

Board of Trustees – February 2022

Research Update

Dr. Brian Dickie, Director of Research Development, was joined by Professors Chris McDermott and Ammar Al-Chalabi both of whom have played an essential role in the #United2EndMND campaign in making the scientific case to Government on the need for more targeted investment.

Dr. Dickie provided a brief recap on progress against our current research strategy and the new directions outlined in our 'Beating MND Together' document. He focused on some of the activities that are complementary to the #United2EndMND campaign and Government investment, in particular the Association's support for health and social care research and the impact this can have in improving multidisciplinary healthcare provision.

Professor Al-Chalabi spoke about the #United2EndMND collaboration and the initial 'pilot' £4.25 million Collaborative Funding Call which is currently in progress. He outlined the specific research activities that will be carried out within this initial piece of work, as well as how a research collaboration involving such a diverse range of scientific expertise and interests would be managed.

Professor Chris McDermott is Chair of the UK MND Clinical Studies Group, which is poised to play an important role in our ambition that 'Everyone who wants to take part in research is able to'. In line with the #United2EndMND collaboration, he outlined the exciting opportunities that were emerging, with an unprecedented number of drug companies looking to conduct therapeutic trials.

Fundraising Report

Director of Fundraising Linda Allen presented a report outlining achievements in 2021, which had been an exceptional year, including a busy final quarter leading to a highest ever total fundraising income. She announced the application by the Association to be the Charity of the Year for a commercial partner. She also reported on the ongoing partnerships programme and the success of the collaborative work that had secured the £50m pledge from the government for targeted MND research.

2021 Financial Performance

Director of Finance Mark Chapman gave Trustees a financial update, and full details of 2021 outturn will be made public in the Impact Report, due to be published in the next couple of months.

Involvement and Co-Production Plans

Chris Wade, Director of Engagement outlined the Association's *User-involvement and Co-production strategy* which aims to increase opportunities for participation and co-production for people living with MND, members and volunteers across all directorates and at all levels throughout the Association.

Healthcare Research Advisory Panel

The Board approved a proposal from Dr. Brian Dickie for the appointment of Dr. Sara Feldman as a member of HRAP.

Re-appointment of Co-opted Trustee

The Board approved a proposal for the re-appointment of Dr. Shaun McGee as a Co-opted Trustee for a second term of two years.