



Research Strategy

2017 -2020

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INTRODUCTION

This strategy aims to build on the our previous experience and successes and seeks to establish MND Scotland as a reliable, trusted and key funder of MND research within the UK.

Our vision is of a world without MND. The only way that this vision can be realised is through progress in MND research.

MND Scotland has a proud tradition of funding MND research. The world’s first MND register, created in Scotland, was funded by MND Scotland in 1989. Much of the data still referenced today is based on the information that came from this register.

Research in the field of MND has increased considerably over the last few years (**Figure 1**).

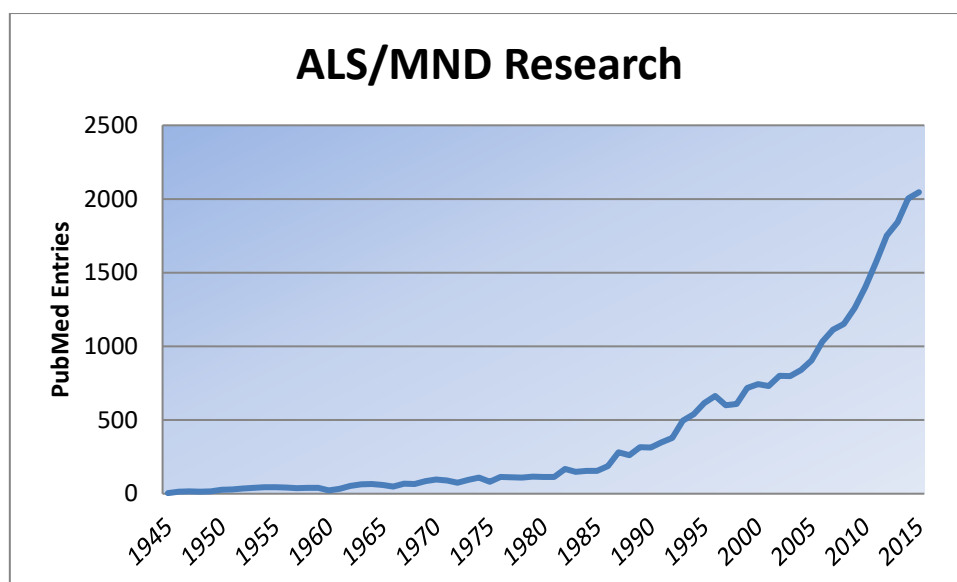


Figure 1 – History of ALS/MND Research

The Research Strategy of MND Scotland intends to adopt an integrated approach to research, covering all aspects such as clinical, scientific and social research, whilst also capturing and measuring the impact that any research funded by MND Scotland has on those affected by Motor Neurone Disease. The ultimate aim of any research funded by MND Scotland is to improve the lives of those affected by the condition now and eradicate the disease in the future.

MND Scotland will fund competitive research projects covering all aspects of MND research in UK. These projects will be judged by an independent peer review process, as set out in the call documentation, with funding being awarded to those applications who can demonstrate high quality research with the outcomes having the ability to demonstrate impact.

Decisions on what to fund will follow a peer review process with a minimum of two written reviews from external experts being required for each application. The final decision on whether to award funding to applicants will be undertaken by MND Scotland’s Board of

Trustees taking into consideration the advice and recommendations presented, the available funds and the expected impact of the research.

PREVIOUS RESEARCH

Over many years, MND Scotland has provided funding for MND research covering basic science, clinical and social science projects. With the help of our members and supporters, we have helped to push forward key areas of MND research. We have invested in young up and coming researchers who have gone on to become lead investigators in MND research. We want to build on this success.

In the area of basic science, we have funded projects that look at the mechanisms of cell death in motor neurones, the role that proteins can play in relation to specific genes, how RNA regulates Glutamate receptors, what role does exercise play in protecting motor neurones in mice, regeneration of motor neurones in zebrafish, in vitro stem cell modelling of neuromuscular junctions, targets to enhance nerve-muscle signalling and the use of viruses to deliver neurotrophic factors to motor neurones.

Outside of the basic science, we have funded projects that look at the communication needs of those with MND, the nature of speech deficits in MND patients, an evaluation of the care pathways available to those affected by MND and an audit of the Neurological Health Service standards relating to MND.

We have also promoted and supported research into breaking bad news in progressive neurological conditions, identifying the dying phase of degenerative neurological conditions and improving the personalisation of health care services.

We have funded projects at the major Universities of Scotland including The University of Aberdeen, University of Edinburgh, University of Stirling, Caledonia University and Glasgow University.

MEASURING THE IMPACT

We need to be able to show our members and stakeholders that the investments that we make in research are appropriate and effective. Through appropriate monitoring, we can manage our research process, demonstrate impact and provide data to influence future funding streams. With this in mind, we will introduce a system based on the framework for research evaluation and reporting to capture the impact of the research which we fund and allow for the production of case studies. We will require six monthly updates on each project to be provided and will monitor the citations of research funded by us in professional publications, policy documents and in the media.

