# Advance: June 2021

# **Building** Partnerships

Who would have thought for our third Advance in a row we would still be coping with the COVID-19 global pandemic. Thankfully there seems to be light at the end of the tunnel and there is some normalcy in place in Australia compared to many other countries. Reflecting this, it is great to see so many of our researchers are up and running full-steam ahead again. For those studies that were materially impacted by shut-downs we have provided "gap-funding" to support staff salaries where projects needed to be extended. This will ensure we will continue to see the great outcomes that our funding has supported previously.

In a big change for MND Australia, I would like to welcome our new CEO, Mr David Ali. After 20+ years of involvement with MND in Australia, Carol Birks is now enjoying a very well-earned retirement. Many of you will be familiar with David as he has served on the MND Victoria Board for 20 years and as a Director of MND Australia since 2008 and is currently on the Board of the International Alliance of ALS/MND Associations. He therefore brings a wealth of experience and knowledge of the MND sector as well as a host of ideas from his professional experience in senior leadership roles in the government and not-for-profit sectors.

There has been a lot of news recently in the drug development space, both good and bad. The bad news was that the initial data from the Phase 3 trial of Brainstorm's Nur-Own showed very limited efficacy with the trial not reaching its primary endpoints. Brainstorm has claimed that the treatment did work in a subset of patients, however they have yet to release the full data so the extent and significance of these benefits is unknown at this time.

On a brighter note, Amylyx has shown strong Phase 2 results for their drug AMX0035 and are moving forward with a Phase 3 trial. Additionally, they are working with both Health Canada and the European Union medicines regulator to look at options for an early approval pathway while the Phase 3 trial is ongoing. We will be keeping a close eye on this process to see how this may relate to the Australian MND community. Exciting developments have also been announced from Biogen concerning their SODI-targeting gene therapy, Tofersen. From July they are commencing an expanded access program intending to provide access to Tofersen to patients carrying the SODI mutation outside of the clinical trial, while it is still underway. This will be a global program, so will be available to Australian patients, and is a very exciting development brought about by strong community pressure. A further development is the announcement that Biogen will be instigating a Phase 3 trial to investigate the benefits of Tofersen in pre-symptomatic individuals who carry the mutation. This could potentially be the first preventative treatment in MND, although we will need to wait for the results of the trial.

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As you might expect, for all of these recent developments, there is a lot of information and opinions available through social media and online. However, much of this information is speculative and some even incorrect or malicious. We strongly advise the MND community to only rely on information from well-established sources, such as national and government organisations or the International Alliance of ALS/MND Associations. As we see with COVID, misinformation can spread quickly and easily distort a message creating false hope or disappointment. MNDRA is always happy to provide advice and respond to queries around treatments and research information.

One thing that COVID has shown us is the value of working together as a community. We have continued to build on the outcomes of the November 2020 National MND Summit we featured in the last Advance. We are now establishing the framework to build a National MND Research Collective that will bring together all the stakeholders across the MND research landscape. It is important that we build a strong framework for such an enterprise to ensure it has strong foundations for durability and crucially for growth. Such a Collective will provide a powerful platform for leveraging research funding, building collaborative networks for clinical trials and resource sharing, information provision, and creating research opportunities. It has been fantastic to work with FightMND and the MiNDAUS Partnership on this initiative and we will continue to bring you updates as the Collective takes shape.





# **Executive Director** Research Report

As the country is opening up it has been great to take the opportunity to meet with some of our researchers and importantly some of our amazing donors. In March I travelled to Hay in NSW to attend the 22nd Shag Gregory Memorial Poker Run. This truly unique community-based fundraising event was a fantastic evening and gave me the chance to meet the many people touched by "Shag" Gregory including his family. I'd especially like to thank Tracy Ellis and Peter May for making me so welcome and supporting MNDRA through this event over such a long period.

We have also heard from many of our other fundraisers that they are planning on holding live events again and we are thrilled to see communities coming together to support our researchers. I am looking forward to popping my head in at as many of these as I can to express our gratitude and to let the fundraisers know where their funds are going and of the great progress being made.

