

the NeuRA

magazine

Issue 32 | Autumn 2020

Research shows chronic pain can change who we are

- Tommy Little:
From snow storms
to spinal cords
- New app helps older
Australians stand tall
- How chronic pain
changes our
personalities
- The 2020 Bridge
for Brain Research
Challenge

Message from our CEO

Professor Peter Schofield AO



Prof Peter Schofield AO

First off, I would like to share my gratitude to our donors for your ongoing support. The research projects that lie ahead this year, and the impact they will go on to have, would not be possible without your generosity. So from everyone at NeuRA, thank you.

Before I touch on some of the exciting new projects taking place over the next 12 months, I would like to recap some of the activities that took place at NeuRA toward the end of last year.

In November, NeuRA's Sydney Brain Bank announced a new brain donor program to investigate the impact of head injuries on former NRL players. The research program is particularly exciting, as it is the first of its kind in Australia - never before has the brain health and wellbeing of NRL players been monitored before their death and then correlated with neuropathology.

We also received a special visit from well-known Australian comedian, Tommy Little, who has partnered with Spinal Cord Injuries Australia (SCIA) to provide generous support for NeuRA's research into nerve and spinal cord injury.

This year we have welcomed new research leaders to groups studying Pain, Aboriginal Health and Ageing, and Spinal Cord Injury. We especially thank our major donors who contributed to the NeuRA Discovery Fund and enabled us to add to the collective firepower of NeuRA's research team.

Also, on a slightly different note, in January we were selected as the charity of choice by Rhonda Burchmore during her time on the Channel Ten series 'I'm a Celebrity Get Me Out of Here'. Rhonda chose to support our research efforts after losing her sister to Multiple System Atrophy (MSA), a relatively rare, but severe neurodegenerative disorder.

NeuRA is committed to the ongoing study and discovery of cures for the brain and nervous system disorders. It is through your support, donations, and bequests that we are able to keep making progress and find solutions.

Prof Peter R Schofield AO *FAHMS PhD DSc*
Chief Executive Officer



"Because I am committed to NeuRA's important work, to alleviate the burden of disease that many Australians have to face, I have left a gift in my Will."

– Stewart Horwood,
Bequestor

Yes! **I would like more information about making a bequest to NeuRA**

Title: _____ First Name: _____

Surname: _____

Address: _____

State: _____ Postcode: _____

Email: _____

Mobile: _____

Preferred method of contact: Phone Mail Email

Please return this form to: NeuRA Foundation,
PO Box 1165, Randwick NSW 2031 Australia

- I'm interested in leaving a gift to NeuRA in my Will. Please send more information to me.
- I would like to speak confidentially with someone at NeuRA, please call me on the number above.
- Yes, I have already included a gift to NeuRA in my Will.
- I intend to include a gift to NeuRA in my Will when I next revise it.
- I'm not in a position to make a commitment at this time.



You can contact the Gifts in Wills Manager with any questions

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BEQUEST FOR CURES

Board member named NSW Australian of the Year



Associate Professor Munjed Al Muderis

Congratulations to esteemed surgeon, human rights advocate and member of NeuRA's Governing Council, Associate Professor Munjed Al Muderis, who has been awarded 2020 NSW Australian of the Year.

Munjed was born in Baghdad, and worked there as a doctor until Saddam Hussein's Republican Guard ordered him to surgically remove the ears of army deserters. After refusing this command, Munjed fled Iraq and sought refuge in Australia, where he became an orthopaedic surgeon.

Today, Associate Professor Al Muderis is a world leader in osseointegration, an innovative procedure which anchors robotic prosthetic limbs directly on to the bone, providing patients with sensory stimulation and some level of feeling.

"My mission in life is very simple. I fight for equality and tolerance and acceptance. I fight for the rights of everybody to get what they deserve and without any discrimination based on colour, race or gender," Assoc. Prof Al Muderis said.

New research looks at the impact of concussions

The Sydney Brain Bank at NeuRA has established a new donor program that will examine the brain health of National Rugby League (NRL) players, and look into the consequences of head injuries.

