Another Crack in MND's Armour

Following approval in Canada in June 2022, the US Food and Drug Administration (FDA) announced in September that it has approved the therapy RELYVRIO™ (sodium phenylbutyrate and taurursodiol), developed by Amylyx, for the treatment of MND. The FDA were happy that RELYVRIO (previously known as AMX0035) showed a sufficient slowing of the loss of physical function in people living with MND from the data from a Phase 2 clinical trial as well as additional data from the open- label extension program.

This is great news for the MND community as it is the first new treatment since Edaravone was approved in 2017 (this treatment has not been approved for use in Australia) and riluzole in 1995. This also might be the first direct outcome for MND patients from the viral ice-bucket challenge campaign. Funds from this campaign supported the early development of RELYVRIO.

The next steps for RELYVRIO will be pricing for the treatment and approvals in other countries, including Australia. Current pricing in Canada is in excess of $200,000 a year so discussions with authorities over subsiding costs will be critical. MND Australia is reaching out to Amylyx to discuss options for bringing the treatment to Australia.

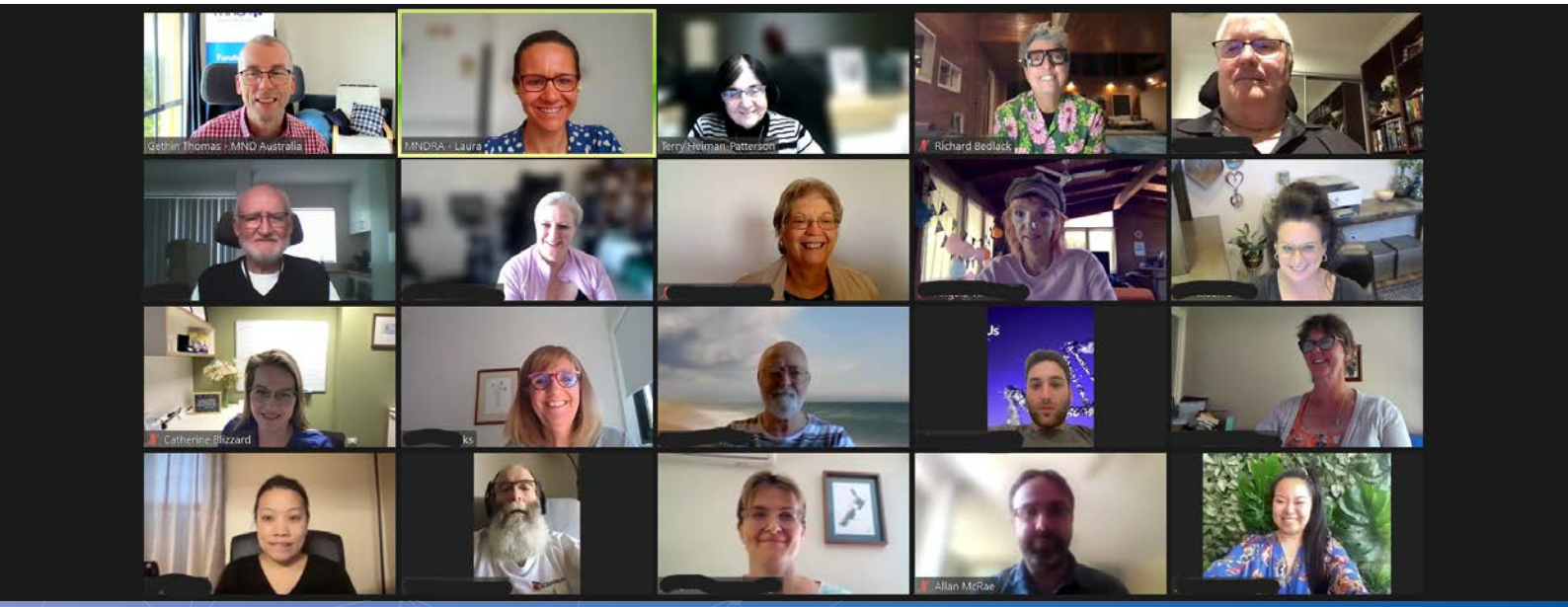
Further advances may be on the way with two other therapies currently under consideration: Biogen's tofersen, a gene therapy targeting SOD1 mutations; and AB Science's masitinib, a tyrosine kinase inhibitor that is thought to decrease neuro inflammation and exert neuroprotective effects.

