

Minutes of AGM 2021
The Neurological Alliance Annual General Meeting
Wednesday 17 November 2021
Online Zia Zoom

Chair: David Martin, Chief Executive, MS Trust.

Present:

Neurological Alliance Board of Trustees:

Alan Bowers, Sue Ryder Care, Katherine Crawford, Director of Services Parkinsons UK, David Garmon-Jones, Independent; Ralph Gregory, Independent; Chris James MND Association, Sue Millman, Ataxia UK; Caroline Morrice, GAIN; Arani Nitkunan Association of British Neurologists, Angie Pullen, Epilepsy Action, Sarah Rawlings MS Society; Marc Smith The Brain and Spine Foundation. Cath Stanley Huntingdon's Disease Association, Amanda Swain, Vice Chair, UKABIF,

Members and friends of The Neurological Alliance:

Pam Archer, Black Country Neurological Alliance, Andy Barrick, Multiple System Atrophy Trust; Marcus Bell, Nerve Tumours UK; Grazina Berry, Overcoming MS; Kripen Dhrona, British Polio Fellowship; Niamh Buckingham Sue Ryder Care; Michael Cousins, Roche Products; Sam Freeman-Carney, Parkinson's UK; Camille Julien, Division of Neuropsychology (DoN) British Psychological Society; John Kemp Sue Ryder Care, Anne Meader, Hampshire Neurological Alliance; Paru Naik, MS Trust; Lesley Perkin, UCB Pharma Ltd; Lesley Pope, Independent Neurorehabilitation Providers Alliance (INPA); Deb Troops Greater Manchester Neurological Alliance; Victoria Wareham, Dystonia UK; Allison Watson Ring20 Research and Support UK; Austin Willett, Different Strokes; Shelly Williamson, IHHUK; Sue Worrall Black Country Neurological Alliance

Neurological Alliance staff:

Georgina Carr, Chief Executive; Caroline Davies, Administrator, Miranda Lloyd, Communications Officer, Sam Mountney, Policy and Campaigns Manager.

Apologies:

1. Welcome and opening remarks

David Martin paid tribute to Suzanne Dobson, former Chair of the Neurological Alliance and CEO of Tourette's Action who died unexpectedly during 2021. Suzanne served on the Board from 2016 – 2020 bringing her energy and enthusiasm to the work of the Alliance and advocating passionately for all members of the Alliance, large and small charities, to ensure that the voices of the people they represented were heard. She had been of great assistance to David particularly as he took over as chair of trustees and to Georgina as CEO of the Alliance.

David thanked the two trustees who had retired from the Board during 2021. Pamela McKenzie of Sue Ryder had left in the spring. Sue Millman had retired in November 2021 after serving four terms as a trustee with the required break of a year between periods in office. Sue had been the longest standing of the trustees and her contributions made a huge impact on the work of the Alliance.

He also thanked the four member staff team, Georgina, Caroline, Miranda and Sam who worked hard to ensure the Alliance conducted its business effectively and efficiently.

During proceedings Caroline Clarke, Chief Executive of the Royal Free London NHS Foundation Trust and trustee at Overcoming MS, gave a [keynote address](#) and answered questions from members.

2. Minutes of the Annual General Meeting 2020

Members approved the minutes as a true and accurate record of the AGM of The Neurological Alliance held on 18th November 2020

3. Matters Arising

There were no matters arising from the minutes of the 2020 AGM.

4. Review of the year – July 2020 – June 2021

Georgina gave a review of the year. She thanked the team, trustees and members for their support in enabling the work of the Alliance.

The Neurological Alliance continued to organise its work in pursuit of [five goals](#) and the highlights of her presentation are as follows;

4.1 A year in Numbers

- Listened to 1600 people with neurological conditions who told us about life during the pandemic.
- Co-hosted focus groups with more than 35 people with neurological conditions.
- 200 attendees at Neurofest 2020.
- Worked with 5 All-Party Parliamentary Groups (APPGs) in Westminster and more than 50 MPs and Peers.
- Recruited three new trustees, Arani Nitkunan, Sarah Rawlings, Cath Stanley and one new Vice-Chair of Policy Group, Sam Carney
- Welcomed two new members of staff, Miranda Lloyd and Sam Mountney.
- Published one piece of guidance on patient-initiated follow-up, now being considered by NHS England.
- 3 new reports
- 6 new organisations joined us

4.2 First Goal

To increase the influence and involvement of people with neurological conditions.

