

Minutes of AGM 2019
The Neurological Alliance Annual General Meeting
Wednesday 20 November 2019, 15:00-16:30
National Council for Voluntary Organisations
Regent's Wharf, 8 All Saints Street, London, N1 9RL

Chair: Suzanne Dobson, Tourettes Action;

Present:

Neurological Alliance Board of Trustees:

Val Buxton, Parkinson's UK; Genevieve Edwards, MS Society, David

Garmon-Jones, Independent; Ralph Gregory, Independent; Pamela

Mackenzie, Director of Neurological Services and Scotland, David

Martin, Chief Executive, MS Trust, Sue Millman, Ataxia UK; Caroline

Members and friends of The Neurological Alliance:

Sammy Ashby, SUDEP Action; Andy Barrick, Multiple System Atrophy

Trust; Hilary Boone, Polio Survivors Network; Chris Bradshaw, The

Dystonia Society; Niamh Buckingham Sue Ryder; Simon Bull, CMT UK;

Sam Carney, Parkinson's UK; Georgia Carr, MS Society; Sharon Carr-

Brown, UKABIF; Fredi Cavander-Attwood, MS Society; Joy Duffen, The

Cure Parkinson's Trust; Wendy Edwards, PSP Association; Bernard

Elwen, Multiple Sclerosis National Therapy Centres; Adrian Hale TNA;

Chris James, MND Association; Eleanor Jayne, Sue Ryder; Joanne

Lawrence, Association of British Neurologists; Alex Massey, MND

Association; Barbara May, Teva UK Limited; Mark McDonald Stroke

Association; Cath Mummery, Association of British Neurologists; Priya

Oomahdat, NHS England; Vittoria Pollito, NHS England; Angie Pullen,

Epilepsy Action; Johnathan Randell, Biogen; Marc Smith, The Brain and

Spine Foundation; Rob Thomas, UCB; Kate Trenam, UCB; Victoria

Wareham, Dystonia UK; Austin Willett, Different Strokes; Shelly

Williamson, IHUK; Adrian Williams, University Hospitals Birmingham;

Amanda Woolley, NHS England; Helen Wood, Myelopathy.

The Neurological Alliance staff:

Sarah Vibert, Chief Executive; Adenike Adebisi, Policy Assistant
Caroline Davies, Administrator; Katharine McIntosh, Senior Policy and
Campaigns Advisor. Hannah Verghese,

Apologies:

Luke Ashton, Merck; Sally Light, Motor Neurone Disease Association,
Matt O'Neil, Narcolepsy UK,

1. Welcome, apologies and opening comments

Suzanne Dobson welcomed members and guests to the meeting.

She thanked the Neurological Alliance team for organising the AGM and members' meeting.

2. Minutes of the Annual General Meeting 2018

It was confirmed that Matt O'Neill had been added to the list of Neurological Board of Trustees instead of members and friends. With that amendment members approved the minutes as a true and accurate record of the AGM of The Neurological Alliance held on 21 November 2018.

3. Matters arising

There were no matters arising from the minutes of the 2018 AGM.

4. Review of the year

Suzanne thanked Sarah and the team for their work during the year which had been a most successful year for The Neurological Alliance.

Sarah gave a presentation to members (attached with the minutes). A summary of this presentation is as follows:

The Neurological Alliance had four main priorities in the previous year:

- Inform and lead the national policy agenda to drive neurology service improvement
- Empower and support members to drive collective action that raises the profile of the issues facing people with neurological conditions
- Improving the collection, analysis, and use of data to provide a robust evidence base to inform improvement of neurological services
- Influence the development of commissioning strategies to ensure neurology is included and proportionately prioritised

Highlights from 2018/19 include:

- Responding to the long-term plan for the NHS and providing a briefing document which has been widely used in the neuro community
- Supporting and influencing the Neuroscience Transformation Programme
- Co-Chairing and through Hannah Verghese undertaking the programme management of the National Neuro Advisory Group (NNAG)
- Publishing a consensus statement on mental health through the policy sub-group
- Developing the rare disease sub-group working towards a report
- Developing a position statement on Cannabis
- Working with SUDEP on medicine shortages and Sue Ryder on inappropriate care home placements
- Using a new methodology for the National Neurological Patient Experience Survey (NES) and improving the response rate (42% increase from 2016) so that the data can be broken down regionally

- Published the results of the PES in a report Neuro Patience with a parliamentary launch and national media attention.
- Used data from PES for a poster for Public Health England's National Conference
- Ran a petition on change.org on social care, using a case study of Nikita who is not receiving the social care she needs.
- Provided the secretariat for the Neuro Intelligence Data
- Added a resource library to the website
- The following new members joined The Alliance; Huntingdon's Disease Association, Matthew's Friends, Myelopathy.org, Ring 20 research and Support, Spotlight YOPD, and associates Bial and Teva.