This recent progress is a really great example of the benefits of the continuing increases in research resources around the world over the last few years. The number of clinical trials attacking MND from different angles has increased substantially and we are now seeing some of these treatments showing effect.

A consistent trend becoming apparent is that longer trials are more effective at identifying true clinical benefit. Many of the measures of clinical disease, such ALSFRS-R, are quite variable both between patients and within an individual's disease course. Often a 6-month treatment period might only see the beginning of a treatment effect and with the additional data provided by Open Label Extension/ Expanded Access Programs we get a much better picture of a drug's effect. There is now a serious debate underway as to whether all trials should be at least 12 months. However, this obviously comes with the drawback of increasing the time to obtain an outcome in a community where time is a precious commodity.

MND Australia and MND Research Australia have moved to a new premises!

Our post box address remains the same (PO Box 117, Deakin West ACT 2600) but our street address has changed to 3/113 Canberra Ave, Griffith ACT 2603.



The attendees at the inaugural Clinical Research Learning Institute.

Closer to home, two large national collaborative initiatives continue to go from strength to strength. MiNDAUS provides a web-based platform for a unique and innovative disease registry combining patient and carer information together with longitudinal research clinical data capture. This has come about through the amalgamation of the original AMNDR Registry and the SALSA Genetic databases, which has now been completed. National deployment of the MiNDAUS Registry started in March 2022 to patients and carers, with the support and involvement of MND clinics and State MND Associations. By the end of 2022 all 11 National specialist MND clinics will be collecting data and it is expected that 80% of incident cases of MND in Australia will be routinely enrolled into the registry within three years. MiNDAUS will provide a valuable resource for researchers, for the development of healthcare policy and to enhance clinical trial enrolment and participation. For more information on MiNDAUS, visit: mindaus.org

The MND Collective has now established a governance framework with a Managing Board and Expert Advisory Teams for Basic and Preclinical Science and for Clinical Care. The first objective is to establish Australia's first MND Research Resource Map that will catalogue research resources such as biobanks, cell and animal models, specialist skills and equipment. Also incorporated will be an audit of healthcare research to enable synergies and potential collaborations to be identified.

The first Australian MND Clinical Research Learning Institute® (CRLI) took place on the 11th and 12th November. Please see later in this edition of Advance for a report.

From December 2022, I will have the privilege of taking over as Chair of the International ALS/MND Alliance Scientific Advisory Council (SAC) from David Taylor from ALS Canada. In anticipation of this role, I was invited to attend the Alliance Board Strategy meeting in Edinburgh in June to contribute to the development of a new strategy for the Alliance and identify priorities which best serve the global MND/ALS community. This was a fantastic opportunity to work with Alliance Board members, to make a significant contribution to the direction of the Alliance going forward, and to ensure that Australia keeps abreast of current best practice. I then attended the Annual Scientific Meeting of the European Network to Cure ALS (ENCALS), also in Edinburgh. The conference was a great opportunity for networking with other international research directors and industry representatives, and to catch up on recent research advances.

We were incredibly fortunate to be able to provide $4M for our research funding program for 2023. This was boosted by an incredibly generous bequest from the estate of Daniel McLoone. We had additional great support from the State Associations, MND and Me, a wonderful variety of community based fundraising events, and individual donations from an incredibly generous MND community.

As always, we are very grateful for the support of these donors which allows us to continue to fund vital research into MND in Australia.

Dr Gethin Thomas
Executive Director, Research

Dr Gethin Thomas at the annual Grants Allocation Meeting in November.

