# NAoS Brain Awareness Week (10 – 16 March 2025) subgroup

# Terms of Reference

**Date: 28 August 2024**

|  |  |
| --- | --- |
| 1. Rationale | There are over 600 known neurological conditions affecting 1 in 6 people in the UK. The cost of just 10 neurological conditions on the UK economy has been estimated to be £96bn in 2019[[1]](#footnote-1) which includes the cost of carers not being able to work full time (or at all).  One of our strategic aims is that the voices and needs of those affected by neurological conditions-and those who support them-are heard by key stakeholders and decision makers across the sectors. Taking part in the annual Dana Foundation run Brain Awareness Week, allows us to raise awareness of neurological conditions and the impact on people’s lives, whilst simultaneously signposting people to our member charities and the support that they offer.  Previously, we have started Brain Awareness Week planning in late December for a March campaign. Going forward, members of NAoS would like to set up the BAW campaign group in the autumn. This will ensure enough time for collaborative, co-produced working with members and the UK alliances.  Feedback from members highlights the benefit of having a unified, collective voice when campaigning; we are likely to make a bigger impact if we co-ordinate across our Neurological Alliance memberships. |

|  |  |
| --- | --- |
| 1. Role and Remit | The role of the group is to come up with a creative campaign theme, and clear measurable (SMART) objectives for the Brain Awareness Week 2025 social media campaign and develop assets for members to use throughout the week.    The central purpose of this subgroup is to work collaboratively to create a Brain Awareness Week campaign and engage all UK Neurological Alliances members to participate in the campaign. The group will meet to discuss the aims, objectives and outputs of the campaign and how best to achieve these. They will facilitate the development of necessary resources for the campaign and member involvement. They will outline SMART objectives and report on these to our wider membership once the campaign has ended.  The aim of the group is to run a successful social media awareness raising campaign with wide member engagement. |

|  |  |
| --- | --- |
| 1. Group membership | Membership is open to all members of NAoS.  **List of members:**  David Coates, Epilepsy Scotland  Kripen Dhrona, British Polio Fellowship  Kitty Gardiner, MS Society  Janet Paterson, Neurological Alliance of Wales  Steve Portelly, FND Hope UK  Miranda Lloyd, Neurological Alliance England  Alicia McKenzie, Craighalbert Centre  Carla Smyth, Northern Ireland Neurological Charities Alliance  Gemma Scullion, Scottish Head Injury Forum  Members of the group can take on responsibility for different elements of the workplan, such as engagement of a co-production group, development of communication resources, design of social media assets, promotion of campaign and member engagement.  Members of the Brain Awareness Week subgroup will select a chairperson who will oversee the running of the group, including setting up the frequency and agenda of the meetings. |

|  |  |
| --- | --- |
| 1. Frequency of meetings | We aim to get the group established with its first meeting in September 2024. The initial priority will be to agree the aims of the group and initiate a workplan. The group will report to all NAoS members at our 20 November meeting with a theme for the 2025 campaign.  Initially the group will meet more regularly to decide and theme and work plan. After this, the meeting schedule can be decided. In the three months leading to BAW, the group may need to meet more frequently to develop and finalise resources. Members can report to each other via email or through ad hoc meetings between the formal subgroup meetings. |

|  |  |
| --- | --- |
| 1. Reporting | This Chairperson of this group will report to members in the members’ meetings, which are every 8 weeks. |

|  |  |
| --- | --- |
| 1. Ways of working | Individuals within the subgroup will take on accountability for individual work strands, taking it to colleagues and other members of NAoS. A fair amount of work will be in developing the design for social media assets and the copy for the communications pack members will use. It may work best for splinter groups to form to take on this work.  This is a creative group with opportunities for sharing design and communications skills.  The group will also need meaningful engagement from a co-production group in the development of theme and resources. Each Alliance will be responsible for nominating someone to join the group to bring the voice of lived experience. Each alliance is responsible for covering any expenses or reimbursements to the individual for this collaboration. |

|  |  |
| --- | --- |
| 1. Aims of the group | 1. Agree the theme of the 2025 Brain Awareness Week campaign 2. Agree a campaign plan including SMART objectives, outputs and timings of outputs 3. Create social media assets which can be shared across all participating charities 4. Create a communications pack to be shared amongst all participating charities 5. Meaningfully engage with a co-production group to formulate the campaign and resources to ensure that they are accessible and reflective of the lived experience of people affected by neurological conditions. 6. Regularly update NAoS members and other UK Alliances with campaign information 7. Report to NAoS members at our 26 March 2025 members meeting with key stats and engagement metrics |

|  |  |
| --- | --- |
| 1. Secretariat | Hester Lee, NAoS Admin Assistant will be responsible for setting up the meetings and minuting, distributing previous meeting minutes and any other papers required seven days in advance of each meeting. |

1. [ei\_the\_value\_of\_action\_mitigating\_the\_impact\_of\_neurological\_disorders\_in\_the\_united\_kingdom\_report\_v4\_17-5-24\_r1.pdf (economist.com)](https://impact.economist.com/perspectives/sites/default/files/ei_the_value_of_action_mitigating_the_impact_of_neurological_disorders_in_the_united_kingdom_report_v4_17-5-24_r1.pdf) [↑](#footnote-ref-1)