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Members Meeting

Online via Zoom

Wednesday 12 July 2023 - 10.30am – 12.30pm

In attendance:

George Allan – Scottish Post Polio Network

Mary Ramsey – Scotttish Tremor Society

Kripen Dhrona – British Polio Foundation

Marc Smith – Brain & Spine Foundation

Emily Holmes – Neuro Hebrides

Gillian Robertson - Compass

Julie Sinclair – Dochas

Vicki Cahill – Alzheimer Scotland

Jonathan Sher – Healthier Pregnancies, Better Lives

Emily Beard – Epilepsy Connections

Nancy Campbell – MSTC Lothian

Penny Earle – Connecting Carers Highland

Tania Burge – MS Trust

Tanith Muller – Parkinson's UK

Steve Portelly – FND Hope UK

Katie Rigg – MSA Trust

Mary Troup – Orthostatic Tremor Society

Ewan Dale – ME Association

Avril McLean – Action for ME

Ross Cunningham – Epilepsy Scotland

Alice Struthers – NAoS

Lorna McGee – NAoS

Guest Speakers:

Alex Bruce – Health, Social Care and Sports Committee Senior Clerk

Scott MacKay – Health, Social Care and Sports Committee Clerk

Apologies:

Dawn Golder – FND Hope UK

Pamela Binny – ME Action

Iain McWhirter – MS Revive Support

Dr Ron Culley – Quarriers

Morna Simpkins – MS Society

Vicki Atherton – MyAware

Claire Winchester

Colin Robertson - Headway

Jacqueline Munro

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| 1 | NAoS Chair, Tanith Muller welcomes all to the July Members Meeting including some new faces who have recently joined the alliance and new members of staff within organisations within our membership.  A full list of our current membership within NAoS can be found [here.](https://www.scottishneurological.org.uk/members/) |
| 2 | [Health, Social Care and Sports Committee seeking views on remote and rural healthcare](https://www.parliament.scot/about/news/news-listing/holyrood-committee-seeks-views-on-healthcare), with Alex Bruce – Senior Clerk and Scott MacKay – Assistant Clerk  Presentation shared during this section of the meeting can be viewed [here.](https://neurologicalscotland.sharepoint.com/:p:/s/TheNeurologicalAllianceofScotlandSCIO/Eb6lAS5MYphIrLsk6CCk2-QB_e00qx0y4jcihxA2clPEtA?e=OwYRzi)  Since Alex Bruce last visited NAoS at the November 2022 Members Meeting to discuss the role of the clerks within the National Care Service bill, there has been some changes to the membership of the Health, Social Care and Sports Committee. List of the current members of the Health, Social Care and Sports Committee can be found [here](https://www.parliament.scot/chamber-and-committees/committees/current-and-previous-committees/session-6-health-social-care-and-sport-committee).  Plans for this inquiry into how people can access healthcare in remote and rural communities came about due to four petitions which were presented to the committee at the start of the year (2023). These petitions mainly focused on Highland and Moray communities and their access to services especially those living in the remotest parts of these regions.  Once reviewed, three of the petitions were closed on the basis that an inquiry would be held in investigate healthcare provision within rural and remote areas and therefore provide a more comprehensive answer to all the petitions.  The plan is that the committee will approach this inquiry in two stages, they are currently in the first stage. This initial stage will consider the key themes and barriers into healthcare that are experienced within more remote parts of Scotland.  Later this year, plans to launch a call for more specific information based upon the key issues which are identified within the first stage.  The first stage opened in June and closes on the **11th August 2023.**  Information is being collected via a platform which is being used is known as ‘Your Priorities’. This digital consultation tool allows individuals to add themes or specific issues and also see what other issues have been raised by others. You can support and/or add comments to those which others have already registered into the platform, which in turn raises the ‘profile’ of a particular issue. You can access the platform to submit your feedback [here.](https://www.parliament.scot/chamber-and-committees/committees/current-and-previous-committees/session-6-health-social-care-and-sport-committee/business-items/healthcare-in-remote-and-rural-areas)  Comments welcomed from members by the committee and those raised in the meeting are noted here:  Rural areas can mean that there is a reduced access to specialised services. Therefore there is an increased importance of prevention to support people and their health before they get to the point of needing specialised services where possible.  Encouragement and recruitment of healthcare and specialised staff into more remote areas is crucial to be able to provide healthcare in these areas.  When recruitment cannot take place, those in these areas are then forced to travel further and more frequently for care. Currently especially those on the West Coast and island communities having to travel to the Central belt with their local health board picking up the cost of these travel expenses.  When having to travel for appointments, there is not only up-front financial commitment but also patients need to have more time and energy for travel to these appointments. Not just part of one day but travel and overnight stays can make one appointment into multiple days.  Cancellation of appointment at last minute once patients and often their caregivers have already made long and expensive journeys happens frequently and is unfair.  Alex Bruce acknowledge that the feedback of members had highlighted the following which were in the feedback already.   * Recruitment * Access to affordable housing in some remote areas creates barrier to workforce * Cost impacts on budget for remote health boards for patients to travel for care * Refusal of central health boards to fund specialists to travel to remote areas to provide care.   Members continued to highlight that is it common for some travelling patients not to receive a full reimbursement for their trip which in turn creates a two-tier system of those who can absorb this shortfall and those who cannot. Those who cannot therefore miss out on specialised care.  Questions raised about funding for health boards who have rural and remote communities to support and if funding received in those areas reflects the demand for services and the cost of patient travel.  Members expressed concerns about how committees work, and how the information gathered is weighted especially when charities submitting responses on behalf of a large group of people verses a submission from an individual.  Alex offered reassurance that not weighing up on numbers but overall, the outcome that will direct the Inquiry and its focused will be informed by Your Priorities as well as work with NHS boards and other stakeholders.  NAoS Chair Tanith thanks everyone for their contribution to the discussion of accessing healthcare in remote communities and Alex Bruce and Scott MacKay leave the meeting. |
