



All-Party Parliamentary Group on Brain Tumours

Remembering Amani: a legacy of change?

Tuesday July 11th 2023, 5pm-6pm, Committee Room 15, Palace of Westminster

Agenda

Welcome from Chair, Derek Thomas MP.

Apologies received.

Matters arising from April meeting and update from the Secretariat including progress on report recommendations.

Introduction of Speakers: Amani's parents Khuram Liaquat and Yasmin Stannard, Dr Anup Vinayan and Dr Thomas Carter (Amani's Neuro-oncologists) and Amani's Clinical Nurse Specialist Tanya Betts.

Speakers share their experience of Amani's journey and hopes for future treatments and clinical opportunities for brain tumour patients.

Discussion with APPG around how our report recommendations dovetail with our speakers' stories and hopes.

AOB and next meeting.

Speakers and Parliamentary Attendees

Speakers:

- Khuram Liaquat, Amani's Father
- Yasmin Stannard, Amani's Mother
- Dr Anup Vinayan, Amani's Neuro-Oncologist
- Dr Thomas Carter, Amani's Neuro-Oncologist
- Tanya Betts, Amani's Clinical Nurse Specialist

Parliamentarians:

- Derek Thomas MP
- Greg Smith MP
- Sarah Owen MP

Apologies

- Alistair Carmichael MP
- Clive Betts MP
- Desmond Swayne MP
- Drew Henry MP
- Luke Pollard MP
- Matt Hancock MP
- Matthew Pennycook MP
- Sir Gary Streeter MP
- Stephen Hammond MP
- Holly Mumby-Croft MP
- James Daly MP
- Keir Starmer MP
- Lord Polak

Discussion Overview

The meeting brought together a unique group of families, clinicians, parliamentarians, and key stakeholder from across the brain tumour space. The meeting facilitated discussion on key issues, such as the limitation of current brain tumour treatment in the UK, and the need for improved access, exploring how MPs can support families and clinicians.

Participants discussed the importance of standardisation in tumour extraction, infrastructure, and genome sequencing, while noting the unreliable nature of brain tumours. The delivery of promises made by the Government in 2016 was questioned, and participants agreed that this would be an area to put increased pressure on Government to uphold its promises. Access to services and support for patients outside of hospitals were highlighted, and Amani's story emphasised the need for change in brain tumour treatment.

Discussion Summary

Hugh Adams (**HA**) opened the meeting by apologising to attendees for the lack of parliamentary presence due to ongoing voting in the Commons.

Khuram Liaquat (**KL**) expressed the purpose of the meeting, which was to share Amari's story with MPs who can bring about change. He requested to reschedule the meeting to ensure parliamentary presence.

Derek Thomas (**DT**) agreed to hold a follow up virtual meeting with attendees to ensure their thoughts and concerns could be raised with the full concentration of parliamentarians. **DT** suggested utilising the present meeting time for productive discussions and encourage attendees to raise relevant issues and discuss how MPs can help families and clinicians facilitate change. He noted the effectiveness of discussions at previous meetings.

KL thanked attendees for their support and confirmed their expectation for a future meeting.

HA suggested proceeding with other parts of the meeting before sharing Amari's story with the MPs who could join the meeting later.

Sue Farrington Smith (**SFS**) assured that minutes of the meeting would be shared with MPs, and Amari's story could be shared when more MPs were present.

Dr Anup Vinayan (**AV**) discussed the limitations of current treatments for brain tumours and the need for improved access to drugs and personalised treatment options. Dr Thomas Carter (**TC**) agreed, emphasising the importance of using drugs sensibly, even if the benefits are temporary, and pointed out barriers in admittance to the compassionate access programme.

Attendees shared their experiences with compassionate access and highlighted the need for improved data capture from individual cases. Attendees suggested involving someone with lived experience, such as a patient or loved one, in the government team supporting patients seeking compassionate access.

AV discussed the need to move toward tumour diagnostic approval and the role of NHS England in supporting this change.

Attendees highlighted the challenges faced in conducting standard trials for certain tumour types, particularly for brain cancer. There was consensus that clinical trials can increase the quality of life for patients.

AV and **TC** highlighted the importance of capturing tissue for up to date data analysis. **TC** raised that due to the unique nature of brain tumours, and the difficulty in obtaining tissue for further diagnosis, capturing data is a significant challenge. He suggested this as an area for MPs to petition for a centralised system to capture data and administration.

SFS championed the idea of a UK-wide multi-disciplinary team and noted the progress made over the last 15 years, particularly Owen's Law.

Attendees further raised the role of freezing tissue for further testing, noting the possible repurposing of vaccine fridges used during the pandemic. Sarah Owen (SO) asked what the road blocks were to this and offered to submit parliamentary questions.

TC noted the complex laws around freezing tissue and the need for the standardisation and investment in infrastructure.

AV highlighted the importance of offering genomic sequencing as a standard treatment option and suggested this as an area for the APPG to explore. **AV** raised that establishing a better practice and pushing for genome sequencing would improve standardisation.

Attendees noted Matt Hancock's 2016 promise for increased genome sequencing, yet only 1% of patients who might have had sequencing were able to access it. Attendees raised that the Government should be held accountable on its promises from 2016.

HA referenced the inquiry conducted by the APPG, pointing to the variation in access to services across the UK. **AV** agreed that greater support is needed for patients outside of hospitals to address the postcode lottery of support for patients.

A video of Armani's story and campaign was played.

Tanya Betts (**TB**) spoke to Amani's story and her fighting spirit. She raised that treatment for brain tumours has not changed in 25 years.

Attendees discussed the challenges specific to brain tumours, the need for a unified voice from clinicians and families, and the importance of communication and standardisation.

Participants stressed the importance of funding and expressed their willingness to contribute to the patient and caregiver voice.

HA highlighted the need to keep pushing for change, noting the work the APPG hopes to do with the MHRA and FDA in the United States.

DT apologised for the disruption and confirmed plans for a virtual meeting in September to discuss the prioritisation of brain tumour care. **DT** thanks attendees for their time and closed the meeting.



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on Brain Tumours

Contact

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