



**The Neurological Alliance Annual General Meeting
Wednesday 22 November 2017, 11:10-12:00
National Council for Voluntary Organisations
Regent's Wharf, 8 All Saints Street, London, N1 9RL**

Chair: Suzanne Dobson

Present: Neurological Alliance Board of Trustees

Val Buxton, Parkinson's UK; Suzanne Dobson, Tourettes Action; Alice Doyle, Brain and Spine Foundation; Ruth Ingledew, Myaware; Sally Light, Motor Neurone Disease Association (Vice Chair); Sue Millman, Ataxia UK; Caroline Morrice, GAIN; Matt O'Neill, Narcolepsy UK; David White, Cavernoma Alliance UK; Simon Wigglesworth, Epilepsy Action (Treasurer).

Members and friends of The Neurological Alliance

Samantha Ashby, SUDEP Action; Barbara Babcock, Transverse Myelitis Society; Andy Barrick, Multiple System Atrophy Trust; Neil Bindermann, Primary Care Neurology Society; Philip Bungay, Medway Neurological Network; Iain Clarke, Action Duchenne; Aaron Cox, Chiltern MS Centre, Bernard Elwen, Multiple Sclerosis National Therapy Centres; Genevieve Edwards, MS Society; Graham Faulkner, The Daisy Garland; Tara Finn, The Migraine Trust; David Garmon-Jones, Medday Pharmaceuticals; Bryan Gould, Black Country Neurological Alliance; Andrew Leach, Hampshire Neurological Alliance; Benali Hamdache, Parkinson's UK; Duncan Lugton, Sue Ryder; Ian Stuart, Cavernoma Alliance UK; Kate Trenam, UCB; Hannah Verghese, Migraine Trust;; Martyn Hooper, The Pernicious Anaemia Society; Helen Hunt, Walton Centre; Dr Jozef Jarosz, King's Health Partners; Karen Larcombe, King's Health Partners; Sarah Marsh, NHS England; Alison McKinlay, King's College London; Lizzie Printer, Brain & Spine Foundation, Stroke Association and RNIB; Don Reading, National Voices; Julie Riley, Walton Centre; Prof Leone Risdale, King's College London; Dr Patricia Spallone, Cavernoma Alliance UK; Daniel Vincent, Motor Neurone Disease Association; Thomas Warner, Association of British Neurologists; Prof Adrian Williams, University Hospitals Birmingham; Gabriella Wojewodka, King's College London; Jane Hanna, SUDEP Action.

Neurological Alliance staff

Sarah Vibert, Chief Executive; Fiona Tate, Communications Assistant; Katharine McIntosh, Senior Policy and Campaigns Advisor; Joe Korner, Chief Executive maternity cover.

Apologies: Hilary Boone, Brian Gould, Pam McFarlane, Amanda Swaine, Arlene

Wilkie.

1. Welcome, apologies and opening comments

Suzanne Dobson welcomed members and guests to the meeting. She also introduced new Alliance staff:

- Joe Korner – Chief Executive maternity cover.
- Katharine McIntosh – Senior Policy and Campaigns Advisor.

Both members of staff start in January 2018.

Suzanne also thanked Fiona Tate for organising the AGM and member's meeting.

2. Minutes of the Annual General Meeting 2016

Members approved the minutes as a true and accurate record of the AGM of The Neurological Alliance held on 23 November 2016.

3. Matters arising

There were no matters arising from the minutes of the 2016 AGM.

4. Review of the year

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 year just gone:

1. Establishing effective national leadership for neurology
2. Developing a strategic approach to service improvement
3. Improving the development and sharing of data and intelligence
4. Increasing commissioner engagement in neurology

Highlights from 2016/17 included:

- Supporting the development of the new National Neuro Advisory Group (NNAG)
- Publishing the results of our second patient experience survey
- Publishing our mental health report
- Publishing our CCG audit as part of an update to our 2014 Going the Distance report. Going the Distance II also included the results of Sue Ryder's STP audit

Sarah also noted the important 'convening' role the Alliance played in bringing together members, as well as different part of the health system, to tackle policy challenges.

Plans for the year ahead. These were informed by a trustee away day in June, as well as the results of our member survey. Overall 85% of full member (and 60% of regional groups) are satisfied or very satisfied with membership of the Alliance. Members cited a number of benefits they valued most from membership which included: having the opportunity to influence public policy through meetings with policy makers or consultation responses, information about the policy landscape and data from the Alliance's patient experience survey.

There were a number of areas that members highlighted for the Alliance to do better:

- Follow through on recommendations in reports

- Consider more press/parliamentary work
- The website!
- Support for RNAs
- Get more organisations on board
- Be more public facing
- Set up more subgroups
- The newsletter
- More data

Sarah then outlined the five priorities for 2017/18

- Inform and lead the national policy agenda – including supporting NNAG, influencing the new NICE guideline, influencing the national service review of neurosciences and influencing the neurology specification.
- Drive collective action to raise the profile of neurology – developing a mental health action plan to follow up on our report last year, influencing the rehabilitation chapter of the stroke national plan, working with subgroups of members including rare conditions and neurodevelopmental conditions, and delivering a new campaign on living with a neurological condition.
- Improve data to provide a robust evidence base – supporting the set up of an NNAG data subgroup, developing a project plan for our 2018 patient experience survey.
- Influence the development of place based commissioning – undertaking our 2018 CCG audit, developing a project in an STP area to show what good looks like for neurology and hosting a joint neurology APPG chairs meeting.
- A sustainable organisation – rebranding and developing a new website, bringing in new members, diversifying our income.

