tumours and whether genomic sequencing could be used to overcome the blood–brain barrier. Dr Birch explained that the Centre of Excellence is highly collaborative and that she also attends Brain Tumour Research researcher workshops, which support the development and sharing of knowledge in this area.

Agenda item 3 - Further discussions on genomic testing building on previous Ministerial pressure and an overview of Scottish Cancer Conference

Finlay Carson MSP commented that the Scottish Cancer Conference was fascinating, and that the individuals who took part in the panel were truly inspirational.

He highlighted ongoing issues with clinical trials, particularly the low number of patients taking part. This lack of participation makes it difficult to assess which treatments are most effective. He expressed hope that genome sequencing may help address some of these challenges.

He referred to the experience of Duncan Campbell's son, noting that the drugs prescribed to counteract treatment side-effects were sometimes just as debilitating as the treatment itself. He urged continued pressure on the government to expand treatment options and clinical trials and suggested that the system should offer tax incentives to pharmaceutical companies developing brain tumour therapies.

Katherine Dew explained that the strong support shown for the panel was important both to the Tessa Jowell Brain Cancer Mission (TJBCM) and to Brain Tumour Research. She expressed frustration at the current situation in Scotland and at the accounts shared by patients. She stressed that geographical inequity in access to diagnostic tools such as Whole Genome Sequencing (WGS) and care should not exist. However, she also emphasised that there is a glimmer of hope in the ongoing research and the positive innovation now emerging and stressed the importance of maintaining a strong advocacy agenda at the CPG and at wider conferences.

Finlay Carson MSP referred to correspondence from the previous CPG meeting noting earlier discussions and engagement with the Scottish Government on genomic testing. Although Neil Gray has confirmed that funding is now in place to enable genome sequencing in Scotland, WGS (a type of genome sequencing) remains unavailable.

Discussion:

Andy Wright from the Tessa Jowell Brain Cancer Mission (TJBCM) began the discussion by stating that, through his engagement with the Scottish Government, he has found them receptive to the idea of implementing Whole Genome Sequencing (WGS). He noted that they have been working closely with TJBCM to make WGS available in Scotland.

Archie Goodburn was invited to share his experience seeking access to Vorasidenib. Neither Edinburgh nor Glasgow were able to offer the drug. He highlighted that, despite the drug being approved in the United States over a year ago and already changing lives there, Scottish patients still do not have access to the same opportunity.

Alexander Stewart MSP commented that there is still a long way to go, and with only a few months left of the current parliamentary term, it is important to identify goals and aspirations for the next six months. He stressed the need to ensure continuity of existing plans so that the CPG can continue its work in the next parliament even if it loses some of the Members of the Scottish Parliament who have supported the group through the upcoming election.

Theo Burrell expanded on the deep inequalities within the current system. She emphasised that individuals who cannot afford private pathways are at a severe disadvantage. Those living on the breadline may die sooner, while those who are more privileged can access treatments, and she urged caution and awareness of this inequity.

Katherine noted that a similar situation exists in Northern Ireland. Patients there often must fly to England for neurosurgery before even beginning their treatment journey. She stressed that this level of inequity is a major issue that Brain Tumour Research is actively campaigning against.

Jeff Goodburn spoke about efforts to simplify genomic testing by reducing multiple tests into a single genome sequencing platform, which he highlighted is not prohibitively expensive.

Andy Wright added that the conversation around genome sequencing has significantly shifted since last year. At that time, discussions felt far more negative and distant. Now, WGS no longer feels out of reach. Scotland continues to lead on innovation; the challenge is that the NHS has not kept pace. He emphasised the importance of maintaining continued pressure.

Questions were raised about the cost of WGS and what drives it, whether it is primarily the sequencing machine itself or the staffing and infrastructure needed to support the process. This will be reported on at the next CPG meeting.

Dr Sarah Kingdon noted that, although WGS is commissioned in England, uptake varies widely. She explained that the pathway must function smoothly, and that there are also cultural and practical barriers - for example, some centres lack adequate freezer space. She highlighted the need for Scotland to learn from England's challenges.

Andy Wright reiterated that providing genomic testing to cancer patients is a stated priority for the Scottish Government.

Finlay Carson MSP asked about the difference between short-read and long-read genome sequencing. Dr Sarah Kingdon explained that short-read sequencing produces more targeted, focused information, whereas long-read sequencing provides deeper and more comprehensive data. She also noted that WGS takes a long time to process, which contributes to its limited uptake in England.

Agenda item 4 - Presentation from Neurochase following up their work on 'Convection Enhanced Delivery'

Sharon Kane, the CEO of Neurochase, worked with Steven Gill to establish the company. She has a long background in the DIPG field and has dedicated her career to improving treatment options for children with this disease. Together, she and Steven developed an innovative drug-delivery system for neurological conditions, supported by an engineering partner that helped turn the design into a functional device.

Using their in-house delivery method, they treated a child with DIPG who survived three years, compared with the typical nine-month prognosis. This unprecedented survival period allowed clinicians to observe the natural progression of the disease in a way not previously possible. Importantly, the child did not die from the primary tumour but from metastatic disease.

Neurochase were ready to advance to a clinical trial, but the company that owned essential devices refused to provide them. This forced Sharon and Steven to start again and work around the intellectual property constraints.

To sustain progress, they chose mission over profitability. Steven provided consultancy services to clinical and pharmaceutical partners, and they secured a deal with Spark Therapeutics, which brought £10 million into device innovation. This funding is now driving development of a new delivery system.