Although we can now travel domestically it does not look like International travel will be on the cards in the near future. A highlight of the research year is the International Alliance Meeting and the UK MND Association International Symposium. For 2020 we were supposed to meet in Montreal, Canada; instead a virtual symposium was held. Although this provided a great forum to hear about the incredible research advances being made around the globe (see Dr Emily McCann's report later in this edition), there was not the partnership building opportunities provided by a face-to-face meeting. However, we are all getting very adept at conducting our business virtually and MNDRA continues to build our profile in the International Alliance through the Scientific Advisory Committee and our increasingly strong relationship with the Directors of the other MND and ALS Associations around the world.

Emphasising MND Australia's role as Australia's peak body for the MND community, David Ali, our new CEO, and I were invited to appear at the public hearing for the Standing Committee on Health, Aged Care and Sport Inquiry into the Approval Processes for New Drugs and Novel Medical Technologies. This was a fantastic opportunity to discuss treatments in development, to present our case for the need for accelerated drug approvals for such treatments, and how we can create an environment that encourages pharmaceutical companies to conduct trials and bring new treatments to Australia.

Dr Gethin Thomas and CEO David Ali in the foyer of Parliament House We are continuing to build our partnership with FightMND. As the two major philanthropic funders of MND research in Australia it is vital that we have complementary research support programs that can provide a continuum of support across the research spectrum. We are planning on jointly hosting a National Research Meeting later in 2021. Plans are still being finalised but watch out in our news and social media feeds for further details – we hope this will adopt a parallel face-to-face and virtual format to maximise ease of attendance for all.

In 2020 we utilised external reviewers in addition to our Research Committee members to review grants. This worked well enabling a broader range of expertise to be accessed and potential conflicts of interest to be avoided. We will be continuing with a similar grant review process in 2021.

You may have already seen that we are continuing with our State-of-Play Research Information webinar series in 2021. We have had two fantastic sessions so far, featuring some great up-and-coming researchers. This series will be running monthly through 2021 and will cover a wide breadth of Australian MND research. If you haven't already dialled in to the sessions make sure you catch the replays on our YouTube channel (MND Research Australia State of Play Seminar Series -YouTube) and sign-up for the rest of the program – it's a great way to learn about the amazing people we support from your fundraising. We will also be running a live MND Connect session in conjunction with the National Research Meeting above – again watch out for further details.

Dr Gethin Thomas, PhD Executive Director Research, MND Australia



# State of Play



MNDRA is continuing "State of Play" throughout 2021, with the next webinar scheduled for Tuesday 15 June at 7pm. We are enjoying Showcasing the work of our researchers around Australia, which is only possible because of the generous and ongoing support of our donors. Keep an eye on the MND Australia Facebook page for upcoming events. Past sessions are available to watch at any time on the MND Australia youtube channel.

https://www.facebook.com/mndaustralia
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# **2021 MNDRA** PhD Scholarships

Funding scientific research has often been a challenge. The meticulous approach and long lengths of time required for better understanding complex health conditions needs steady, comprehensive financial support. In the past, universities have been an important source of that financial support, for MND and other kinds of medical research.

But with reports of the university sector losing at least 17,300 jobs in 2020 due to COVID-19 and being in budget deficit, there is great cause for concern when it comes to continued financial support for scientists. As universities struggle, an already tough career path becomes more uncertain for those at the beginning of their research.

We spoke with Natalie Grima and Anna Ridgers, the 2021 recipients of the MNDRA PhD Top Up Scholarship grants, about their experience conducting research during the financial challenges of COVID-19. PhD top up scholarships are awarded as an incentive to outstanding PhD students and provide a yearly sum of money during their degree, in addition to their regular income. We also asked Dr Parvathi Menon and Assoc. Prof. Rebekah Ahmed, past recipients of MNDRA PhD top-up scholarships, about their experiences and how it helped them continue their work in MND research.

# Can you tell us about the research you are currently undertaking?

**Natalie Grima:** My research aims to identify novel risk and protective genetic factors influencing the development and variable progression of sporadic MND. Thousands of MND patient genomes will be searched for an understudied, complex genetic variant called short tandem repeat expansions, which have been linked to over 20 neurodegenerative diseases. In parallel, I will examine samples from multiple brain regions from sporadic MND patients to determine what molecular changes may cause or protect against development of the neurotoxic TDP-43 pathology. Findings from this work will provide new targets for MND diagnosis, research and treatment.

