

Board of Trustees – February 2021

Research Strategy Update

Director of Research Development Dr. Brian Dickie updated the Board on the research strategy and highlighted the progressive move since 2015 from the Association supporting mainly basic exploratory science to include more patient-focused and treatment orientated activity. He introduced Dr. Lucie Bruijn, Senior Director in Translational Medicine at Novartis, who explained how advances in research were leading to new translational opportunities. There were challenges as well as opportunities for drug development and she referred to the need for strategic academic-industry partnerships, giving several examples initiated by ALSA and funded through Ice Bucket Challenge funds. Brian also introduced Associate Director of Technology Transfer at LifeArc, Dr. Catriona Crombie, who described the ways LifeArc supports translational medical research, and highlighted work being undertaken with the Association. Co-funding for a new gene therapy study was already in place and a new £1 million joint funding call had recently been launched.

Appointment of co-opted Trustees

Trustees confirmed the appointment of Jim Marshall and Usman Khan as co-opted Trustees.

Assisted Dying Policy

Director of External Affairs Chris James outlined the policy setting out the Association's neutral stance on a change in the law and reminded the Board that it had last been fully reviewed in 2017, following approaches to individual Trustees from members. An additional statement, agreed by the Board in 2018, set out further reasons why the neutral stance was being maintained. After discussion, it was agreed that the policy would remain and not be amended. The MND Association has developed its support and advice on end of life issues over a number of years including its award-winning End of Life Guide.

Annual Report and Consolidated Financial Statements for the year ended 31 December 2020

Director of Finance Mark Chapman presented the final draft of the Annual report, which would be published following sign-off at the AGM in July, together with the Financial Statements once themselves signed off by the auditors.

Biomedical Research Advisory Panel recommendations

Director of Research Development Dr. Brian Dickie Brian put forward a proposal to support the three highest rated projects identified at the April Biomedical Research Advisory Panel meeting, with a further two to be considered later in the year. This was approved by the Board.

Articles of Association

Chair of the Board Richard Coleman outlined revisions proposed to the Association's Articles of Association, which had not been fully reviewed since 2017. The Board approved that the revised version be put to the membership for formal approval at the AGM in July.