Sharon went on to describe the Neurochase Delivery System, which ensured effective coverage of the relevant brain structures. This system allowed therapies to cross the blood–brain barrier and reach their target areas without causing pressure or damage. Each patient's treatment was tailored individually, using guided tubes and cannulas that could be placed on the day of surgery.

Addressing the cost of gene therapy, Sharon explained that while such treatments were typically very expensive, Neurochase's approach was more cost-effective. Their method used smaller amounts of therapy (around $30,000 worth) compared to other treatments that could cost up to $200,000, avoiding unnecessary waste. Infusions were done simultaneously and efficiently, with no complex treatment regimens. The exact therapeutic dose was delivered directly to the targeted location, making it a quick, day-surgery procedure.

Simultaneous infusions in awake patients for neurological / MRI monitoring are also carried out - this procedure works with equipment that hospitals in the UK already use meaning no adjustments have to be made for this new technology to be rolled out.

Neurochase have also treated patients with GBM using their delivery approach.

Three weeks ago, Sharon and Steven acquired all the assets related to the DIPG device. This means that a clinical trial can now go ahead next year, creating a full-circle moment: they have finally overcome the barriers that previously prevented the device from reaching clinical trial stage.

Discussion:

The Convener opened the discussion with Theo Burrell asking how anyone can monitor Neurochase's activity. Sharon encouraged attendees to email her with any further questions and to keep an eye on Neurochase's social media channels for updates.

Sharon shared that she hopes to begin clinical trials next year at Great Ormond Street Hospital, with plans to offer compassionate access to both the drug and the delivery device. She noted that the work is progressing from mouse models to larger models as part of the development pathway.

Archie Goodburn asked how the therapy overcomes the blood–brain barrier. Sharon explained that the delivery system bypasses the barrier entirely, so it does not present a problem for treatment.

When discussing the appraisal of these medicines, Sharon repeated an idea that had been put to her about adopting a new mindset for assessing gene therapies. In this model, gene therapy would be viewed more like a chronic condition: the NHS would pay for treatment over time, while the company would cover upfront costs, allowing for a more sustainable funding approach.

Finlay Carson MSP added that following the election, the Scottish Government should revisit its approach to approving new drugs to ensure innovative treatments can reach patients more effectively.

Agenda item 5 - An update from Dr Scott Arthur MP's office on his members bill for rare cancers bill going through the UK Parliament

Olivia Clarke provided an update and gave a brief introduction to the Bill. First introduced in October last year, the Bill was inspired by Scott's experience of losing his father-in-law to GBM. It has now progressed to the House of Lords.

The aims of the Bill include requiring the Secretary of the State for Health to:

1. Promote research into rare cancers by placing a duty on the UK Government to act, including the appointment of a national specialty lead to drive collaboration.
2. Increase patient access to clinical trials by strengthening the "Be Part of Research" registry, and building a central database of willing patients, making it easier for researchers to find participants, and easier to attract trials to the UK.
3. Trigger a review of orphan drug regulations to encourage pharmaceutical companies to trial both innovative new treatments and the repurposing of existing medicines for rare cancers. Together, these steps will break down barriers, increase the number of trials, and accelerate access to life-saving treatments.

Olivia outlined that the Bill also changes definition of rare cancer bringing it into framework of rare diseases.

Because health is a devolved matter, implementation is more complex, but the last part of the Bill will apply to Scotland.

The next step is the second reading in the House of Lords on 16 January. With strong government support, the Bill is expected to move through the Lords quickly. Once passed, the implementation of the Rare Cancers Act is anticipated to begin rapidly - likely within two months of the Bill becoming law.

<u>Discussion:</u>

The group's convener once again invited anyone to share their comments. Archie Goodburn asked whether the Vaccine Launchpad could be used to support brain tumour patients. Dr Sarah Kingdon explained that the initiative is designed for situations where a tumour has been fully removed, which is a very different clinical setting from what is typically required for brain tumour patients. As a result, the Launchpad would not directly meet the needs of this patient group.

Agenda item 6 – Brain Cancer Justice

Nicola Nuttel delivered a speech on behalf of Brain Cancer Justice (BCJ), drawing on her daughter's experience. She said she had expected the NHS to fully support all cancer patients and for all cancers to be treated equally; however, this was not the

case. She emphasised that brain tumour patients and their families often have no choice but to become experts themselves, and that the patient voice is essential for driving change. “Help us to be heard,” she urged.

Nicola highlighted that she was not there simply to outline the challenges, but to share lived experience. She spoke of families waiting weeks for results, being unable to apply for clinical trials, or lacking access to whole genome sequencing (WGS). Some families have had to seek access to treatments such as Vorasidenib or other therapies only available abroad.

She stressed that early diagnosis remains a major challenge. BCJ is collaborating with other charities to address this, and the creation of a Scottish Centre of Excellence is a positive step. She welcomed the opportunity for ministers to meet patients directly and encouraged continued parliamentary debate on brain cancer.

Nicola concluded by reaffirming BCJ’s mission: to amplify the patient voice.

Agenda item 7 - Date of Next Meeting

Katherine stated that work is under way for the final meeting of the Parliamentary session, due to take place in February on Teams. The CPG will be informed of the date of next meeting in due course.

Katherine presented the Convener of the Group with a present on behalf of the CPG given her inspirational leadership on campaigning for brain tumour patients.

The Convener thanked everyone for their attendance and closed the meeting.