Anna Ridgers: During my time at the Austin Hospital, I have worked with the Victorian Respiratory Support Service (VRSS), which provides a statewide service for approximately 1100 patients on home mechanical ventilation therapy, many of whom have MND. Patients require different ventilator settings to optimally support breathing and improve symptoms and survival. Usually, these settings are based on daytime assessment, followed by subsequent overnight laboratory sleep study and face to face appointments. My work aims to assess whether remotely recorded ventilator data could be used to optimise ventilator settings without having to rely upon a hospital sleep study. This will allow us to better understand whether a home-based model of care for NIV setting titration would be appropriate for patients with MND and other causes of breathing failure.

# Why did you apply for a PhD top up scholarship and what does the scholarship mean for you?

**Natalie Grima:** I applied for a PhD top up scholarship to help support my living costs over the next 3 years while I work full time on my research. As an added bonus, I recognised the scholarship could raise awareness of my project in the Australian MND community, providing opportunity to communicate my research to a broader audience and establish collaborations with other MND researchers. It is amazing to see organisations like MNDRA and their donors continuing to provide essential support to Australian researchers. The scholarship reminds me of the importance of my research and inspires me to continually give it my utmost effort, even when experiments are not going to plan. The top up scholarship lessens the financial stress that can often accompany PhD studies and will enable me to focus my full attention on my research project. Receiving the scholarship has also given me a great boost of confidence as I enter my research journey.

Anna Ridgers: I was fortunate to receive a research scholarship with the Institute for Breathing and Sleep in late 2020. I applied for the additional top-up scholarship from MNDRA to not only allow me to focus on my research, attend research educational courses but also to present my work and findings at international conferences. Receiving the scholarship from MNDRA has been an incredible honour. I was particularly grateful that MNDRA has chosen to sponsor my research, as MND patients are a large cohort afflicted by breathing failure. The financial support provided by MNDRA will allow me additional time to conduct a number of experiments to fully understand the role of ventilation in clinical practice, and how this may change care for patients with breathing failure.

Mirroring the words of our early career researchers, Dr Menon and A/P Ahmed have also pointed to the collaborative benefits that arise from a PhD top up grant, and the great connections and opportunity for focus that this stipend provides. We asked these established researchers what the scholarship top-up meant for them, earlier in their career, and what advice they would give to those early career researches considering applying for a top up scholarship.

Associate Professor Rebekah Ahmed: The top up allowed me to join a network of MND researchers and form collaborations with other MND researchers. I am now a member of the MNDRA Research Committee. Do apply, it will provide you with strong connections to other MND researchers and open avenues for future research.

**Dr Parvathi Menon:** The PhD scholarship was vital to allow me to dedicate time away from clinical employment to learn research techniques that I continue to employ in my clinical academic career. The PhD scholarship helps you dedicate time to research while also improving your academic profile. It is a competitive award which needs good planning and preparation.

An expanded version of this article is available on the MND Australia blog via www.mndaustralia.org.au



# Reflections on the 31st International MND Symposium on ALS/MND by Dr Emily McCann from Macquarie University: Recipient of the 2021 Beryl Bayley MND Postdoctoral Fellowship

This year's symposium was unlike any other with attendees from across the globe meeting virtually through a web based platform. For those of us here in Australia, sitting quietly alone in our own homes or offices in the middle of the night, to interact with our colleagues on the other side of the world was a stark contrast to our usual conference experience in a packed out hall brimming with excitement and eagerness for the conference to officially open. The plus side being we could wear our comfiest pyjamas and munch on crunchy snacks with no one any the wiser.

Before official proceedings began, we were treated to a light hearted session hosted by Cytokinetics featuring preeminent ALS clinicians Professor Benjamin Brooks, Professor Ammar Al-Chalabi and Dr Caroline Ingre to ease us into conference proceedings. This session took us on a journey through time, examining our approach to diagnosing, understanding, and treating MND. Each speaker spoke with great passion and the session as a whole set the tone of the conference and served as the perfect introductory platform to dive into the more specialised presentations that lay ahead.

