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Members’ Meeting Summary

27 April 2022

Attendees: Apologies:

Tanith Muller, NAoS Chair, Parkinson’s UK Karen Garrot, Stroke Association

Mary Ramsay, Scotttish Tremor Society Kyla McDonald, Tourette Scotland

Shirley Maxwell, Epilepsy Connections Kirsten Walker, SHA

Katie Rigg, MSA Trust Anna Hunter, CP Scotland

Marc Smith, Brain and Spine Foundation Caroline Morrice, GAIN

Rachel Morrison, QNIS John Watson, Stroke Association

Anna Telfer, Epilepsy Scotland Claire Winchester, MS Trust

Avril McClean, Action for ME Andy Wynd, SBUK

Beth Strachan, CBIT Brian Kenny, Headway

Gerard Anderson, CBIT Stoo Brown, ME Action

Carol Cochrane, Brainstrust Alistair Haw, SHA

Colette McDiarmid, MND Scotland Jill Douglas, MyName5Doddie

Colin Robertson, Headway Dundee and Angus

Ewan Dale, ME Association

Phil Robson, Lanarkshire Epilepsy

George Allan, Scottish Post Polio Network

Janice….MS Trust

Jennifer Hall, Alzheimer Scotland

Leith-Ann Little, The Oxygen Works

Rebecca Packwood, PSP Association

Rob Music, Migraine Trust

Sue Millman, Ataxia UK

Victoria Wareham, Dystonia UK

Dawn Golder, FND Hope

Alice Struthers, NAoS

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| 1 | Chair’s welcome and Scottish Government update | Tanith welcomed everyone to the meeting and introduced Rachel Morrison, a MS Nurse with NHS Borders, but representing QNIS who has just been co-opted onto the NAoS Executive.  The Scottish Government has agreed to continue to fund the NAoS for another year, enabling us to engage the Programme Director and some admin support. We are pleased to be on a sound footing for now.  Tanith raised the concern that the funding stream Section 10 is being reduced in scope, and flagged this up in case charities are reliant on it. |
| 2 | NACNC update | NACNC met in March 2022, with some changes to the membership. Richard Davenport, the clinical advisor to the Scottish Government stood down in March and has been replaced by David Breen who is a neurologist specialising in movement disorders, based in NHS Lothian.  Funding decisions for round 3 applications to the Neurological Framework have been made, so hopefully all members have been made aware of their status.  More information can be found here:  <https://www.gov.scot/publications/neurological-framework-funding-list-of-organisations-funded/>  NHS Inform has information on some neurological conditions and is being updated. Dr Breen and Dr Sloane are approving the clinical data on 9 conditions (grouped around movement disorders) including:  Spinal Muscular Atrophy  Myasthenia Gravis  MS  Tourette’s  Huntington’s  Ataxia  Parkinson’s/PSP  Transverse Myelitis  Dystonia  There’s a paucity of information on prevalence and incidence of neurological conditions. The Scottish Government is interrogating the General Practice database but efforts here have been delayed due to covid. The other way is to use the disease register to check prevalence. There is already an MND and a MS register. The Scottish Government is funding the establishment of an epilepsy register. The idea is to pilot the epilepsy register to roll out similar registers for other conditions.  There are ongoing issue of access to anti-viral treatment and how that list is being used to limit access to free lateral flow tests and the booster vaccination programme. This is a worry as if people are not on the list, they won’t receive antiviral treatment at all. Also because even if your conditions is one of the 4 conditions listed – MS, MND, Myasthenia Gravis and Huntington’s – which are listed as passporting access to consideration for antiviral treatment, those on the list might *still* find it hard to get access to anti-viral treatment. If you have any other neurological condition, you can’t be considered for use of anti-virals. There is not much difference between end stage PSP and MND in terms of assessing their clinical risk factor – so it’s a blunt instrument and we’ve raised these concerns with the clinical priorities team who have vowed to raise it within the SG.  Rebecca@PSP – PSPA has written to Chris Whitty to request that PSP is added to the list. Additional complication is that people can’t use the home LFT kit – instead you must prove you have covid through the LFT provided through the scheme.  Katie Rigg@ MSA – Our understanding is that unless there’s a proven immunodeficiency then an individual won’t automatically qualify for anti-virals. It has nothing to do with frailty rather how your immune system is working. If someone is on meds that will impact their immune system, they should qualify for antivirals. Some people with MSA with immune issues are eligible, others with MSA alone are not eligible. It’s confusing to the general population for the government to put out generic lists of conditions without qualifications as to why.  Tanith – this doesn’t explain why MND and Huntington’s are on the list.  Katie – that’s the answer we received when we enquired. There is lots of mixed messaging which isn’t helpful for people.  Tanith – We are concerned that the CEV list has been replaced with this list which is a huge worry in terms of other variants or booster programmes. It is not an appropriate list to use. NAoS is keeping an eye on this.  We want to flag up that the Scottish Government has issued guidance on access to LFTs makes it clear that unpaid carers are eligible for free LFTs applied for via the UK Govt website. The Scottish Government has not publicised this guidance although it’s in their actual policy. There are an estimated 800,000 unpaid carers in Scotland. As neuro charities we should make sure our unpaid carers are aware of this change in policy. Please disseminate this info widely.  Actions:   1. Charities to disseminate carer info widely 2. NAoS keep an eye across CEV list |