The research team, led by Sydney Brain Bank director, Dr Claire Shepherd, will examine whether there are cellular changes to the brains of NRL players. Our goal is to learn more about the impact of head injuries, such as whether they are causing chronic traumatic encephalopathy (CTE).

"This is a research area that will require long-term commitment and funding. This is a complex area of research and the findings from this new donor program will help us to answer key questions about sports-related brain injuries," said Dr Shepherd.



Dr Claire Shepherd examining an image of a brain at NeuRA's Sydney Brain Bank

About the
Sydney
Brain Bank



More than
650
brains in storage

5,224
samples supplied in 2019
for 18 tissue requests



L to R: Michael Rabbitt (SCIA Chair), Peter Schofield AO (NeuRA CEO), Tommy Little, Simon Gandevia (NeuRA Professor), Dianne Lucas (SCIA CEO)



Tommy at the end of his marathon

Tommy Little raises \$115,000 for spinal cord injury

Late last year, NeuRA had the good fortune to receive a generous donation from Australian comedian and media personality, Tommy Little. Known for his stand-up comedy acts and work as a presenter on Channel Ten, Tommy decided on this occasion to embark on a slightly different adventure for a very good cause.

He participated in the Antarctic Ice Marathon, often referred to as the “world’s hardest marathon” to raise money for spinal cord injury research at NeuRA.

To prepare for the harsh conditions, Tommy, who had never done a marathon, chose to train for the event by running on a treadmill in the back of a container truck that was cooled to -20°C.

The conditions during the race were freezing with plenty of ice. Tommy completed the 42km challenge in just over five hours, and managed to raise over \$115,000.

“It was by far the hardest thing I’ve ever done. The only thing that got

me through was the dire need for a cure. You can’t undo spinal cord injury but research is bringing us closer to being able to treat the paralysis it causes,” said Tommy.

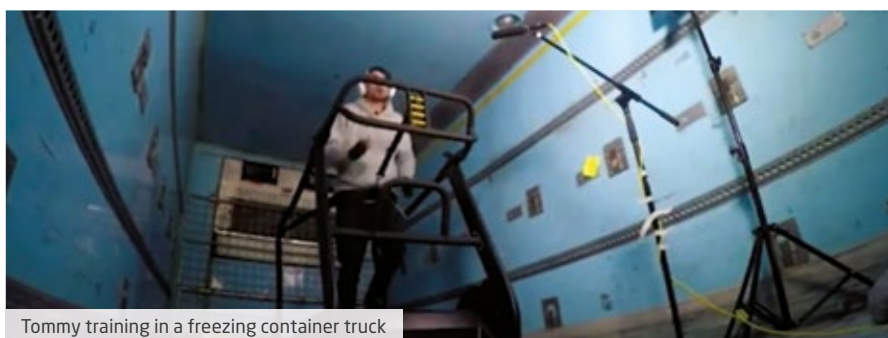
In partnership with Spinal Cord Injuries Australia (SCIA), Tommy decided to donate his hard-earned funds to NeuRA’s research efforts into spinal cord injury. The funding will go towards work led by Simon Gandevia, Senior Principal Research Fellow at NeuRA.

“The effects of a spinal cord injury go far beyond the loss of the ability to walk. Normal functions which we take for granted, such as bladder and bowel control, sexual function

and cardiovascular stability, can be profoundly affected,” said Professor Gandevia.

Research in this area has delivered some highly compelling results, such as returning significant feeling and function to people who have been paralysed for many years. However, the paralysis caused by severe trauma to the spinal cord is still considered one of the most challenging of medical problems.