The opening session began with a brief welcome from the organisers (looking a little like breakfast television hosts) on set in the MND association headquarters studio. We then had the privilege to hear from Lucy Hawking, chair of the Stephen Hawking foundation set up by her late father. The inaugural Stephen Hawking Memorial Lecture was then presented by Professor Rudolph Tanzi, a self-termed "accidental ALS scientist". Professor Tanzi shared his story starting with his involvement in identifying the gene causing Huntington's disease in the 1980s, which led to his generating of a genetic map for chromosome 21, which facilitated the eventual discovery of SOD1 as the first MND gene. His recent work in Alzheimer's disease has again spilled over into the MND field, with two promising Alzheimer's therapeutics Cromolyn and Taurursodiol also showing promise for treating MND. Further accolades followed, with Professor Ammar Al-Chalabi from London awarded the Forbes Norris award for his outstanding commitment to fighting MND as both a clinician and researcher. MND Australia's own Carol Birks' tireless work to give a voice to individuals and families affected by MND for more than 20 years was recognised with the Humanitarian Award for her significant international contribution for people affected by ALS/MND, an honour she is most deserving of as she transitions to a well-earned retirement following her service as CEO.

MND Australia's outgoing CEO, Carol Birks, with the 2020 Humanitarian Award, awarded virtually during the Symposium



While the length of this year's symposium program was limited by the virtual format, the quality of speakers was as high as ever. Session topics ranged from lab-based research on protein dysregulation and molecular pathogenesis to clinical research and translational medicine.

The protein dysregulation and proteotoxicity session consisted of three presentations providing different perspectives on what goes wrong with proteins that trigger MND. Firstly, Professor Adriano Aguzzi gave an overview of the specific features of prions that facilitate their infectivity, neuroinvasiveness and neurotoxicity. This was followed by a presentation from Dr Daryl Bosco exploring the differences in mechanisms underlying the dysfunction of two MND proteins, PFN1 and FUS, illustrating the diversity of the processes that may lead to the onset of MND. The session was rounded out by Dr Serena Carra, who demonstrated how the accumulation of various defective protein products can cause solidification of particular cellular structures which is detrimental to cell survival, particularly of the motor neurons.





Professor Orla Hardiman from Trinity University in Dublin started off the From Research to Care session with some of the great insights afforded by MND patient registries. While noting that many fantastic registries have been set up, Professor Hardiman made special note of how well the Australian MND registry functions. Such registries have proven to be powerful resources for unravelling the epidemiology, genetics and observable characteristics of MND, and have facilitated the development for predictive tools for the prognosis of MND for individuals. She was followed by Professor Carolyn Young and Dr Fernando Vieira who presented on novel approaches for measuring and assessing numerous aspects of the patient experience of MND.

This year's Pathogenesis session focused on the interlinked fields of epigenetics, transcriptomics and RNA metabolism. A/Professor Hemali Phatnani and her team applied spatiotemporal dynamics to characterise MND progression, and after building the workflows in mice were able to successfully apply their approach to human spinal cord samples identifying gene expression differences between subpopulations of glial cell types, namely microglia and astrocyte populations. Next, Professor Ekaterina Rogaeva presented evidence showing that advanced "biological" age based on DNA methylation profiles was associated with shorter survival and earlier onset of MND, independent of gene mutation status. Importantly, her team also demonstrated that minimally invasive blood samples could be used to measure this biological age in the brain, presenting a potential option for use in the clinic. Finally, a critical role of the major MND protein TDP-43 in causing defective RNA metabolism, particularly through a role in compromising the stress response was shown by Professor Christine Vande Velde and her team.

As part of the Clinical Trials and Therapeutics Strategies sessions, we heard about some of the most promising new approaches to treating MND using pharmaceutical agents. As part of his presentation, Dr Agessandro Abrahao proposed a novel approach utilising MRI-guided focused ultrasound technology to directly deliver therapeutic molecules to the brain in order to maximise their effectiveness. The Cognitive Change session delved beyond the classic motor impairments implicated in MND and explored the broader neurodegenerative spectrum with particular emphasis on the overlap of MND with frontotemporal dementia.

