

Minutes of AGM 2018
The Neurological Alliance Annual General Meeting
Wednesday 21 November 2018, 13:45-14:45
National Council for Voluntary Organisations
Regent's Wharf, 8 All Saints Street, London, N1 9RL

Chair: Sally Light, Motor Neurone Disease Association

Present:

Neurological Alliance Board of Trustees:

Val Buxton, Parkinson's UK; David Garmon-Jones, Independent; Ralph Gregory, Independent; Alice Doyle, Brain and Spine Foundation; Sally Light, Motor Neurone Disease Association; Sue Millman, Ataxia UK; Caroline Morrice, GAIN; Simon Wigglesworth, Epilepsy Action.

Members and friends of The Neurological Alliance:

Sammy Ashby, SUDEP Action; Andy Barrick, Multiple System Atrophy Trust; Hilary Boone, Polio Survivors Network; Sam Carney, Parkinson's UK; Katherine Carpenter, The British Psychological Society; Theresa Dauncey, The National Brain Appeal; Joy Duffen, The Cure Parkinson's Trust; Gaynor Edwards, Spotlight YOPD; Bernard Elwen, Multiple Sclerosis National Therapy Centres; Helen Evans, Cavernoma; Una Farrell, The Migraine Trust; David Garland, The Daisy Garland; Bryan Gould, Black Country Neurological Alliance; Chloe Hayward, UKABIF; Kim Hearne, FND Action; Michael Jackson, Public Health England; Chris James, MND Association; Martin James, Kings College London; Joanne Lawrence, Association of British Neurologists; Andrew Leach, Hampshire Neurological Alliance; Cam Lugton, Neurology Intelligence Network; Duncan Lugton, Sue Ryder; Sarah Marsh, NHS England; Pamela Mackenzie, Sue Ryder; Linden Muirhead, MS Trust; Cath Mummery, Association of British Neurologists; Fardousa Musa, Association of British Neurologists; Matt O'Neil, Narcolepsy UK; Bruce Pollington, NHS Right Care; Stephen Powis, NHS England; Sigita Stankeviciute, Parkinson's UK; Cath Stanley, Huntington's Disease Association; Constantinos Skinitis, Novartis; Maxine Smeaton, Epilepsy Research UK; Ingrid Spickett, Brain and Spine Foundation; Dafydd Thomas, Association of British Neurologists; Kate Trenam, UCB; Karen Walker, MSA Trust; Prof. Adrian Williams, University Hospitals Birmingham; Jordan Webb, Spotlight YOPD.

The Neurological Alliance staff:

Sarah Vibert, Chief Executive; Fiona Tate, Projects Coordinator;
Katharine McIntosh, Senior Policy and Campaigns Advisor.

Apologies:

Luke Ashton, Merck; Suzanne Dobson, Tourettes Action;
Genevieve Edwards, MS Society; Graham Faulkner, The Daisy
Garland; Barbara May, Teva UK Limited; Martin Nagler, Transverse
Myelitis Society; Ian Stuart, Cavernoma; Rob Thomas, UCB; David
White, Cavernoma; Joe Wildy, Sanofi; Austin Willett, Different
Strokes; Shelly Williamson, IIHUK.

1.	Welcome, apologies and opening comments Sally Light welcomed members and guests to the meeting and apologised for Suzanne Dobson's absence. Sally thanked The Neurological Alliance team for organising the AGM and member's meeting. Sally announced David White, Ruth Ingledew and Alice Doyle will be stepping down as trustees and thanked them for their work.
2	Minutes of the Annual General Meeting 2017 Joy Duffen asked that Richard Wise, Cure Parkinson's be added to the minutes. With the above addition, members approved the minutes as a true and accurate record of the AGM of The Neurological Alliance held on 22 November 2017.
3	Matters arising There were no matters arising from the minutes of the 2017 AGM.
4	Review of the year Sally thanked Sarah for her work and Joe Korner for covering Sarah's post during her maternity leave. Sarah gave a presentation to members (attached with the minutes). A summary of this presentation is as follows: The Neurological Alliance had five main priorities in the year just gone: <ul style="list-style-type: none">• Inform and lead the national policy agenda to drive neurology service improvement• Influence the development of commissioning strategies to ensure neurology is included and properly prioritised• Empower and support members to drive collective action• Improve the collection, analysis and use of data to provide a robust evidence base to inform improvement of neurology services

