**Neurological Alliance of Scotland, 2023 Annual General Meeting**

**20 September 2023, 10.30am – 12.30pm**

**Minutes**

**Registered attendees:**

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| Aaron Cox | Brain and Spine Foundation |
| Alistair Haw | Scottish Huntington's Association |
| Andrew Lindsay | Epilepsy Scotland |
| Avril McClean | Action for ME |
| Carol Cochrane | Brainstrust Scotland |
| Colette McDiarmid | MND Scotland |
| Colin Robertson | Headway Dundee & Angus |
| David Mulligan  | Funding Neuro |
| Daniel Huggins  | Muscular Dystrophy  |
| Ewan Dale | ME Association |
| Farhan Khan | Muscular Dystrophy UK |
| Gerard Anderson  | Child Brain Injury Trust |
| Iain McWhirter | Revive MS Support |
| Jane Haley  | MND Scotland  |
| Jenn Hall | Alzheimer Scotland |
| Kasia Wilczynska  | Connecting Carers  |
| Kate Sanger  | The Migraine Trust  |
| Mary Ramsay | Scottish Tremor Society |
| Morna Simpkins | MS Society  |
| Pamela Binny  | #ME Action  |
| Phelim O Toole | Headway Edinburgh |
| Rebecca Packwood | PSPA |
| Ron Culley | Quarriers |
| Stephanie Fraser | Cerebral Palsy Scotland |
| Tanith Muller | Parkinson's UK |
| Vicky Cahill  | Alzheimer’s Scotland  |
| Victoria WarehamAlice Struthers Lorna McGuire  | Dystonia UK NAoSNAoS |

