JUNE 2019

ADVANCE

MND Ice Bucket Challenge - 5 years on

The ALS/MND Ice Bucket Challenge came out of the blue in August 2014 and created an international avalanche of donations to ALS/MND organisations around the globe that is unlikely ever to be equalled. Donors to MND Australia chose equally between supporting care (MND Australia) and research (MND Research Institute of Australia). The research share all went into one 'bucket' and funded the largest project grant that had ever been possible for MNDRIA to award. Collaboration was a requirement for applications. Researchers from all over Australia combined in collaborative groups to collectively compete for this prized grant.

The winner was a consortium headed by Prof Naomi Wray (University of Queensland) and Prof Ian Blair (Macquarie University). The **S**poradic **ALS** **A**ustralia—**S**ystems **G**enomics **C**onsortium (SALSA-SGC) brought together clinicians and basic scientists from all around Australia, with additional input from international collaborators. With such a large group it took some time to get going – and to arrive at completion – but here we report on the outcomes of the MND Australia Ice Bucket Challenge Grant.

From the outset SALSA-SGC had a long-term vision. The goal was to set up some foundational infrastructure that would underpin human MND research for the next decade or more. MND is a heterogeneous disorder with unknown causes for more than 90% of those diagnosed. Site and age of onset and rate of disease progression all vary between people. We live in an era of "big data" where we recognise that from large data sets patterns of factors can be extracted which have meaningful interpretation. In some countries, big data resources for MND had already been established.

The goal of SALSA-SGC was to enable all Australians with MND to contribute to a big-data research resource that integrates clinical, lifestyle and biological information and hence contribute to local and international research.

The long-term goal is that biological samples taken at the first clinic visit (or before) could be used to predict disease sub-types, which may be key to success of future clinical trials of new drugs. Understanding the complex mix of genetic and non-genetic factors that contribute to MND may be a key for prevention.

For many human diseases, there is a growing recognition that more personalised approaches to clinical care are needed responding to the biological make up of each person, but data are needed to be able to generate evidence-based decisions for such individualised treatment.

Building on the strong research base and collaborations that already existed, SALSA-SGC brought together the seven major MND clinics to establish consistent collection of longitudinal clinical information and biological samples across all clinics in Australia.

We first conducted in-depth consultations with the clinical teams at each site to understand their needs. As a result, we developed a data management tool so that the data collected for research can also be used immediately in the clinic for patient and clinic management. The data collection platform was rolled-out gradually across sites following training of research nurses at each site.

To date, we have recruited more than 600 people with MND with both clinical data and biological samples. We think that steady state recruitment will be about 350 MND participants per year. The MND Australia Ice Bucket Challenge Grant provided some funding towards generation of genomic data to meet the long-term goal of a "systems genomics" resource. Systems genomics means the integration of different types of "omics" data. In the long-term, dependent on funding, this may include measures for urine, faeces or muscle. However, currently we have focussed on blood sample collection. From blood samples we measure the genome (DNA) and the epigenome (changes in the DNA perhaps in response to environmental exposures). The stored samples are available to other researchers to measure other omics data (such as lipidomics or metabolomics). Such biological systems data will build a picture of the heterogeneous nature of MND. Moreover, the biological samples are carefully stored and can contribute to currently impossible research that will be made possible by

(Continued on page 3)

The MND Research Institute of Australia (MNDRIA) has been funding the best research in Australia since 1987.

Thanks to the generosity of the people of Australia, donations of over $30 million have helped to advance MND research to understand its causes and develop effective treatments and enhance clinical care for people living with MND.

MNDRIA continues to attract and develop outstanding researchers with support at all stages of their careers.

Executive Director Research Report

Research is off to a flying start in 2019. The MNDRIA Research Committee completed their exacting task of scrutinising 90 grant applications for award of $4 million to new research projects commencing in 2019. Thirty new research projects and 10 continuing multi-year projects are now underway in 14 research institutions across all Australian states. Results of some projects funded by MNDRIA in 2018 are reported in this newsletter.

Since taking on the executive role at the MND Research Institute of Australia in 2005 I have seen extraordinary growth in the number of researchers participating in MND research - in Australia and around the world - and a surge in the discoveries that are bringing the hope of stopping the progression of MND closer. While others have concentrated their attention on clinical trials, MNDRIA maintains a comprehensive research program from discovery of underlying causes to healthcare. The MND Ice Bucket Challenge produced a sudden injection of funds at a level never seen before and large collaborative projects became possible all around the world. The collaborative spirit continues and the legacy of clinicians and scientific researchers working together has resulted in the growth of multidisciplinary centres with both clinical care and scientific research laboratories working side by side. There has been an increase in translational research, where basic scientific research in the laboratory is directed towards discovery of new compounds for therapies, diagnostic tools or biomarkers that can track the effect of interventions. Healthcare research advances have resulted in life extending interventions and improved quality of life.