	<ul style="list-style-type: none"> • Build a sustainable organisation capable of bringing about change <p>Highlights from 2017/18 include:</p> <ul style="list-style-type: none"> • Supporting the development of the new National Neuro Advisory Group (NNAG). • Clinical reference group - attended by Katharine, has been reviewing the suite of neuroscience specifications. Also reviewed various policies and developed an algorithm for disease modifying therapies in MS. Trying to take advantage of the focus on stroke. • Development of policy sub-groups, including mental health, Rare Disease and neurodevelopmental coalition. • Patient experience survey pilot completed, with new methodology. • Rebrand and website completed. • Made policy group meeting more accessible by introducing a webinar. • 8 new members joined The Alliance. <p>Plans for the year ahead include:</p> <ul style="list-style-type: none"> • Continue work on making NNAG more transparent. To achieve this action, The Alliance has added information to our website. Keen to have feedback. • Set up a care planning and mental health workstream through NNAG. • Bring more resources to continue programme and support of NNAG. • Influence next year's RightCare programmes. • Clinical commissioning group audit and work to influence the Sustainability and Transformation Partnership/Integrated Care System five-year plans. • Diversify income. • Continuing to populate the resource library on website. • Retain membership. <p>Sarah thanked Katharine McIntosh and Fiona Tate for their work and the members for their support.</p>
5	<p>Financial review of the year</p> <p>Simon Wigglesworth gave an overview of The Alliance's financial position:</p> <p>SW reminded members:</p> <ul style="list-style-type: none"> • 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. <p>During the year the trustees agreed to set up a Finance & General Purpose Committee 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.</p> <p>The membership is the chair, vice-chair, treasurer and one additional board member, last year that was Alice Doyle.</p> <p>In 2017-18, the Alliance's funds came from two main sources: membership subscriptions and corporate supporters.</p>

	<p>Income from membership subscriptions fell by 2% in the year to £98,841 (2016-17: £100,597). This was due to one large charity member leaving the Alliance.</p> <p>The corporate funding is continuing, with £82,480 core and £6,000 restricted (NNAG) funding being committed in the year.</p> <p>In addition, 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.</p> <p>We also received restricted donations from UCB and three charity members to support the NNAG work. We would like to thank UCB and the charity members for their support of this important work.</p> <p>Overall there is a deficit of £8,618 on the unrestricted funds (2016/17: surplus of £1,209) and a surplus of £6,000 on restricted funds (2016/17: £nil).</p> <p>This leaves an overall deficit of £2,618 (2016/17: surplus of £1,209) for the year.</p> <p>At the end of the year unrestricted reserves of £132,189 were held.</p> <p>Having considered the key income and expenditure risks to the Alliance the trustees consider reserves of £50,000 should be maintained. This is £82,000 above the level of reserves the trustees calculate are required.</p> <p>As such in approving the 2018/19 budget, £38,000 of the reserves have been allocated for expenditure in 2018/19 to support the Alliance's key projects, supporting the National Neuro Advisory Group and the Patient Experience Survey.</p> <p>Simon added his thanks to all members and corporate supporters for their past and continued support of the Alliance.</p>
6	<p>Resolutions 2018</p> <p>6.1 Receiving of Annual Report and Accounts for the year ending 30 June 2017</p> <p>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 The Neurological Alliance members.</p> <p>6.2 Appointment of Independent Examiners</p> <p>Resolution 1.2, to delegate responsibility for selecting The Neurological Alliance's Independent Examiners for the forthcoming year ad 2018-19 accounts to the Board of Trustees, accepted by The Alliance members.</p> <p>6.3 Election of Trustees</p> <p>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.</p> <p>Standing down from the Board as she is leaving the Brain and Spine Foundation, Alice Doyle. Sally thanked Alice for her commitment to the Alliance during her term.</p>

	<p>Standing down from the board as she has left her role within The Neurological Alliance member charity Myaware is Ruth Ingledew,. Sally recorded thanks to Ruth for her commitment to The Alliance during her time on the Board.</p> <p>David White, Cavernoma Alliance UK, is standing down from the Board also. Sally recorded thanks to David for his commitment to The Alliance during his time on the Board.</p> <p>Standing for re-election:</p> <ul style="list-style-type: none"> • Sue Millman, Chief Executive, Ataxia UK <p>Sally reminded attendees that:</p> <p>The current Trustee standing for re-election will be re-elected using a show of hands of those present at the meeting.</p> <p>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)</p> <p>Sue was unanimously re-elected to the board.</p> <p>Sally then introduced three new nomination for the board:</p> <ul style="list-style-type: none"> • David Martin, Chief Executive, MS Trust • Pamela McKensie, Director of Neurological Services and Scotland, Sue Ryder • Amanda Swain, Vice Chair, UKABIF <p>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.</p> <p>David Martin, Pamela McKensie and Amanda Swaine were unanimously elected to the Board.</p>
7	<p>Any other business</p> <p>Helen Evans introduced herself as the new Chief Executive at Cavenoma UK and expressed her thanks to the Alliance for their work and the meeting today.</p> <p>Date of next AGM: Wednesday 20 November 2019</p>
8	<p>Close</p> <p>The Chair thanked those present for their attendance and declared the meeting closed.</p>

