the NeuRA magazine

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FIGHTING FALLS:
Innovation, policy and a new community campaign

● *Introducing NeuRA's next-gen philanthropists*

● *Ketamine not proven for chronic pain*

Prenatal genomic testing delivers lifesaving outcome

FIVE MINUTES
with **the Shirvingtons**

NeuRA
Discover — Conquer — Cure

It's been an incredible couple of months here at NeuRA with our inaugural NeuRA Industry Open Day, a new affiliation agreement with the University of NSW and the launch of our new research strategy.

Our Industry Open Day was officially opened by the NSW Minister for Medical Research, the Hon David Harris MP. We were pleased to welcome representatives of our founding partners and the pharmaceutical industry for discussions about how we can collaborate on better diagnoses and treatments to improve brain health across the community.

Many of these themes were also continued in the affiliation agreement signed with the University of NSW. Building on our long history of collaboration, the 10-year agreement will open up opportunities to co-invest in neuroscience ventures and to target recruitment to bolster our existing ranks of brilliant researchers.

We have just launched our new research strategy to focus our work for the next five years. *NeuRA Forward 2025–2030: Tackling the brain challenges that shape our lives* sets our key areas as protecting brain health across the lifespan, maximising brain function and advancing precision brain diagnostics. This strategy puts NeuRA at the forefront of brain research and reflects our ongoing commitment to excellence and impact. I look forward to continuing to work alongside you as we implement it.

Warm regards,

Professor Matthew Kiernan AM
CEO, Neuroscience Research Australia

Above: *Viv Dore participated in NeuRA's virtual reality falls prevention research, which used interactive games to build obstacle avoidance skills.*

Welcome to the Spring Edition of The NeuRA Magazine!

NeuRA's researchers are working to improve brain health throughout the lifespan and in this edition we're pleased to share updates on their work.

This includes information on a new treatment for Motor Neurone Disease, plus the introduction of our new next generation philanthropy program, NeuRA Next.

With falls an increasing problem, we take a look at the work being done by NeuRA's researchers, including their role in shaping policy, embracing technology to improve prevention and a community campaign to boost awareness.

NeuRA's prenatal genomic testing helped save a life. Find out the role our researchers played during a difficult time, including the impact of their work and how they worked with the family and their medical team to achieve such a positive outcome.

Philanthropists are so vital in supporting our work and we're pleased to feature a Q&A with long-time supporters Tony and Virginia Shirvington this month. Tony shares some of his lived experience with schizophrenia, while they both open up about why they support NeuRA's work.

We hope you enjoy these stories and look forward to hearing your feedback. •

NeuRA Next members at their first event that helped raise funds to support the PhD Pearl program.

Introducing our next-gen philanthropy initiative

A new next-generation philanthropy initiative, NeuRA Next, has been established to support NeuRA and the work of its emerging neuroscientists.

NeuRA Next was formed by a group of young philanthropists who are passionate about neuroscience research. Founding members are Alexander Benze von Fritz, Sophie Utz, Lucas Hejtmanek, Emily Harris (nee Hartman) and Amelia de Haan (nee Hurley).

Ms Utz said the committee recognised a widening generational gap in the philanthropic landscape, alongside an increasing prevalence of conditions impacting the brain and being researched by NeuRA.

"We wanted to empower a new generation of philanthropists and bring together people from diverse backgrounds to support NeuRA and its research," Ms Utz said.

"We are witnessing first-hand the impact of anxiety, depression, trauma on our peers. We are witnessing the cognitive decline of our loved ones and facing the long shadows cast by conditions like Alzheimer's and Parkinson's disease. We are acutely aware of how brain health will shape the social, economic and personal realities of our future.

"We want to help NeuRA realise its goals."

Funds raised by NeuRA Next will support the Pearl PhD Program, which empowers early-career researchers to explore bold, innovative ideas in brain and nervous system science.

The committee held its first event in June with great success and they are now planning future events.

People interested in joining NeuRA Next, or attending an event can reach the committee at next@neura.edu.au •

Ketamine: no clear benefit for chronic pain

Ketamine is regularly used for the treatment of chronic pain, but researchers from NeuRA, UNSW Sydney and Brunel University in London have found there is no clear evidence of its benefit for this off-label use.