| 3 | CYPSIG discussion | CYPSIG was set up in response to ensure that the focus on adults through the framework didn’t obscure the needs that children with neurological conditions have.  There is an issue with the group, due to low capacity in the sector, of people attending the group. Purpose of raising it now is to get a sense from members as to the way forward if capacity is not sufficient to support such a group, or if there’s another way of ensuring that children’s issues are properly represented in the NAoS.  Gerard@ CBIT – there is a real need to support children and young people. The CYPSIG needs a secretary to organise it properly.  Mary Ramsay@ Scotttish Tremor Foundation – suggestion to get a young person with tremor to attend the group to see what her suggestions are about getting more young people involved. |
| 4 | Women and neurological conditions – breakout rooms | The reason for this discussion is about the fact the SG has published a Women’s Health Plan, which looks at menstrual health, menopause and sexual health and also cardiac health. Treatment outcomes, symptoms and even the way people are diagnosed is very different for women, and fewer women take part in clinical research. We think we can make the same case for some neuro conditions – for instance, MS, FND and ME are more common in women.  There’s going to be a women’s health research fund, each board will have a women’s health champion and women’s health lead, but there’s no funding attached.  Move into breakout rooms.  Action- facilitators to send Alice their breakout room summaries which will be used to write to the Minister for Women’s Health - done |
| 5 | My Neuro Survey update | There have been over 8500 responses across the UK, which is a great result given the situation with covid.  784 adults and 50 children and young people surveys completed in Scotland.  All neurological alliances are now writing a report for their nation. The English NA is also writing the UK report. The campaign is launching on the 8th June which is also when the English NA is doing a Parliamentary launch at Westminster. NAoS will launch our report in the Scottish Parliament at the epilepsy and MS joint CPG on the 9th June Everyone is welcome to attend.  The English NA is holding a webinar on the 23rd May about the UK campaign.  There are separate data sets for children and adults in Scotland and we have just received specific condition info which will be available to all members from the 20th June.  The English NA has worked with a co-production group which has been helpful for the themes and responses and to ensure that understanding from the research is correct.  We don’t have a co-pro group but the core themes are the same across the UK. Things that aren’t working well in Scotland are also not working in other parts of the UK. |
| 6 | NAoS campaign update: #WeMindWeListen | In March we started our #MindYouListen social media campaign – over 1000 twitter tweets, retweets and other social media activity. This was a great way for charities to reach out to their communities and share the common frustrations that people have with living with their condition.  Thanks to those who joined our campaign meetings and who have given guidance as to how we proceed. We have now moved onto the second phase of our campaign which is #WeMindWeListen. We have created a new set of infographics which have been shared as a template for you to edit with your own brand colours and wording, which point to the services that your charity does that supports people across different areas.  This phase also touches more on getting non-neuro medical staff to reach out to charities to find out more about specific neuro conditions.  If people want to use this, please go ahead and use it up until the 8th June, where we will be moving to a third set of infographics, which will use the headlines from our reports. The third phase will be more to catch the attention of the media. |
| 7 | Consultations NAoS Members are interested in | There are four consultations that are on the horizon but we want to understand from members which should be our priority and also to understand which members can help in drafting our response to them.   1. [Health and Social Care in Older People, closes 19 June - priority](https://consult.gov.scot/healthcare-quality-and-improvement/health-and-social-care-strategy/) 2. UK ABI call for evidence, closes on 6 June and NAoS hasn’t had capacity to submit a response 3. Scottish Carer’s Assistance Consultation, closed 23 May and NAoS has not had capacity to submit a response 4. Guidance on access to equipment and adaptations, closes on 6 June and NAoS hasn’t had capacity to submit a response |
| 8 | AORB | Marc@ Brain and Spine – 2021 launch of a programme to gather real-world experience from people with lived experience. Based on an app and web application, which puts out a survey every couple of months to ask about how people have accessed their treatment and care and if they haven’t managed it, then what alternatives have been put in place.  To date, we have had over 2000 responses from a community of 900. Representation in Scotland is about 10%. This demonstrates good potential and that people with conditions are using the platform as a trusted means to share their story. Ambition is to grow Neuro Life Now in scale to get better representation across Scotland. Part of its value is in analytics of the data to get evidence of where treatment and care can be improved.  Action – Marc will bring back a more specific analysis of situation the programme in Scotland that can be shared so that members can support it in some way  Tanith thanked everyone for their contributions and closed the meeting. |
| 9 | The next meeting date will be the 16 June, 10.30 – 12.30pm |  |