

Neurological Alliance of Scotland 2025 AGM

Meeting Minutes

Wednesday 24th September, 10.30am – 12.30pm

Alzheimer Scotland National Office, 160 Dundee Street, Edinburgh, EH11 1DQ/ hybrid via Teams.

Attendance

Keith Park, Chair
Vicki Cahill, Vice Chair
Iain McWhirter, Treasurer
Stephanie Fraser
Nicky Cowsill, Neuro Hebrides
Rachel Edwards
Avril McLean
Colette McDiarmid, MND Scotland
Kripen Dhrona, British Polio Fellowship
Alison Philipps, Craighalbert
Deborah Harling, Fife Carers Centre
Emily Holmes, Neuro Hebrides
Gillian Mathewson, PANS PANDAS UK
Pamela Binny, MEAction
Donald MacPhee
Rich Collins, Inflammatory Neuropathies UK
Ellie Kirkland, Muscular Dystrophy UK
Katie Rigg, MSA Trust
Richard Wood, Headway UK
Carol Cochrane, brainstrust
James Jopling, Parkinson's UK
Una Ni Bhriain, Edinburgh Headway Group
Ryan Bailey, Tourette Scotlakd
Archie Campbell, The Neuro Therapy Place
Steve Portelley, FND Hope UK
Phil Bosworth, Ataxia UK
Mary Ramsey, Scottish Tremor Society
Mary Troup, Orthostatic Tremor Support Group
Alice Struthers, NAOs
Hester Lee, NAOs

Apologies

Lesslie Young, Epilepsy Scotland
Claire Winchester, MS Trust

Markus Bell, Nerve Tumours UK
George Allan, SPPN
Carol Levin, BPF
Becky Duff, Carers Trust
Kasia Wilczynska, Connecting carers
Ron Culley, Quarriers
Ian Gourley, AIMS
Tejesh Mistry, VHS
Simon Bull, CMTUK
Karen McCurry, MS Therapy Centre Argyll
Lawrence Cowan, Spina Bifida Hydrocephalus Scotland
Sue Millman, Ataxia UK

Guest speakers

Shelley Gray, Scottish Human Rights Commission

1. Chair's welcome

Keith Park, chair of the Neurological Alliance of Scotland, opened the meeting.

Keith gave an overview in the changes to the executive board over the past year, with six trustees standing down and six trustees joining. Keith welcomed Vicki Cahill as the new Vice Chair and gave thanks to Jenn Hall who stood down as chair earlier in the year. Thanks were also given to all exiting trustees, particularly Ewan Dale who served as a trustee for over 20 years.

2. Guest speaker Shelley Gray, Member of the Scottish Human Rights Commission with Q&A

Shelley Gray, Member of the Scottish Human Rights Commission, delivered a presentation on human rights and their relevance to policy, health and social care, and the work of neurological charities in Scotland. Download Shelley's presentation [here](#).

Shelley provided an overview of the role of the Commission as Scotland's independent national human rights institution, responsible for promoting and protecting human rights and monitoring compliance with international human rights obligations.

Shelley outlined the key principles of human rights and explained how international human rights treaties, including the UN Convention on the Rights of Persons with Disabilities (UNCRPD), shape policy and practice in Scotland. She highlighted the relevance of the UNCRPD to people living with neurological conditions, covering areas such as access to healthcare, independent living, participation, accessibility, education, employment and an adequate standard of living.

The presentation explored how a human rights-based approach can be applied in practice through the PANEL principles. Shelley described how these principles can help ensure that policies and services place people's rights at their centre and improve outcomes for those experiencing barriers to accessing services and support.

Shelley highlighted concerns about the current state of disabled people's rights in the UK and Scotland. She reported that the UN Committee reviewing implementation of the UNCRPD concluded that insufficient progress had been made and that, in some areas, rights protections had deteriorated.

She also discussed the proposed Scottish Human Rights Bill, which would incorporate a broader range of international human rights into Scots law. Shelley explained that, while the Bill has been delayed until the next parliamentary session, it has the potential to strengthen accountability, improve access to justice for individuals whose rights are breached, and provide stronger mechanisms for public bodies to uphold human rights.

