Board of Trustees – April 2010

The Association’s board of trustees met on 24 April 2010 in Kettering, where they:

- Approved a new four-year Care Centre programme grant for King’s College Hospital, London – the Association’s longest-running MND Care Centre
- Provided clarification on the Association’s position on assisted dying, by approving a new position policy statement for use in campaigning and as guidance for our staff and volunteers. The statement confirms that we neither support nor oppose a change in the law on assisted dying, and that we are here to support all people with MND, regardless of their individual views in this area.
- Received the first results from an enhanced monitoring survey of health and social services for people with MND. This aims to provide an ‘early warning system’ of where cuts in public spending are being felt – as the basis for taking action to mitigate the impact on people with MND
- Approved the 2010-15 Association biomedical research strategy, to give direction to the way we fund and promote world-class research and thus ensure we keep on track for a world free of MND
- Agreed funding for five new research projects, to be undertaken by Dr Kevin Talbot (Oxford), Dr Richard Wade-Martins (Oxford), Prof Richard Ribchester (Edinburgh), Prof Chris Shaw (King’s) and Prof Jackie de Bellerocche (London)
- Also agreed to £800,000 of funding over three years for a high-profile international collaboration to develop the use of stem cells at the leading edge of MND research
- Appointed Peter Bickley, a retired economist whose father died from MND in 2003, as a co-opted member of the board, filling the remaining vacancy
- Reviewed the register of strategic and operational risks. This was subsequently scrutinised by the board’s governance committee, where it was agreed that for easier management operational risks would be administered within directorates, with major risks being reported regularly to the board
- Re-confirmed their acceptance of the code of conduct for trustees
- Agreed to retain a flexible approach to the process of selecting and endorsing nominations for public honours, e.g. MBEs and OBEs, and to consider each case on its own merits
- Approved a new strategic approach to managing and developing the Association’s people resources – that is, our volunteers and staff
- Discussed potential contingency plans in case the Association suffers a drop in income as a result of planned public spending cuts. These cuts may affect us as a charity that is almost entirely dependent on voluntary donations. Currently, our income is holding steady, as was reported to trustees in the regular management accounts.
• Approved in principle the setting up of a new incorporated structure for the Neurological Commissioning Support (NCS), a joint initiative between the Association, the MS Society and Parkinson’s UK which works with councils and primary care trusts to ensure the needs of people with long-term neurological conditions are kept at the heart of commissioning.
Board of Trustees – July 2010

The Association’s board of trustees met on 10 July 2010 in Kettering, where they:

- Re-appointed Prof Victor Patterson, retired neurologist and former director of the Northern Ireland MND Care Network, as a co-opted member of the board.
- Approved and signed the Trustees’ Annual Report, including our audited accounts for 2009/10, ahead of its circulation to all members for adoption at our Annual General Meeting in September. The board also endorsed the content of a separate ‘Impact Report’ which focuses on the impact of our activities for people affected by MND.
- Examined a report by our auditors, produced as part of our annual accounts auditing process, which highlighted the need to improve our practices in some areas, for example, how we ensure cover for essential financial processes – this is in hand.
- Approved an amendment to our reserves policy, which sets out a target for how much of our income we should ‘set aside’ to ensure we can continue providing services for people with MND if there was a dramatic or unforeseen cut in our expected income. The amendment reflects the need to recognise amongst our reserves readily realisable assets or ‘near cash’, such as amounts invested in fixed-interest deposit accounts.
- Discussed a reforecasting of our budgeted income and expenditure for 2011/12 and beyond in light of the current economic situation. The aim is to ensure our budget planning is robust in balancing the demands on the Association to provide support with our likely income.
- Renewed grant support for the Oxford MND Care Centre, a centre of excellence within the UK for MND support.
- Agreed to confer honorary membership on all founder members of the Association, as a way to acknowledge their role in forming the Association and their continuous 30 years plus contribution to supporting its development.
- Approved the establishment of a clinical fellowship in MND from 2011 following completion of a successful pilot.
Board of Trustees – October 2010

The Association’s Board of Trustees met on 16 October 2010 in Kettering, where they:

- Agreed that a review of the Association’s website was a priority and noted that a new section would be added to provide further information about trustees and Board committees.

- Reviewed the Annual Conference and AGM and discussed the balance of business and interaction and also the structure of the event. It was suggested that work be done in partnership with other charities to draw up a specification of the needs of disabled people for future conference provision. It was proposed that trustees become more involved in the planning process for 2011’s event.

- Confirmed or conferred honorary memberships for Branch Presidents and Patrons, and also agreed on an additional category of ‘life membership’ to reward volunteers with long and exceptional service. This will require a special resolution which will be put forward at the next AGM.

- Approved a grant recommended for funding by the Biomedical Research Advisory Panel (BRAP). The project will be led by Dr Emily Goodall, at the University of Sheffield, who will study a family of molecules (microRNAs) and determine if a distinctive ‘fingerprint’ of these occurs in the blood of people with MND. If so, this work could lead to development of a blood test to aid MND diagnosis, track the progression of disease and monitor responses to treatment.

- Congratulated the fundraising team on its continued success in the current difficult external environment. Fundraising remains above budget despite fewer company donations and reduced responses to cash appeals.

- Supported the principles of an agreement for a new incorporated structure for the Neurological Commissioning Support (NCS), a joint initiative between the Association, the MS Society and Parkinson’s UK to represent the voices of the partner organisations in commissioning services. The Board recommended that further negotiations relating to the incorporation be delegated to the Governance Committee and that a formal report and business plan be presented in January.

- Requested that management work within the constraints of maintaining a six month general reserve when constructing the budgets for 2011/12 and a target to raise the proportion of the revenue of the Association devoted to charitable purposes to 80% (it is currently 79%). The Board confirmed trustees would work with directors to ensure everything possible be done to maintain and improve services for people living with MND.