This has all been made possible by the extraordinary generosity of the people of Australia. MNDRIA receives no government funding. All grants are funded by donations. Over the years, increased donations have enabled bigger grants which in turn have brought discoveries that lead to major project funding from government to continue the work initiated by the MNDRIA grants. It is difficult to express our thanks adequately, but MND research in Australia would not be as strong as it is today without the support of thousands of donors. We value and thank every one of them and hope they will continue their generous support.

There are changes this year as MNDRIA prepares to step up to the challenges of the future.

An independent Research Committee Chairman will be appointed to take over the role from Professor Matthew Kiernan at this year's MNDRIA Research Committee meeting in October. Matthew will step aside after an incredible five years of leading MNDRIA through a period when the focus on research that will lead to potential treatments has grown and several clinical trials have commenced in Australia.

The expert MNDRIA Research Committee ensures that available funds go only to the best research that has the greatest chance of making a difference. Committee members agree to serve for a two-year period but usually renew that commitment many times. After 10 years' service, Professor David Berlowitz has stepped down from the committee where, as a research physiotherapist, he provided an important voice for healthcare research. We thank him for the time he gave and particularly for his assistance in reviewing the grants allocation process.

A new research team is now in place in the MND Australia office in Canberra. We welcome Dr Gethin Thomas who takes over the role of MND Australia Executive Director Research in June. The experience Gethin brings to the role will ensure that he is well equipped to help guide the future of MNDRIA's strategy of investing in innovation and partnering for progress. Gethin will work with the research committee, researchers and other organisations nationally and internationally, and help to determine priority areas for MND research that will lead to effective treatments. Laura Birks will assist Gethin with grant administration and will help with donors and MNDRIA finance.

My years with MNDRIA have been rewarding in many ways and I am confident and grateful that the future of MNDRIA is in good hands for working towards the vision to find effective treatments and ultimately a cure for motor neurone disease.

Janet Nash
Acting Executive Director Research
MND Australia

Dr Gethin Thomas, Executive Director Research

Gethin has over 20 years of experience as a biomedical researcher in musculoskeletal diseases, publishing more than 65 papers and securing close to $4M in research funding. He has extensive reviewing experience both as a manuscript reviewer and serving on Australian and international grant review panels.

As a Research Manager, he has directed a university Research Office and Higher Degree by Research programs and served as an Associate Dean of Research. He has extensive experience of high-level research strategy as well as a deep understanding of the grant system from the preparation, application and review process through to management of funded projects.

When not immersed in research he can be found enjoying time at home with his wife and 9-year old son, taxiing said child to sporting events or out on his bicycle enjoying any big hill he can find.

Laura Birks, Research Coordinator

Laura joined the MND Australia team as Research Coordinator in November 2018. Together with Gethin Thomas, Laura will continue to manage MNDRIA's grant application processes, the annual research meeting and fundraising for the research grants program.

Laura has a background in science and environmental law and a masters in education. She worked part time at MND NSW while studying at university. Since moving to Canberra in 2009, Laura has worked in a policy role at an industry association, undertaken committee work at Parliament House and has worked at a local publisher.

Outside work, Laura is kept busy with her three children and loves to get out in the Canberra bush for a run.

Rodney Harris OAM has played an enormous role in promoting MND research in Australia.
Rod has recently retired after 25 years as CEO of MND Victoria where his primary commitment was to ensure that people with MND receive the best possible care and support. This included a passion for promotion of healthcare research to advance practices that help people with MND to live better for longer. Rod was awarded an OAM in 2005 for his work to make palliative care available to everybody. He worked tirelessly at state and federal levels to influence policy to ensure the needs of people with MND and their families are met.
We wish Rod a long and happy retirement, knowing that he will continue to offer his support to the MND community.

Carers' Behavioural Screen for clinical care and research

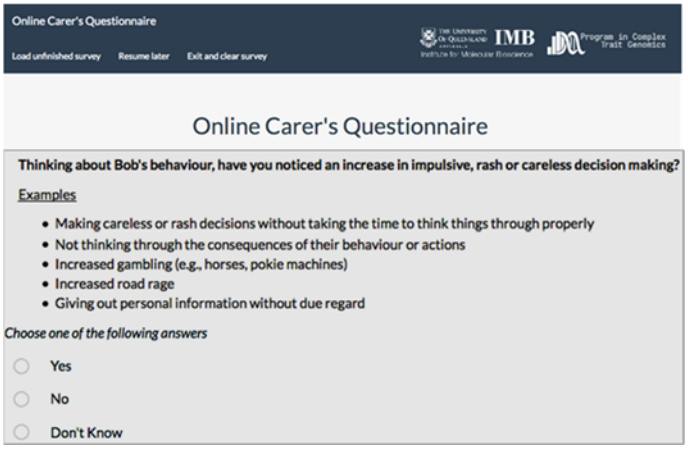
Associate Professor Gail Robinson explains the validation of a new online tool for identifying cognitive and behavioural changes in MND with the help of patients and their carers, and its role in understanding the nuance and complexity of MND clinical presentations.