Finally, Shelley highlighted several areas of ongoing work by the Commission, including projects on independent living, social care, mental health, access to justice, poverty and human rights in rural and island communities. She encouraged members to consider how human rights frameworks can support their own advocacy and policy work.

Q&A discussion

Steve Portelley, FND Hope UK, asked about the timetable for the proposed Scottish Human Rights Bill. Shelley explained that the legislation had originally been expected to progress during the current parliamentary term, following several years of development involving charities, disabled people's organisations and the Scottish Government. However, the Bill has been postponed until after the 2026 Scottish Parliament election. Shelley noted that while the current Scottish Government remains committed to the legislation, its future will depend on the priorities of the next Parliament and the degree of cross-party support. She suggested that greater awareness is needed among politicians about the practical benefits the legislation could bring.

Members reflected on the risk that the legislation could be delayed further or abandoned if there is a change of government. Shelley agreed that this was a possibility and emphasised the importance of collective advocacy by disabled people's organisations and charities to ensure human rights legislation remains a political priority. She also highlighted ongoing discussions about how disabled people's rights, particularly those contained within the UN Convention on the Rights of Persons with Disabilities (UNCRPD), would be incorporated into Scots law.

Discussion on whether, from a government perspective, stronger human rights legislation could lead to large numbers of court cases against public bodies. Shelley acknowledged this could be a concern for the government but argued that the existence of legal remedies often encourages organisations to improve practice before disputes reach the courts. She also noted that access to legal support, advocacy and legal aid would remain important considerations, particularly for disabled people and their representative organisations.

Gillian Mathewson, PANS PANDAS UK, asked whether incorporation of the UN Convention on the Rights of the Child (UNCRC) into Scots law had led to significant legal challenges, particularly in relation to children and young people whose rights to education were not being realised due to health conditions. Shelley explained that additional powers had been given to both the Children and Young People's Commissioner Scotland and the Scottish Human Rights Commission following incorporation of the UNCRC to be able to take issues to court. The role of the Scottish Human Rights Commission is to identify issues which could be affecting lots of families and bring these to court rather than individual families.

Alison Philipps, Craighalbert Centre, added that there seems to be reluctance to challenge decisions on a children's rights basis. She highlighted tensions between what the ASL Act requires local authorities to provide against the UNCRC expectation that we work in the best interests of children. This tension is further exacerbated by the financial constraints that local authorities. Alison also noted that the Children and Young People's Commissioner's powers are principally focused on systemic issues rather than individual cases. Shelley agreed and stressed the importance of human rights-based budgeting to ensure that available resources are allocated in ways that support people's rights and wellbeing. She also highlighted the role of child law centres which operate across Scotland in supporting individuals seeking legal redress.

Keith Park, NAOs Chair, thanked Shelley for her presentation and the accompanying resources shared. Shelley encouraged organisations to continue engaging with the Scottish Human Rights Commission and to use human rights frameworks to strengthen their advocacy and policy work. She also offered to provide additional information and support following the meeting where useful.

3. Annual General Meeting Business

Keith Park, NAOs Chair, welcomed everyone back to the second half of the meeting. Noted that there are no trustee elections and no constitutional votes.

1. Apologies

Apologies noted (see first page of minutes).

2. Approval of AGM 2024 minutes

AGM 2024 minutes proposed by Steve Portelly and seconded by Iain McWhirter. Minutes approved with no changes.

3. Annual Report and financial statement for the year to March 2025

Keith Park, NAOs Chair, gave presentation on NAOs achievements over April 2024- March 2025 period, highlighting progress against the organisation's strategic priorities of Inform, Connect, Influence and Sustain. Download presentation [here](#).

Iain McWhirter, NAOs treasurer, presented the annual accounts and explained that NAOs, as a charity with income below £250,000, prepares receipts and payments accounts which are independently examined.