GOALS

Over the course of this strategy we are seeking to advance five strategic goals which have been identified as being important to our members.

- To build clinical and scientific capacity
- To attract clinical trials to Scotland
- To further advance the understanding of the causes of MND
- To improve quality of life of those affected by MND
- To share knowledge

In order to achieve these five strategic goals, there are some underlying principles which run through the whole of this strategy.

Principle 1 -Building Partnerships

We will build and strengthen our role with researchers, clinicians, policy makers, other funders and people affected by MND. We will seek to promote collaborations amongst researchers both in the UK and worldwide.

Principle 2 - Involve people affected by MND

We will ensure that the views of people affected by MND inform and influence the priorities for research going forward.

Principle 3 - Monitor the impact of our investment

We will monitor and report on the progress and impact of the research which we fund.

GOAL 1 - To Build Clinical and Scientific Capacity

In order to ensure continuing and future progress in the field of MND research, investment needs to be made in attracting and developing outstanding young clinicians and scientists into the MND field. Only through such investment can we hope to create the future scientific leaders in the field and build further Motor Neurone Disease research capacity within Scotland.

Clinical Research Fellowships

Clinical research fellowships are designed to encourage clinicians to undertake academic research in MND. They aim to provide training in clinical and/or laboratory research techniques leading to a higher degree (usually a PhD). Fellowships are normally awarded for three years and aren't renewable. Projects must demonstrate a clear relevance to MND and be supervised by an established sponsor, within a multidisciplinary research group in a UK university department, hospital or research institute.

PhD studentships

The PhD studentships are designed to encourage young science graduates to embark on a research career in MND. These awards provide practical research training through a time-limited research project related to MND, under the direct supervision of a senior and experienced researcher.

The Studentships are awarded to the Supervisor who is responsible for identifying a suitable candidate. Each award will be for a three year period and will hopefully lead to the successful completion of a PhD.

By investing in the careers of young scientists and clinicians this will stimulate a life long interest and return in MND research.

For the next three years we will seek to award at least one PhD studentship in each year.

During the course of this strategy we will appoint an additional Clinical Research Fellow over and above the existing Fellowship.

GOAL 2 – To Attract Clinical Trials to Scotland

A major priority for Scotland's MND patients and their families is the demand to be able to participate in clinical trials. The lack of clinical trials deprives those affected by the condition of the hope associated with participating in studies.

Given the low incidence and prevalence rates of MND, in order to obtain robust data, clinical trials generally need to use multiple centres and have high volumes of patients taking part. Historically Scotland has not been seen as a trials centre due to it being viewed as having small centres with low numbers of MND patients. This together with a lack of interested and suitably qualified clinicians has meant that other major centres in the UK have been seen as more appropriate.

Worldwide there are few clinical trials. The challenge for us is to ensure that when there are trials being developed, that Scotland is seen as having the infrastructure and expertise to host such trials and that those developing the trials see the benefits that Scotland can offer to them.

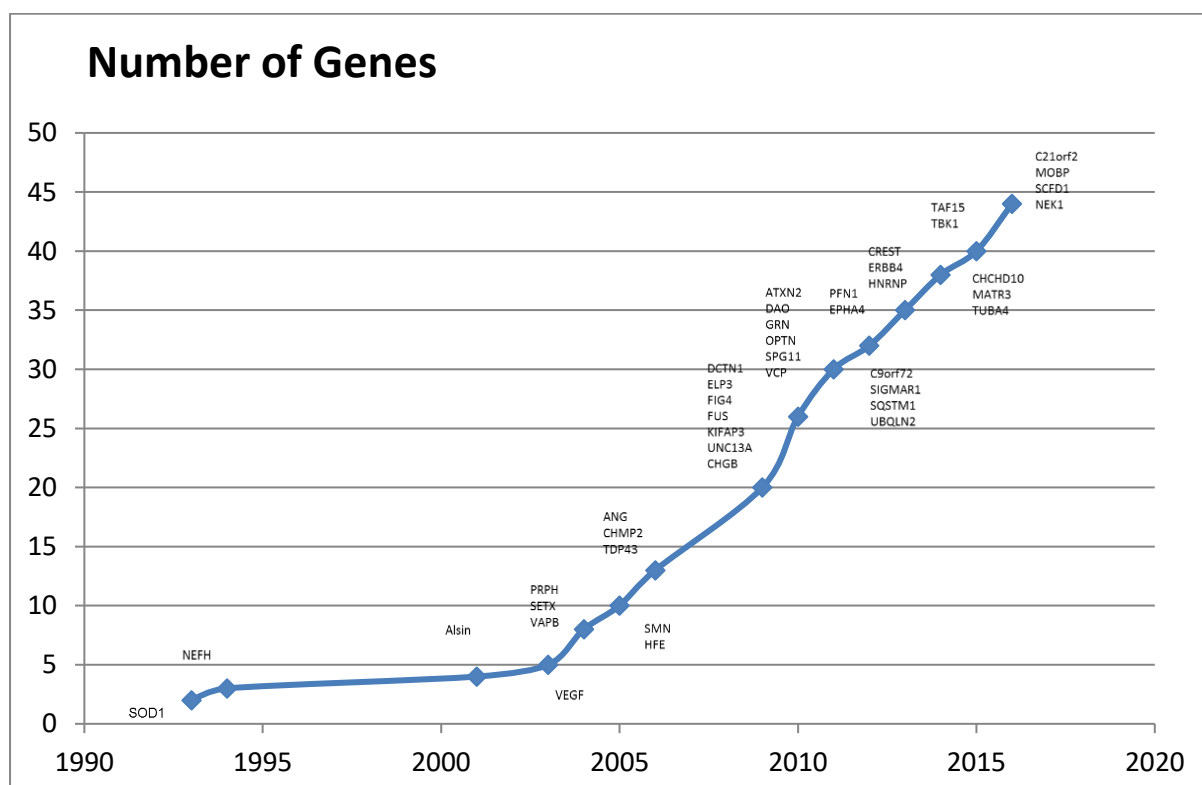
We will build on the existing work which we have started in collaboration with Edinburgh University and the Scottish MND Clinical specialists in developing and implementing a national proforma to standardise clinical data capture which can be used for audit purposes and improve patient care. This together with genetic data collected on the Scottish MND population will allow us to position our population as globally one of the best characterised longitudinal MND cohorts and thus ideal for recruitment into both investigator and Pharma led-clinical trials.