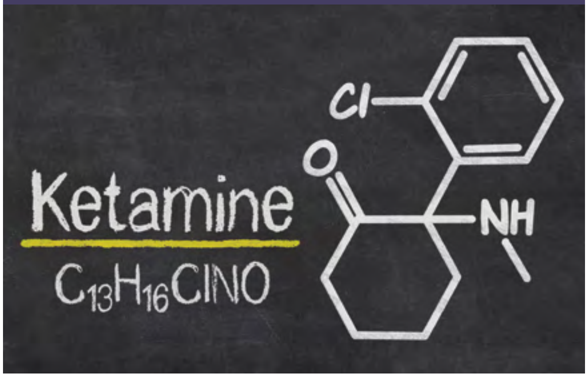
Ketamine is an anaesthetic commonly used to sedate people for medical procedures and short-term pain relief, but it is also frequently given to manage chronic pain conditions such as nerve pain, fibromyalgia and complex regional pain syndrome.

The Cochrane review examined trials for Ketamine and other Nmethyl-D-aspartate (NMDA) receptor antagonists – a group of drugs thought to reduce pain by blocking certain brain receptors involved in pain signalling. It compared the drugs to placebo treatments or other medicines in adults with chronic pain to assess their effectiveness and safety.

NeuRA and UNSW Doctoral Candidate, Michael Ferraro, said the results showed no clear evidence of benefit for ketamine in chronic pain and identified an increased risk of adverse effects such as delusions, delirium, paranoia, nausea and vomiting.

"We want to be clear – we're not saying ketamine is ineffective, but there's a lot of uncertainty," Mr Ferraro said.

"Our findings indicate that recommendations to use ketamine may be premature. Given the widespread use and uncertainty around benefits, policymakers should urgently consider funding definitive trials of ketamine for chronic pain." •



Professor Kim Delbaere with actor Michael Caton as part of preparations for a new falls prevention campaign.

FIGHTING FALLS:
Innovation, policy and a new community campaign

It can happen in a split second: a slip, a trip, a loss of balance resulting in a fall.

In Australia, falls are a leading cause of hospitalisation and injury-related deaths for people aged over 65 years. They also cost the health system more than $2.8 billion annually.

The Falls, Balance and Injury Research Centre at NeuRA has world-leading experts working to tackle the challenge, developing tools, guidelines and campaigns. This year alone the team has launched new National Falls Guidelines, released new research about the impact a fear of falling can have, developed technological-based solutions and teamed up with other researchers and community organisations for an awareness campaign.

New Falls Guidelines were released by the Australian Commission on Safety and Quality in Health Care in June, reflecting best practice and the result of more than five years of work supported by NeuRA researchers, including Senior Principal Research Scientist, Professor Stephen Lord, and Senior Research Scientist, Associate Professor Jasmine Menant.

“The Falls Guidelines 2025 combined research, community consultation and more to develop recommendations and best practice for a range of settings,” Assoc Prof Menant said.

“The guidelines build on our work at the Falls, Balance and Injury Research Centre, by translating the highest level of scientific evidence into effective fall prevention initiatives into evidence-based guideline care. They recommend a tailored approach with different interventions to different people, according to whether they have fallen in the recent past and what additional individual risk factors they have.

“For all settings, there is an emphasis on implementation of interventions, rather an assessment of risk.”

However, understanding risk remains important and Senior Research Scientist and Director of Innovation and Translation at the Centre, Professor Kim Delbaere, led research which found that concerns – or ‘fears’ – about falling are now a strong predictor of future falls.

“Our analysis found that older adults with high concerns about falling were significantly more likely to experience a fall,” Prof Delbaere said.

“While we already knew having had prior falls was a risk factor for developing concerns about falling, this research found falling can be both a cause and consequence

> “Using existing knowledge and the right strategies, we could reduce the burden of falls upon older Australians by 30 per cent.”
>
> – Prof Delbaere

of falls. Importantly, this increased risk was observed even after accounting for key physical risk factors such as age, previous falls and balance impairments.

“This means that concerns about falling are not just a reflection of physical frailty but an independent factor influencing future falls.”

So, what can we do to reduce our falls risk? Well, researchers are doing a lot of work in this space too, including looking to technological solutions that add fun to prevention.

NeuRA researchers have looked to gaming technology like virtual reality (VR) for obstacle avoidance and arcade games inspired exer-game program SmartStep.

Dr Yoshiro Okubo, a NeuRA Research Fellow and Conjoint Senior Lecturer at the School of Population Health at the University of NSW, led the VR study and said these sorts of interventions aimed to make falls prevention enjoyable as well as effective.

Alongside all this, the researchers are also teaming up to spread awareness and fight for more funding for prevention services. NeuRA researchers have joined other researchers and community organisations to form the Falls Prevention Alliance of Australia.

“Using existing knowledge and the right strategies, we could reduce the burden of falls upon older Australians by 30 per cent,” Prof Delbaere said.

“We know what works and we need investment to support the implementation of new falls guidelines, a public awareness campaign and a community-based falls prevention campaign.

