

the NeuRA magazine

News and breakthroughs from Neuroscience Research Australia • neura.edu.au

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BRAIN DONATIONS: Building hope and unlocking answers

*Tackling pain
in the body
and the brain*

PLUS:

- Ask a researcher:
what is MND?
- Remembering
Marc Girod



Welcome to our Spring edition of NeuRA Magazine.

The prevalence of brain and mental health conditions continues to increase, but with your help NeuRA is continuing to work

to tackle these challenges.

Our NeuRA researchers are working to embrace the opportunities of new technologies, including the role they can play in identifying biomarkers and delivering personalised treatments.

In recent weeks we've been pleased to announce new partnerships that enable us to improve diagnosis, treatment and prevention of conditions that affect brain health. Building partnerships and collaborations brings together different perspectives and expertise, allows the sharing of resources, supports our research and increases our impact.

Your generosity, and that of all our supporters, is also accelerating and expanding our efforts. Throughout the year we have been recipients of your gifts, including during our recent Giving Day. We are truly appreciative of all your support and every donation we receive. Thank you for your ongoing support, which enables our scientists to continue to make life-changing discoveries.

This edition includes a snapshot of some of our recent research, shares the story of one of our supporters and gives insight into the important work of our Sydney Brain Bank.

We hope you enjoy this edition and welcome your feedback.

Warm regards,

Professor Matthew Kiernan AM
CEO, Neuroscience Research Australia



Above: Professor George Paxinos AO and Dr Steve Kassem hope to improve accuracy and consistency in naming and abbreviations for central nervous system structures.

Neuroscientists propose a 'periodic table' for brain structures

Researchers from NeuRA have proposed a unified list of terms and abbreviations for central nervous system structures, inspired by the 'periodic table'.

World-renowned brain cartographer and NHMRC Senior Principal Research Scientist, Scientia Professor George Paxinos AO, led the team developing 'Central Nervous System Terms and Abbreviations', an online resource for more than 3,300 brain and spinal cord structures to improve clarity and accuracy in communication.

At present, terminology and abbreviations for the same structure are often in conflict across species, developmental stages and neuroanatomical traditions.

"Imagine one airport used 'SYD' for Sydney and another used 'SDN' for Sydney, whilst a third used 'SYD' for a completely different city," Prof Paxinos said.

"There would be confusion, similar to what happens now among neuroscientists when they explore the brain."

The new resource, Central Nervous System Terms and Abbreviations, was inspired by the periodic table offering a unified system of brain and spinal cord terms and abbreviations across species.

The resource is intended to evolve and is available online now. ●

Promising new psychiatric treatments not yet delivering

New psychiatric treatments that boost the brain's natural 'bliss molecule' levels offered promise, but researchers have found they are not yet delivering.

Neuroscience Research Australia (NeuRA) Research Fellow, Dr Timothy Couttas, led the review that looked at the progress of fatty acid amide hydrolase (FAAH) inhibitors as a treatment for conditions like major depressive disorder, psychotic disorders and post-traumatic stress disorder.

FAAH is an alternative to medicinal cannabis and works to enhance what's sometimes called the 'bliss molecule', a principal endocannabinoid called anandamide, or AEA.

The review examined the influence of FAAH on AEA, plus their safety and efficacy across a range of psychiatric conditions, and concluded that FAAH inhibitors have not yet fulfilled their clinical promise from preclinical data.

Researchers found further work was required before treatments could be implemented, including identifying predictive biomarkers to help identify individuals most likely to benefit from FAAH-targeted interventions. •



Dr Timothy Couttas says while new psychiatric treatments offer promise, more work is needed.



NeuRA's Professor Kaarin Anstey helped draft the new World Health Organization dementia guidelines.

Looming global dementia crisis is avoidable

The World Health Organisation has released the first update of its guidelines on 'Risk reduction of cognitive decline and dementia' since 2019, bringing together years of subsequent global evidence on effective strategies.