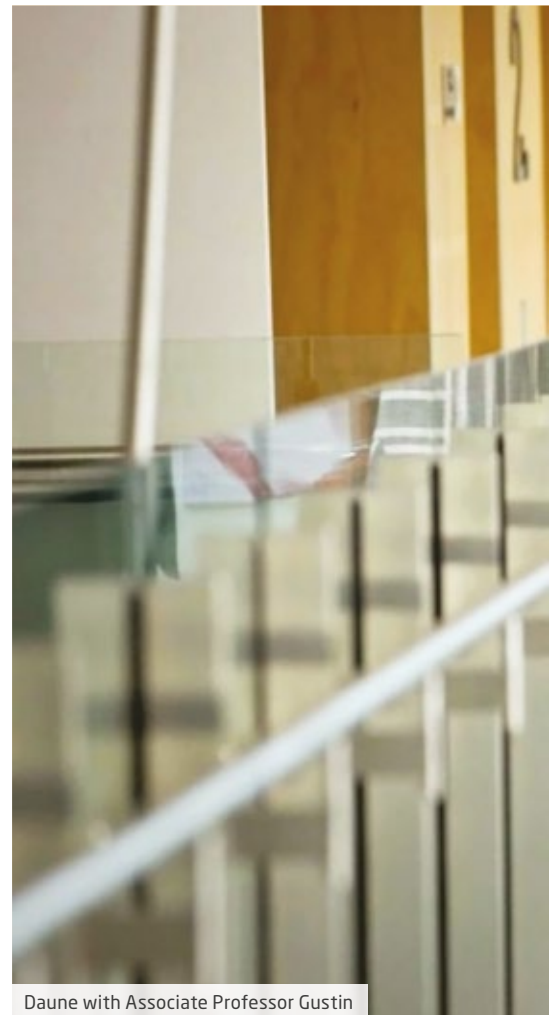
With about 200,000 new cases of traumatic spinal cord injuries reported each year, NeuRA is incredibly grateful for this funding and for the impact it will have on those who have been paralysed, and those around them.



Tommy training in a freezing container truck



Daune entering NeuRA's MRI machine



Daune with Associate Professor Gustin

NeuRA discovers chronic pain changes our personalities

Daune Coogan first enlisted the help of NeuRA's leading pain researcher, Associate Professor Sylvia Gustin, after she realised the unbearably excruciating pain she felt in her face was not going away.

The pain first arrived 14 years ago when Daune was diagnosed with Ramsay Hunt Syndrome (RHS), a rare neurological disorder that paralyses the facial nerves.

"It was like no other pain I had ever experienced. The pain was completely debilitating, as if someone had put a hot poker in my ear canal, across the left side of my face, behind my left eye and the left side of my head. It was so extreme that I basically collapsed and was rushed to hospital," Daune recounted.

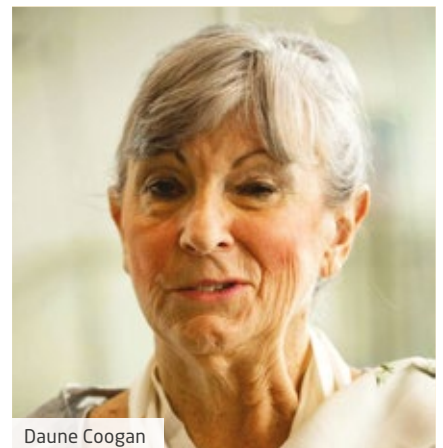
Despite the disease having healed, Daune's pain remained.

"I cried nearly every day for many years when I found out the pain wasn't going away. Even now, the pain can be so horrid that I have to stop or have to adjust my daily activities to enable myself to cope," she said.

"The realisation that this pain was going to be a permanent fixture in my life was dreadful. It was heartbreaking."

Hoping that it would help reduce the pain she was experiencing, Daune volunteered to participate in Associate Professor Gustin's investigative work.

Associate Professor Gustin's research was looking into the relationship between mental health, negative emotions and chronic pain.



Daune Coogan

"Understanding this link is important for people with chronic pain, as they are often unfairly labelled as having certain personality traits that make them more likely to experience pain. What we discovered, proved this is not the case," Associate Professor Gustin explained.



“Working with Associate Professor Gustin has been crucial in exploring my condition, and helping me understand why I have changed. Now I see how chronic pain is linked to my brain and the long-term effect it has had on the person I am today,” Daune said.

