

Board of Trustees - September 2018

Board members

Dr Peter-Scott Morgan and Alan Graham were welcomed to the Board following their successful elections earlier in the year, and Dr Nikhil Sharma was welcomed back for his second term as a co-opted Trustee.

Awareness raising

External Affairs Director Chris James and Colin Morris, Head of Digital & Communications, delivered a presentation on our new awareness raising campaign, which was launched across England, Wales and Northern Ireland the week after the Board meeting. This campaign has been informed by a group of members including two people living with MND and several others who have personal experience of the disease. We have secured 280 digital sites, where the 'poster' will tell a story, and it includes a website address www.takeoverMND.org together with an invitation to make a donation to 'help us find a cure'. They also outlined the work largely completed on a film called 'The Ride', subsequently launched on social media.

Managing our information

Director of Finance Neil Fray and Head of ICT Simon Cooper delivered a presentation and a live demonstration of the new CRM (Customer Relationship Management system – a system which holds and enables users to manipulate different pieces of information as an aid to providing services, management and decision making). The system will offer significant benefits over and above the previous, outdated one. Training on this is has been completed for staff members and is now being made available to Branches and Groups.

Finance

Tim Kidd, Honorary Treasurer and Chair of the Finance & Audit Committee gave a full report from the Finance & Audit Committee including encouraging news and confirmation of the financial health of the MND Association.

Research funding

Trustees approved funding for a research project at the University of Bath aimed at establishing a greater understanding of possible linkages between genes known to be associated with incidence of MND. The project had been peer reviewed by the Biomedical Research Advisory Panel and recommended for the allocation of funding.

Professor Stephen Hawking

CEO Sally Light reported that she and three other members of staff had been privileged to be invited to the internment of Professor Stephen Hawking in Westminster Abbey. Alun Owen, then Chair of the Board of Trustees, also attended as a representative of HRH The Princess Royal, which was a tremendous honour.