MND Research Grants commencing in 2023

MND Research Australia is very grateful to our supporters who have continued to fund amazing research via donations to our MND research grants program. On November 7, the MNDRA Research Committee met to allocate the Board approved sum, $2,994,675, across 21 projects: the Daniel McLoone MND Research Prize, two postdoctoral fellowships and 18 Innovator Grants. An additional $1M will be awarded through the Daniel McLoone Major Research Initiative which will be announced in December.

Without philanthropic funding Australian MND research would be in a very tough place rather than having the world-class reputation it currently holds. A key aspect of our funding is the support we provide to early- and mid-career researchers who ensure Australian MND research can continue to grow.

The Daniel McLoone MND Research Prize for 2023-2024

is a new grant made possible due to an incredibly generous bequest from the estate of Daniel McLoone. This grant replaces the Betty and John Laidlaw awards. The bequest will also support four Innovator Grants and the Daniel McLoone Major Research Initiative, due to be announced later in the year. This $500,000 two-year grant was awarded to Dr Catherine Blizzard at the University of Tasmania for her project *"A collaborative multivariable approach to prevent the spread of corticomotor dysfunction in ALS".* The project will investigate (1) the cell signalling pathways through which TDP-43 triggers hyperexcitability, (2) how hyperexcitability spreads through the network, (3) if different regions require excitability to be selectively and differentially treated. This project may establish a novel and targeted drug delivery approach for patients with MND.

The Bill Gole MND Postdoctoral Fellowship for 2023-25

has been awarded to Dr Jeremy Lum at the University of Wollongong. His project is titled *"Identifying drivers that contribute to the loss of neuronal connections in the early stages of ALS".* This project will study the degeneration of motor neuron extensions, which cause loss of muscle stimulation and motor neuron death. He will focus on identifying alterations to molecular-networks that lead to the loss of these extensions and identify targets that can resolve these molecular alterations in patient-derived cells. The best targets will then be converted into a gene therapy and their therapeutic efficacy assessed in an animal model of ALS to restore a key contributor of disease.

The Beryl Bayley MND Postdoctoral Fellowship for 2023-25

was awarded to Dr Alison Hogan from Macquarie University. Her project is titled *"The multifunctional protein SFPQ offers a novel avenue to understand disease mechanisms and identify therapeutic targets in MND "*. Dysregulation of a new protein, SFPQ, has recently been linked to MND, presenting an exciting new opportunity to understand disease biology from a fresh perspective. This project will be among the first in the world to examine how SFPQ interacts with other key MND proteins and how these interactions contribute to disease progression. This will provide insight into disease biology and offer a new direction to identify novel interactions and targets for therapeutic modification.

Innovator Grants for 2023

MNDRA awarded 18 Innovator grants to commence in 2023. These one year projects are designed to test out an innovative idea, and to drive the pipeline of MND research to improve the lives of people living with MND. The top ranked Innovator Grant is awarded the Charcot Award. This prestigious award has been awarded annually by MNDRA since 2016. In addition to the Charcot Award, a further 17 innovator grants were awarded across a range of research areas – clinical measurement, speech pathology, cell biology, genomics, metabolism and natural compound screening as potential new therapeutics. The titles of each of these projects is.

For 2023 the Charcot Award went to Professor Trent Woodruff at the University of Queensland for his project titled "Linking C9orf72 dipeptides to inflammation in MND". Mutations in the C9orf72 gene are the most common genetic cause of both familial and sporadic MND. One of the consequences of these mutations is the formation and accumulation of toxic products, termed dipeptides. It is currently unclear how these dipeptides lead to motor neuron degeneration. We have evidence that these dipeptides can activate the brain's immune cells so that they release substances that are toxic to neurons. In this project, we will examine exactly how this happens and then test drugs that can stop this process in order to find new MND treatments.