For the financial year ending 31 March 2025, the total income was £60,421 and total expenditure was £57,970. NAOs had an annual surplus of £2,451. Funds held at year end totalled £42,541. Income consisted of a £50,000 Scottish Government grant and membership fees totalling £9,794 with some interest gained on reserves. Expenditure was largely associated with charitable activities, including programme delivery and staff support, with only a small proportion spent on governance costs such as independent examination of the accounts. In comparison to the past 5 years, there has been a recent trend growth in income accompanied by a slight overall trend growth in expenditure.

Iain reported that the organisation remained in a reasonably stable financial position, with reserves equivalent to approximately eight months of operating costs, which was considered a healthy level of reserves for a charity of this size.

Question from members about the relatively small proportion of income generated through membership fees and how we can have a growth of members but less income through fees. Noted that there is a fee structure for membership and that fees have been increased four times in the last 6 years. The potential for reassessing this structure is on the agenda for today's meeting. It was explained that membership income had fallen slightly following changes in membership composition, with several larger organisations leaving and being replaced by organisations paying lower membership fee rates. Members also discussed the need to review the membership fee structure to ensure it remained fair and sustainable.

Question about why there are 57 members but the newsletter goes out to 130 people. It was noted that most charities have two or more representatives who receive the newsletter and there is no limit on our newsletter distribution. It is also sent to stakeholders such as Scottish Government officials as well as associate members. NAOs aims for the newsletter to be a key mechanism to inform and influence wider relevant networks about our work and the work of our members.

Question on whether holding 8 months worth of reserves is an issue for applying for funding. Iain McWhirter, NAOs treasurer, noted that the landscape of how funders are viewing charities is changing because of external challenges. Having eight months of operating reserves may make us more attractive to funders, particularly multi-year funds. Suggestion to have a statement prepared if anyone were to query why we have 8 months of reserves.

Overview of the year

Keith Park, NAOs Chair, provided an update on work undertaken since March 2025, including publication of the UK-wide Patient Experience Survey report, development of the Neurological Alliance manifesto for the 2026 Scottish Parliament election, engagement around the forthcoming Long-Term Conditions Framework, and continued work on mental health and neurological conditions.

Members asked whether NAOs had reviewed other sector manifestos, such as SCVO's, to identify shared priorities and opportunities for collaboration. In response, Alice Struthers explained that, through her involvement in the SCVO intermediaries' group, organisations have been sharing manifesto priorities to identify common themes and strengthen collective advocacy across the sector.

Question as to whether NAOs had been engaging with the Scottish Government on the development of the Long-Term Conditions Framework and whether NAOs is involved in the ongoing palliative care strategy work. Keith Park confirmed that NAOs has maintained dialogue with the Scottish Government, including a recent meeting with Minister Jenni Minto, who appeared supportive of involving NAOs in future discussions on the framework. He also noted that while NAOs has engaged with palliative care policy work, it is not currently a major area of focus.

The discussion then turned to the role of NAOs in influencing policy development as an umbrella organisation. Members recognised the value of having NAOs represented in discussions on the Long-Term Conditions Framework but raised concerns about whether any intermediary body can fully represent the diverse views and priorities of all member organisations. Keith acknowledged these concerns and highlighted a related risk that neurological conditions could lose visibility if the Scottish Government adopts an overly generalist approach to long-term conditions policy. There was broad agreement on the importance of ensuring that the needs of people with neurological conditions remain prominent as the framework develops.

4. Long term financial strategy review

Keith Park, NAOs Chair, explained that Scottish Government funding has represented the largest proportion of NAOs' income over the past four years. Although the Alliance has secured funding until March 2026, officials have confirmed that no further grant funding will be available after that point.

Keith noted that while the loss of funding presents a significant challenge, it could also provide an opportunity for NAOs to become a stronger and more independent campaigning voice, without concerns about criticising a major funder.