| 3 | **NAoS and NACNC update**  NAoS Chair Tanith advises members that Scottish Government grant has been successful regarding the NAoS submission. Primarily this funding covers the costs for our contracted staff who delivered the planned work within the strategy set out by the executive team.  Tanith highlights an email that was circulated on Tuesday 11th July regarding the Health Care Improvement Standards.  This work will be looking at the care and support that all people with neurological conditions receive during and after their diagnosis.  All 14 health boards asked to self-evaluate against 7 standards and the seventh of these standards is focused on people's personal experiences. During this part of the self-evaluation, it is hoped that health boards will look to the voice of lived experience and will engage with the third sector. Currently it not mandatory for health boards to complete this self-evaluation but there has been a strong steer from government that they should take part.  Currently boards are nominating a lead for this process to take place and once this person is in place, we expect that there may be a call for involvement from the third sector. Members asked to please keep an eye out for this opportunity to be involved.  Scottish Government and NHS Scotland have been discussing neurological service provision. Three regional networks looking to be developed and staff will be recruited to assist with this project. The recruitment of staff seems a positive step that action will be taken once these positions are filled. Potential opportunity for engagement with the third sector to complete this work – members encourage to keep an eye out for an opportunity to be involved.  Question from member about Stage Four funding.  Tanith will ask for an update but believes that majority of Stage Four funding will be continuation of funding of previous projects.  Number of Health boards under scrutiny of behaviour and bullying tactics towards those raising issues and campaigning for change. NAoS would take a very strong view if any members received health board behaviour which was deemed inappropriate. Members always welcome to raise any concerns with NAoS.  Comment regarding the large volume of very similar consultations which is currently taking place. Need to see some tangible action and hope that within parliament, there is someone connecting all the information which organisations are providing.  Further frustration regarding the cost of these consultation and value for money spent. |
| 4 | **AGM update**  NAoS AGM is booked for Wednesday 20th September, thank you to Quarriers for hosting us at their venue in Glasgow. This is a bigger space than last year, so hopefully more members can attend in person. There is also the option to join virtually also and details of this will be shared in due course.  Address for AGM: William Quarriers Scottish Epilepsy Centre, [20 St Kenneth Drive, Glasgow G51 4QD](https://www.bing.com/maps?&mepi=109~~TopOfPage~Address_Link&ty=18&q=The%20William%20Quarrier%20Scottish%20Epilepsy%20Centre&ss=ypid.YN1029x8489865632777016170&ppois=55.86183547973633_-4.330567836761475_The%20William%20Quarrier%20Scottish%20Epilepsy%20Centre_YN1029x8489865632777016170~&cp=55.861835~-4.330568&v=2&sV=1)  **Action: Members please respond to Lorna regarding attendance and staying for lunch/dietary requirements etc.**  Alistair Haw will be speaking to us at the AGM regarding the framework for Huntington's Disease and how this is working 10 years on from creation.  Agenda for the AGM will be circulated to all members in the run up to the event.  Discussion of role of the executive team and vacancies available. Role description for a trustee is here and the application form.  Role description for the role of Chair is here, application form here.  **Action for members thinking of applying: Applications for joining this team, should be received by Alice or Lorna by the 20th August.** |
| 5 | **Fair Work First policy**  As part of the submission for funding from the Scottish Government as a grant recipient, NAoS was asked to submit a policy regarding Fair Work First.  You can read the NAoS policy regarding Fair Work First principles [here.](https://neurologicalscotland.sharepoint.com/:w:/s/TheNeurologicalAllianceofScotlandSCIO/EcybmmSSbB1Pmb_0X6K_5RoBJ18Gh24RFncmjJJHwMTfig?e=H17PKs)  Fair Works First guidance from the Scottish Government is available [here.](https://www.gov.scot/publications/fair-work-first-guidance-2/pages/1/)  Other members applying for funding may find that this topic may become more prominent and may wish to formulate their own policy regarding this prior to their next funding submissions. |
| 6 | **AOB**  Mental health subgroup that was discussed at the Policy Group Meeting will be led by Keith Park from the MS Society, if anyone wants to get involved with this sub-group, please get in touch with Alice.  Announcement that a new addition to Lorna’s family due around the time of the NAoS AGM.  Item raised about numbers recorded for individual conditions.  Documentation found regarding Polio survivors published in 2012, good indication of polio patients, with 6,793 documented within Scotland between period of 1934 –2004. Numbers much higher than previously stated as previous ‘counts’ suggested around 200.  The notifications based in the report possibly don’t deal with mild case of Polio. With these sorts of numbers in this report, the chances of those who have PPS likely also much higher than previously thought.  Others may be interested in researching their numbers for the condition they are representing.  In future could be very difficult to identify cause of illnesses, wider picture is now dominated by Long-Covid numbers.  Having condition on a patient's record is difficult to get recorded in some cases – which in turn creates difficulty to ‘count’ numbers.  Members thank Tanith for her contribution within the Executive Team and as Chair. |
| 7 | Members thanked for their contributions to today's members meeting and meeting formally closed.  **The AGM will be an in-person meeting (where possible) on the 20th September, 10.30 - 12.30pm** |