### Minute of NAoS Exec meeting

**28 January**

**Zoom call 11 - 12pm**

**Present:**

Tanith Muller, Chair – Parkinson’s UK Scotland

Rona Johnson, New Vice Chair - Epilepsy Scotland

Stephanie Fraser – Cerebral Palsy Scotland

Alison Love – Ataxia UK

Gill Dickson- PSPA

Ewan Dale – ME Association

Iain Morrison – Revive MS Support

Craig Stockton – MND Scotland

Alice Struthers – Programme Co-ordinator NAoS

**Apologies:**

Morna Simpkins – MS Society, Elinor Jayne – Sue Ryder Care, John Eden – SHA, Alistair Haw – SHA, Leigh-Ann Little – Oxygen Works

**Actions carried over from December meeting due to family commitments.**

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| **7.** | **Neurological Alliance (England) survey update**  The situation regarding whether or not there is a cost to NAoS for getting involved is unclear. Tanith estimates there may be a nominal charge of up to £3,500 to survey Scotland. Gill agreed it would be worth being involved even if there is a fee of up to £3,500, if the NAoS has editorial control of the questions we want to ask. | Tanith to ask SG if they will cover any costs relating to this England NA survey in Scotland |

Minutes from the meeting:

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| **1.** | **Apologies**  We had apologies from Morna Simpkins, MS Society, John Eden, Scottish Huntington’s Association and his successor, Alistair Haw, new CEO SHA. | **Actions** |
| **2.** | **Minutes from December Meeting**  Tanith Muller explained that due to family circumstances, there is one outstanding action from the December Minutes which will be actioned this month instead.  Minutes were approved by the Executive and signed off. |  |
| **3.** | **Executive Membership Changes**  The executive acknowledged John Eden’s resignation from Scottish Huntington’s Association and therefore from the NAoS Executive. John was thanked in absentia for his contribution to the NAoS over the years and wished him well for his future endeavours. The executive then co-opted in new SHA CEO, Alistair Haw as executive member of the NAoS and stated how glad they are that SHA continues to be represented on the Executive. |  |
| **4.** | **NAoS Strategy and Membership Review Update**  Since starting work in October, with the support of chair and coordinator, we have developed, circulated and collated our membership survey. This has given us insight into the priorities and drivers for membership. There were 28 responses to this survey, which represents more than 50% of the membership. We have also developed a survey for non-members.  As a result of the lockdown, Becky will be doing one to one calls with around 10 members and a further two potential members, rather than focus groups. She have also had focussed discussions with all but one of the executive members. | Becky/Alice to organise |
| **5.** | **Neurological Alliance (England) Survey Update**  There was no update here due to time constraints in the run up to the meeting. Fieldwork is due to take place in the Spring and early Summer. It is unclear as to whether there would be a charge for NAoS to add some questions, and if there is a charge, will SG cover the costs via a grant. | Tanith Muller to speak to Georgina Carr. |
| **6.** | **Executive Member Check in**  A mixed picture emerged whereby some organisations are managing with reduced enquiries and furloughing staff, whereas others have increased enquiries and referrals.  The question of vaccinations arose both in terms of eligibility for access through the Government’s priority scheme, but we also discussed staff members who have contact with vulnerable people but who are not happy to receive the vaccine. There are employment implications around asking people to be vaccinated and how to work with vaccine refusers who have direct contact with vulnerable people. Do people have the right to know of their colleagues who have refused the vaccine?  The executive also discussed shielding, and the acknowledgement that having a neurological condition makes you more at risk of serious covid than any other factor other than age and yet neurological conditions are not on the shielding list. This does not affect everyone. Some conditions for instance, MND are so degenerative that people would not be working and would be shielding even if they hadn’t been told to, however those living with MS and epilepsy with would benefit from being allowed to stay at home.  People with epilepsy are concerned that the vaccine will set their seizures off. Whilst there is no evidence this could happen, there is no evidence that it will not and so advisors are limited to reassuring callers by saying it is unlikely that the vaccine will trigger seizures.  People with ME are also sensitive to the potential of a bad reaction to the vaccine. Many people are just getting by, with no margin for a negative change to their health, so there are fears that the vaccine will cause a downward spiral to their health. | Stephanie Fraser to circulate CP Scotland vaccine report to executive  The NAoS will write to SG raising concerns about high risk people not being informed of their risk and being priority for future vaccines and boosters |
| **7.** | **Section 10 Update**  It is understood that the Scottish Government is planning to restructure Section 10, and we would like to know if this is true, what will it mean for organisations who rely on Section 10 funding. | Tanith will ask Alistair Haw (SHA) to circulate his findings to the executive. |
| **8.** | **Events**  We are planning a Ministerial Event in March (the invite has been extended to the Minister for Public Health, Mairi Gougeon) and a hustings in April.  The annual schedule of events was agreed to be as follows:  A members meeting every 3 months, followed by an executive meeting (the executive meeting would be using the same Zoom link and open to observers). The next members’ meeting is due on 28 April 2021.  We will also introduce a policy group in order to share campaigning information and to provide a bit of horizon scanning each quarter. These will be bi-monthly meetings (every other month, not twice a month), open to all members. The first meeting is pencilled in for 24th February. | Alice and Tanith/Rona to liaise and organise  Alice to find 4-6 policy experts to come on board and help. Exec to email Alice with contacts. |
| **9.** | **Co-ordinator Update**  We have gained 3 new members since December. One new member (Brainstrust) joined after finding out about us through our non-members’ survey. One (MSargyll) joined after being invited to do the non-members’ survey, but also may have joined as they are close contacts with the Dochas Fund, a new member who joined in December 2020.  18 members have not paid 2020/2021 fees (issued in October 2020). The Migraine Trust (existing members) is postponing paying 2020/2021 fees and ‘re-joining’ until they have a Policy Officer in place.  We are trying to identify a payee who had no reference for their membership fee (£125) and still chasing fees for 2020/2021.  On the comms side, we are have been using MailChimp for the past 2 months which has achieved an open click rate of about 44%. We have also increased our twitter followers from 70 – 87 since December.  We have £9,286 in the bank and c.£33k Section 10 funding is due any minute to fund the Strategy Director and Programme Co-ordinator role until March. |  |
| **10** | **AORB**  It was agreed that the NAoS should purchase Teams. | Alice/Tanith to liaise to purchase |
| **11** | **Close of meeting**  Tanith thanked the team for their time today. The next meeting will be on 25th March at 12pm following the Members’ meeting at 10am. |  |