Supported by the Mavis Gallienne and Graham Lang MND Victoria Research Grant, our team at the University of Queensland (UQ) has developed an Online Carers' Questionnaire (OCQ), based on the Carers' Behavioural Interview from the Edinburgh Cognitive and Behavioural Screen (ECAS). The OCQ aims to identify changes in MND patients' experience in behaviour and cognition (i.e. thinking skills), as noticed by their carers. The OCQ is designed to detect subtle and occasional changes, as well as more noticeable alterations in behaviour. This is important for understanding the range of different clinical presentations in MND as not all individuals have the same changes and difficulties in behaviour and cognition, or the same MND motor symptoms. Understanding changes with the OCQ is also important to guide ongoing clinical management.

We are now validating the OCQ by checking that behavioural data obtained online accurately captures changes, as would be assessed by an expert clinician working in a specialist MND clinic. To do this, MND patients and their carers have been recruited from the Royal Brisbane & Women's Hospital MND Clinic. Carers have been filling in the OCQ at home, which takes between 20-30 minutes, prior to both the MND patient and carer attending the UQ Neuropsychology Research Clinic.

The UQ Clinic is a residential house with easy access and parking, which our participants enjoy visiting. At the Clinic visit the MND patient completes the ECAS and the carer completes the ECAS Carers' Behavioural Interview with a clinical neuropsychologist. The ECAS Behaviour screen has ten questions that are either endorsed with an example behaviour (score 1) or not endorsed (score 0) and the items scores are summed to generate an overall score. The OCQ captures information about the same behaviours and, in addition, it extends our understanding by capturing the frequency and onset of behaviours.

For the example shown in the screenshot, if a behaviour is ticked (Yes), further questions are asked about how often this occurs (i.e. frequency) and when it started (e.g. before/after or at the same time as the onset of MND motor symptoms).



Data collection is almost complete and we are analysing the consistency between the online OCQ and in person clinician-rated scores. We anticipate that the OCQ will be a useful and valid behavioural screening tool. In terms of clinical care, the OCQ will allow MND patients and their carers to be assessed remotely from home, regardless of whether they are located in a city that has a specialist MND clinic or if located in a regional or remote rural setting with limited access.

For research, the OCQ is now fully integrated with the **S**poradic **ALS A**ustralia (SALSA) Systems Genomics Consortium database. The fundamental aim for SALSA is to collect and share data on different clinical presentations and biological samples collected in ALS research clinics across Australia. Specifically, the OCQ will capture behavioural data every 6 months that can be analysed with genetic, environmental and life style data to investigate and understand onset and progression of cognitive and behavioural changes and the biological heterogeneity of MND.

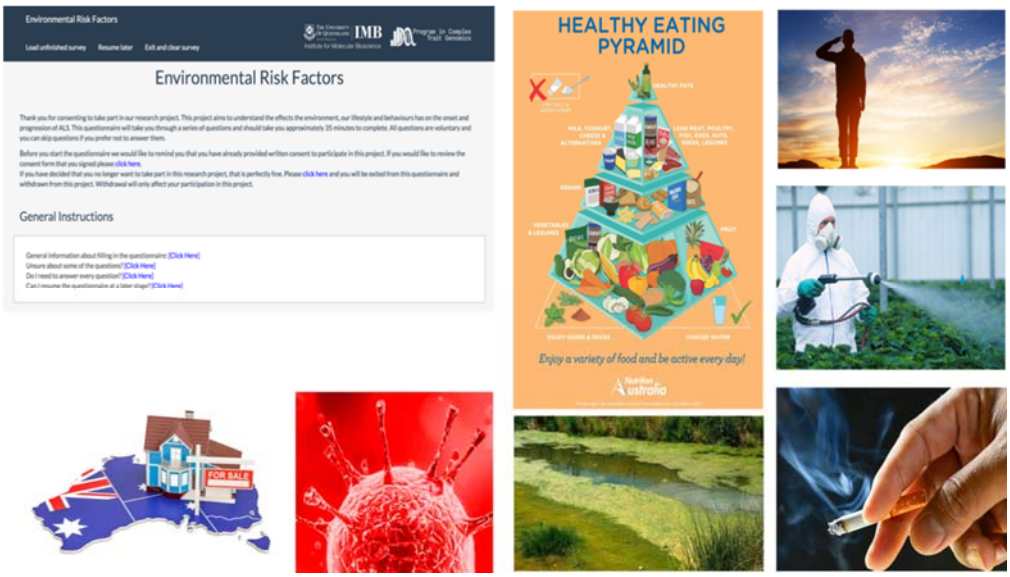
(Continued from page 1): Report on MND Australia Ice Bucket Challenge Grant

the technological advances of tomorrow.