We will produce marketing material to showcase Scottish MND research and the advantages that Scotland has for researchers wishing to carryout clinical trials.

GOAL 3 - To Further Advance the Understanding Of The Causes Of MND

The last few years have seen tremendous advances in the discovery of genes associated with Motor Neurone Disease.

In order to make our vision of a world without MND a reality, we need to support research which helps us to understand the underlying causes of MND. The development of new treatments and therapies relies on having an understanding of how the motor neurones and associated cells are being affected by the disease. We need to be better at matching up the genetics with the symptoms that people present and what that means in terms of onward treatment and prognosis.



GOAL 4 - To Improve Quality of Life

In order to influence politicians and decision makers we need to be able to understand, justify and articulate the social and economic burden that a diagnosis of MND can have. As part of this research strategy the importance of research which can help us to change attitudes and improve the lives of those living with the condition now needs to be considered.

In order to be able to put our case to government and key decision makers, we need to be able to highlight the impact that a diagnosis of MND can have on individuals, communities, the NHS and the economy. This argument needs to be backed up by evidence based on robust social and economic research.

During the course of this strategy we will commission social and economic research to back up our campaigning and service development work.

GOAL 5 - Knowledge Exchange

Our membership are interested in what is happening in the world of research for MND; in research we have funded and in latest developments in research around the world. It is part of our role to keep them up to date and informed. To do this we will assimilate, interpret and translate scientific language into an easily understood format. We will regularly share with our members and supporters, the progress of the research that we fund through our Aware magazine, website, social media and annual reports. We will also, in conjunction with the International Alliance of ALS/MND Associations, provide a summary of the research that is being undertaken across the world.

Every two years we will organise a Scottish symposium to highlight the research work that is being carried out, to provide networking opportunities for researchers to develop collaborations and to assist with cross discipline cooperation. Funded researchers will be asked to present their findings to policy makers, other researchers, clinicians, health and social care professionals and people affected by MND. Through this we will aim to alert decision makers and the MND community within Scotland to the potential policy and practice implications of the research findings.

At key times throughout the year, funded researchers will be required to provide updates on their research; its progress, the challenges that have arisen, the likelihood of successful completion and how their research findings will be disseminated. They will be asked to present to audiences of those affected by MND at such events as the annual conference, regional study days or local support groups.

This strategy aims to introduce a tighter framework under which research funding and projects will be awarded and managed. It will ensure that we only fund high quality research that has the potential to benefit those affected by MND and can demonstrate value for money for our donors.

Our strategy is flexible enough to allow us to respond to new developments and opportunities that may materialise during the period of the strategy.

HOW WE WILL FUND OUR RESEARCH

It is our view that our funding of research should be on an 'open' basis in response to competitive calls. We will not seek to dictate which specific areas of work researchers should be concentrating on but rather we will consider all appropriate projects which are of sufficiently high quality and which have the potential to impact on the lives of those affected by MND.

Annual calls will be made at the same time each year so that interested researcher become familiar with our processes and actively look out for the call.

In order to achieve the aims of this strategy, we will fund research through the following mechanisms:

Research Project Grants

These grants will be made available for scientific, clinical and social research. Funding for each individual project will be for a maximum of three years. Calls will be made on a rolling basis every six months.

Fellowship and Studentships

Awards will include a set fee for student stipend, university fees set at the level for UK students and an amount for appropriate and justifiable consumables. Each award will be made for a maximum of four years.