Each day also included poster sessions unlike any other we had experienced before. Instead of standing in front of a poster as tall as ourselves in a humming and bustling hall with food and drinks circling the floor, all the while searching for a familiar or interested face amongst the crowd, we were once again sitting solitary in front of our computer screens wondering who might be doing the same on the other side of the globe. After having uploaded rapid fire 3-minute video explanations of our work, we waited to see if we had piqued anyone's interest just enough that they might drop into your virtual meeting room to ask a question. Once we had the hang of things, jumping between virtual queues and hearing new voices through the speakers felt like second nature.

Professor Ammar Al-Chalabi (left) and Dr Brian Dickie (right) getting set up for a virtual symposium in 2020 This also gave us the chance to get around to more posters than we would have had we been running around the floor of a poster hall.

The closing session started off with the winner of the Healy award being announced as the team behind Project MinE - a global initiative aiming to sequence the complete genetic profiles of 15,000 individuals affected by MND. With over 7,000 genetic profiles from 24 countries (including Australia) already completed, Project MinE has already facilitated the discovery of numerous MND genes and provided profound insights into the genetic basis of MND. We all watch with great anticipation to see what novel discoveries will result from this consortium over the coming years. We then heard from Professor Aled Edwards from Canada's Agora Science Trust, who spoke about using open science to drive more efficient research and therapeutic development, and their hope that this approach will ensure medicines are affordable for those who need them most. His team has made significant inroads in this quest, having identified the best characterised antibodies available for proteins encoded by MND genes, and also having produced extensive data on the WDR41 protein, a known interactor of C9orf72, which they hope will aid in MND therapeutic development. For the last presentation, Professor Matthew Kiernan, from the Brain and Mind Centre at the University of Sydney, went over the Gold Coast Criteria - a significant revision of the gold standard process to diagnose MND. The Gold Coast Criteria provides a simplified framework for MND diagnosis thus speeding up the process. It is also anticipated that these criteria will facilitate more straightforward enrolment into clinical trials. Lastly, to wrap up the meeting, we heard from Dr Brian Dickie and Professor Kevin Talbot about the great success of the meeting despite the added complexities of the virtual format, and the strength of the worldwide community of MND researchers.

You can read more about the 31st Symposium here: https://mndresearch.blog/category/symposium/31st-symposium-virtual/





# **Dr Jennifer Fifita, Macquarie University** 2017-19 MNDRA Bill Gole MND Postdoctoral Fellowship Summary

Gene mutations were first established to cause MND in 1993 when mutations in the SOD1 gene were identified in a family with a history of MND. Since then, gene discovery efforts have largely focused on the familial forms of MND, leading to the discovery of over 30 MND-linked genes. This has gone hand in hand with the development of an exciting and powerful genetic technique, called next-generation sequencing, which enables scientists to sequence, or 'read' the entire genetic code of individuals with MND and their family members. Because of this, the MND-causative gene mutation has been identified in over 60 per cent of familial MND cases. While this has been a monumental achievement, 40 per cent of familial MND patients still have an unidentified gene mutation. Gene mutations also play a role in sporadic MND, however, known gene mutations currently explain only 10 per cent of sporadic cases. We therefore still have a long way to go towards understanding the genetics behind both sporadic and familial MND.

The Bill Gole Fellowship has enabled me to pursue my vision of bridging the knowledge gap in the genetic origins of MND by the identification of gene mutations that cause MND, as well as other gene factors that increase one's risk of developing MND. To do this, I examine next-generation sequencing data from both familial and sporadic MND patients and their family members, using bioinformatic tools to search through thousands of gene changes for those most likely to cause MND. I then study these genetic discoveries in cells and zebrafish in the laboratory at the Centre for MND Research at Macquarie University to determine which gene changes cause neurodegeneration. During my fellowship, I have been involved in over 10 published studies on genetic analysis of novel MND genes including the recent discovery of the gene CYLD. Along with my research team, I have completed a study that identified 43 gene alterations that were previously linked to MND in a large group of Australian sporadic MND cases. We found that individuals carrying more than one of these alterations also had an earlier age of onset of MND. This result signifies that genetic alterations might not only cause MND, but also affect the variable presentation of MND between individuals. I have also continued to work on novel gene discovery in Australian families. In one family, two mutations have been identified that are working together to cause MND, and studies are continuing further investigate exactly how these mutations contribute to disease.

