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Members’ Meeting Summary

Attendees

Tanith Muller, Chair, Parkinson’s UK

Rona Johnson, Vice Chair, Epilepsy Scotland

Ewan Dale, Exec member, ME Association

Gill Dickson, Exec member, PSPA

Alistair Haw, Exec member, Scottish Huntington’s Association

Alison Love, Exec member, Ataxia UK

George Allan, Post Polio Network

Valerie Maxwell, Sue Ryder

Carol Cochrane, Brainstrust

Jonathan Sher, QNIS

Karen Garrott, Stroke Association

Rob Music, Migraine Trust

Beth Strachan, Child Brain Injury Trust

Stoo Brown, ME Action

Michelle Keenan, Edinburgh Headway

Paul Rimmer, Neurocentral

Nancy Campbell, MS TC Lothian

Melissa, Tourette Scotland

Alice Struthers, NAoS Programme Co-ordinator

Apologies

Helen MacDonald, Lanarkshire Epilepsy

Leigh-Ann Little, The Oxygen Works

Karen McCurry, MS Therapy Centre Mid Argyll

Avril McClean, Action for Me

Caroline Morrice, The GAIN Charity

Sue Millman, Ataxia UK

Iain Morrison, Revive MS Support

Morna Simpkins, MS Society

Jackie Munroe, MDUK

David Mulligan, Funding Neuro

Victoria Wareham, Dystonia UK

Lorraine Jackson, Quarriers UK

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| 1 | Chair’s welcome and Scottish Government update | Further to everyone introducing themselves,. Tanith and Alice attended a H&SCA meeting this week with Kevin Stewart MSP (Social Care Minister). The Scottish Government (SG) is committed to implementing all 59 of the Feeley recommendations from the independent review of adult social care. People with neurological conditions are heavy users of social care. We will be keeping a close eye on this. Members of the NAoS have set up a Children and Young People’s Special Interest Group (CYP SIG) and one early outcome was raising the issue that the Neurological Framework does not apply to children other than transition to adulthood. This is due to the way the NHS is structured. The SG accept that more work needs to be done on paediatric policy. NAoS also have reps on the MSN for Neurosurgery. This group was set up to manage the 4 Scottish neurosurgery units centrally.  ACTION: if members have encountered issues with neurosurgery for their networks, please tell Tanith who can feedback to the MSN at their next meeting in August.  Tanith also mentioned the large capital infrastructure project in Glasgow that is about to start. This will be a refurb or rebuild of all the neuro units at the Queen Elisabeth University Hospital (neurosurgery, neurology, in patient wards, spinal injuries, rehab and imaging). There is a call for service users who currently use the facilities at QEUH as the building works will directly affect them. The NAoS has been asked to find service users who are prepared to help steer the project, supporting Greater Glasgow and Clyde (GGC) Managers as they consider how best to upgrade the facilities.  Gill Dickson (PSPA) raised the question of workforce and who is considering how to ensure we have sufficient neurology workforce in Scotland going forward.  Members agreed that workforce is a major issue and is of concern. Both the acute workforce in hospital settings and the community workforce. Jonathan Sher, QNIS said that the community workforce had been majority disrupted through the pandemic, not just specialist nurses but primary care nurses as well. NAoS needs to inform ourselves about who currently serves people with neuro conditions so we can put emphasis on their importance to our communities going forward and make sure provision is being made to ensure posts are filled.  Stoo Brown, ME Action said that currently there is no ME workforce however with the NICE guidelines for ME coming out in August, this needs attention.  Action: Are there enough interested people to set up an NAoS Workforce Special Interest Group? Please email Alice via [info@scottishneurological.org](mailto:info@scottishneurological.org) to register your interest. |
| 2 | NACNC update | Tanith explained that the National Advisory Committee on Neurological Conditions (NACNC) was established in 2019 to support the implementation of the Neurological Framework for Action. There are various NACNC subgroups and one of which looks at Workforce |
| 3 | Members' Check-in | Parkinson’s UK – just starting to re-introduce face to face exercise programmes. Current issue is that people are generally anxious about moving from virtual to face to face.  Epilepsy Scotland – are keeping their well being support and youth groups virtual until August to avoid switching back and forth from virtual – face to face and back.  Scottish Huntington’s Association- reported challenging behaviour from clients in lockdown, with some safeguarding issues arising.  The Stroke Association are adopting a blended approach and will be re-opening face to face appointments from 5 July, but with the option of attending virtually to those who prefer to stay at home.  Edinburgh Headway had to get approval from the Care Inspectorate and the Health & Social Care Partnership in order to open. They are also offering a blended approach. If other organisations also need to undergo risk assessments, Michelle Keenan (CEO Edinburgh Headway) is more than happy to offer advice. |