5. Financial review of the year

Simon Wiggsworth gave an overview of the Alliance's financial position:

SW remaindered members:

Our accounts were prepared by our accountants, Taylor Cocks.

As a small organisation, our accounts are not audited; they are independently examined, by HW Fisher and Company.

Our financial year runs from July to June.

In 2016-17, the Alliance's funds came from two main sources: membership subscriptions and corporate supporters.

Income from membership subscriptions fell by 8.7% in the year to £100,597 (2015-16: £110,232).

This was due to two larger members leaving the Alliance, Alzheimer's Research UK and Royal Hospital for Neurodisability. However, we had a net gain in number of members in the Alliance last year (7 joined) – but those we recruited we generally smaller hence the reduction in income.

The corporate funding is continuing, with £70,000 being committed in the year, less than the £120,000 last year which was artificially boosted by delayed

income from 2014/15.

The accounts show that our income overall has decreased from £231,252 in 2015-16 to £170,597 this year, explained as I previously noted.

Our expenditure during the year was £169,388, slightly above the previous year of £166,591.

Our general fund (unrestricted) had a surplus of £43,339 and the restricted fund a deficit of £42,130, spending up all the restricted funds.

This leaves an overall there is a surplus of £1,209 (2015-16: £64,761) for the year.

Our reserves carried forwards were £140,807, very similar to last year.

As discussed at last year's AGM the trustees reviewed the reserves policy and adopted a new' risk based, reserves policy during the year.

The details can be found on page 18 of the annual report.

Having considered the key income and expenditure risks to the Alliance the trustees consider reserves of £50,000 should be maintained.

As noted our reserves coming in to 2017/18 are above the required level at £140,807, as such, with Sarah, we are considering how best the excess funds can be used to support the Alliance's work.

Finally, can I add my thanks to all members and corporate supporters for their past and continued support of the Alliance.

6. Resolutions 2017

6.1 Receiving of Annual Report and Accounts for the year ending 30 June 2017

The Neurological Alliance's Annual Report, including the statement of financial activities, has been confirmed as true and accurate by our Independent Examiners H.W. Fisher, and was approved by Neurological Alliance members, with one exception as outlined below. SUDEP Action was mistakenly omitted from the list of members in the Annual Report and Accounts (post meeting note: this was due to reformatting by our accountants). The updated version including SUDEP Action has been created and will be submitted as our final annual report and accounts to the relevant authorities.

6.2 Appointment of Independent Examiners Members agreed to delegate responsibility for selecting the Neurological Alliance's Independent Examiners for the forthcoming year and 2017-18 accounts to the Board of trustees.

6.3 Election of Trustees

Suzanne invited Sally Light to Chair this part of the meeting, as Suzanne was standing for re-election.

Sally explained that under item 27 of the 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 as she has served two terms of three year: Amanda Swaine, UK. Amanda had sent apologies for the meeting but Sally recorded thanks to Amanda for her commitment to the Alliance during her term.

Also standing down from the board as he has left his roles within Neurological Alliance member charity MS Society is Nick Rijke, MS Society. Sally recorded thanks to Nick for his commitment to the Alliance during his time on the Board.

Standing for re-election:

- Suzanne Dobson, Chief Executive, Tourette's Action
- Caroline Morrice, Chief Executive, Guillain-Barre and Associated Inflammatory Neuropathies (GAIN)

Sally reminded attendees that:

- The two current Trustees standing for re-election will be re-elected using a show of hands of those present at the meeting.
- Only those present at the meeting, not those voting by proxy, can vote on the re-election of Trustees (in accordance with item 27.2 of our articles)

Suzanne and Caroline were unanimously re-elected to the board.

Sally then introduced one new nomination for the board:

- Genevieve Edwards, Director of External Affairs, MS Society

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.

As this is a non-competitive election, members were not invited to vote, but were instead asked to ratify the appointment of Genevieve. This resolution was passed unanimously.

7. Any other business

This section was used to open the floor to members to ask questions of Suzanne, Sarah and Simon. Questions covered the following areas:

- The Alliance should consider issues beyond what happens in neurologist's clinics – the wider MDT and other areas of support (Aaron Cox)
- What are the plans to ensure continuity of the NNAG model? (Hannah Verghese)
- Personal health budgets and access to continuing health care funding (Bungay)
- What is the Alliance doing in relation to welfare benefits? (Matt O'Neill)

8. Date of next AGM: Wednesday 21 November 2018

CLOSE

The Chair thanked those present for their attendance and declared the meeting closed at 12:00pm