A full report on the project will be available in June, which will document how the SALSA-SGC has delivered on the outcomes promised. Teamwork and attention to detail have been key ingredients and we thank all those who have helped to make this project a success. Notably, the foundations laid have already helped to attract several million additional research dollars to MND, and to promote Australia for new international clinical trials.

Long-term funding is needed to continue this big-data collection and we are working towards that goal.

Professor Naomi Wray
University of Queensland



SALSA-SGC participants will soon be invited to complete a lifestyle questionnaire online. In this way, clinical, genetic and lifestyle risk factors will be collated for the same individuals While several lifestyle risk factors have been reported, these reports need validation.

Proteome homeostasis dysfunction as a cause of MND

Professor Justin Yerbury from the University of Wollongong, explains how this project aims to understand protein homeostasis, and how this relates to how motor neurons stop working properly and then die in MND.

To start to understand this project, the first thing that needs explanation is – what is a protein?

A protein is a molecular machine that is made from the instructions stored in your DNA. These molecular machines do vital work in all parts of your body, and include things like haemoglobin to transport oxygen, enzymes to digest food, collagen to provide physical structure. In addition, other things like hormones, immune systems and electric signals in the brain are all also controlled by proteins.

Proteins are able to do all these jobs because each protein has its own unique 3 dimensional shape that has evolved to allow for a very specific function. When we talk about protein homeostasis, we are talking about keeping all proteins made by a cell in a steady state. Which means, making just enough protein, in the right shape, at the right place, at the right time.

This might sound simple, but this is not an easy task, as there are almost as many individual protein molecules in an average human body as there are stars in the universe.

Keeping all these protein molecules in balance is a gigantic task and, sometimes, it can be too much for a cell to deal with. In this case, proteins will accumulate into what we call aggregates or deposits. We think these protein aggregates are detrimental to cells.

Our analysis has identified that the motor neuron cells that die in MND are particularly at risk because their proteins are supersaturated. Supersaturated means there are many more protein molecules in solution than what we might expect. Supersaturation is a word used more generally to mean that a solution has more of a substance in it than possible under normal circumstances. This means that if conditions change, the substance is at risk of crashing out of solution. We think this concept applies to the proteins of motor neurons, where the proteins are ready to fall out of solution or aggregate when conditions change.

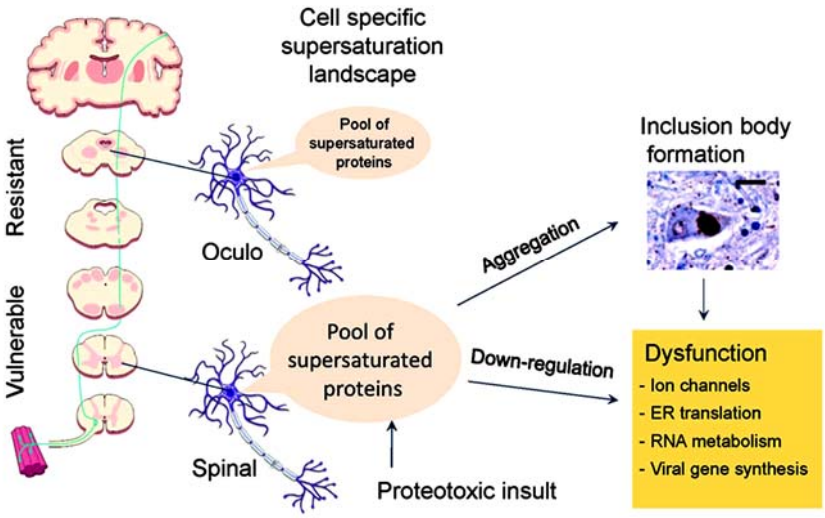
An important part of what we have found is that when aggregates do form, one thing that motor neurons do to respond is that they slow down the production of the proteins that are at most risk.

By making less of the at risk proteins, they make sure that there are less proteins aggregating. However, this strategy used by the cell is like turning off your water at the mains if the bath tub is over flowing. This will stop the bath water but will also mean lots of other taps in the house won't work.

In motor neurons some of the most at risk proteins are in charge of controlling electrical signals. They do this by moving charged molecules across the boundary of the neuron. By slowing down the production of all proteins at risk, many of the proteins that control electrical signals are reduced.

This reduction leads to the motor neurons not firing properly, which can be measured in people with MND, and which in some people with MND is thought to result in muscle fasciculation or twitching. These motor neurons are thought to be the ones that go on to die.

