# Members Meeting minutes

# 10:30 – 12:30, 2 April 2025

**Attendance**

Jenn Hall, Chair

Keith Park, Vice Chair

Simon Bull, CMTUK

Farhan Khan, Muscular Dystrophy UK

Alison Phillips, Craighalbert

Jane Ormerod, Long Covid Scotland

Carol Levin, British Polio Fellowship

Emily Holmes, Neuro Hebrides

Stuart McIver, Long Covid Scotland

Vicki Cahill, Alzheimer Scotland

Mary Ramsay, Scottish Tremor

Paula Gribben, Scottish Head Injury Forum

Jo Anderson, MS Society

Katie Rigg, MSA Trust

Pamela Binny, #MEAction Scotland

Samantha Matson, Parkinson’s UK

Liam Mac Lua-Hodgson

Mary Troup, Orthostatic Tremor Support Group

Kim Leslie,

Avril McLean, Action for ME

Ewan Dale, ME Assocation

Collette McDiarmid, MND Scotland

Sharon Buckland, CBIT

**Apologies**

Stephanie Fraser, Cerebral Palsy Scotland

Charlottee Encombe, Compass

Steve Portelley, FND Hope UK

Claire Winchester, MS Trust

Lawrence Cowan, SBHS

Kripen Dhrona, British Polio Fellowship

## Chair’s Welcome

NAoS Chair, Jenn Hall, welcomed members to the meeting and gave update on the most recent meeting from the National Advisory Committee for Neurological Conditions (NACNC)

* Jenn noted that Stephanie Fraser will be stepping down as Chair of the NACNC and gave thanks to her for her time leading the committee
* Louise Scott from the Long Term Conditions (LTC) strategy unit gave the NACNC a presentation on the LTC strategy plans – neurological conditions will sit within this strategy. The Long Term Conditions strategy consultation will soon be opening- it was hinted that this will now be going live end of April. There wasn’t a huge amount of information given in the meeting, so NAoS is still unclear about the detail of the strategy.
* A decision was also made in the meeting to discontinue the Service Improvement Forum which was a subgroup of the NACNC and had oversite of improvement plans as Susan Walker, chair of the Service Improvement Forum, is stepping down. It was decided that the NACNC would assume responsibility and oversite for the work being undertaken by the members.

NAoS Vice Chair, Keith Park, gave update from UK Neuro Forum:

* UK Neuro Forum was established after the #Backthe1in6 campaign by the Neurological Alliance in England to work out how we can improve neurological care across the UK.
* First meeting took place 10 March, Minister for Health and Social Care for UK Government, Ashley Dalton MP, attended.
* Meeting focused on terms of reference and priorities for how to improve things going forward. All four governments reflected the same issues identified by members and the meeting felt like a strong starting point for collaborative working across the four governments and nations.
* Keith gave overview of the priorities identified in the meeting: building a workforce fit for the future; addressing issues in cross border care (which also includes across health board and ICB borders); supporting research and research partnerships; improving transition between paediatric and adult services; addressing variation in care; treatment & therapy pipeline; building quality data for neurological conditions. Data and workforce were the two main issues as they go hand in hand- you can’t build a workforce until you have accurate population data.
* Four alliances are keen that the Forum is transparent as possible and the minutes are shared. The meeting was chaired by Department of Health and Social Care for the UK Government and they had some concerns around how transparent it should be because this might limit how open clinicians and governments would be in sharing information. This was pushed back on by the four alliances as we believe the information should be shared as widely as possible. No updated terms of reference yet to outline how this will proceed.
* Next meeting will be in the autumn and the four alliances will have another open meeting to get feedback from members to feed into the next meeting. The alliances highlighted to the Forum that there must be task working groups under the Forum to make sure that the work is progressing between meetings.

Discussion regarding whether the Forum could hold accountable the work that was supposed to be undertaken by the now disbanded SIF and keep pressure on the Scottish Government after the end of the Neurological Framework for Action.

## Brain Awareness Campaign update

Hester gave presentation to members on Brain Awareness Week 2025 campaign, #InvestInNeuroResearch. [See presentation here](https://www.scottishneurological.org.uk/file-download/68/baw-2025-member-presentation.pptx).

Feedback from members:

(Muscular Dystrophy UK) - The campaign pack material was very easy to use and adaptable graphics to include organisational logo was great too. The updates prior member/policy group meetings were really useful to get ongoing insight into the development of the campaign. Comms colleagues internally appreciated the notice period from when the campaign pack was made available and the awareness week took place. The joint letter as a key ask was great to see, include the breadth of organisations signing on, and across the UK. That's usually the type of ask that colleagues internally are happy(er) to sign onto when we're not directly involved.

We did also receive notice from the other alliances about signing onto the letter and share material during the awareness week, so we did feel like there was some communication from other parts of the UK (although admittedly, considerably less than from Scotland). But appreciate there may be other considerations as to why that might be the case. Personally, I feel the co-badging of the letter and the graphics helped internally to partly overcome any more comms from the other alliances. Generally speaking, we'd be happy to continue to participate in this type of activity moving forward.

## Patient Experience Survey Topline Results

Alice gave overview of My Neuro Survey results, [see presentation here](https://www.scottishneurological.org.uk/file-download/69/members-ppt-.pdf).

**Reflections and questions from members:**

ME have seen an estimated rise in numbers of people experiencing ME – 21,000 on Scotland pre covid and post covid it is estimated at 58,000. ME is also often misdiagnosed as FND (anecdotal evidence). Therefore, this might skew the respondent rate.

Question regarding response rate- overall respondent rate has increased but this is due to the carers survey. The child response rate slightly increased.

Essential tremor in the UK has new figures of prevalence- over 1 million with essential tremor, 8 times more prevalent than Parkinson’s.

Discussion around response rate from children - important to make sure these responses and experiences are still captured. There is a real challenge in capturing the voices of Children and Young People at the more complex end of the disability spectrum due to communication/ physical barriers. Something to think about ahead of the next survey, perhaps with support of an advocacy organisation.

Query around the rationale for having dementia and Alzheimer’s disease as separate. Challenges identified with diagnosing dementia and Alzheimer’s which may impact responses. Suggestion that it may be helpful to isolate different forms of a condition in the future e.g dementia. However, consideration that this may make the list lengthy.

Question as to if there is a way of recording the amount of surveys that are started and then abandoned to see if there are particular conditions where participants find it more challenging to finish the survey.

Comment regarding low clinic response rate – could be due to overlap from members promoting the survey and also asking the clinics they work with to promote the survey. Could be that NAoS’ relationship with clinics is not very mature. Another important factor is if people didn’t include their post code, responses just went into the general UK data set.

Alice noted that if members would like to help analyse the data and draft the report they are welcome to express interest. Alison Phillips noted interest.

## AOB and close

Alice gave overview of the [NAoS 2024/25 Impact Report](2024/2025%20Impact%20Report).

NAoS launched a survey for members to complete understand the value of meetings and areas of improvement.

Comment from member that what you get out of membership is what you put in. Suggestion to consider how to encourage other members to take a more active role in the organisation.

Time and capacity is often the biggest barrier to participation. Alice noted that if members have colleagues who would like to participate in the working groups then we’d welcome their participation.

No other business. Chair thanked everyone for joining and closed the meeting.

**The next NAoS meeting will be Wednesday 25 June 2025 10:30 - 12:30**