MonSTaR MND Research Grant

Associate Professor Mary-Louise Rogers, Flinders University

Refinement of p75 ECD measurement as a biomarker for clinical trials for MND

Mavis Gallienne and Graham Lang MND Victoria Research Grant

Dr Brooke-Mai Whelan, University of Queensland

Save Our Speech (SOS) Study

Jenny Simko MND Research Grant

Dr Duncan Crombie, University of Melbourne

Utilising stem cells derived from people with MND to create artificial 'mini-organs' in the search for MND therapeutics

Superball XV MND Research Grant

Professor Aaron Russell, Deakin University

Investigating the role of neurturin (a specific protein) as a therapeutic strategy to delay ALS disease progression

Daniel Veysey MND Research Grant

Dr Rosie Clark, University of Tasmania

Releasing inhibitions – a novel approach to determine targets of inhibitory dysfunction in ALS

Daniel McLoone MND Research Grant

Dr Fleur Garton, University of Queensland

An Australian Sporadic ALS transcriptome resource

Daniel McLoone MND Research Grant

Dr Rita Mejzini, Murdoch University

Development of RNA-like precision therapies to reduce toxic MND protein in the neuron

Daniel McLoone MND Research Grant

Associate Professor Peter Noakes, University of Queensland

Stabilising Neuromuscular Signalling in Motor Neuron Disease

Daniel McLoone MND Research Grant

Associate Professor Sean Millard, University of Queensland

Understanding how the ALS risk factor, GGNBP2, impairs a cellular process defective in many people with ALS

Ian Sneddon Two Rivers Run MND Research Grant

Professor Mark R Wilson, University of Wollongong

Identifying new drugs from Australian native plants and animals to treat motor neuron disease

Dr Paul Brock MND Research Grant

Dr Shu Yang, Macquarie University

CHCHD10, a novel molecular target to understand mitochondrial TDP-43 accumulation in MND

Run MND NSW Research Grant

Dr Jennilee M Davidson, Macquarie University

Characterising the interactome of sequestosome-1 (p62) – the peacemaker between protein homeostasis and dysfunction

Peter Stearne Familial MND Research Grant

Dr Sonam Parakh, Macquarie University

Nucleoredoxin (NRX), a novel gene therapy target against TDP-43 multifaceted pathogenic mechanisms

NTI MND Research Grant

Dr John Lee, University of Queensland

Therapeutic potential of targeting one of the core players of inflammation (Inflammasome) in MND

Col Bambrick MND Research Grant

Dr Adam Walker, University of Queensland

Finding enzymes to remove MND pathology from neurons

Fat Rabbit MND Research Grant

Dr Margreet Ridder, University of Queensland

Drug Controlled Gene Therapy for Motor Neurone Disease

Murray Geale MND Research Grant

Dr Derik Steyn, University of Queensland

Decoding disease impact on the hypothalamus across the ALS-FTD spectrum of disease

MND Australia
International Research Update

Dr Luke McAlary, Bill Gole MND Postdoctoral Fellow, University of Wollongong

An excellent meeting of international researchers to tackle the problem with protein aggregation

I am writing this article after having finished organising and attending a conference on protein aggregation and disease in Wollongong New South Wales. Whilst protein aggregation plays a role in many neurodegenerative diseases, MND-focused research constituted a sizable bulk of presentations and posters at the conference. This focus on MND is highly encouraging and stimulating.

This issue of the MND international research update highlights research improving patient monitoring, targeting mitochondria, degrading toxic C9 RNA, and identifying patients who may respond better to CuATSM.

Patient monitoring to improve care for patients[1]

A common issue in the care of MND patients is that the time and resources available to monitor progression is inadequate. This is due to the cost and difficulty in providing continuous in-person care and monitoring. A research group from the Netherlands has proposed and tested how e-monitoring (think telehealth or online healthcare) of patients would be received and how useful it would be to provide more effective assessment.

Multiple ALS care teams were encouraged to join the program, which was implemented across 10 care teams. First, the research team engaged the care teams and their patients to explain and describe the proposed care trial. Next, the researchers advised the care teams and patients on the implementation of the e-monitoring. The monitoring itself was performed using a mobile phone application where patients would record their weight, well-being, and functional status, along with regular online check ins from a healthcare coach specialised in ALS care.