Dementia expert and NeuRA Senior Principal Research Scientist, Professor Kaarin Anstey, was the only Australian expert involved in drafting the guidelines and said they are a "vital step forward" in tackling the looming cognitive crisis.

The guidelines reinforce the message that addressing common risk factors and ensuring access to preventative strategies through public health systems, education and healthy environments could avoid close to half of future cases.



More than 57 million people worldwide have dementia and some 10 million more are diagnosed each year.

Prof Anstey said the guidelines were the culmination of a systematic and wide-ranging review of the evidence on efficacy of interventions and recommendations offered real-life actions to reduce dementia risk and promote brain health.

"We need to underline the message that many cases of dementia may be prevented and these guidelines are a vital step forward in reinforcing that," she said.

The guidelines build on previous recommendations. Key updates include that cognitive training and stimulation can be offered as a preventative strategy and social activities should be encouraged, whilst vitamin supplements are not recommended. •

BANKING ON THE FUTURE:

how donations are helping tackle our brain health challenges



Sydney Brain Bank Director, Associate Professor Claire Shepherd.

Our brains do so much for us during our lifetime, but at the Sydney Brain Bank at NeuRA, the legacy of this incredible organ lasts even longer.

Located inside NeuRA's Randwick headquarters, the Sydney Brain Bank is an internationally-recognised biobank helping researchers around the world unlock the secrets of our brains. Inside the lab, the precision work of scientists helps to improve our understanding of the brain, the diseases that affect it, improve diagnosis and unlock new treatments.

However, that work begins long before the precious donations arrive in the lab.

Sydney Brain Bank Director, Associate Professor Claire Shepherd, who oversees the facility and its research said many people are unaware of the process of donation and that the generous gift begins in life.

"The Sydney Brain Bank and our team work with donors in their lifetime to build a comprehensive understanding of them and their clinical background," she said.

"Relating the disease symptoms and the brain pathology is an important piece of the puzzle for us.

"Then, their donation can go on to support research projects here at NeuRA, nationally and even internationally."

The Sydney Brain Bank team is hands-on, working with donors and their families throughout the process. While these researchers are highly skilled scientists in the lab, they are also on-call 24 hours a day to take the call when a donor passes away. And this is critical: time is short when it comes to preserving brain tissue and they are responsible for retrieval and care.

Research Officer, Dr Kathryn Laloli, is one of those involved in this vital work. It's with passion and compassion she describes her role, which includes the collection and processing of tissue, as well as neuropathological analyses.

"We work with a range of stakeholders once there is a donation to collect and do the retrieval ourselves within 48 hours," Dr Laloli said.



"This helps ensure the brain remains in good condition, but also supports the family to progress with their funeral arrangements."

**Sydney Brain
Bank Manager,
Heather McCann.**



“These samples are used in a range of research projects that are helping us better understand conditions such as Parkinson’s disease, various dementias and chronic traumatic encephalopathy, or CTE.”

– Sydney Brain Bank Manager, Heather McCann

Once at the Sydney Brain Bank, the team continues their care of the donation.

Sydney Brain Bank Manager, Heather McCann, said every brain is individually prepared, including a neuropathological analysis.

“The neuropathology results can be linked to the donor’s clinical information to help refine future diagnosis, but we also provide it to the family should they wish to know the outcome,” she said.

“These samples are used in a range of research projects that are helping us better understand conditions such as Parkinson’s disease, various dementias and chronic traumatic encephalopathy, or CTE.

“We use this tissue in research here at NeuRA, but we also support the research at other institutions.”

The Sydney Brain Bank currently houses more than 900 specimens, plus 250 spinal cords.

Many people decide to donate their brains after they or a family member receive diagnosis of a neurodegenerative condition, but the Sydney Brain Bank also needs more healthy donors.

“It’s important for our research to have healthy brains to access as controls for our research,” Assoc Prof Shepherd said.

