**Summary of Policy Group Meeting**

**9 June 2021**

**Attendees:**

Shirley Maxwell, Epilepsy Connections, Chair

Catherine Paterson, Dochas Fund

Jonathan Sher, QNIS

Mary Ramsay, Scottish Tremor Society

Carol Cochrane, Brainstrust

Helen MacDonald, Lanarkshire Epilepsy

Gill Dickson, PSP Association

Sue Millman, Ataxia UK

Stoo Brown, ME Action

Alice Struthers, NAoS Co-ordinator

**Apologies**

Colette McDiarmid, MND Scotland

Phil Robinson, Lanarkshire Epilepsy

AGENDA ITEMS

1. Chair’s welcome

After an introduction and welcome from Shirley Maxwell (Executive Director, Epilepsy Connections), general housekeeping points were discussed so that everyone was clearly named on the call and apologies were made.

1. Action points from previous meetings – follow up:

**Outstanding actions from the April Policy Group meeting:**

a. To raise awareness between LCV (long covid) and ME with key stakeholders – need to help growing cohort of LCV patients and benefit existing ME patients at the same time (in terms of recognition). This still needs to be actioned – we had been waiting for the new Minister to be named and for them to get settled.

b. To find out who is collecting data on LCV in Scotland. Following discussions with the Scottish Government, we found out that data on LCV has been collected in Scotland since January 2021 by the Office for National Statistics (ONS). C. 75,000 people in Scotland with LCV 4 weeks +, C.50.000 people with LCV 12 weeks +.

1. To submit an NAoS response to the Patient Safety Commissioner consultation. NAoS did not submit formal response although many of our members did, and with different points of view. It was felt that NAoS couldn’t take a common stance on how the role of the PSC should be configured.
2. To set up a Children & Young People’s group. A Children & Young People’s Group has been set up with the first meeting held on 25th May with 16 NAoS members attending. Stoo Brown (ME Action) was elected Chair and the Secretary is David Mulligan. A Facebook page has been set up for those interested – click here to join: <https://www.facebook.com/groups/naoscypsig/permalink/1483707768638717/?notif_id=1623140404760720&notif_t=group_post_mention&ref=notif>

3 Ensuring children’s’ voices are heard by decision makers

**Discussion:** There is a discrepancy in children’s services within neurology as well as across wider healthcare conditions, with some neurological conditions in children being very well reviewed, with treatment guidelines and mechanisms in place for gathering feedback (for instance, epilepsy) and other conditions having very little in place for children (for instance, ME). Some adults who have lived with a neurological condition did not get a diagnosis until much later in life, and agree that earlier observation and intervention as children, would have been beneficial. One suggestion was to place more young people in the Youth Parliament to act as advocates. ME Action do have a Member of Youth Parliament but the nature of ME means it is impossible to consistently be an ME advocate when they themselves are unwell.

There may be an opportunity through the implementation of the National Care Service which the Scottish Government has committed to, to help young people influence polices that affect them (with their experience of the condition they live with, or as young carers themselves). Critical to engage with young people through the delivery of the NCS, in order to avoid disenfranchising an already vulnerable cohort of society.

The challenge is not so much in creation of new legislation to protect and support young people with neurological (and other) healthcare conditions, but in the actual implementation of existing laws and recommendations. The postcode lottery of service provision is the crux of the problem.

**Actions:**

1. NAoS to look for wider allies – e.g. Children’s Health Scotland (<https://www.childrenshealthscotland.org/>) and tap into these new networks as together we will have a stronger voice. Develop closer links with professional network as well (Association of British Neurologists, speech and language therapists and the British Paediatric Neurology Network (<https://bpna.org.uk/>**).**
2. Spend the next few months thinking about what a children’s campaign would look like – work in conjunction with the C&YP SIG. Needs to connect health, education, caring etc.
3. In due course, approach young people living with neurological conditions and involve them in the campaign.
4. Welfare Rights / Social Security Scotland progress

The move of all Scottish benefits from the Department for Work and Pensions (DWP) to Social Security Scotland (SSS) is underway and many NAoS member charities have been involved in the consultation, particularly around campaigning for a more dignified social security process. Adult Disability Payment is the new term for PIP (Personal Independence Payment) however it does not appear to be greatly different from PIP, and that includes the way the payment is structured and the method by which people are assessed, which is a great source of misery for thousands of disabled people.

There is a great opportunity for SSS to improve the way benefits are managed in Scotland particularly around improving the way people with progressive neurological conditions are managed. Fast-changing neurological conditions should naturally fall outwith any re-assessment guideline. Furthermore, we would like to see a change to ensure that anyone who is responsible for ADP (adult disability payment) assessment actually understands the condition of the person they are assessing. This may require a combination of a clinical letter as well as a letter from a charity, explaining how that condition presents.

There may be an opportunity for NAoS to intervene on behalf of everyone living with a neurological condition in Scotland, to influence the handling of their benefits once they are controlled by SSS, remove some of the stress involved and ensure that the right people understand the condition of those they are assessing for benefits.

Actions:

1. NAoS to look at inviting the SSS and the Minister to meet our members at an Autumn/Winter event. We have our AGM in September and a Members’ Meeting in November, so plenty of opportunity to draw them in and hear our concerns.
2. Neuro Hub update

**Discussion:** Further to some outreach with members at the end of May/start of June, we can see that there are differences in opinion as to how the neuro hub works, who the audience is and how best to present it. Therefore we met with Third Sector Lab to discuss the project and will be working with them on creating an overarching digital strategy, which will include digital comms, social media and the neuro hub. We are looking to create a working group of experienced members who can help guide the creation of the digital strategy and help with the early stages of neuro hub development. The appetite is certainly there, but we need to ensure we are all on the same page before we begin. We will be calling out for interested members to volunteer for this group in the coming weeks.

**Actions:**

1. NAoS to set up a Neuro Hub working group
2. Horizon scanning

**Discussion:** Members will have seen the email about HIS (Health Improvement Scotland) who are seeking views on joint inspection of adult social care services. All comments need to be submitted to NAoS by 17th June, or directly to HIS by the 22nd June. (Contact details for HIS are on the email).

HIS are also conducting a separate piece of work, evaluating the implementation of HIS general Standards for Neurological Care and Support.

The Scottish Government is about to launch a formal consultation on the National Care Service.

**No actions**

1. A.O.B

None raised

1. Next meeting date: 8 September 2021, 11-12pm via Zoom