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“Having this chronic pain limits my ability to function normally. It’s easy to come off as moody, upset, tired and anxious. The pain itself is not visible, but these side effects are, and because the brain is responsible for these symptoms, controlling them is very difficult.”

The implications of Associate Professor Gustin’s discovery are significant, and could potentially explain why almost half of people with chronic pain experience mental health conditions, such as depression and anxiety.

“It’s important to remind people that there is more behind these behaviours than meets the eye. The more aware people are of chronic pain, the more empathetic they might be toward others who are suffering from these unfortunate emotional changes,” Associate Professor Gustin explains.

Through the study that Daune was participating in, Associate Professor Gustin discovered that the communication process in the brains of people with chronic pain is disrupted. This disruption is caused by a lack of the brain’s key chemical messenger, glutamate, which is normally responsible for regulating thoughts and emotions.

“A reduction of glutamate prevents us from being able

to effectively process emotions – including joy, interest and hope – and makes people more likely to become more pessimistic. This can lead to the personalities of people with chronic pain changing for the worse, where they become more down, angrier and more fearful,” Associate Professor Gustin said.

“Working with Associate Professor Gustin has been crucial in exploring my condition, and





The *StandingTall* app

NeuRA launches new app to help older Australians stand tall

At the age of 85, Harold Berman has recovered from a detrimental fall, said goodbye to his walker, and is moving in public with confidence and stability - all thanks to a new exercise program.

StandingTall is a home-based exercise app designed specifically for older Australians by senior NeuRA researcher, Associate Professor Kim Delbaere and her team. It contains over 2,000 exercises that train balance and cognitive functions to reduce the likelihood of falling.

Harold first started using the program five years ago, after a bad fall that left him with a fractured ankle and fibula. Required to wear a knee-high surgical boot and use a walker to get around, the incident left Harold feeling wobbly on his feet and fearful of falling again.

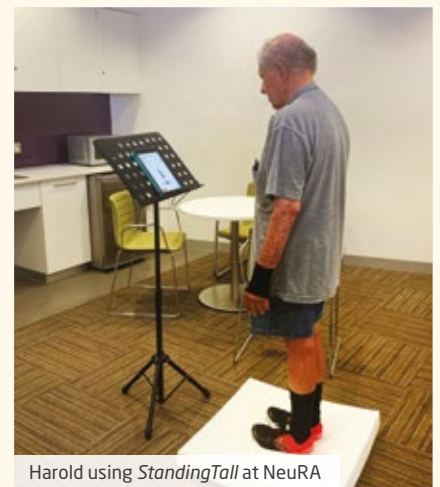
Once he was able to walk without his recovery equipment, Harold signed up to NeuRA's trial and began using *StandingTall* in his home.

"I started off doing 10 minutes a day and gradually increased my time over the course of a few weeks," Harold said.

"Eventually I was practicing up to 30 minutes a day, consecutively! It didn't take me long before I was back to my normal routine of going for daily walks with great confidence," he said.

"In fact, prior to my fall, I used a walking stick to get around, but as I used the app, I felt surer and more stable and needed my stick less.

"In fact, prior to my fall, I used a walking stick to get around, but as I used the app, I felt surer and more stable and needed my stick less. I still take it with me whenever I go out but only as a 'security blanket' for use when necessary."



Harold using *StandingTall* at NeuRA

I still take it with me whenever I go out but only as a 'security blanket' for use when necessary."

Harold is one of 500 people Associate Professor Delbaere is working with to finalise *StandingTall*, which is now being used by healthcare workers in NSW and Victoria. Her trials have found that *StandingTall* improves balance, which can reduce the likelihood of falling during daily life activities.

"We've designed *StandingTall* so that it's very easy for older Australians to use. Already, 85 per cent of people using the app have said integrating it into their daily routines has helped them improve their balance, confidence and overall health. We're now making the app available for communities across Australia," said Associate Professor Delbaere.

Could smoke from Australia's bushfires affect brain health?



