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Members’ Meeting Agenda

**Online via Zoom**

**23 February 2022**

**10.30am – 12.30pm**

Join Zoom Meeting  
 <https://us06web.zoom.us/j/97467566596>

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| George Allan | Scottish Post-Polio Network |
| Rona Johnson **(Vice-Chair)** | Epilepsy Scotland |
| Jonathan Sher | QNIS |
| Mary Ramsay | Scottish Tremor Society |
| Alistair Haw | Scottish Huntington’s Association |
| Anna Telfer | Epilepsy Scotland |
| Avril McLean | Action for ME |
| Sue Millman | Ataxia UK |
| Ben Peter | Scottish Huntington’s Association |
| Beth Strachan | Child Brain Injury Trust |
| Carol Cochrane | Brainstrust |
| Charlotte Encombe | MS Therapy Centre Lothian/Compass |
| Dawn Golder | FND Hope UK |
| Ewan Dale | ME Association |
| Gerard Anderson | Child Brain Injury Trust |
| Rebecca Packwood | PSP Association |
| Robert Music | The Migraine Trust |
| Victoria Wareham | Dystonia UK |
| Tanith Muller | Parkinson’s UK |
| Alice Struthers | Neurological Alliance of Scotland |
| Charlotte Sarrau | Neurological Alliance of Scotland |
| Colin Robertson | Headway Dundee and Angus |
| Stephanie Fraser | Cerebral Palsy Scotland |
| Lynn Hugues | Welsh Neurological Alliance |
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| 1 | **Chair’s welcome and Scottish Government update**  The Neurological Framework Funding - Round 3 is open until March 7. Organisations that didn’t send a note of interest can still apply for that funding. You can find more information [here](https://www.gov.scot/publications/neurological-framework-funding/).  The Chair and Vice-Chair of NAoS will be involved in the scoring process of applications, to make sure the 3rd sector is represented in the Framework bids.  The NAoS is not in a position to help members with bids. | 10.30am | 10 mins |
| 2 | **National Advisory Committee on Neurological Conditions (NACNC) update**  Clarification on what the NACNC is: it is a Scottish Government oversight committee, with people with a speciality or interest in neurological conditions. It includes clinicians, the Scottish Government’s Clinical Priorities team, and 3rd sector representation with the Chair and Vice-Chair of the NAoS. The full list of members is [here](https://www.gov.scot/groups/national-advisory-committee-for-neurological-conditions/).  What should the NAoS raise at next NACNC (March 23rd)?  FND Hope: Not many clinicians in Scotland know how to treat FND, it’s a postcode lottery. Edinburgh and Aberdeen do treatment, but in other areas there’s nothing and it’s very difficult to get a referral to another health board. The longer someone’s FND symptoms are left untreated, the worst outcomes they have. We would like somebody to take ownership to set up an FND service, but don’t know if NACNC is the right forum.  Vice-Chair: I will bring up inequity of access to care.  Action for ME: You could raise our free module (created by Action for ME) which clinicians can use for diagnosing and managing symptoms of ME.  **Action: send it to Rona** | 10.40am | 5 mins |
| 3 | **Members' Check-in**  What 3 Priorities do you think the NAoS should be focussed on in 2022? What are your priorities this year?  Ataxia UK: Normally we have a large fundraising and communications team, but currently at half capacity. We are having great difficulty recruiting fundraising people. Is this a common problem across charities?  In Scotland we are looking to introduce a specialist nurse service and an advice service. We know how we will provide it and are currently fundraising for this. Copying MSA Trust model – using peripatetic nurses.  Our 4 priorities are:  - speed of diagnosis,  - patient data,  - workforce issues (number of neurologists/specialist nurses),  - patient information (created by us for clinicians, but not endorsed by NHS – lack of legitimacy).  Scottish Huntington’s Association: Not all conditions have specialist nurses. There are specialist HD services in all health boards except in Forth valley. Would like to identify which health boards are particularly unreceptive/badly provided in neuro specialists – something we could map as an Alliance and collectively campaign on.  Re: peripatetic specialists, is this something that is in place in Scotland for some conditions? Would like to share learning on this point.  Epilepsy Scotland: Some health boards are very open to having specialists and others aren’t, despite clinical guidelines. Inequity of access to care in Scotland. Could write pan-neuro report on neurology services across Scotland. Scottish Government is working on clinical nurse specialist report, we could bring a 3rd sector perspective to it.  Epilepsy Scotland: Our priorities are clinical nurse specialists and patient data.  Scottish Tremor: NHS Highlands do not have specialists that I know of, patients get sent to other hospitals.  CBIT: Our priority is a neurological care and support framework for Children and Young people.  QNIS: Our priorities are:  1. Focus on prevention (pre-birth) of neuro/neurodevelopmental conditions.  2. Broad Scottish policies which are missing a neuro component. → e.g. new [Women’s health plan for Scotland](https://www.gov.scot/news/womens-health-plan/).  → [2004 ASL](https://education.gov.scot/improvement/research/education-additional-support-for-learning-scotland-act-2004/) – despite the law, children with neuro conditions are not well served.  Must ensure neuro conditions are represented and taken seriously.  Vice-Chair: could write letter to Maree Todd on cross between Women’s health and neuro conditions.  Will also be working on PES, with a launch on June 9 (1-2pm via Zoom) during our CPG meeting, Maree Todd has been invited.  Scottish Tremor: priority is our current petition. Trying to find out how many people have essential tremor in Scotland, to present to Scot Gov. Advice on how to do this?  Vice-Chair: Could send FOI request to all Health Boards.  QNIS: Can find sympathetic MSP that can take question to Scot Gov. Ask for best estimate in absence of exact numbers. If it gets raised publicly regularly by different MSPs it might get moved up the priority ladder.  Epilepsy Scotland: FOI requests often ignored and health boards estimates are very different from ours, they refer to patients on waiting list who haven’t been diagnosed yet.  ME Association: If people are sent cross-border for referrals, could find out what coding/description is being used. Could give basis for MSP question. Essential tremor might be getting initially misdiagnosed as FND.  Ataxia UK: We struggle with cross-border referrals. Would be interesting to make FOI for all cross-border referrals by condition and to where. | 10.45am | 20 mins |