The research team found that most patients adhered to the schedule and were very happy to use the mobile phone application and check in regularly with a health coach. The major complaints from patients were that the mobile application itself was slow and sometimes difficult to log on to, and that use of the application made them confront their condition more often than they would have liked. The healthcare coaches reported that they disliked the inability to integrate the mobile phone application with their own patient monitoring software.

Considering the difficulty associated with sending experts to various locations to determine the status of patients, this sort of approach could be a game-changer in many ways. First and foremost, it provides patients a routine and consistent model of care.

Secondly, it may allow for a larger cohort of patients to be monitored over time so that more accurate estimates and predictors of disease progression could be generated. This information would be invaluable for clinical trials. However, consideration would have to be given to finding a balance between frequency of monitoring and convenience and intrusiveness for patients and carers.

Mitochondria are a fragile component in cells[2]

You may have heard the phrase that 'mitochondria are the powerhouse of the cell', which is a brief way of describing the role this organelle plays in cell biology. More specifically, mitochondria are small organelles within cells that carry out the oxidative phosphorylation to generate the main energetic molecule that cells use, ATP i.e. they literally power the cell. When mitochondria get sick, cells get sick, so one would imagine that this important organelle would be well-protected by cells. In fact, mitochondria can be found to be sick in most neurodegenerative diseases, suggesting that perhaps they are a good target for us to attenuate these disorders.

A team of researchers from Washington University in the USA theorised that by using some new drugs that keep mitochondria healthy they may effectively slow disease in MND models. To test this theory, they utilised patient-derived cell models and the SOD1 animal model of MND. They treated these models with compounds that activated and protected mitochondria from becoming sick.

Tests of the drugs in human cells showed that the mitochondria were well-protected in cells derived from patients with SOD1-associated, FUS-associated, and TDP-43-associated cases of ALS. The team found that the drugs were capable of improving mitochondrial health in all these cases by measuring how mobile the mitochondria were. They then tested the drug in mice, finding that a sustained dosage was protective in the animals too.

This research provided more information that mitochondria are a good target in MND. I would propose that the next step that these researchers should take is to combine this drug with others. By targeting multiple pathways in disease, we may see better outcomes as compared to a single drug treatment.

New drugs for C9-associated ALS[3]

One of the major causes of familial MND is large expansions of repetitive code in the C9orf72 gene. Following the central dogma of biology, that DNA produces RNA, and this RNA then provides the template to produce a protein, we have three potential targeting strategies for treatment, i.e. DNA, RNA, or protein. In the case of C9-ALS, RNA targeting is likely the best option, as there is good evidence to suggest that the RNA itself is toxic to cells. Trying to just delete the gene is often too difficult and can have unforeseen side-effects

Researchers from the USA have developed a new molecule with good qualities that may potentially be used against C9-ALS. This drug binds to C9 RNA and eliminates the repeat expansions within it by forcing the cells to degrade the RNA. They tested this molecule on several models of C9-ALS and found it was effective at lowering the expression of toxic protein and lowering the RNA-toxicity in all of these models. The researchers also determined a very important feature of the molecule, that it was capable of crossing the blood-brain barrier.

The blood-brain barrier is an extremely important part of our physiology. It is a layering of tightly packed cells that separates the central nervous system from circulating blood. It allows nutrients and essential molecules to cross into the nervous system so that neurons have food, but stops most other molecules from crossing. Although this protects the brain, it can often prevent some drugs that have shown good results in pre-clinical models from proceeding further through the development pipeline, as they can often not cross this barrier.

The researchers have a very promising molecule in their hands. Considering that the molecule is capable of crossing the blood brain barrier and it appears effective in both human cells and mice, there is good potential for a clinical trial of this molecule. Although this molecule only would be effective for C9 cases, any drug that can modify ALS progression is an incredibly welcome prospect and worth pursuing.