During my fellowship, I was also fortunate enough to receive a MNDRA Innovator grant to launch a new project that aims to identify large changes to the structure of DNA in the genome that cause both familial and sporadic MND, rather than the mostly single base-pair changes we see in mutations. My gene discovery projects will remain the focus of my research, where I will incorporate exciting new genetics and bioinformatics tools to continue to find genetic alterations that are linked to MND.

The identification of genetic alterations that cause MND will improve genetic testing options for patients and their families in the clinic, which includes pre-implantation genetic diagnosis and IVF. Identifying novel MND genes and mutations will also give us a greater understanding of the mechanisms of disease, and provide new targets for much needed therapies in the future.

I am very grateful to have received the Bill Gole Postdoctoral Fellowship. After my PhD, this funding allowed me to continue to pursue my passion for researching the genetics MND, and establish my own research program at the post-doctoral level.



The Bill Gole Postdoctoral Fellowship was first awarded in 2005 and has been awarded and funded every year since by a philanthropist friend of Bill Gole, who died of MND in 2003. In 2021, the 20th young Australian MND researcher (Dr Thomas Shaw from the University of Queensland) commenced their Bill Gole Fellowship grant. The Bill Gole Fellowship leaves a tremendous legacy.

Dr Jennifer Fifita in the Macquarie Lab



# Dr Nicholas Geraghty, 2021 Marisa Aguis Post-Doctoral Fellow

Cells are the building blocks of life, and proteins perform all the necessary functions within these cells. In normal cells, DNA acts as a blueprint for proteins, which are synthesised when necessary, perform their function, and are broken down when no longer needed. When synthesised, proteins fold into a specific shape that is necessary to perform their function. However, in some cases, these proteins either fail to fold properly, or sometimes become misfolded within cells. In these cases, how they interact with other protein molecules becomes disrupted, and they can bind together or "aggregate", eventually forming "inclusions" within the cells. Unfortunately, if it reaches this stage, these inclusions can be toxic to the cells and they become damaged, and can die.

In the case of MND, around 97 per cent of cases are associated with the TAR-DNA-binding protein of 43 kDa (TDP-43) (A). My project involves "transfecting" (introducing) a fluorescent mutated form of TDP-43, which readily aggregates and forms inclusions (B) into neurone-like cells in culture (C). I then spread these cells across a plate that contains a number of drugs (D), and grow these cells in the presence of these drugs. When this mutated TDP-43 protein forms aggregates, the fluorescent signal changes. Using a machine called a flow cytometer (E), which uses lasers to measure fluorescence, I can determine if any of the drugs tested can reduce the large amount of aggregation in these cells (F).



With two of these high-throughput flow cytometers in the Molecular Horizons Institute at the University of Wollongong, I am able to run 12 plates a day, two days a week, allowing me to test over 2,000 compounds a week, for their drug-like potential. This fellowship will allow me to test a large number of compounds from a range of sources including chemical libraries, as well as naturally extracted compounds. To date, I have been able to test 50,000 compounds using this method, due to my fellowship from MND Research Australia.

After this initial screening, I will be able to take any promising hits and test them in a microscopic worm model, and observe the effects on movement. Furthermore, these worms are transparent, allowing us to observe the fluorescent proteins inside the worms. Subsequently, the best hits will be progressed to a mouse model of MND, which will help demonstrate the pre-clinical effects of the drug, eliminating any drugs that are toxic or that do not work, hopefully finding an effective treatment for people with MND.



The Marisa Aguis Fellowship was awarded for 2021 in memory of Marisa Aguis who passed away in 2018. The Fellowship is aimed at supporting research to develop and test new MND treatments.

2021 Marisa Aguis Postdoctoral Fellowship recipient, Dr Nicholas Geraghty



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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:**

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# For more details on how your bequest can help MND research

Contact Dr Gethin Thomas, Executive Director Research:

Phone: 02 8287 4989 Email: research@mndaustralia.org.au

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