**Summary of NAoS Policy Group Meeting**

**14 April 2021 at 11.30am**

**Attendees:**

Alistair Haw, Scottish Huntington’s Association, Chair

Leigh-Ann Little, Oxygen Works

Shirley Maxwell, Epilepsy Connections

Colette McDiarmid, MND Scotland

Rona Johnson, Epilepsy Scotland

Anna Telfer, Epilepsy Scotland

Avril McClean, Action for ME

Stuart Brown, ME Action

Sue Millman, Ataxia UK

Jonathan Sher, QNIS

Joyce Davies, FND Hope

Mary Ramsay, Scottish Tremor Society

Tanith Muller, Parkinson’s UK

Alice Struthers, NAoS Co-ordinator

**Apologies:**

Paula MacGillivray, MS Society

Elinor Jayne, Sue Ryder

Katie Rigg, MSA Trust

Victoria Wareham, Dystonia UK

Morna Simpkins, MS Society

Catherine Paterson, Dochas Fund

Stephanie Fraser, CP Scotland

AGENDA ITEMS

1) Chair’s welcome

Alistair Haw welcomed the group and everyone introduced themselves.

Q1: What opportunities if any, may present through increased awareness of long covid and the creation of long covid centres to push for better designed approaches to targeting neuro service development?

**Discussion:** Although NICE is currently updating their ME guidelines (with reference to Graded Exercise Therapy), some concerns remain that GET will be recommended for long-covid treatment. Most members see long-covidas a risk rather than an opportunity for other neuro conditions, particularly as long-covid recovery falls under the framework for recovery and rehabilitation which has no attached funding. The concern is that long-covid

recovery will divert funds from neurology. One benefit may be that research into long-covid may find treatments that also help with ME.

The connection between long-covid and ME is not well understood. This is an opportunity for NAoS to raise awareness about long-covid and ME and influence key stakeholders, to benefit existing ME patients and the growing cohort of long-covid patients. Recognition and concerns raised that the existing workforce is not large enough to manage long-covid on top of neuro conditions although community nurses could potentially help. It’s difficult to lobby for workforce when it is not clear how many people suffer from long-covid for longer than 12 weeks and within that group, we don’t know the size of the cohort with intense needs who would need help.

Action for ME are already promoting a CPD for AHPs and professionals, on ME with is relevant for long-covid. Action for ME is also creating a podcast about ME, which with additional funding could be expanded to include long-covid.

**Actions:** As a first step, NAoS will ask the hustings candidates about the rehabilitation strategy and how they plan to implement it without any ringfenced resources. Once a new parliament has been formed, we can actively lobby key decision makers.

ME Action / Action for ME to send bullet points to NAoS re their concerns. NAoS to then write to Cabinet Secretary and the Minister about it and we will raise it with SG contacts and NACNC. We will also ask for confirmation on how data on long covid is being collected (who is collecting the info and how are they doing it).

Q2: Patient Safety Commissioner – should non-pharmaceutical therapies be part of their remit?

**Discussion:** Currently the patient safety commissioner role which is out for consultation, focuses on pharmaceutical and medical device therapies only. The role is being established as one of the recommendations from the Cumberlege report which looked into the harm specifically caused by sodium valproate for epilepsy, pelvic mesh and the contraceptive pill, Primodos.

On the understanding that the new role is there to act as champion for all people who have been harmed by medicines or medical devices, we explored whether there was appetite to lobby for their role to include non-pharma and non-medical device therapies. Clarity is lacking over how far the role of the patient safety commissioner extends as the focus is currently on the three issues named above, and yet it should extend to act as champion for all people.

The Consultation website reads: “…our commitment for Scotland is that the Patient Safety Commissioner would focus first on patient safety in these areas [sodium valproate, Primodos and pelvic mesh] and then possibly expand to cover other areas in the future.

This limited initial role may present challenges in separating safety issues to do with medicines and medical devices from wider safety issues.  This could confuse patients, who may want to highlight a safety issue which does not relate to a medicine or medical device. ”[[1]](#footnote-1)

**Actions:** NAoS can point out what could usefully be done by the Patient Safety Commissioner, giving examples such as sodium valproate being used not just for epilepsy but is prescribed for a variety of mood disorders, pain and migraine. The issues of deformities in babies will affect any woman of childbearing age taking sodium valproate, not just those with epilepsy.

In addition, the PSC role should consider the importance of timing of medicines – for instance insulin for diabetes and tablets that help people swallow, who have Parkinson’s. Mis-timed consumption of medicine is an avoidable cause of suffering and death.

NAoS to poll our members to see what issues if any, our members want to highlight about the PSC role. It would be useful to hear specifically about conditions for which sodium valproate is relevant. We would also like to hear which members are putting in a response and let us know which issues they are covering.

NAoS to then use the Government form to provide our response to the consultation. The consultation closes on 28th May 2021.

Q3: Children with ME have considerable problems accessing education.  Inconsistencies between Local Authorities and lack of experience in some schools. Is there appetite from NAoS members to set up a Special Interest group in Children and Young People to campaign to improve the educational set up for children with neurological conditions?

**Discussion:** Ensuring children with ME have access to education has always been difficult. With the world’s attention focused on education through the pandemic, it feels like this is a good time to campaign for the rights of each and every child living with a neurological condition to get the diagnosis and support they need to access a full education throughout their childhood. There was a lot of interest in this campaign idea from members. Useful to raise awareness of epilepsy and other conditions including rare conditions such as Friedreich’s Ataxia in schools. The issue with the neurological framework is that it does not include children under the age of 16. There’s a legal right for children to be able to access education and yet so many of our children are failed on this currently.

**Action:** There was a strong consensus that a special interest group for children and young people should be set up. NAoS to email all members to see who wants to be part of it, and get it going ASAP.

4) General Q&A

**Discussion:** SHA raised alert that the Scottish Huntington’s Association has been removed from the NHS Inform website as the leading contact, having been replaced by the Citizen’s Advice Bureau. This could be teething problems with the work done currently on the NHS Inform site.

**Action:** NAoS to raise this directly with SG. Please can all members check their pages to see if they have also been affected.

5) Horizon scanning – Next meeting date: 9 June 2021, 11-12pm  <https://zoom.us/j/96688670154>

1. [Patient Safety Commissioner role for Scotland: consultation - gov.scot (www.gov.scot)](https://www.gov.scot/publications/consultation-patient-safety-commissioner-role-scotland/pages/5/) [↑](#footnote-ref-1)