In 2019, NeuRA's senior researcher Dr Ruth Peters found a clear link between air pollution and the risk of getting dementia later in life. The study showed rates of dementia are higher in people that have been exposed to certain air pollutants, especially particulate matter 2.5, which is found in bushfire smoke.

Here's what you can do to help reduce your exposure to particulate 2.5:



- Stay indoors when the air quality is low



N-95
P-100

- If you do go outside, wear a disposable respirator (known as N-95 or P-100 respirators) and make sure it is fitted properly



- Avoid physical activity while outside that makes you breathe quickly or deeply



- Consider purchasing an air cleaner so the air in your home is filtered

DONATION & RESEARCH VOLUNTEER FORM

All gifts over \$2 are tax deductible

- Yes, I would like to donate to research at NeuRA
 Yes, I am interested in participating in research at NeuRA

Title:

First Name:

Surname:

Address:

Suburb:

State:

Postcode:

Phone:

Email:

How I choose to give my gift:

- Please accept this one-off gift to support research at NeuRA
 I would like to invest in the future and become a *Discovery Partner* with a regular donation of \$ _____ monthly / quarterly (please select)

\$50 \$100 \$250 or

A cheque payable to the NeuRA Foundation is enclosed OR

I wish to make my gift by credit card:

Visa Mastercard American Express Diners

Card No:

Expiry Date:

Cardholder's Name:

Cardholder's Signature:

If you do not require a receipt, please tick here

Please send me:

Details about how I can support NeuRA in my Will

- Mail this coupon in the reply paid envelope
- Call us on **1300 888 019** to make a donation over the phone
- Make a secure online donation at neura.edu.au/donate

A message from the NeuRA Foundation: The NeuRA Foundation may co-operate with other like-minded reputable Australian charities to promote our work to our respective donors. If you'd prefer that NeuRA does not share your information with other charities, please phone us on **1300 888 019**, email us at foundation@neura.edu.au or write to us using the enclosed envelope.

Thank you for generously supporting our research into diseases

Neuroscience Research Australia Foundation, PO Box 1165, Randwick NSW 2031 ABN 57 008 429 961

POSTPONED: 2020 Bridge for Brain Research Challenge!



Due to the COVID-19 pandemic, our annual Bridge for Brain Research Challenge planned for the first week of May will be pushed back to a date later in the year. We will announce the new date over the next few months

As a research institute, we are of course following health advice being given by authorities and are committed to taking every precaution to help protect the welfare of NeuRA's staff, our research participants, and the community.

Given our mission to improve health outcomes for Australians, especially our senior citizens, we are deeply concerned about the potential impact of COVID-19.

We are all aware that this virus has the biggest impact on those who are frail or have underlying health conditions. The impact on this demographic is particularly close to home for us as many of the participants in our research are older Australians.



For NeuRA, events like the Bridge for Brain Research Challenge are vital. Last year, a record 3,000 players signed up! Although the future is currently uncertain, our hope is that we can continue to grow in numbers as more people participate in this great competition.

Through the support of Australian bridge players, NeuRA has made inroads in Alzheimer's research. For example, we have developed a guide to genetic testing for dementia and identified some genes that are modified by factors such as diet or strenuous mental activity (such as playing bridge).

Every year, 1 in 5 Australians is struck down with a major brain or mind disorder. So if you would like to do something to help these people, while having fun at the same time, we encourage you to join in the Bridge for Brain Research Challenge when we have a confirmed date for the challenge.

**For information about the Bridge for Brain Research Challenge, please visit our website: foundation.neura.edu.au/bridge
Email: bridge@neura.edu.au Phone: 1300 888 019**

NeuRA entered the Jungle

Rhonda Burchmore selected NeuRA as her charity of choice for the Channel 10 series 'I'm a Celebrity... Get me Out of Here!' because of our research into neurodegenerative diseases, such as Multiple System Atrophy (MSA).

Sadly, MSA took the life of Rhonda's sister. We are incredibly grateful to Rhonda, who was one of the final three contestants, for promoting our work during her time on the show.



Thank you for your support

If you wish to update your preferred communications from NeuRA, please call 1300 888 019.

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