

## Goal 1: Advancing research

- We funded a project to convert blood cells from donors into 'induced pluripotential stem cells', which can be turned into motor neurons for research and accessed by researchers across the world.
- By the end of 2018 we had sequenced over 2,000 genomes in the international Project MiNE genetic research programme, almost 10% of the total worldwide target.
- Almost 1,250 delegates attended the 2018 International Symposium from across the world - a record number for a European venue – with over 110 speakers and 500 poster presentations.
- Participants were recruited into 16 Association-funded, NHS registered clinical and healthcare studies, including recruiting 108 people and five clinics to MIROCALS and 1,100 people to our MND Register.
- Our research grant portfolio stood at 90 grants, valued at £16 million with new grants for seven biomedical projects, three clinical and healthcare projects, one in partnership with Marie Curie, and funding for three new fellowships.

## Goal 2: Ensuring quality health care

- 45 NHS services completed our *Transforming MND Care Audit and Patient Experience Survey* during 2018. Our summary of the results from the 2017 audit *The State of MND Care* included best practice examples of the care provided in some trusts.
- Our 22nd Care Centre and Network, the North Midlands MND Care Centre launched at the Royal Stoke Hospital in June. It will be formally opened by HRH The Princess Royal in June 2019.
- People affected by MND helped shape the first year of our support volunteering project, with new roles planned to support carers and help with more practical tasks.
- Our new web hub for children aged 4-10 includes simple MND information, interactive games, competitions and stories.
- We tested the concept of an Affiliation model with NHS services as a way of improving the quality of care for people with MND, but we realised this is unlikely to deliver the benefits required.

## Goal 3: Strengthening professionals ability to treat and care for people affected by MND

- 350 health and social care professionals attended our respiratory masterclass programme to learn about the impact of MND on respiratory function.
- We also ran masterclasses providing training and accreditation to administer the Edinburgh Cognitive and Behavioural ALS Screen (ECAS).
- We held the RCN Annual Hawking MND Lecture on cognitive change with 140 attendees and 70 sign ups for the live stream.
- The Competency framework for progressive neurological conditions was launched – a partnership between the MND Association, MS Trust and Parkinson's UK.
- Our new "Enhancing Care Practice in Northern Ireland" award, funded by the Northern Ireland Branch, was made to six allied health professionals to develop their skills in caring for people with MND.

## Goal 4: Working together

- 85 students enrolled on our new free online open access modular course on MND designed for care workers which we launched in partnership with the University of Northampton.
- We launched the ALS Reproducible Antibody Platform to provide the 'best tools' for laboratory research and drug development progress.
- Our work with the End of Life Coalition and NHS England Ambitions Partnership contributed to significant reference to end of life and palliative care in the NHS 10-year plan.

## Goal 5: Raising awareness

- Supported by us, the All-Party Parliamentary Group (APPG) on MND held meetings on Personal Independence Payments (PIP), Special Rules for Terminal Illness (SRTI) and MND research, with 61 MPs attending.
- We launched our Scrap 6 Months campaign to improve access to benefits for terminally ill people and supported the APPG Chair to develop a Ten-Minute Rule Bill to reform the fast-track process.
- Over 850 people, including 140 people with MND, gave their views on housing and housing adaptations for people with MND.
- Thanks to our campaigning, people with MND will no longer be reassessed for PIP once they are on the highest rate of benefit.
- We launched a report on the impact of Universal Credit on people living with MND and worked with the Disability Benefits Consortium to scrutinise government plans for roll out.
- Our new awareness film 'The Ride', developed in partnership with an interest group of people affected by MND, had over one million online views between September and December reaching over 1.1m people via social media.
- By the end of 2018, campaigners had secured over 80 MND Charter adoptions across the country.

## Goal 6: The difference we make

- In the first year of our equality, inclusion and diversity strategy 'Reaching Out', all our staff learned how to identify and address any barriers to involvement and positively promote inclusion. We are also implementing an equality impact assessment system and the *Disability Confident* scheme.
- In 2018, we established three new local groups and recruited 411 new volunteers. We now have volunteers in 1,993 roles and offer 83 local support groups.
- We ran three focus groups involving 17 bereaved carers to help us improve the support we offer to them.
- We recruited 13 volunteers to our voice banking pilot to support 69 people bank their voices and educated over 50 speech and language therapists to use this technology.
- We designed a new website which will be easier to navigate, have a better search function and work well on mobile devices.
- Our volunteers, supporters and staff raised or donated over £18 million to fund our research, care and campaigning. £2.4 million of this was raised through branches and groups with over £5 million left in legacies.