Now that we have gained a little insight into what is happening in motor neurons we have started to think about ways that we can restore the protein balance. This is shown in the diagram below.



Particular thanks to the Laidlaw family who have supported this project through the Betty Laidlaw Prize. This project would not be possible without their very generous support.

Justin Yerbury, Professor of Neurodegenerative disorders
Illawarra Health and Medical Research Institute (IHMRI), University of Wollongong

It wasn't until the late 1990's that Justin realised MND was inherited in his family. First an uncle died from MND, then a cousin, his mother, grandmother, aunt and sister. More have followed. Justin wanted to understand this killer disease in his family so enrolled in a science degree at the University of Wollongong and graduated with 1st class honours in 2004. He has since had a stellar rise in his research career with well-earned support and accolades for his achievements. Justin's research is recognised nationally and internationally through collaborations with other researchers. He has always been a magnet for students, attracting young researchers to learn from him and work with him at the IHMRI. They have thrived and picked up his passion and dedication to discovering why motor neurones die and what can be done to restore a healthy state.

Justin was diagnosed with MND in 2016. His drive to further his research did not abate and he continued his work with national and international collaborative research projects. At the end of 2017 he won MNDRIA's prestigious Betty Laidlaw Prize for an outstanding mid-career researcher with a demonstrated background of excellence in neuroscience research. A few months later Justin's MND had robbed him of his breath. He was not ready to die so made the decision to have a tracheostomy and now, with assisted ventilation and after 6 months in hospital, he is back at home with his family and back in his laboratory carrying on his research. Using eye-gaze technology for communication, he continues to find novel research approaches. MNDRIA awarded Justin the Dr Paul Brock MND Research Grant to continue his research in 2019.

New brain sensor translates thoughts into speech

Associate Professor Thomas Oxley and his team from the Vascular Bionics Lab at the University of Melbourne have developed Stentrode™, a new form of assistive technology that will help people paralysed by MND communicate again.

Speech may become slurred, soft and totally lost due to MND. When MND affects the muscles associated with speech it creates weakness and paralysis of the lips, tongue and other muscles of the face and mouth. Feelings of isolation and low self-esteem commonly accompany loss of communication.

Stentrode™ has been developed as a brain-computer interface to record brain signals that can help people generate text with their thoughts without the need for speech, writing or other forms of communication. The software development and computer interface were funded by MNDRIA with a grant named in recognition of a $100,000 donation received from Grant Mackenzie who was living with MND in WA. At the time of Grant's very generous donation he was rapidly losing his ability to speak due to the increasing paralysis of the muscles controlling his speech. It seemed fitting that his donation should go to a project that was aiming to help people in a similar situation. Grant died in August 2018 knowing that his donation was helping to pave the way to communication for other people paralysed by MND.

How the technology works

Stentrode links the human brain with a computer. Using a tiny, matchstick length sensor inserted into a blood vessel in the brain, Stentrode can record high-fidelity brain signals, and share that information wirelessly. Users will have the ability to control external devices, just with their thoughts, such as text on a computer screen.

The researchers are aiming to develop the technology so that it generates text at a rate comparable to texting speeds on a smartphone.

Insertion of the Stentrode implant is minimally invasive and does not require open brain surgery.

A first-in-human clinical trial for Stentrode

The project has received international attention, and successfully progressed to a first-in-human clinical trial, funded by NHMRC. The trial begins in mid-2019 with five patients at the Royal Melbourne and Bethlehem Hospitals.

Understanding the role of a new form of FUS in MND

Professor Julie Atkin and her team at the MND Centre at Macquarie University have identified a novel extracellular form of the protein FUS.

By examining normal function of the new protein, and how it becomes abnormal in disease, the team aims to learn whether the unique form of FUS plays a role in spreading MND and, if so, how this could lead to treatment.

In 90% of cases of MND the disease is seen in only one member of the family and is known as sporadic MND. In the other 10% of cases, MND is inherited (familial) and the faulty gene can be passed on to offspring.

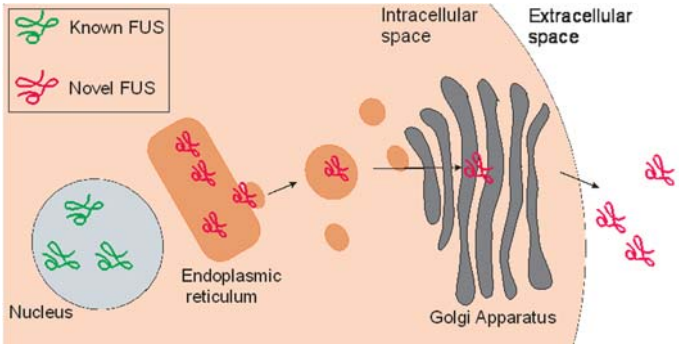
FUS (fused in sarcoma) is a protein that helps to repair DNA and regulate production of proteins from genes. Mutations in the FUS protein cause 5% of cases of familial MND. FUS also causes a proportion of frontotemporal dementia (FTD) cases which are closely associated with MND. There is also an abnormal build-up of the normal FUS protein in the brain and spinal cord of patients with sporadic MND.

