



Board of Trustees – March 2017

Chair elect:

The role of chair elect is obviously an important post as it allows the successful person to immerse themselves in the activities of the Board and the Association a year before taking up the position of Chair of the Board.

We wanted to ensure we had a strong list of candidates so advertised widely and were pleased that we were rewarded with a good number of applications. These were whittled down to three shortlisted candidates to enable us to arrive at a final choice of a preferred candidate. We were fortunate to be able to include the Association's President (Prof Sir Colin Blakemore), current Chair (Alun Owen), CEO (Sally Light) and an external assessor (Richard Leaman) – himself the CEO of a charity – on the interview panel to maintain a balanced and rigorous process.

At the most recent Board meeting, the Trustees agreed to the panel's recommendation and this candidate's details will now be shared with the Association membership in the 2017 voting guide which will be sent to all members at the beginning of June. All the members will have the opportunity to vote to approve the candidate and thus, if approved at this year's AGM, will become the Chair-elect. There then follows a year of shadowing the current Chair until he steps down in July 2018.

Performance of the Association:

The Board received the quarterly key performance indicator report from the CEO, which details our performance on a number of agreed priorities. Trustees were pleased to hear that the Association again finished the year in a strong financial position. This was helped by legacy income that was significantly above the forecast budget.

At the same time, our spending on financial support for people affected by MND exceeded our planned budget – mainly due to high demand – but we were glad that we were in the position to be able to support.

Overall, 335 people have been supported by grant payments in the last quarter of 2016. Spending on research is at an all-time high due to the IBC investment and currently we have around £15m invested in research. Our 2016 accounts will be presented at the AGM, which is being held in July this year, and will subsequently be available on our website.

By the end of 2016, 29 local councils had signed up in support of the MND Charter and this figure has risen again through January and February to 38 councils! Thank you to every one of our campaigners, volunteers and the local councils for responding to our call to support people living with MND

Research presentation:

The Board received a comprehensive presentation on our research portfolio by Dr Brian Dickie. Brian outlined the key aims of our research strategy and shared some of the huge amounts of work that we are funding both nationally and internationally.

Particular highlights include the development of the [MND Register](#), [Project MiNE](#), the biomarkers [project AMBRoSIA](#) and the drug trial of an anti-inflammatory agent Interleuken II, due to start later this year.

Brian also emphasised [the growing portfolio of health care research](#) including the [TONIC project](#) on quality of life and some new partnership work on end of life with Marie Curie. Trustees agreed to have a research presentation annually to help them all keep up-to-date.

Review of the 2013-16 strategy:

The previous strategy period came to an end in December 2016 and trustees were presented with a report which detailed all of our progress in the final year of the strategy.

It was agreed that this report contained such positive comments on the impact of the strategy, that it would be shared more widely in the interests of openness and transparency, letting members review the progress that has been made. The report will be made available on the website and through our usual social media channels in the next 2-3 weeks.

Co-opted trustee:

The Board approved the appointment of a new co-opted trustee, Tim Kidd. Co-opted trustees are people with specific skills that the Board has identified would be more than useful to the work of the Association.

As the Board had previously agreed to recruit a trustee with financial skills following the stepping down of Anne Bulford in September 2016 and the fact that we lose Honorary Treasurer Mike Ranson at the end of his third term in September 2017, we advertised for someone to succeed them both.

Tim is an accountant, has a strong commercial finance background and was selected by a panel of trustees and the CEO following a national advertisement. Tim will join the Board with immediate effect and his first Board meeting will be in May this year.

New Association patron:

The Board were pleased to hear that BBC broadcaster, Jeremy Vine, has accepted the Association's offer of the role of National Patron. Jeremy is already a Patron of the West London and Middlesex Branch and has been extremely supportive of the Association both locally and nationally.

The Board meeting was a very busy one in February and a summary of the other agreements and discussions are detailed here:

Care Centres:

The Board welcomed the imminent opening of the 21st Care Network in Norwich and approved a grant to support the further development of the work of the Southampton Care Centre

Fundraising:

We received the first report on the new and exciting partnership with Credit Suisse which seeks to both raise funds and awareness. It is the first major charity partnership of this magnitude in which the Association has been involved.

Branches and Groups:

We approved revised agreements for our partnership with Branches and Groups (previously called Charters) to make working as a volunteer simpler and more transparent. These will be shared with Branches and Groups over the summer.

Financial:

The Board agreed to review the financial reserves Policy to ensure it was still fit for purpose. This policy ensures that any reserve funds held by us are managed effectively for maximum benefit for the Association and people supported by the charity.

Governance:

We made some minor amendments to the 'Articles of Association' and these will be shared with our members and hopefully approved by them at the AGM.

We also discussed a recent 'Board effectiveness' review and agreed some actions to improve the smooth running and effectiveness of the Board in carrying out its duties.

Memoriam:

Sally Light acknowledged the very sad news of the death of Gordon Aikman. Diagnosed with MND in 2014, Gordon became a trustee of MND Scotland and was also a fierce campaigner to gain support for everyone affected by the disease. As his many obituaries mentioned, his passion to help raise awareness and his relentless campaigning remained undimmed during his MND journey. He will be sadly missed by everyone who knew him.

Next meeting:

The next meeting of the Board of Trustees will be 19th and 20th May 2017 with a further update of 'News from the Board' published on the website shortly afterwards.