CuATSM still showing benefit[4]

CuATSM is well known within the Australian MND community due to the ongoing clinical trial that was carried out here. For those that don't know, CuATSM is a small molecule that binds copper and is capable of carrying the copper into the central nervous system and alleviating various issues. This compound has shown great promise in multiple cell and mouse models of MND as well as early stage clinical trials.

Although successful in mice, what hasn't been explored is whether CuATSM is capable of working in multiple systems to alleviate MND pathology. Researchers from the USA set out to examine the effect that CuATSM may have on a human cell model where astrocytes and neurons were cultured together. This model is much closer to what we see in humans, where MND astrocytes can kill healthy neurons. Here, the researchers used healthy neurons in culture with diseased astrocytes, so they could examine the role that astrocytes play.

Interestingly, the researchers found in most cases that CuATSM was capable of rescuing the neurons, but not all the time. The researchers followed this thread of evidence and determined that in some patient-derived cell lines the mitochondria were unable to effectively produce energy. Those lines where the mitochondria appeared to be working OK were rescued by CuATSM, others were not.

It is becoming increasingly evident that MND is an extremely variable disease. This issue has impeded molecular characterisation and treatment of the disease. The system established here in this research exemplifies why a personalised approach to medicine is warranted (even beyond MND). It would be a good idea to establish personalised treatments for patients on the basis of culture of their cells.

MND Research Shorts

- TDP-43 regulates the expression of many genes, and perhaps in disease this regulation becomes dysfunctional. Dr Emanuele Burrati from Italy led a team that discovered that a gene called NOS1AP was dysregulated by TDP-43 in MND. This gene is part of the nitric oxide cell-stress response in neurons, suggesting that perhaps this system is involved in MND pathogenesis[5].

- Understanding how MND progresses in patients is paramount to better designed clinical trials and determining if therapies actually work. A research team from Boston USA closely examined the progression of disease in roughly 2000 patients. They found that C9-ALS patients had a more rapid progression than sporadic, but that C9-ALS patients with thyroid dysfunction had a slower progression. This suggests that alterations to thyroid function may be protective in disease[6].

- The underlying physical structure of protein aggregates (clumps) has implications for how these aggregates cause disease. Researchers from Sweden mapped the structure of SOD1 aggregates arising from several MND experimental models finding that aggregates produced in mice differ from those produced in cell cultures or from test tube. This has implications for the role that the central nervous system may play in shaping the toxic and propagative SOD1 aggregates in disease[7].

- Axons are one of the primary sites of degeneration in MND, and as such they are a target for therapy. Researchers from the USA deleted one axon gene (DLK) whilst overexpressing another (ATF3) in the SOD1 mouse. They found that this promoted survival of the mice and improved outcomes. Figuring out the interplay of genes within the motor neuron axon is important for gaining more insight into MND[8].

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What does buying a new car have to do with MND?

By Nicole Merrick,
MND Australia Project Officer

A full version of this piece is available at:
www.mndaustralia.org.au/buyingacar

We all make decisions every day. Some are minor and require very little thought, while big decisions can take a long time to make. Some are informed, while others are less-well informed. We all like to think that we make important decisions based upon the best information and advice available, but is this really the case? Sometimes wading through available evidence is not as simple as you might first think.

Buying a new car is one of the biggest purchases you might make. Cars require significant financial investment and we tend to keep our car for several years. There are a lot of different variables to contemplate such as which make and model to buy, will the car suit your needs, and for how long, and will this car be reliable or might it cost a lot to maintain?

So where can you find reliable unbiased information? Friends and colleagues will offer advice but this might be influenced by their own experiences (so called anecdotal evidence). You could ask the car dealer but they have a vested interest in selling you a car i.e. they have a conflict of interest. Perhaps you could go online and look up some reviews, but how do you know which reviews are reliable? Have the writers been paid by car manufacturers? Does the reviewer really know what they are talking about?