Keith outlined income generation options currently being explored including:

a) Fundraising and trust applications:

- NAOs has recruited a consultant fundraiser on a part-time basis to identify trust and foundation funding opportunities and submit applications
- Emphasised that clear performance measures and monitoring arrangements are in place to assess whether this investment delivers a return

b) Review membership fees

- Membership fees currently account for only a small proportion of total income and the existing structure does not always reflect the varying size and income levels of member

organisations. 25% of members pay no fee and medium sized charities have been paying proportionally more towards fees than larger charities

- Possible proposals include:
 - Introducing a lower threshold for fee-paying membership by reducing the exemption level from organisations with an income below £50,000 to those below £25,000.
 - Increasing fees for larger charities and organisations with annual incomes over £1 million.
 - Creating a fairer balance between small, medium and large members while increasing overall membership income.

Keith stressed that any proposal for changing fee structures would be circulated to members before being brought to an Extraordinary General Meeting for approval.

c) Industry Reference Group

- NAOs is developing an industry reference group modelled on arrangements already used by the Neurological Alliance in England.
- Pharmaceutical companies and other industry partners would pay a fee to participate in discussions about service improvement and policy issues.

Keith opened discussions to the floor, noting NAOs would like to know what members priorities are for the coming year and where NAOs should focus attention, and members' views on the proposed changes to membership fees:

Members raised several concerns about NAOs's proposed approach to financial sustainability. These included the risk that changes to membership fee bands could lead some organisations to reconsider their membership, the need to protect NAOs's independence when working with pharmaceutical companies, and whether NAOs has considered a limit on the proportion of income received from industry funding. Questions were also asked about alternative corporate fundraising opportunities, such as partnerships with assistive technology and medical device companies, and whether efforts had been made to secure renewed Scottish Government funding. In addition, concerns were expressed about the potential cost and effectiveness of appointing a fundraising consultant and the possibility that seeking grants from charitable trusts could place NAOs in competition with its member organisations.

In response, Keith confirmed that NAOs is exploring a range of fundraising options, including corporate partnerships and pro bono support, while trustees continue to consider how best to implement a fairer membership fee structure. He emphasised that robust governance arrangements and clear terms of reference would be put in place to safeguard NAOs' independence when working with industry. While NAOs does not currently have a constitutional cap on pharmaceutical funding, independence would be protected through these governance measures. Keith also reported that the Scottish Government has made clear it will not provide ongoing funding, despite NAOs proposing alternative models. To address wider financial concerns, scenario planning is underway, including consideration of different operating models, contingency arrangements and cost management measures. He further reassured

members that any applications to charitable trusts would focus primarily on securing core organisational funding rather than competing with members for service delivery funding.

5. Launch of NAOs manifesto for the Holyrood Elections 2026

Keith formally launched the Neurological Alliance of Scotland's manifesto, "Today's Challenge, Tomorrow's Hope", and encouraged members to share it widely. The Manifesto subgroup has transitioned into an Election Subgroup to coordinate engagement throughout the election period and beyond. Members were invited to join the subgroup and help shape campaigning activity. A key element of the campaign is the recruitment of Neuro Champions- parliamentary candidates who commit to supporting the manifesto's principles.

Discussion have also taken place regarding the possibility of establishing a Cross-Party Group on Neurology in the Scottish Parliament. Members invited to share their thoughts on this possibility with Alice or Hester.

Steve Portelly, FND Hope UK, noted he attended a Westminster event hosted by the Neurological Alliance (England), and there was significant interest from MPs about attending a similar event in Holyrood. Agreed that once we have candidates signed up, we can assess whether hosting a similar event in Holyrood is feasible.

6. AOB

Query as to whether NAOs should consider joining Volunteer Scotland. Keith noted that as we don't have many volunteers, it might not be totally relevant but can be revisited in the future.

7. Close of meeting

In closing the AGM, Keith thanked members for attending and contributing to the discussions. He reiterated that any proposals relating to changes to membership fees will be brought to an Extraordinary General Meeting (EGM) for a vote.

The next Members' Meeting will be held on Wednesday 26 November 2025, 10:30-12:30 on Microsoft Teams.