| 4 | NA My Neuro Journey survey | Alice ran through the timeline for the UK-wide patient neurological survey which is going to fieldwork on 1st Sept – 31 October. This will be the first time that Scotland will be part of this survey. The survey is organised by the English Neurological Alliance and runs every two years. In 2019 they achieved over 10,000 respondents. This year we are hoping to get between 700-1000 Scottish respondents with help from our members. The 4 neuroscience centres in Scotland (Dundee, Aberdeen, Glasgow and Edinburgh) will be sent paper copies of the survey, there will be ballot boxes set up at the centres which can be used by those waiting for appointments. There will also be an online link. Keen to get more diversity of responses this time from BAME people as well as LGBTQI. There will also be a bespoke children’s survey available for the first time. The final UK Report should be available in December and we then have to use the data to draft a Scotland report which will be completed by March 2022. |
| 5 | Awareness Campaign 2022 of neuro conditions: call for lived experience stories from members | We are also looking for qualitative data in the form of patient experiences or case studies, for our Scotland report.  Action: Please can any NAoS member who captures qualitative patient experience data consider sharing it with the NAoS to form part of our Scotland report?  Scottish Huntington’s Association put a link in the Chat box to a recent campaign they have run and offered it for use. (Thanks!) |
| 6 | Neuro Hub | Alice gave a bit of background to the reasons for creating a neuro hub. NAoS members are in favour of creating a hub however there are some differences in opinion of what the hub should do and how it should look. Ultimate aim is to provide an online space that has been endorsed by the CMO, and which therefore provides reassurance to clinicians and non neuro specialists, for info gathering and referrals. It is not intended to replicate ALISS. Next steps are a conversation with the Tailored Talks team (POGO) and then to form a Neuro Hub working group with members interested in taking this forward.  Jonathan Sher, QNIS raised the point that most NAoS members are also H&SCA members and their website gets much more traffic and so why not just promote members through the H&SCA. Tanith Muller, Chair NAoS replied that outwith the sector, knowledge of the H&SCA is not that high and so it wouldn’t necessarily reach the new audiences that we are looking to engage with. However it would be good to connect with the Community Links project which links workers in the 100 most deprived health boards in Scotland. Making them aware that we exist is important for getting referrals in from people with multiple deprivation alongside neurological conditions. |
| 7 | Comfort Break |  |
| 8 | Knowledge sharing events – what do people want? | Alice announced idea of holding knowledge sharing events, which are member – member events. We ran through those present to come up with some initial ideas for themes that would be useful to members. Initial ideas are:  **Campaigning** – strategies and ways of running a successful campaign  **Volunteers** – recruiting and managing them  **Scotland’s NHS** – run through the differences with NHS England, explanation of all quangos and relevant health bodies (e.g SIGN, HIS etc).  **Pathway information** – useful for conditions where diagnosis comes through a variety of specialists. How to ensure everyone diagnosed gets on the right track as soon as possible.  **Running events online** – best practice, how to get virtual bums on seats etc  **Referral process** -what are the best ways of navigating the paperwork journey and how do we make it simpler for referred patients to attend services offered.  Action: Alice will email members to get additional ideas for learning, and we also want to know who can provide these sessions, so if you have experience in any of the popular themes, please consider hosting one of the knowledge sharing events. We would like to host 4 sessions by April 2022. |
| 9 | AORB | The meeting ended at this point as the Exec meeting started on the same Zoom link. Apologies to all as we had to cut things off.  However, we do have a matter for AORB regarding understanding if conditions other than ME have cohorts of patients who suffer a severe version of the disease and so are very disabled by it.  Action: See note from Stoo Brown at the bottom of these minutes.\* |
| 10 | Next meeting date and close of meeting | The next meeting will be our AGM on the 29 September, from 10.30 – 13.30  We will be looking to recruit 2 new Exec members to the team so please send your note of interest to [info@scottishneurological.org.uk](mailto:info@scottishneurological.org.uk) if you would like to be considered. |

\*AORB:

Dear Colleagues

I had to leave the NAoS Members' Meeting this morning just before the end, when I had planned to raise a simple question under the topic of AORB.

In the ME community there is a sub-group of patients who are severely ill:  certainly house-bound and usually bed-bound.  They number about 25% of the total ME cohort and are thus known as "Twenty five percenters".  They are extremely poorly treated:  despite their severe need they have no services whatsoever.  Their condition makes it almost impossible for them to advocate for themselves.

I was wondering:  **in other neurological conditions are those with severe disability similarly ignored?**

Your answer will inform they way we pursue better services for this cohort:  if your severely disabled members get a sympathetic treatment from service providers then we will be more justified in asking the Scottish Government why Twenty five percenters get nothing.  If you can provide me with a written answer then we may use it in submissions to the Scottish Government - please let me know if this is OK with you.

Thank you for your time and consideration.

Stoo Brown

#MEAction Scotland

Email: stooibrown@yahoo.com