The genetic information of an organism is stored in DNA, in specific functional subunits of the genome. This information is transferred from DNA into a 'messenger RNA' (mRNA) template, by a process called transcription. The mRNA then produces each protein. However, before the mRNA can be converted into protein, some of its information must be removed. The remaining parts of mRNA are then re-joined to produce a mature mRNA that produces the protein. Alternative splicing is how regions within the mRNA are differentially joined. This results in multiple types of protein forms being encoded by a single gene. Impairment in the regulation of mRNA and alternative splicing are increasingly implicated as central features of pathogenesis in MND.

This project has identified a novel type of FUS produced by alternative splicing. This new protein is unique among MND proteins, because it is found outside the cell. Most other MND proteins are found within the cell. The new extracellular FUS protein has unique features that are not yet defined but the study has shown that it induces cellular features typical of MND. Moreover, sporadic MND patients produce more of this protein in the spinal cord compared to non-affected people, further suggesting that it has a role in MND.

MNDRIA funding through the David Flett MND Research Grant has supported continued investigation of the properties of the new form of FUS and its role in MND.

Defining the unique characteristics of the new protein could lead to the identification of new therapeutic targets.



While the known form of FUS (green) is localised within the nucleus of the cell, the new type of FUS (red) has a unique localisation; it is secreted so it is found outside the cell. This completely new form of FUS is likely to have new functions compared to the normal form, which has implications for our understanding of MND.

Understanding the role of neuroinflammation in MND

Inflammation of the brain and spinal cord is common in motor neurone disease. But there are differences in the neuroinflammation seen in slow and fast progressing forms of MND and these differences might provide clues as to how new treatments can be developed.

Associate Professor Anthony White and his team at the QIMR Berghofer Medical Research Institute are exploring the role of neuroinflammation in people with motor neurone disease, and are trying to find a way of slowing down the destructive disease.

The progression of MND is frequently rapid, creating high levels of disability that require support in many areas of daily life. Feeding, communication, movement, toileting, breathing and other activities all require assistance. For some people, however, progression will be slower and life expectancy longer.

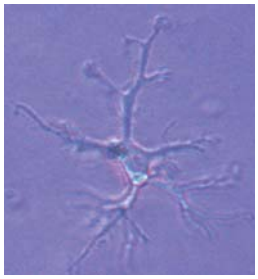
This project seeks to understand the role of brain and spinal cord inflammation in MND. Inflammation is now recognised as a major factor in driving the disease process and is often seen in the spinal cord of people with MND. This is supported by studies on animal models of MND in which blocking inflammation slows the disease process. Improving our understanding of inflammation may lead to new treatments for MND.

The main cells involved in brain inflammation are called 'microglia'. They have similar functions to white blood cells, such as fighting infection and removing damaged or dying cells. Microglia can also become overactive in MND, however, leading to damaging effects on other brain cells that control memory and movement.

Funded by MNDRIA through the Col Bambrick Memorial MND Research Grant, this project is examining differences between microglia from people with slow progressing disease and those with rapidly progressing disease.

Microglia are grown by adding specific chemicals to white blood cells taken from people with rapid disease and slow disease (and people without MND for comparison). After two weeks, these cells have grown into microglia that are largely identical to those found in the brain. This allows comparison of patient-specific differences in microglia, and has the potential to determine how microglia are different in people with slow, compared to fast, progressing disease.

The study has found differences between microglia from people with slow and rapid progressing disease, including accumulation of an important MND-associated protein called TDP-43, which shows more discrete localisation in the periphery of microglia in people with slower disease.



Differences are also seen in expression of proteins called cytokines that are important for communication between each microglia, and between microglia and neurons. There are also changes to the shape of the microglia with cells from people with slow and rapid disease having different numbers and lengths of the branches that monitor the neurons around them.

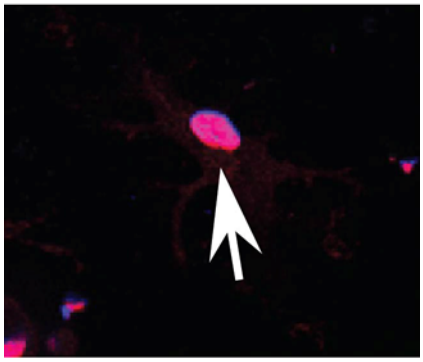
We continue to investigate what these changes in microglia from people with slow and rapid disease mean. If we can understand how microglia control the rate of disease progression, this could allow us to find new ways of slowing MND progression by controlling the microglia.