Using the responses of the 1600 people the Alliance published a [report](#) 'Restarting services for people with neurological conditions after the Covid-19 pandemic and planning for the longer term' in July 2020 which was picked up by the press. There was coverage in HSJ and Pharma Forum and the report led to discussions with Professor Powis about elective recovery. The report and its findings were presented to an All-Party Parliamentary group (APPG) and three people with neurological conditions were able to explain their experiences to a cross party group.

The Alliance went into partnership with The Brain and Spine Foundation to produce an app, 'Neuro Life Now', which was piloted during 2021. The app has approx. 800 users and there

are six months of reports. Being able to take snapshots of what was happening to people, for example in outpatients, was providing the backbone for influencing work.

Together with the APPGs on Parkinsons, Traumatic Brain Injury, MS, MND and Epilepsy the Alliance was able to secure a House of Lords [debate](#) on 27th May 2021, led by Baroness Gale.

None of this work would be possible without the support and contributions from member

4.3 Second Goal

Empower and support members to drive collective action that seeks to address the issues facing people with neurological conditions.

Together with key partners, the ABN and the Royal College of Psychiatry the Alliance and NNAG had published a report on mental health and neurological conditions. This had resulted in engagement with three national clinical directors and one specialty adviser who were considering how best to meet the needs of people with neurological conditions in their work. In addition, the Alliance had hosted a webinar, with NHS England for IAPT practitioners.

The Alliance had developed [guidance](#) on patient initiated follow-up which was being seen as one way to tackle waiting list times. The Alliance was participating in NHS England's strategic programme on outpatient transformation.

Thanks to the Rare Conditions sub-group members the Alliance had been able to publish a [report](#) 'Out of the Shadows'. Many of the recommendations were reflected in the Rare Diseases [Framework](#) which was published in January 2021. Work would continue on ensuring that this was implemented and the Alliance would continue to collaborate with key partners such as the Genetic Alliance.

4.4 Third Goal

To ensure the voices of people with neurological conditions are at the centre of national neurology policy and service improvement initiatives in order to increase the prioritisation of neurology

In April 2021 NNAG and the Alliance published a report on 'Lessons learnt from the Covid-19 pandemic Priorities in care for people with neurological conditions', which took a multi-disciplinary view and was being seen as a valuable resource by policy makers. It had resulted in a place on the elective care recovery taskforce, the highest level national body. It was important that neurology was represented. Similarly, the Alliance has a place on the Long Covid taskforce which was advising NHS E on its plans for people with long covid.

In January 2021 the [NICE quality standard](#) on Suspected neurological conditions; recognition and referral was published. These were an improvement on the previous guidelines with important amendments made to ensure FND and Dystonia were included.

4.4 Fourth Goal

Increase and support local action to improve neurological services

Over the past year the Alliance nationally had been meeting with Neurological alliances regionally at six weekly intervals. This forum allowed sharing of what was happening on the 'front line' and how the ICS roll-out was happening. It had been a difficult year for regional groups.

4.5 Fifth Goal

To build a sustainable organisation capable of bringing about change

The Alliance had welcomed a number of new member charities, the Association of Chartered Physiotherapists in Neurology (ACPIN), the Brain Research Trust, Overcoming MS and the neurology Academy and two new corporate partners, Boston Scientific and Kyowa Kirin.

There were 49 responses to the annual membership survey in the spring which was more than double the number in previous years. As testament to members engagement all said the value of their membership of the Alliance as excellent or good (none said poor). The three most important aspects of being part of the Alliance were

- Information about policy developments
- Data on patient experience
- Influencing public policy

4.6 Equity, Diversity and Inclusion (EDI)

The Alliance was committed to EDI and had a policy and plan in place for the last 12 months as well as going forwards. Work was on-going to improve the evidence base of what was known about access to care across different conditions and across different characteristics. The Alliance had worked with clinicians on a literature review which was ready to be submitted to journals. EDI had been a feature of preparations for the patient experience survey, My Neuro Survey, to ensure there were no barriers to people taking part.

4.7 Key Areas of Impact

The CEO summarised the key areas as follows

- Neurology and neurosurgery were both prioritised as part of elective care recovery NHS plans and in the guidance – every ICS was asked to set out their plans for recovery of these services.
- Neuro has a seat at the table at the highest levels of NHSE/I.
- NHSE/I Neuroscience transformation programme, looking at the specialised commissioning model for neurosciences, is back at work, thanks to pressure from the neuro community.
- NHSE/I outpatient transformation programme is focussing on neurology.
- New data available via NeuroLifeNow to enable the understanding of real-time experience of care and NHS activity via the Which tool.