“Unfortunately, this may not be on people’s radar, or they may think it comes under the organ donor program, but we always need people aged 60 years and over to sign up to be a healthy donor.

“It really is a gift to future generations and helps us find answers to our brain health challenges.” •

WHY is brain donation important?

Brain donation is vital for researchers to understand how cellular changes occur in our brains, supporting improved diagnosis, treatment and even prevention. Brain donation through the Sydney Brain Bank supports research here at NeuRA, but also globally.

WHO can donate their brain?

The Sydney Brain Bank currently works with 10 brain donor programs. These focus on conditions such as Alzheimer’s disease, Parkinson’s disease, Motor Neurone Disease, Huntington’s disease, frontotemporal lobar degeneration.

People aged 60 years or older who are neurologically healthy are also encouraged to donate to support the NeuRA Volunteers Brain Donor Program.

HOW do you donate your brain?

You can find information about brain donor programs on the Sydney Brain Bank website, <https://sbb.neura.edu.au/>

Donations are made through different brain donor programs who recruit individuals and collect clinical information during life.

**Scan to find
out more**



Holistic pain treatments tackle links between pain and wellbeing

Professor Sylvia Gustin
with her Pain and
Emotion Therapy.



Chronic pain impacts daily life and functioning, but researchers are exploring the intertwined links between pain and psychological wellbeing.

The Centre for Pain IMPACT at NeuRA has been working to improve our understanding of pain on the brain and central nervous system, evaluate treatment efficacy and develop new treatments. This includes understanding the impact of pain on wellbeing.

Director of the Centre for Pain IMPACT, Professor Sylvia Gustin, said chronic pain affects around 20% of people worldwide and evidence is growing on the bidirectional link between pain and psychological wellbeing.

“While pain is absolutely real, chronic pain affects every aspect of a person’s life, including their emotions, relationships and overall wellbeing,” Prof Gustin said.

“However, there have been very limited treatments available that specifically target the emotional impact of chronic pain.

“That’s why I started my research dedicated to understanding the emotional aspects of chronic pain: to better understand how pain affects the brain, emotions and psychological functioning, and ultimately to develop treatments that address the whole person, not just the sensation of pain.”

The Centre’s work on this theme includes projects like Pain and Emotion Therapy, PAINCODE, Psychosocial factors associated with spinal cord injury, ENIGMA, and TMS and tDCS as a treatment for chronic pain and mental health.

Prof Gustin said the stigma of pain was ongoing but chronic pain is a real neurological issue.

“People living with chronic pain are often stigmatised,” she said.

“Unfortunately, there is still a misconception that if pain cannot be seen, it’s not real – but chronic pain is very real.”

“Our research has shown that chronic pain is associated with measurable changes in the brain, including changes in brain structure, function and biochemistry, particularly in areas involved in emotional processing. These findings demonstrate that chronic pain is not simply ‘in someone’s head’, but rather that it reflects real changes in the central nervous system.”

Researchers are developing therapies that target the emotional aspects of pain and can improve both emotional wellbeing and the pain itself.

“Recognising the emotional and brain-related aspects of pain validates people’s experiences because it shows that there are real biological processes involved,” Prof Gustin said.

“Chronic pain involves both physical and emotional processes and we need treatments that address both.”

This includes interventions like Pain and Emotion therapy, developed by Prof Gustin and Dr Nell Norman-Nott, which has shown improved emotional aspects plus reduced pain intensity.

Alongside development of new treatments, Prof Gustin and her team are improving their understanding of the brain mechanisms in chronic pain and have established ENIGMA Chronic Pain, a world-wide consortium to combine global data.

“We are continuing to investigate why some people develop chronic pain and why, for some individuals, pain persists long after the original injury or illness,” Prof Gustin said.

“We work closely with people living with chronic pain and want to help them receive the understanding and treatments they deserve.