“The Falls Prevention Alliance is bringing together people with falls expertise, health professionals, community members and others who are passionate about advocating for change.”

Right now, the Alliance is putting the finishing touches to the exciting new campaign that will bring together some famous faces and impactful messages to spread the word further.

“We’re really grateful to have had support from some high-profile Aussies, community organisations, plus some creative individuals to develop campaign videos and materials that we believe will highlight the issue of falls, but also share tips about how to prevent them,” Prof Delbaere said.

“Falls are preventable so let’s work together to turn the tide, save lives and reduce risks.” ●

Above: *Sandra Harris participated in Dr Yoshiro Okubo's virtual reality falls prevention research project.*

Participant Fred Reader with NeuRA Senior Research Scientist, Associate Professor Jasmine Menant, and one of the exer-games being tested for falls prevention in stroke survivors.

Prenatal genomic testing provides a lifesaving diagnosis

For a Victorian family, sophisticated prenatal genomic sequencing uncovered a baby's rare but potentially lethal blood condition, allowing life-saving treatment within moments of birth.

Pathologists in the genomics program based at NSW Health Pathology and Neuroscience Research Australia (NeuRA) – who are working in the Medical Research Futures Fund PreGen program, to make genomic tests available for families around Australia – provided the lifesaving diagnosis for the now healthy toddler.

NeuRA Neurogenomics leader and Staff Specialist in Clinical Genetics and Genomics at NSW Health Pathology Randwick Genomics, Professor Tony Roscioli, said the team had worked collaboratively with the Randwick Genomics laboratory, Monash Health Clinical Genetics and other clinicians.

"Prenatal genomic testing was recommended to the parents after a routine ultrasound at 31 weeks detected an abnormality," Prof Roscioli said.

"This was done through the PreGen program, based at NSW Health Pathology and NeuRA, where the analysis of the baby's DNA happened.

"This prenatal DNA sequencing identified a rare and potentially lethal condition, congenital thrombotic thrombocytopenic purpura (TTP) caused by a deficiency of ADAMTS13 protein, which is crucial for blood clotting."

The detailed results were shared with specialists in Victoria overseeing the family's care, who made specific recommendations and arrangements to take care of them during the birth. Monash Health Clinical Genetics Clinical Geneticist and Director, Dr Andrew Fennell, said this included ensuring the baby would be born at a specialist hospital and interventions would be available immediately.

"A discussion among members of a multidisciplinary team developed a perinatal management plan for delivery at a hospital equipped to provide the level of care required," Dr Fennell said.

The team set up precautions for things like urgent cord-blood testing and fresh frozen plasma for immediate administration.

They also had Recombinant ADAMTS13 approved by the US Food and Drug Administration for use only days before the baby's delivery and which had not been available locally.

When the baby boy arrived a little over a month later at 38 weeks, treatment targeting the specific gene was commenced with the ADAMTS13 replacement therapy.

"Now we see a healthy toddler whose measures of growth, development, heart and liver function are normal," Dr Fennell said.

This case exemplified the work being done by the PreGen program and the hope that such testing offered families.

"There have been so many families who are getting answers through the PreGen program, and it would be wonderful for this to be able to continue after it finishes," said Dr Sarah Long, senior PreGen genetic counsellor.

"This case illustrates the power of prenatal genomics in guiding precision medicine and enabling lifesaving therapy," Prof Roscioli said. ●

Above: *Mitchell, pictured with his mum, Melissa, and family, is now a healthy toddler, thanks to life-saving prenatal genomic sequencing.*

Life-saving science: 'unreal'

The baby who received that life-saving diagnosis and treatment was Mitchell, a now healthy two-year-old.

For mum, Melissa, it was a scary time, but she's also conscious that the prenatal screening was vital.

"It still seems unreal, that it's possible to pick up such fine details in Mitchell's DNA and be prepared for his birth in a way that was literally life-saving," she said.

"I remember being so worried when we were first told, but the most important thing for us was to figure out how we would be ready and prepared for his birth.

"Knowing in advance what the issue was and how it was going to be treated meant we were able to give birth with the treatments available straight away."

Melissa says the early intervention possible because of the genomic testing changed everything.

"The science saved Mitchell's life."

5 MINUTES with Tony and Virginia Shirvington

Left: *Virginia and Tony Shirvington have been long-time supporters of NeuRA.*

> *"They don't understand that schizophrenia sufferers are ill, not lacking in intellectual ability or deliberately engaging in violent or aggressive behaviour."*

Tony Shirvington was diagnosed with schizophrenia in 1983 and was treated with psychotherapy and medication for the next 20 years. In 1987 he married Virginia, and worked as a solicitor until retiring.