4.8 The forthcoming year

Looking ahead to the forthcoming year My NeuroSurvey was progressing well with over 3k responses since the end of October. This was thanks to member charities supporting and promoting the survey. Data from the survey would be used to support a focus on mental health with particular reference to the impact of the pandemic. Referring to the keynote address from Caroline Clarke, Georgina said that the Alliance would be working to ensure the NHS reforms improved things for people with neurological conditions. This work would include influencing the Health and Care Bill as it passed through parliament and changes to clinical leadership. Georgina thanked all the member charities who had signed the letter to Stephen Powis calling for the appointment of a National Clinical Director for Neurology and Neuroscience. She was confident of the favourable outcome to this pressure by the end of 2021.

The Alliance has been working with Rand Europe on the available data on the numbers of neuroscience professionals in secondary and tertiary care in England and which included stroke and dementia. Following on from the initial report the aim would be to model need for the future based on factors such as expected retirements and changing treatment paradigms. This important piece of work should be complete by the summer of 2022.

The Alliance's commitment to EDI remained part of all of its work. The Alliance was working with the MS society and MNDA on mapping these commitments.

Members asked if the presentation slides could be made available after the meeting and this was agreed.

5. Financial review of the year

Caroline Morrice (Treasurer) gave an overview of The Alliance's financial position. The accounts were prepared by the independent examiners Goodman Jones on receipt from the accountants Godfrey Wilson. The Finance & General Purposes Committee continued to monitor the Alliance's finances closely. The committee is made up of the Chair of the Board of trustees, the Vice-Chair, the treasurer and two other trustees. The treasurer thanked the chief executive for her work in the past financial year in keeping the Alliance on budget.

CM reminded members:

- Our financial year runs from 1st July to 30th June.
- The reserves policy was agreed by the trustees during 2021 and is a risk-based policy.
- Trustees considered it prudent to hold reserves to cover the loss of income from one third of all significant income sources (approx. £59k for 2021).

At the end of the financial year the Alliance had reserves of £125,222 (£66,585 above the level of reserves that trustees felt were required). Unrestricted funds totalled £88,486.

Income from membership subscriptions decreased by 0.7% in the year to £96,254 (previous years £96,732, £90,545 2017-18 £98,841, 2016-17: £100,597).

The corporate funding has increased to £109,118 from £96,732 from £94,694. The Alliance received charitable donations totalling £2k.

Given the pressures on member charities due to the pandemic the Board of Trustees decided to lift the cap on corporate income which had previously been restricted to less than 50%. This would remain the case for three years until 2023-2024.

The Alliance wished to thank the University Hospitals Birmingham charity for providing funds to support the work of NNAG (the National Neurosciences Advisory Group). Unrestricted funds had also been used to pay for this work. The Alliance also received support of £5k from the Brain and Spine Foundation to help develop the NeuroLifeNow app.

Overall, there was a surplus of £22,871.

The treasurer thanked members and corporate supporters for their support during the past year. She thanked her fellow trustees and the staff team for their hard work.

6. Resolutions 2021

6.1 Receiving of Annual Report and Accounts for the year ending 30 June 2021

Resolution 1, to receive the report of the Trustees and accounts for the financial year ending 30 June 2021 and the report of the Independent Examiner Goodman Jones, was approved by The Neurological Alliance members.

6.2 Appointment of Independent Examiners

Resolution 2, to delegate responsibility for selecting The Neurological Alliance's Independent Examiners for the forthcoming year 2021-22 accounts to the Board of Trustees, was approved by The Neurological Alliance members.

6.3 Election of Trustees

David Martin passed the responsibility for chairing to the Vice-chair Marc Smith for the following item.

6.3.1 Re-election of Trustees

Under item 27 of the current Articles of Association, each Trustee shall retire at the AGM held in the third year following their appointment. They may then stand for re-election, but after two consecutive terms must retire for a year before standing for re-election again.

The Neurological Alliance members agreed to re-elect the following trustees who having reached the end of their first term and standing down and putting themselves for re-election.

David Martin, MS Trust

Amanda Swain, UKABIF

6.3.2 Election of Trustees

There are two vacancies on the Board (to replace Pamela McKenzie and Sue Millman. New nominations were received from:

- Alan Bowers, Sue Ryder
- Kripen Dhrona, The British Polio Fellowship
- Victoria Wareham, Dystonia UK

As there were two trustee vacancies available and three applicants, an election was held among members present at the meeting. Alan Bowers, and Kripen Dhrona were elected to the Neurological Alliance board.

7. Date of Next AGM

Wednesday 16th November 2022.

8. Close

The Chair thanked those present for their attendance and declared the meeting closed.