| 4 | **Children and Young People’s SIG update**  **Presented by Gerard Anderson (CBIT).**  **CYP Special Interest Group**  Purpose: Looking at ways NAoS can engage with Scot Gov to advance the agenda of Children and Young People with neurological conditions, and improve support services across Scotland.  Often strategy and guidance is developed for adults and CYP are only mentioned in a supplement if at all. Doesn’t go far enough.  Explored ASL Act and educational support needs of CYP.  **Update on Acquired Brain Injury strategy** –  Chris Bryant MP and Gillian Keegan MP have been creating ABI strategy for British Gov. A UK Programme board will drive strategy. Noted there was no mention of neuro rehab.  Relevant charities submitted key priorities to inform ABI strategy. Will go out to key organisations and stakeholders.  Board will look at key figures to involve in each of the devolved nations. Looking for involvement with key politicians who will push it in their nation, especially Scotland.    [Call for evidence](https://www.gov.uk/government/consultations/acquired-brain-injury-call-for-evidence-easy-read) (UK Gov website).  **Action**: In Scotland, if there are names of key department staff or MSPs, please send them over to Gerard at gerardanderson@cbituk.org  Parkinson’s UK: Scot Gov’s Clinical Priorities team have not been approached yet. Most of what is in the strategy is devolved so will need thinking through to make a UK-wide strategy work.  Could talk to Rare Disease UK about their experience of implementing a UK-wide strategy.  CBIT: Acknowledged devolved powers in Scotland and NI. What matters is achieving the same outcomes, even if it’s not done through a UK-wide strategy.  Cerebral Palsy Scotland: We have had success working with pan-UK organisations. Offer to push ABI strategy in Westminster. Seems MPs are driving it rather than civil servants – need to feed in Scottish good practice and examples. | 11.05am | 10 mins |
| 5 | **Movement Building – Welsh Neurological Alliance**  Welcome to Lynn Hugues, Vice-Chair of Welsh Neurological Alliance (Day job – director of MS Society in Wales).  Lynn gave an overview of the WNA before Covid:  Mission statement was raising awareness, influencing policy, improving services. But in practice mostly focus on policy, and never developed services.  Faced challenges:  Over-reliance on executive and key individuals from bigger charities. No members meetings outside of AGM. Members were organisations only.  Sat on a number of groups (Cross party group, Neurological Conditions implementation group) but they didn’t drive change forward, had a narrow focus, recommendations to Welsh government were ignored, didn’t succeed in engaging with local health boards.  Felt like they were putting a lot of resources towards actions that had little impact. Wanted to engage with and represent people with neuro conditions more directly.  → Covid was opportunity to reassess the direction of the WNA.  The [Social Change Agency](https://thesocialchangeagency.org/resources/movement-building-canvas/) hosted workshops for them to help them rethink the role they wanted to have in the neurological community.  **Action: Lynn to share report with NAoS**  As a result, the WNA changed its activities, and co-produced a plan with charities and individuals:  - move power away from executive board to community members;  - make better use of social media/communications;  - sustainability of funding and movement (received Lottery Fund’s People and places grant).  Came up with a 5-year project with paid staff: priority was people with neuro conditions wanted to feel connected with each other, build their resilience (peer support, neuro cafes) and improve local services. Support people to connect with decision-makers at the local health board level (service user forums).  WNA is now supporting the creation of a new charity (Llais Niwro/“Neuro Voice”) as a sister organisation which would focus on grassroots campaigning, service development and community support. The WNA would focus on working with the Welsh government to get neuro conditions on the agenda, which still receive less attention than other health issues. | 11.15am | 30 mins |
| 6 | **NAoS campaign update**  Slides attached.  Alice presented the campaign plan, and polled members on the campaign name, and campaign messaging.  Scottish Tremor: March is an awareness month for various neuro conditions. In April we will have a stand at Holyrood to raise awareness of essential tremor. Co-hosted with MSP.  **Action**: send info/materials about NAoS to Mary, and it will be added to the table. Date TBC.  CBIT: ABI Week this year (16 - 22 May) the theme is Hidden Disability, resonates with a lot of neuro conditions. | 11.45am | 20 mins |
| 7 | **Long term sustainability of the NAoS**  Please get in touch with Alice if you have any fundraising experience. | 12.05pm | 10 mins |
| 8 | **AORB**  Invoices will be sent in April. Fee bands have changed at last AGM. Smaller charities (under 50k) have free memberships.  Dystonia UK is organising conference in Edinburgh – ‘[Dystonia Matters Live](https://www.dystonia.org.uk/pages/FAQs/category/dmlive22)’ on Saturday 18th June.  Ataxia UK has its [Members’ conference](https://www.ataxia.org.uk/support-services-ataxia-uk-conferences/) in Edinburgh on the same date. | 12.15pm | 10 mins |
| 9 | Next meeting date will be the 27 April (10.30-12.30) and close of meeting | 12.25pm | 2 mins |