

Cross Party Group on Brain Tumours

29-04-24 13.00

Minute

Present:

MSPs:

Beatrice Wishart MSP
Colin Smyth MSP
Foyso Choudhury MSP
Ben McPherson MSP
Finlay Carson MSP

Non-MSP Group Members:

Thomas Brayford, Brain Tumour Research

Apologies:

Jackie Bailie MSP
Jackson Carlaw MSP

1. Welcome by Beatrice.

Beatrice Wishart MSP welcomed everyone to the initial meeting.

2. Apologies.

Beatrice gave apologies from Jackie Baillie MSP who has indicated support for the group. Apologies from Jackson Carlaw MSP were also received.

3. Selection of Convener/s.

Beatrice Wishart was nominated for Convener by Colin Smyth, seconded by Foyso Choudhury. There were no other nominees.
Beatrice Wishart was appointed as Convener.

4. Selection of Deputy/ies.

Beatrice Wishart proposed that Colin Smyth, Finlay Carson and Ben McPherson were nominated as Co-Deputy Conveners. There were no other nominees.
Colin Smyth, Finlay Carson and Ben McPherson were appointed as Co-Deputy Conveners.

5. Selection of Secretariat.

Beatrice Wishart introduced Brain Tumour Research and proposed them as the secretariat. Colin Smyth seconded the proposal. There were no other nominees.
Brain Tumour Research was appointed as the secretariat.

6. Discussion on future meetings.

Beatrice Wishart asked if members would be interested in hybrid meetings in the future. Colin Smyth said hybrid meetings seem to be working quite well but noted there is no IT support. Beatrice Wishart said this can be revisited this once group is formalised and there is a date for the first meeting.

Finlay Carson put a note in the chat of ideas for the Cross Party Group to cover. The note is replicated below.

Ideas of things to consider:

- * 1% of cancer budget is totally inadequate*
 - * More funding to be made available in brain tumour research*
 - * Funding into specific brain tumour support available to patient and family eg: at point of diagnosis referral to key/link worker specialist in brain tumour not generic cancer nurse there to offer ongoing support to patient and family (our experience was of feeling alone and isolated trying to cope with this awful disease)*
 - * cancer charities don't seem to offer specific brain tumour support*
 - * Glioblastoma treatment is limited and life expectancy extremely short*
 - * patient quality of life very poor after treatments*
 - * limited support available for patient and family especially in rural areas*
 - * Highlight challenges in rural areas (D&G) eg : distances travelling to appointments in Edinburgh / Dumfries .appointment times are challenging for patients to attend when experiencing numerous symptoms*
 - * online appointments offered but again in rural areas broadband connectivity is poor*
 - * Some staff have limited knowledge of complex symptoms patient is experiencing especially on the wards both in Edinburgh and Dumfries*
 - * Pressure on family to take responsibility for medication/ blood glucose monitoring/ taking temperature/monitoring patient incase of seizures !*
 - * More awareness needed of how debilitating this disease is*
 - * NHS is understaffed and we were shocked that some staff have very limited knowledge of brain tumours and how the patient is affected.*
- Not sure if this is what you were looking for Fin, come back to me if you want anything specific. I feel really strongly that there needs to be a focus for change in funding towards Brain Tumour Research and Patient/Family support.*

7. Screenshot/photo of the group.

Thomas Brayford from Brain Tumour Research asked to take a screenshot of the first meeting as a record. Thomas took a screenshot of the meeting.

8. Any other business.

There was no other business.

9. Close of meeting.

Beatrice Wishart thanked everyone for their support and closed the meeting.