At the end of the day, finding a reliable and trustworthy source of information is not easy

The spreading of false or inaccurate information, and a lack of understanding about how to find credible information, can have significant consequences for people living with MND and their loved ones. Misleading information can lead to poor decisions for medical care, the risk of harm from unproven treatments, wasting valuable time on procedures that don't work, and cruelly, creating a false sense of hope.

So how does this relate to MND?

There is an unprecedented number of new treatments for MND currently being tested in clinical trials around the world. This means the MND community is presented with a barrage of information around the results of these trials and it can be very difficult to ascertain what is important and relevant to those living with MND.

Sensationalist news media stories and press releases, or even journal articles about results of clinical trials or new treatments, might emphasise the benefits at the expense of other important details within the study, creating a mismatch between perceived and real benefits to the general public[1]. News and stories are shared quickly amongst the community via social media, and public commentary can further contribute to a "bandwagon" effect[2]. We are all aware of the impact of this, having seen the media reporting of the COVID-19 pandemic and how rapidly media can propagate information, whether accurate or not.

One of the major causes of familial MND is large expansions of repetitive code in the C9orf72 gene. Following the central dogma of biology, that DNA produces RNA, and this RNA then provides the template to produce a protein, we have three potential targeting strategies for treatment, i.e. DNA, RNA, or protein. In the case of C9-ALS, RNA targeting is likely the best option, as there is good evidence to suggest that the RNA itself is toxic to cells. Trying to just delete the gene is often too difficult and can have unforeseen side-effects.

A trusted MND organisation like MND Australia have their own rigorous processes when assessing information. They only share information once it has been carefully checked and reviewed. MND Australia, your state association or a member of your healthcare team's prime motivation is to improve the lives of people living with MND and are reliable and trustworthy sources.

Peer review means that others within the scientific community, with no conflict of interest, have reviewed and appraised the research. Peer-reviewed information could be considered more trustworthy and reliable than a company press release, for example. Company press releases are circulated by the company who might present their results in a favourable light, while downplaying any concerns or issues with the product.

Finally, you need to decipher whether the information is relevant and has value for you.

For example, some therapies need to be commenced at a specific stage of disease. Others might only be suitable for a certain subset of patients or those with a specific phenotype, or classification, of motor neurone disease. Some products may only be approved or available in specific locations.

Developing your health literacy and critical thinking around clinical trials and scientific research is important, but it is always advisable to get professional input. Speaking to your neurologist or GP, your MND clinic health professional or State Association support person will help you wade through all the information and to decide whether it is relevant to you.

Negotiating and making sense of the vast array of information on scientific research and clinical trials is not easy, but it is important and achievable by increasing your health literacy and applying a critical lens.

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Inaugural Australian Clinical Research Learning Institute (CRLI) Report

On Friday 11th and Saturday 12th November 2022 we had the pleasure of hosting the first ever Australian Clinical Research Learning Institute (CRLI).

CRLI is a program that educates attendees on the research process and development of new treatments. The program was originally developed by the Northeast Amyotrophic Lateral Sclerosis Consortium (NEALS), which is based in the US. It was created in the USA in 2011 by the director of the ALS Clinic at Duke University School of Medicine, Dr Richard Bedlack, to facilitate direct interactions between researchers and people with ALS and their caregivers.

Through the learning institute they have trained over 500 Research Ambassadors who are now contributing to MND advocacy at many levels in the US and internationally. From these engagements, researchers have been prompted to formally include patients in the design process, to design more patient-centric trials and to create new ways to help patients find trials. Research ambassadors are improving awareness and clearing up misconceptions about participation in research, improving research availability, and helping to create more patient-centric trial designs.

The object of the workshop is to empower attendees to be strong advocates and contribute their lived experience voice to the field of MND. People with MND, caregivers, and family members were all encouraged to apply.

MND Australia together with Iggy Get Out supported by GenieUs (https://genieus.co/) worked with our colleagues from NEALS to develop a program to establish a cohort of Australian MND Ambassadors.