In 2018, Tony became ill and was treated in hospital for 10 days on new medications which helped him become "a more rounded person". The Shirvingtons are passionate supporters of NeuRA's schizophrenia research.

Tony, what difference did having a diagnosis and treatments make to you?

The initial treatment stabilised me and enabled me to continue to work, form a relationship with Virginia and enjoy a successful marriage. However, in 2002 I suffered a panic attack probably caused by the stress of work. I stopped working until 2004 when I took up part-time legal work until 2009 when I retired (aged 58).

Over the past seven years since my medications were changed, I have endeavoured to bring into balance my intellectual pursuits and social interactions. My greatest challenges remain fatigue and lack of energy, plus cervical dystonia, a side effect of previous anti-psychotic medications which severely limits my physical activity.

Tony, if there was one overarching message you'd like people to know about schizophrenia, what would it be?

I think because schizophrenia is often accompanied by introversion it is commonly interpreted by people as a cold, unfeeling aloofness. This perceived aloofness reflects the inner turmoil that people with schizophrenia are going through.

Virginia, can you give us the perspective of supporting a loved one with schizophrenia?

I feel very protective towards Tony and I feel very angry and sad if people upset him with their inconsiderate comments and behaviour.

The reactions of family to Tony's illness and the fact we didn't have children are significant challenges.

Virginia, what do you think is the public perception of schizophrenia – and what do you wish more people understood about it?

It disturbs me that people stigmatise schizophrenia and do not give sufferers of mental illness the same understanding and consideration they give sufferers of physical illness. They don't understand that schizophrenia sufferers are ill, not lacking in intellectual ability or deliberately engaging in violent or aggressive behaviour.

Tony, you've both been long-time supporters of NeuRA, including as supporters of our PhD Pearl program and have so generously included a gift to NeuRA in your Will. How did you first become involved with NeuRA?

We have supported NeuRA for about 20 years in its various forms, initially the Schizophrenia Research Institute.

The research at NeuRA into schizophrenia provides hope that the insidious illness will one day be cured and in the shorter term managed with more effective medications. We are so pleased to be supporters of NeuRA. ●

Ask a Researcher

A new treatment for amyotrophic lateral sclerosis (ALS), a type of Motor Neurone Disease, has been listed on the Pharmaceutical Benefits Scheme (PBS) for eligible adults. We caught up with NeuRA CEO, Scientia Professor Matthew Kiernan AM, (pictured) to find out more about Radicava IV infusion from Teva Pharma and what it means for patients.

Q: What can you tell us about this new medication and how it works for people with ALS?

A: ALS is the most common type of Motor Neurone Disease and Radicava has been approved as a treatment option for people who have this diagnosis.

Specifically, this medication has been approved for people within two years of disease onset and who are independent in their activities of daily living and with normal respiratory function.

Q: What does the approval of this new medication mean for people with ALS?

A: ALS is a rapidly progressing disease, placing a substantial physical, emotional and financial burden on individuals and their families. Early symptoms can be subtle and ALS is difficult to diagnose.

Radicava IV is the first new PBS-listed treatment for ALS in more than 20 years, so this is quite significant. It offers another treatment option to help people remain in the milder form of the disease for longer.

This is important because ALS symptoms can progress quickly, but early treatment can help slow the progression of the condition and reduce decline in quality of life.

Q: What makes this medication different from other treatments that are currently available?

A: Radicava has been demonstrated to slow down and reduce disability. The pivotal international trial incorporated disability as an outcome measure, as reflected by scores using the ALS Functional Rating Scale-Revised (ALSFRS-R). The trial results established that patients receiving edaravone, now known as Radicava, had a significantly smaller decline in ALSFRS-R scores compared with placebo, a difference of approximately 33% in the rate of decline.

If healthcare professionals suspect ALS or MND, it is important to refer to a neurologist who can diagnose MND to meet the individual's needs as early as possible, including the commencement of protective treatment, to keep patients in the milder form of the disease for longer periods. •

Include NeuRA in your Will

Including a gift to NeuRA in your Will is a powerful way to accelerate research that will transform people's lives. A gift of just 1% of your estate will allow us to deliver world-first clinical trials, effective treatments, early interventions and crucial research that we simply could not do otherwise.

With your gift, we will help people lead happier and healthier lives for longer and we will shape the future of neurological wellness for generations to come.

NeuRA's Philanthropy Team is available to help you to organise a gift in your Will and keep you up to date with NeuRA's research.

Please feel free to phone us on 02 9399 1093 or email bequests@neura.edu.au

NeuRA
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