The success of the Association’s International Research Symposium on MND was one of the highlights discussed at a meeting of the Board of Trustees in January.

Chief Executive, Sally Light said that 850 of the world’s brightest scientists and clinicians had attended the event in Florida, which is organised by the Association.

It is the largest scientific and medical conference for MND in the world and gives leading researchers the chance to meet and share knowledge.

Delegates from 30 countries attended, including those from Australia, Japan, South Korea and Denmark.

The Board also heard about the new guideline on MND which was published in February by the National Institute of Health and Care Excellence (NICE).

The guideline describes the care people living with MND can expect to receive and is the result of more than four years of campaigning by the Association and its supporters.

Sally said the Association would now work with its members and supporters to make sure that the guideline had a positive impact on the care and support available to people living with MND across England, Wales and Northern Ireland.

The trustees also heard further details about the new fundraising regulator which is due to be set up in July.

The regulator will oversee the setup and running of the new Fundraising Preference Service (FPS), which is being created to allow people to opt out of receiving any and all fundraising communications from charities.

This is being developed in response to instances of poor practice highlighted last year by some telephone fundraising agencies acting on behalf of a small number of large charities.

It was noted that the Association was not one of those charities and does not use telephone cold-calling.
Board of Trustees – September 2016

Positive news about the MND Association’s financial situation was discussed at the September meeting of the Board of Trustees.

It was reported that the MND Association is in ‘robust health’ with higher than expected legacy notifications and expenditure in line with budgeted activities.

The Board also discussed the MND Association’s new five-year strategy which will steer its work from 2017-21. The strategy will be presented to the Board at its meeting in November for implementation in January 2017.

The Board voted to update the Acceptance and Refusal of Donations Policy and agreed that it will be circulated to all Branches and Groups for information.

Chief Executive Sally Light also talked about her recent visit to Holland as a guest of ALS Nederland. She attended the Amsterdam City Swim which is organised by a third party fundraiser, with the proceeds going to ALS Nederland. She talked about her visit and early discussions about the possibility of a group of people organising a similar event in London with some of the proceeds coming to the Association.

11/10/16