“Our goal is to continue developing effective treatments that are accessible to everyone, whilst also improving our understanding of the mechanisms driving chronic pain so treatments can become more personalised and effective.” •

Living positively, with purpose

*Right to the end,
Marc Girod was
determined to
live positively.*



Marc Girod was a French-born artist, who made his home in Australia and became a NeuRA supporter after being diagnosed with Motor Neurone Disease.

Two years ago Marc was diagnosed with Motor Neurone Disease in his early 40s. Yet even as it took hold, Marc maintained a positive outlook, despite his diagnosis. His positivity came, he said, because “rational thinking should make you use your time and energy on elements you have control over, and therefore you can change”.

For Marc, that meant living life on his terms, in the full knowledge of what an MND diagnosis would mean. He travelled the world, took in every experience, and sought out the company of his friends, in person and online.

As an extraordinary column by Marc reveals – published posthumously in *The Guardian* – he was determined not to waste a minute, until his last few weeks became increasingly grim.

“I always wanted to get married and have kids but I didn’t get the chance,” he wrote. “Instead I made sure to have a good single man’s life: I could party all weekend, and travel a lot.

“At 39, I decided to be an artist and spent every evening painting. I organised an exhibition less than a year later.”

During his last few months, Marc used social media both to chart the horrible progression of his disease, but also his determination to enjoy life while he could – and to leave a legacy.

For more than a year Marc had been fundraising and driving awareness for NeuRA, where he had been receiving care.

Generating more than \$30,000 so far for research, Marc hoped that sufferers of neurodegenerative diseases in the future can look forward to a more positive diagnosis.

Equally, his determination to enjoy the company of his friends went on until the hours before Marc passed away on April 20, with a party he held on the beach the day before.

“Life is amazing because it ends,” he wrote in *The Guardian*. “Everybody dies. I’ve had a great life with a lot of people who love me – I’ve been really lucky.” •

Generating more than \$30,000 so far for research, Marc hoped that sufferers of neurodegenerative diseases in the future can look forward to a more positive diagnosis.

Scan the QR code if you'd like to make a donation in Marc's memory





Ask a Researcher



Motor Neurone Disease has made headlines due to its impact on high profile Australians, so we asked NeuRA CEO Professor Matthew Kiernan AM to tell us more about the disease and research underway at NeuRA.

Q: Motor Neurone Disease has been in the news a lot lately, but what is it?

A: Motor Neurone Disease, or MND, is a rapidly progressive neurodegenerative condition. It leads to progressive muscle weakness and eventual paralysis, and unfortunately it is universally fatal.

It occurs when the cells in the brain and spinal cord, known as motor neurons, that control essential muscle movements gradually stop working. These muscles enable you to move, speak, breathe and swallow, meaning the disease significantly impacts a person's everyday life.

Q: Who is typically affected by MND?

A: The condition most commonly affects people in their mid-to-late-50s and early 60s, and survival is typically two to five years from the onset of symptoms. However, MND does affect people in other age groups too.

While we have medications that can slow the progression of the disease, there is currently no cure.

Q: What research is underway into this condition and treatments?

A: At NeuRA, our goal is to better understand why the motor neurons die and how to slow or prevent this process. We still don't know the precise cause of MND, but current research suggests it involves a complex interplay of genetics, environmental factors and neurological changes.

We conduct clinical trials to test novel treatments that could change the course of the disease. Our scientists have identified several promising therapeutic targets and we are the Australian sponsor and lead site on an innovative platform trial that uses a 'precision medicine' approach to deliver targeted treatments.

We launched the Asia-Pacific MND Imaging Initiative (AMII), which has established a growing repository of over 900 brain scans to support discovery in diagnosis and disease mechanisms.

We have identified novel neurophysiological biomarkers, which are now being integrated into projects using artificial intelligence to improve patient outcomes and accelerate the search for effective treatments. •

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



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