



# THE NEUROLOGICAL ALLIANCE

Dear Friends of The Neurological Alliance,

I am writing on behalf of the Board of Trustees to invite you to our 2023 Annual General Meeting (AGM) and members meeting, on **Wednesday 22<sup>nd</sup> November**, which will be held at the National Council for Voluntary Organisations, Regent's Wharf, **8 All Saints Street, London, N1 9RL**

Registration will begin at 10:30, and the first keynote speech will be at 10.50. The Annual General Meeting will be held 11:30 – 12:30. Please note that you are welcome to attend the AGM in the morning, but are not eligible to vote.

The members meeting (including a networking lunch) will be held 12:30 – 15:00. The afternoon will include a panel discussion on NHS Transformation with Richard Sloggett of Future Health and Dr Niran Nirmalanathan, National Clinical Director for Neurology and chaired by Rhys Holmes of our co-production group.

Please see the following documents enclosed:

- [Agenda](#)
- [Minutes of AGM 2022](#)

Yours sincerely,

David Martin, Chair, The Neurological Alliance

**Minutes of AGM 2022**  
**The Neurological Alliance Annual General Meeting**  
**15 November 2022**  
**National Council for Voluntary Organisations**  
**Regent's Wharf, 8 All Saints Street, London, N1 9RL**

**Chair:** David Martin, Chief Executive, MS Trust.

**Present:**

Neurological Alliance Board of Trustees:

Kripen Dhrona, British Polio Fellowship, Marc Smith Brain and Spine Foundation. Caroline Morrice, GAIN, Cath Stanley Huntingdon's Disease Association, Ralph Gregory, Independent, David Garmon-Jones, Independent, Chris James MND Association, Alan Bowers, Sue Ryder Care, Amanda Swain, Vice Chair, UKABIF.

Members and friends of The Neurological Alliance:

Ian Brown, 3 Million Steps, Amanda Mortensen, BDFA, Tony Thorburn, Behcets UK, Jessica March, Biogen, Aaron Cox Brain and Spine Foundation, Thomas Brayford Brain Tumour Research, Simon Bull CMT-UK, Austin Willett Different Strokes, Claire Eldred Dravet Syndrome UK (on-line), Victoria Wareham, Dystonia UK, Charlotte Gerada Huntingdon's Disease Association, Lesley Pope, Independent Neurorehabilitation Providers Alliance (INPA); Graham Levy, Intractable Epilepsy, Alex Massey, MND Association, Bernard Elwen, MS Therapy centres, Jonathan Blades, MS Society, Marcus Bell, Nerve Tumours UK; Daiga Heisters Neurology Academy; Stephen Richards, Overcoming MS, Juliet Tizzard, Parkinson's UK; Sam Freeman-Carney, Parkinson's UK; Rebecca Packwood PSPA; Michael Cousins, Roche Products; Monika Hermansson and Felix Boucher Sandoz Ltd; Chris Ward Sanofi UK; Sammy Ashby SUDEP UK; Teresa Dauncey, The National Brain Appeal; Katrina Burchell, The Pernicious Anaemia Society, Dr John Burn Consultant Rehabilitation and Brain Injury

Neurological Alliance staff and Co-production team

Georgina Carr, Chief Executive; Caroline Davies, Administration and Membership Officer, Miranda Lloyd, Communications Officer, Jessica Mansel Co-production.

Debbie Williams (Co-production), Rhys Holmes (Co-production online), Jeanie King (Co-production online),

**Apologies:**

Arani Nitkunan Association of British Neurologists, Sarah Rawlings MS Society.

**1. Welcome and opening remarks**

David Martin welcomed members to the first in-person meeting since 2019. The AGMs in 2020 and 2021 had been held online in observance of the covid restrictions. Today arrangements have been made for those not able to travel to London to take part via Zoom.

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.

**2. Minutes of the Annual General Meeting 2021**

Members approved the minutes as a true and accurate record of the AGM of The Neurological Alliance held on 17th November 2021. There were no matters arising.

### **3. Review of the year – July 2021 – June 2022**

David Martin and Georgina Carr presented a review of the year, including a video of the work of the Co-production group edited by a member of the group Rhys Holmes. They thanked the team, trustees, co-production group 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 are as follows;

1. Listened to 8,500 people with neurological conditions through My Neuro Survey
2. Set-up the Alliance co-production group – 12 people on the group, more than 80 people applied
3. 7 members joined us, 1 new corporate supporter
4. 2 National Clinical Directors on the way, 2 National Specialty Advisors TBC
5. More than 13,500 people have shown their support for #Backthe1in6
6. Over 100 organisations promoted My Neuro Survey online
7. Worked with the College of Psychiatrists to improve support
8. Part of the covid CNS trial working group
9. Working closely with to support the development of the UK ABI strategy
10. Outcomes day of November 2021 with the National Neurosciences Advisory group (NNAG) on the features of good outcomes
11. Renewed our commitment to equity, diversity and inclusion including reviewing our internal processes, supporting members to share approaches to EDI
12. 34 members responded to the March Annual member survey saying that the NA represents value for money, provides a strong voice at national level, is a good place for collective action but could give people affected by neurological conditions a stronger voice in Alliance work and do more to communicate changes of health policy

### **4. Financial review of the year**

Caroline Morrice gave an overview of The Alliance's financial position during the past year. The accounts have been prepared by Goodman Jones and financial matters remain subject to the oversight of the Finance and General Purposes committee (including the treasurer, Chair of trustees, Vice-chair of trustees and two trustees), reporting to the Board.

In 2020-21, the Alliance's funds came from two main sources: membership subscriptions and corporate supporters. Income from membership subscriptions was £96,883 and corporate funding was increased £110, 296. The Alliance received charitable donations of £2,500. Overall, there is a deficit of £60,267 (before transfers) on the unrestricted funds (2020/21 surplus of

£41,646) and a deficit of £19,632 (before transfers) on restricted funds (2020/21: deficit of £11,238). This leaves an overall deficit of £64,198 (2020/21 surplus of £30,408) for the year. In response to a question from the floor the CEO explained that the Alliance had decided to invest in additional funding for the Patient Experience Survey (My Neuro Survey) which had resulted in the planned deficit.

## **5. Resolutions**

### **5.1 Receiving of Annual Report and Accounts for the year ending 30 June 2022**

Resolution 1, to receive the report of the Trustees and accounts for the financial year ending 30 June 2022 and the report of the Independent Examiner Goodman Jones, was approved by The Neurological Alliance members.

### **5.2 Appointment of Independent Examiners**

Resolution 2, to delegate responsibility for selecting The Neurological Alliance's Independent Examiners for the forthcoming year 2022-23 accounts to the Board of Trustees, was approved by The Neurological Alliance members.

### **5.3 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.

- Chris James, Motor Neurone Disease Association
- Marc Smith, Brain and Spine Foundation

### **Election of Trustees**

Standing down from the Board as she has completed her second three-year term on the Board of Trustees is Caroline Morrice of GAIN. Standing down from the Board as they have left their member charities are Angie Pullen, Epilepsy Action and Katherine Crawford, Parkinson's UK.

As there were three trustee vacancies available and five applicants, an election was held among members present at the meeting in person or on-line. The following were elected to the Neurological Alliance board.

- Victoria Wareham, Dystonia UK
- Alison Fuller, Epilepsy Action
- Rob Music, The Migraine Trust

## **4. Close**

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