Plans for the year ahead include:

- Taking the next steps with the Patient Experience Survey including an academic article, ABN conference, and a Directory of Conditions
- Organising an NNAG awayday
- Taking part in the NICE Quality Standard Committee through Katharine McIntosh
- Shaping the GIRFT (Getting it right first time) report recommendations
- Producing a pledge for the General Election in December 2019 and following up with the new government
- STP project
- Influence future RightCare priorities.
- Diversify income.
- Growing professional links

Sarah thanked the members for their support.

5. Financial review of the year

Simon Wigglesworth gave an overview of The Alliance's financial position:

SW reminded members:

- Our financial year runs from 1st July to 30th June.
- Our accounts were prepared by our accountants, Taylor Cocks. From 1st July 2019 our accountants will be Godfrey Wilson
- As a small organisation, our accounts are not audited; they are independently examined, and this year we appointed new independent examiners, Goodman Jones to do this.

The Finance & General Purposes Committee continued to meet with a brief to monitor the budget and accounts and provide advice and support to the Board about the financial and administrative affairs of the charity.

In 2018-19, the Alliance's funds came from two main sources: membership subscriptions and corporate supporters. Income was lower this year

Income from membership subscriptions fell by 8% in the year to £90,545 (2017-18 £98,841, 2016-17: £100,597). This was due to three medium-sized members leaving the Alliance, with some of the shortfall made up by recruiting new, albeit smaller, members.

The corporate funding has increased by 15% from £82,480 to £94,694. As in the previous year, we received gift in kind support from The Strategy Unit, NHS Midlands to support the NNAG work. We would like to thank The Strategy Unit for their support.

We also received restricted donations from three charity members to support the NNAG work. We would like to thank the charity members for their support of this important work. We also received funding from a non-member charity in return for consultancy support for their patient experience survey, which in turn provided a contribution towards the costs of The Neurological Alliance patient experience survey.

Overall there is a deficit of £44,605 on the unrestricted funds (2017/18: deficit of £8,618) and a deficit of £3,244 on restricted funds

(2017/18: surplus of £6,000). This leaves an overall deficit of £47,849 (2017/18: deficit of £2,618) for the year.

At the end of the year unrestricted reserves of £87,484 were held. This is £35,539 above the level of reserves the trustees calculate are required. As such in approving the 2019/20 budget, £20,155 of the reserves have been allocated for expenditure in 2019/20 to support the Alliance's key projects, such as the National Neuro Advisory Group. Simon added his thanks to all members and corporate supporters for their past and continued support of the Alliance.

He would be standing down as Treasurer and wished his successor, Caroline Morrice every success in the role.

6 Resolutions 2019

6.1 Receiving of Annual Report and Accounts for the year ending 30 June 2018

The Neurological Alliance's Annual Report, including the statement of financial activities, has been confirmed as true and accurate by our Independent Examiners Goodman Jones, and was approved by The Neurological Alliance members.

6.2 Appointment of Independent Examiners

Resolution 1.2, to delegate responsibility for selecting The Neurological Alliance's Independent Examiners for the forthcoming year 2019-19 accounts to the Board of Trustees, was approved by The Neurological Alliance members.

6.3 Election of Trustees

Suzanne explained that 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.

Standing down from the Board are Simon Wigglesworth of Epilepsy Action and Sally Light of the Motor Neurone Disease Association.

Also standing down are Val Buxton of Parkinson's UK and Matt O'Neill of Narcolepsy UK.

Suzanne wished for thanks to be recorded to them all for their commitment to The Alliance during their time on the Board.

Suzanne then introduced four new nominations for the board:

In accordance with item 27 of our Articles of Association, nominees have been endorsed by the member organisation to which they belong and have been recommended by Trustees.

All were unanimously elected unopposed to the four vacancies.

Katherine Crawford, Parkinsons UK

Christopher James, Motor Neurone Disease Association

Angie Pullen, Epilepsy Action

Marc Smith, The Brain & Spine Foundation

6.4 Revised articles of Association

Suzanne explained that work had recently been undertaken to bring the Articles of Association up to date. They had last been revised in 2012. The areas which needed to be revised was the re-election of trustees after their first term of three years, enabling the Board of Trustees to co-opt and providing a clearer route for local alliances to be involved in decision making.

Those present had no comments to make on the proposed revisions. The new Articles of Association would be presented for approval at an extra-ordinary general meeting to be held in early 2020.

7 Any Other Business

This was the last meeting for Sarah Vibert, the chief executive before she left the Alliance at the end of December. She was presented with a leaving cards and flowers and all present wished her well for the future.

8. Date of Next AGM

Wednesday 18th November 2020

9. Close

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