There are many new drugs being developed that have the potential to control how microglia behave. For example, we have shown previously in work funded by MNDRIA that drugs called 'kinase inhibitors' can control accumulation of TDP-43. These drugs could modify TDP-43 in microglia, and alter the behaviour of the cells, leading to a healthier function.

Using our patient-targeted approach, we are in a strong position to identify which drugs provide the best opportunity to help microglia slow the progression of disease in MND patients.

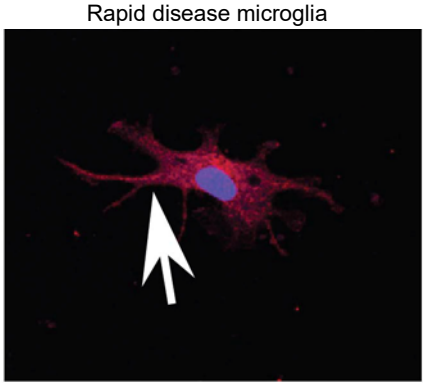
"Understanding how the microglia are different from people with slow and fast progressing disease means we may then be able find a way of slowing down the disease, especially in those with rapid disease."

Healthy control microglia



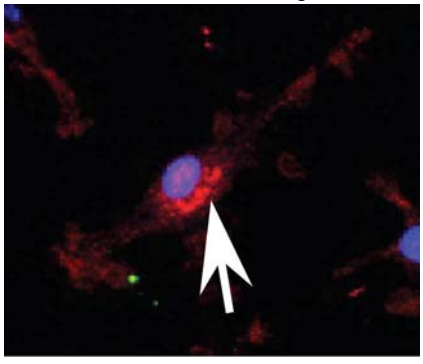
TDP-43 (red) all in the centre of the cell in the nucleus (blue)

Rapid disease microglia



TDP-43 (red) spread throughout the cell but not in the nucleus (blue)

Slow disease microglia



TDP-43 (red) in a cluster next to the nucleus (blue)

Supporting emerging researchers

MNDRIA encourages young researchers to take up the challenge of motor neurone disease through provision of PhD top-up grants to Australia's best students, and sponsorship for travel to participate in meetings and learn from others..

MNDRIA PhD Scholarship Top-Up Grant 2019

Marcus Dyer, University of Tasmania

Neuronal excitability in ALS – a focus on TDP-43 mislocalisation

In the vast majority of ALS cases, pathological movement of the protein TDP-43 from the cell nucleus into the outer parts of the cell occurs. The pathological mechanism of how mislocalised TDP-43 causes motor neurone death is not known. This project hypothesises that the presence of TDP-43 in the cytoplasm affects the activity of neurones, which eventually causes their death. The aim will be to identify if alterations in activity are one of the earliest changes as a consequence of TDP-43 misprocessing and if it is possible to prevent this pathogenic mechanism from driving the onset and progression of ALS.

MNDRIA PhD Scholarship Top-Up Grant 2019

Megan Dubowsky, Flinders University, SA

Endogenous Retroviruses as a cause of MND

Anti-retroviral treatment given to MND patients in the Lighthouse trial has suggested that endogenous retroviral expression may be a cause of MND.
This project aims to define a link between endogenous retrovirus and MND pathology.
MND patient-derived stem cells will be examined for evidence of endogenous retroviral activity and the association with TDP-43 pathology and inflammatory signals.
The TDP-43 mouse model of MND will be used to determine effectiveness of antiretrovirals in decreasing the disease associated protein, TDP-43.
If successful, this project would demonstrate how endogenous retrovirus can be a potential therapeutic target for MND using antiretrovirals.

Jenny and Graham Lang Travel Grants

MNDRIA encourages attendance at conferences to promote sharing of expertise among researchers, to enable interaction of researchers and foster the development of research collaborations, and to inspire the urgency for research to produce change.

The Jenny and Graham Lang Travel Grants are provided by MND Victoria and administered by MNDRIA. They are offered for early career researchers to support the cost of attendance at the International Symposium on ALS/MND in Perth.

Applicants must be researchers with an interest in MND; preference will be given to final year PhD students or early postdoctoral researchers. The grants will only be awarded to applicants who intend to register for Symposium attendance. Applications to MNDRIA close 8 July.

30th International Symposium on ALS/MND and associated meetings in Perth December 2019

MND Australia, in partnership with MND WA, is proud to host the International ALS/MND meetings in Perth in 2019.
This will be an opportunity for the Australian MND community to come together with their peers and leading international researchers from around the world to present and debate key innovations in their respective fields. All meetings will be held at the Perth Convention and Exhibition Centre.