The program included presentations covering an overview of the Australian research ecosystem, ethics, statistics, the current treatment pipeline, ow to read a scientific paper, genetics, basic research and healthcare research. We also had a session around advocacy for MND.

Fifteen participants with lived experience took part including those early and late in their disease journey as well as relatives and carers of those living with MND. We had fantastic interaction from our participants with great discussions and many questions across all the presentations.

Following completion of the workshop, attendees are now certified as an MND Research Ambassador® and it is hoped they will embrace this new role and pledge to educate and advocate to/for others living with MND and decision makers. We look forward to many future interactions with this founding group of Australian MND Ambassadors and integrating them fully into the governance, advocacy and education programs of MND Australia.

State of Play webinars will continue in 2023

Due to their continued success the online State-of-Play webinar series will continue into 2023, allowing the MND community to hear directly from funded researchers. The range of topics covered in 2022 has been broad, from an overview of why there is so much diversity in disease presentation and progression between patients, to hearing about the MiNDAUS registry, advances in brain-computer interfaces, through to finding out about what goes wrong with nerve cells.

We are very grateful to the researchers who have been involved in these webinars, providing a great deal of well-presented and easy-to-understand information. With another talented group of researchers funded in 2023, we are looking forward to the State of Play webinars continuing as a core communication channel to keep our community up-to-date. Keep an eye on the State of Play webpage (www.mndaustralia.org.au/stateofplay) or the MND Australia Facebook page (facebook.com/mndaustralia) for the 2023 schedule. We would love to hear your suggestions of topics to cover in 2023, so please send through any ideas to research@mndaustralia.org.au.

As always, the 2023 webinars will continue to be interactive with time for questions posed directly to researchers at the end of the webinar. Don't miss out!

Canberra Rally

With COVID restrictions lifting during the year, it has been wonderful to have the opportunity to attend some wonderful fundraising events with very different approaches.

One of our favourites was the adrenaline-pumping Canberra Rally Experience. For this event, the Brindabella Motor Sport Club, the Light Car Club of Canberra and the Shoalhaven and Kiama Districts Auto Club joined forces to raise money in memory of Graham Sporne who passed away from MND in 2019. The event raised funds by selling "hot laps" of the rally track driven by rally race drivers in ridiculously fast rally cars. Both Gethin Thomas, Executive Director of Research, and Laura Birks, the MND Australia Research Coordinator, took the opportunity to hurtle along narrow fire trails at close to 100km/hr – definitely an experience! And a great way to raise funds for vital MND research.

MNDRA's Dr Gethin Thomas and Laura Birks having a ride through the Canberra bush in a rally car.

MND Research Australia relies on the generous support of donors to maintain its important MND research grants program. Please fill in the form below or visit **www.mndaustralia.org.au**

My gift (donations over $2 are tax deductible)

I would like to make a donation to MND Research Australia of:

☐ **$20** ☐ **$100** ☐ **$200**
☐ **$50** ☐ **$1000** ☐ **$** _____

Payment Details

☐ **I enclose my cheque payable to MND Research Australia**

☐ **I have made a direct deposit to MND Research Australia BSB: 062-152; Acc No: 00902053**

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For information on becoming a monthly donor please visit; **www.mndaustralia.org.au/donate**

Return this form in the reply paid envelope provided or:

- Donate online at **www.mndaustralia.org.au/donate-research**
- Call us on **02 8287 4989**
- Post to: **MND Research Australia PO Box 117, Deakin West, ACT 2600**

Governance

MND Australia is the principal member of MND Research 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 MND Research Australia Research Committee and up to three independent directors.

Research Committee

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

Research Committee Members:

- Chair Professor David Burke AC, NSW
- A/Prof Rebekah Ahmed, NSW
- Professor Samar Aoun, WA
- Professor Ian Blair, NSW
- Professor Tracey Dickson, TAS
- Professor Michelle Farrar, NSW
- Dr Anne Hogden, NSW
- Professor Marina Kennerson, NSW
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Phone: 02 8287 4989
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