**Apologies**

Steve Portelly FND Hope

Kripen Dhrona British Polio Fellowship

Linda Lucas Scottish Huntington’s Association

James Joplin Parkinsons UK

**Agenda**

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|  | **Introductions and welcome from the Neurological Alliance of Scotland**Tanith Muller welcomed online and in person guests to the meeting and gave some housekeeping.Clarification of agenda and tabled business:1. Tabled application for co-opted trustee from Clare Stevens, an associate member.
2. Tabled application from Jenn Hall to stand as Vice Chair if Morna Simpkins is confirmed in position of Chair.
 | 10.30 - 10.40 |
| 2 | **Introduction from Alastair Haw, CEO Scottish Huntington’s Association, about the Huntington Disease Framework.** [See slides here.](https://neurologicalscotland.sharepoint.com/%3Ap%3A/s/TheNeurologicalAllianceofScotlandSCIO/ERWmwb6IHQ5GkTfEOIF2sIcBKn9Uk6xtutIIDgSYiyeMfQ?e=19ErKe)Alistair Haw (AH) shared a PowerPoint to give an update on the National Care Framework for Huntington’s Disease.AH gave a brief introduction to Huntington’s disease followed by outlining the core services offered by the Scottish Huntington’s Association to demonstrate their starting point when they began the framework. AH then outlined the framework; it’s development, implementation and achievements. AH reflected on the wide-ranging support from international bodies, Scottish government and political parties, and local support as a result of including key players in each local health board in the development of localised frameworks. Chair thanked AH for his presentation and opened the floor for question and comments from members: **Ron Culley, Quarriers:** Asked for elaboration on the role of clinical lead and the HD specialist with regard to funding and appointment. **AH:** HD clinical leads are employed by the health boards and have certain amount of time set aside for them to focus on Huntington's disease. They come from a variety of backgrounds but typically have an interest in Huntington's Disease. They lead the clinics which are typically hospital based with the support from Huntington’s disease specialists. The clinical leads have built up slowly over many years and the framework helped drive it forward.The HD specialists are employed by Scottish Huntington’s Association (SHA) via statutory funding. That has come over time from building up the evidence that general neurology nurses may not have the specialist skills required to deal with people with Huntington's disease. HD specialists typically come from a background in nursing, occupational therapy and social work. They work together as a national team.**Ron Culley:** Is there Scotland wide coverage of those roles? **AH**: HD specialists covering every area in mainland Scotland now, with the exception of Scottish borders. **Ewan Dale, ME Association:** Is there national coordination between all of these services and leads? **AH**: Quarterly meetings with the lead clinicians chaired by SHA. Proven very helpful for sharing experience and knowledge. HD specialists are all employed by SHA so meet at regional and national team levels to share experiences. **Ewan Dale:** Is there any difficulty in prescribing between the different disciplines who are leads? **AH:** HD specialists generally don’t prescribe but that’s why they work closely with the lead clinician. The HD specialist will be in contact with the families most regularly but in emergency situations or when things become particularly difficult it can be hard for the specialist to get the support that they require from the health and social care service without an HD clinical lead. **Ewan Dale**: Are you seeing interest outside of Scotland taking any real form? **AH:** Norway and Germany have shown specific interest but also had interest from Australasia and certain states in America. Not sure if any frameworks have been created as of yet. **Chair:** Do you have any specific tips for dealing with cases where you’ve got an NHS CP that seems to act almost independently of its sponsoring board, covering a particularly vulnerable population because of the rurality of the area it serves? **AH:** Moray is the clearest example – HD specialist in Grampian who operated through Aberdeen city and Aberdeenshire and lead clinician based in Aberdeen Royal Infirmary, neither of whom engaged in Moray. Important to get the key players of the area involved in both the national and regional development of the framework and understanding the benefits of having the specialist services throughout the whole of the health board and surrounding boards. In particular, there’s a need to combat false economy that general neurology are able to take on these patients. It was political influencing which helped to break this down. Dumfries and Galloway is another example. The whole NHS board area had no engagement with SHA for decades and said there was no need for a service. The momentum of the framework got them to the stage of accepting. **Chair:** Have you noticed any backsliding from boards and HSCPs on the need for condition specific services for people with Huntington’s in light of the post covid staffing crisis/ waiting times, or do you feel like the framework has been a good ballast against that type of thinking by commissioners? **AH:** Pressure throughout Scotland on budgets and as a there is a turn for commissioners to look at where they can save money. New staff often lack understanding of importance of specialist support but this is often changed by illustrating the framework, who was involved and the public endorsement. **Ron Culley:** How have you navigated the relationship with commissioners, HSCPs and Health Boards with respect to who should be funding the framework? **AH:** It was difficult to get the right people involved in the framework – often required the CEO to nominate someone. Not uniform across Scotland and funding varied dramatically from area to area. Inevitably you would not receive full funding so funding would have to be topped up independently. The framework did not develop a uniform funding model throughout Scotland. **Stephanie Fraser, Cerebral Palsy Scotland:** Outlined from her work at Cerebral Palsy Scotland the discrepancy between health boards in their approach to services and difficulties of this. Rather than a national framework, CPS has adopted a ‘link worker’ approach, developing relationships with local services and advising people on best route to services depending on the area. As a small condition specific organisation Stephanie noted this is the best approach they could take.**Chair:** Thanked Stephanie and noted the differing approaches organisations may take. Also noted the defunding of the community link working model in Glasgow City HSCP which was backed by Scottish government.  | 10.40 -11.20 |
| 3 | Comfort Break | 11.20-11.30 |
| 4 | **Annual General Meeting Business:****Apologies**: 4, names noted separately. **Minutes for AGM 2022** [(attached)](https://neurologicalscotland.sharepoint.com/%3Aw%3A/s/TheNeurologicalAllianceofScotlandSCIO/ESiGyQ_qBQpKmeN_DZKenWgBt4IN4KG44oLeB8CT-9cO7Q?e=hBdC2u):Overview two main issues of 2022 AGM:* Discussion with Minister for Social Care on plans for new social care service. This is going back to parliament in January 2024.
* National epilepsy register and outcomes.

