

Board of Trustees – September 2020

Diversity, Equity and Inclusion

Prior to normal Board business, the Trustees reviewed and discussed progress against the Association's Diversity, Equity and Inclusion Strategy, which was initially launched in 2017. Whilst significant progress has been made, it is recognised that full achievement of the strategy will take time. Examples of progress are that referral and data collection systems have been refined and developed and, although still largely manual, it is now simpler and easier to make referrals to and from the Association; DEI learning has been provided for all staff; revisions to the website have resulted in it now being more accessible, easier to find and simpler to use; and the Human Resources team is exploring recruitment strategies to increase the ethnic diversity of our workforce. Within the Association considerable progress has been made towards promoting mental wellbeing; we are now signed up and working to the Disability Confident scheme; and work is in hand with a leading consultant to increase awareness of the Black Lives Matter (BLM) movement and to promote our anti-racist principles.

2020 Financial Forecast

Director of Finance Mark Chapman and Director of Fundraising Linda Allen updated the projected scenario that had been presented at the July Board. Recent fundraising performance illustrated the generosity of our supporters and the advantages of the Association having many diverse income streams. The one area which was showing expected below budget performance was Community, where although events such as walks which Branches and Groups would normally organise as fundraising events during the summer months were not possible under Covid restrictions, there was ample evidence of successful virtual events.

Lessons learnt during the Covid-19 Pandemic

Nick Goldup, Director of Care Improvement outlined the lessons learnt, including, as an example, the very high level of volunteer engagement: when making calls and providing support to the 3,700 people living with MND who were contacted, 70% of the calls had been made by volunteers. The formation of an expert panel made up of neurologists and health professionals was very well utilised, and continued to provide significant support and advice to the Association. Staff and volunteers had rapidly embraced virtual contact and working, and that had helped speedy decision making across the organisation.

Biomedical Research Advisory Panel

Dr. Brian Dickie, Director of Research Development outlined two proposals from the spring grant application round, both of which were approved by the Board.

Potential impact of Brexit

Chris James, Director of External Affairs, presented an update on the key risks and the impact on the Association of Brexit, where a 'no deal' situation was appearing increasingly likely, and this could have an impact on drug trials and would most likely result in workforce problems in the health and care sectors for EU citizens in the UK.