On Sunday 1 December members of the **International Alliance of ALS/MND Associations** will gather for the AGM and annual meeting. This meeting is an opportunity for ALS/MND support and advocacy organisations from around the world to share best practice and ideas for better supporting people living with ALS/MND in their communities.

Observers are welcome to register to attend this meeting.

Ask the Experts on the afternoon of Monday 2 December is a free session specifically for people living with MND, their families and friends and the wider MND community. This will be an opportunity for the Australian MND community to hear about the latest research advances from leading national and international researchers and clinicians. Registrations open soon.

The **Allied Professional Forum** is a full day meeting on Tuesday 3 December where health and community care professionals from around the world present on evidence based and best practice models of care and support for people living with MND, their carers and families. All are welcome to register to attend.

The **30th International Symposium on ALS/MND** will run from Wednesday 4 to Friday 6 December. Concurrent platform and poster sessions will focus on scientific and clinical advances. We expect to see many MNDRIA funded researchers presenting their findings this year. All are welcome to register to attend. NB: Early bird rate for registration for the symposium ends on 27 August.

For more information on all these meetings and links to registration pages go to www.mndresearch.org.au/Discover-our-research/grants-and-research-meetings/International-Symposium-on-ALS-MND.

Stay up to date with information about research

at www.mndresearch.org.au

Research Strategy

Read MND Australia's research strategy for 2018-2021: Investing in Innovation, Partnering for Progress at www.mndresearch.org.au/Documents/Research-documents/MND-Australia-Research-Strategy-2018-2021

Research news in Australia

For previous issues of *Advance* and other MNDRIA news go to www.mndresearch.org.au/Discover-our-research/Latest-research/Research-news

Research news abroad

United Kingdom

MND Research Blog**:** Up-to-date information on ALS/MND research, as well as the activities of the MND Association's research development team. Go to www.mndresearch.blog

USA

Research News*:* ALS Association's webpage featuring newsletters, blogs and webinars on ALS/MND research Go to www.alsa.org/research/research-news/

ALS Today News webpage of the ALS Therapy Development Institute, which covers research developments from both their own and other research labs. Go to www.als.net/news/

Clinical trials - Be Informed

Clinical trials are an essential step in the development of new treatments for motor neurone disease. MND Australia has recently updated its clinical trials web page to include up-to-date and relevant information on the clinical trials currently underway in Australia. There are a number of trials being conducted around the country, some of which have received critical start-up funding from MNDRIA.

There is an enormous global effort to develop new and effective treatments for MND. These include a number of new therapeutic trials focused on treating MND, as well as trials focused on improving quality of life for those currently living with MND.

MND Australia is the trusted source of information for Australian clinical trials. The website includes information on the following:

- a brief description of each trial and the participating clinics
- inclusion and exclusion criteria for participation in a trial (where available)
- recently completed trials
- results of clinical trials, as they become available.

For more information about clinical trials, go to www.mndresearch.org.au/Discover-our-research/Latest-research/Clinical-trials

Governance

MND Australia is the principal member of the MND Research Institute of Australia.

The governance and operations of both organisations are the responsibility of MND Australia.

Directors

The board of MND Australia consists of an independent elected President and a nominated representative from each member MND Association board, the chair of the MNDRIA Research Committee and up to three independent directors.

Research Committee

The MNDRIA Research Committee reviews research grant applications and determines the distribution of funds within the set policies and criteria for scientific assessment.

Research Committee Members

Chairman: Professor Matthew Kiernan AM, NSW
Professor Samar Aoun, WA
Professor Ian Blair, NSW
Professor Tracey Dickson, TAS
Professor Simon Foote, ACT
Professor Glenda Halliday, NSW
Dr Susan Mathers, VIC
Professor Pamela McCombe, QLD
Dr Shyuan Ngo, QLD
Professor Dominic Rowe AM, NSW
Professor Dominic Thyagarajan, VIC
Associate Professor Bradley Turner, VIC
Professor Steve Vucic, NSW
Professor Naomi Wray, QLD

Bequests

Your Will can provide an important way of making a gift that can have lasting influence on MND research and give hope for the future.

If you would like to consider the MND Research Institute of Australia in your Will by providing a Bequest from your Estate, please contact your solicitor.

For more details on how your bequest can help MND research

Contact Dr Gethin Thomas, Executive Director Research:
Phone 02 8287 4989 or
Email: research@mndaustralia.org.au

Donations

Research funded by the MND Research Institute of Australia is dependent on donations.

To contribute to this vital work, please send your gift to:

MND Research Institute of Australia
PO Box 117, Deakin West, ACT 2600

Donations can be made by cheque (payable to MND Research Institute of Australia).
Visa or MasterCard donations can be made by phone to 02 8287 4989 or online at www.endmnd.org.au

All donations of $2 and over are tax deductible.

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