Both remain to be a live issues on the political agenda. No factual amendments to the minutes or agenda proposals.Proposer for the minutes: Stephanie Fraser Seconder: Morna Simpkins**Annual Report and financial statement for the year to March 2023** [(attached)](https://neurologicalscotland.sharepoint.com/%3Ab%3A/s/TheNeurologicalAllianceofScotlandSCIO/EfQGcmjBX8RErKy7N1X_ozoBm9nfdB8HU6T9i8TVaGneLQ?e=1A5CFi) Tribute paid to former Chair Gerard Gahagan, who passed away in July. **Trustee Report and Accounts presentation :**[**See slides here**](https://neurologicalscotland.sharepoint.com/%3Ap%3A/s/TheNeurologicalAllianceofScotlandSCIO/EcIjdoAyqs9FmF6yi6nWMEMBdqN--rWNIm0YRzOY4B84Mg?e=BLfXBP)Chair gave presentation which detailed the aims and objectives of three year strategy of NAoS: to inform, to influence and to connect and the work of NAoS’ over the last year to achieve these. Success measured against 10 outcomes, in line with ambition, mission and values. Thanks given to trustees who stood down earlier this financial year- Rona Johnson from Epilepsy Scotland, Alison Love from Ataxia UK, and Rachel Morrisons from Queen’s Nursing Institute of Scotland. **Stephanie Fraser, Cerebral Palsy Scotland:** Comment regarding the self- evaluation of the Neurological Standards- third sector service providers would be welcome to also evaluate their services in line with the HIS standards. **Chair:**In agreement, encouraged members to evaluate themselves using the self-evaluation guide from the Scottish government- contact Alice Struthers if you need a copy of this information.**Accounts** Overview of accounts given and no questions or comments from members on the balance sheet or accounts. Chair makes note for executive to write off the fixed assets listed in forthcoming year- they represent obsolete equipment. Proposer for the report: Morna Simpkins Seconder: Ron Culley **Proposed change of membership fees** [(attached)](https://neurologicalscotland.sharepoint.com/%3Aw%3A/s/TheNeurologicalAllianceofScotlandSCIO/EZBngfssGmJHlPZsXWrPZ5sB5yYLQpIUfWUP2Q0KH9uCQA?e=Hd9G2M)Slight increase in fees to: generate more income from members to run Neurological Alliance; reduce dependence on Scottish government; provide funding buffer in context of funding uncertainty from Scottish government. Keep no fee for smaller charities and increase fee for larger charities. Comments: **Stephanie Fraser, Cerebral Palsy Scotland:** What proportion of our membership paid no fee? Comment also that we will not be able to make up the government funding from membership fees. **Chair:** The aim of the increase is for NAoS to have a hedge in case funding were to be withdrawn at short notice, so that we could maintain some kind of freelance support until alternative funding is found. No change for the 14 members that don’t pay fees. The executive maintained no fee band because chasing fees for small organisations that are often have limited to no bank access and are voluntary run is difficult. **Iain McWhirter, MS Revive:** Have we done the calculation to show what the additional income this would generate would be? **Chair: F**ee band of 2023 would increase income to £7,025\* a year. This represents an income increase of a £800\* on base. \*Please see corrected figures in below comment. **Aaron Cox, Brain and Spine Foundation:** Comment regarding other sources of funding outwith government funding and membership fees. **Chair:** NAoS are continuing to look at diversifying funding. Limited by capacity to pursue fundraising but several trustees have this expertise. **Alice Struthers, Programme Director NAoS**: A comment, Lorna McGee has joined us online and she thinks the increase would be more in line with about £4,000. There may be an issue with the columns on accounts not reading correctly. **Chair: Correction-** Current model gives us a fee band of £7,025 a year, the future model actually raises us to £11,325 a year. A difference of £4,300 in membership. **Vote on fee change:** **Stephanie Fraser, Cerebral Palsy Scotland:** Question as to whether members that don’t pay anything will get to vote.**Chair:** In constitutional terms all of our members are full members regardless of which fee band they’re on and therefore can vote.**Chair:** Reminder to vote on what is best for the Alliance and organisation’s own members, if the vote does not pass it will be revised. Vote was taken by supporters raising their hand. **Supporters of the change**: not audible on recording **Dissenters**: OneThe vote is passed. **Action**: Speak to Dystonia UK outside the meeting about their concerns. **Election of Executive Committee and new Chairperson** Tribute paid to two trustees who are leaving in the current financial year- Ross Cunningham, Epilepsy Scotland and Stephanie Fraser, Cerebral Palsy Scotland. **Morna Simpkins, MS Society:** Notes too that Tanith Muller (Chair) is stepping down after a very long time on the board and gave thanks on behalf of NAoS. **Four new nominations for the board of trustees:**Three are eligible to be returned on the basis of their representation of member organisations: Andrew Lindsay (Epilepsy Scotland), Avril McLean (Action ME) and James Jopling (Parkinson’s UK). Proposer: Iain McWhirter, MS ReviveSeconder: Morna Simpkins, MS Society One tabled application, Claire Stevens (Voluntary Health Scotland).Proser: Tanith Muller, Parkinson’s UKSeconder: Jenn Hall, Alzheimer's Scotland [Application for Chair position – Morna Simpkins](https://neurologicalscotland.sharepoint.com/%3Aw%3A/s/TheNeurologicalAllianceofScotlandSCIO/EQcmhxf2L7NDr4olv50_mrsB4FD27qpsZkC5gQ7jNeXC4Q?e=aJ8Roj) (MS Society)Proposer: Tanith Muller, Parkinson’s UKSeconder: Carol Cochrane, Brainstrust **Stephanie Fraser:** Noted that the position of Vice Chair now vacant **Chair: F**ormally nominate Jenn Hall, Alzheimer's Scotland for the position of Vice Chair. Proposer: Tanith Muller Seconder: Alistair Haw, Scottish Huntington’s Association. There will be a feedback form sent out to you to tell us how you think the AGM went. 1. AORB
2. CLOSE of meeting
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