Board of Trustees – January 2012

The Association’s Board of Trustees met on 27/28 January 2012 in Northamptonshire, where they:

- Approved the 2012/13 budget, following detailed consideration at committee level to each of the income and expenditure lines, using comparative data from the last seven years. The aim in setting this budget has been to steer a course between meeting the increasing demands on the Association resulting in part from NHS and social services retraction, while also setting realistic income targets during a time of economic uncertainty. Achieving a balanced budget has meant finding ways to reduce spend, while protecting our frontline delivery of services to people with MND.

- Awarded a new four-year grant to the Leeds MND Care Centre.

- Agreed to fund a further 12-month period for the Online Forum Co-ordinator, who had initially been appointed on a one-year contract.

- Established a new trustee-led Care Committee to ensure good governance of Association activity connected with the care part of our mission for people with MND.

- Discussed the nature of complaints received by the Association over the previous 12 months.
Board of Trustees – April 2012

The Association’s Board of Trustees met on 27/28 April 2012 in Northamptonshire, where they:

- Noted with great regret the resignation of Kirstine Knox and established initial steps to recruit a new Chief Executive.
- Agreed to award research grants to the applications recommended by the Biomedical Research Advisory Panel. A number of high quality applications had been received and only A-rated projects were proposed for support. The total cost of the projects was £726,000.
- Agreed to award a grant to a project recommended by the Healthcare Research Advisory Panel, concerning end of life care for people on non-invasive ventilation (NIV). The Board agreed to allow a maximum budget of £55,000, with the expectation that with a reduced time commitment, this may be reduced to around £40,000.
- Approved applications for Branch presidents and patrons.
- Congratulated the fundraising team, and those selling advertising space in Thumb Print, on a good start to the year.
- Agreed to adopt the Education Strategy. The strategy has a three-year timeline, it was expected that income generated in the first year would enable the continuation of the strategy for years two and three.
- Agreed to adopt the ICT Strategy.
The Association’s Board of Trustees met on 20/21 July in Northamptonshire, where they:

- Approved and signed the Trustees Annual Report, including the annual accounts for 2011/12, for adoption at our AGM in September.
- Received an update on applications for the post of Chief Executive, and agreed arrangements for short-listing and interview.
- Approved an amendment to our reserves policy, which sets out how much the Association should ‘set aside’ to ensure we can continue providing services for people affected by MND if there was an unexpected, or dramatic, cut in expected income. Charity regulators had revised their advice about the level of recommended reserves and the Board considered both the risks of falling income and the Association’s ability to control spending. It was agreed that our reserves policy should be set at four to six months reserves, rather than the six to nine months in the current policy.
- Approved a grant for a Voice Banking Project, as recommended for funding by the Health Research Advisory Panel. The product was expected to be marketable within five years.
- Approved Prof Mike Stewart as the new chair of the Biomedical Research Advisory Panel (BRAP). Jean Waters has stepped down as a trustee representative and it was agreed that Christina Lloyd should fill the vacancy.
- Approved applications from Peter Bickley and Victor Patterson to renew their membership of the Board as co-opted trustees.
- Heard the Association’s first MND Awareness Month had been very successful and that the MND Charter, launched to mark the start of awareness month, had received over 3,000 signatures.
- Heard that *Choices and Control when you have a life shortening illness*, which sets out the findings of a study commissioned by the Association and carried out by the Picker Institute Europe, has been recommended for publication as an academic paper and will also be presented at the International Symposium on AL/MND in Chicago.
Board of Trustees – October 2013

The Association’s Board of Trustees met on 26/27 October in Northamptonshire, where they:

- Welcomed newly-elected trustee Mark Stone to his first Board meeting.
- Reviewed the forecast for the Association’s year-end financial position and welcomed indications that this would be close to break even. If delivered this would be a remarkable turnaround from a deficit of £1.9 million last year. The Board congratulated staff on the work which had led to this position.
- Approved grants for MND Care Centres in Liverpool, Sheffield and Preston.
- Agreed to fund five PhD studentship projects as recommended by the Association’s Biomedical Research Advisory Panel (BRAP).
- Heard Chair, Mark Todd, pay tribute to the valuable contribution Alasdair McLeish, who has resigned from the Association, had made both in his role as Director of Finance and as Acting Chief Executive. A vote of thanks was proposed.
- Received presentations from Farah Nazeer, Director of External Affairs and Steve Bell, Director of Care (North).

Farah explained how changes to the NHS, social and welfare reforms, would affect those living with MND and described the Association’s work to pro-actively find ways to influence at all levels.

Steve gave an update on the main priorities in care, described potential challenges for people living with MND in the light of social care reforms, and outlined developments to MND Connect.