

Welcome to the eighth edition of "PAIN PALS", a newsletter which provides friends and supporters of the Pain Management Research Institute with news about recent research breakthroughs, some patient stories and events in support of the work performed at PMRI.

### In this issue, we highlight:

- **Nikki Gemmell's story about her mother's journey through chronic pain**
- **New research into cannabis medicines**
- **New researcher kicks off spinal cord stimulator trial**
- **Michael Cousins AO named as Patron of Pain Management Research**

### MY MOTHER'S SECRET

Nikki Gemmell, ABC Journalist and award-winning author.

My mother had chronic pain. It was her tormenter and bully. Eventually she felt she could not escape the pain, that it had vined her entire existence. She euthanised herself one bleak and lonely night to escape it. She was in utter despair over the situation.

Yet it could have been so very different for her.

After her death I went down the rabbit hole of chronic pain and pain management to try and understand what had happened, and why my mother, Elayn Gemmell, did what she did. This investigation into a whole world of pain resulted in my new book, *After*.



Elayn had had a foot problem for several years before her death. A persistent pain in her right foot that she blamed on punishing ballet lessons all throughout her childhood and into her late teens, and then a lifetime of wearing fashionable shoes. Ten months

before she died a surgeon of silky persuasiveness had assured mum he could fix her foot problem. She was an elderly woman who was not wealthy, yet she parted with a lot of money, and excited hope, because she believed him.

When I saw Elayn in hospital after the operation, she was euphoric. My mum was as high as a kite. Literally. She had been introduced to the world of

opioids, and she loved them. She left hospital with an opioid dependency that rapidly turned into an addiction. And her foot pain did not go away.

It worsened. Despairingly. It vined itself up Elayn's leg and into her hip and lower back. Hugely frustrated, she went back to her surgeon. He recommended a physiotherapist who made the condition worse for her. "I'm in a desperate situation," she wrote to me in an email, "every step I take is like scissors digging into my groin, back and right leg, causing excruciating pain and making me almost immobile."

The pain situation took over Elayn's entire life, effecting every facet of it. How she moved. How she slept (or didn't.) How she prepared herself for each day (Or didn't.) How she drove. A week before she died Elayn was told she should no longer be driving because the pain was too severe, and she was a danger behind the wheel.

Fighting the great bully of pain consumed every minute of my mother's waking hours in her final months. It was hugely exhausting and draining. She rang me one night, weeping like a child. She was at her wit's end and could see no way clear of her new nightmare. I had



little understanding of chronic pain. I hugely regret that now.

Elayn's solution: to just take more and more opioids. But they were helping her less and less as her body became immune to them; and in fact, they may well have been increasing her pain. In her desperation she began doctor shopping to obtain more pills – a humiliating situation for such a beautiful, proud woman. Her regular GP prescribed anti-depressants but she didn't take them.

Her GP referred her to a Pain Management Clinic. She didn't go. This breaks my heart. Because I undertook a lot of research for my book and know now that a Pain Clinic would have opened up many other avenues of pain management – meditation and relaxation techniques, mindfulness, exercises like stretching, yoga and walking, help with sleeping. Pain Clinics do not believe that drugs are the only answer. They label them "passive therapy" and help find other, more active paths.



**Professor Glare interviewing Nikki Gemmell at the PMRI Reception at Ernst & Young.**

Elayn, in her despair, turned to Philip Nitschke's Peaceful Pill Handbook. It was beside her when her body was found. Her unheralded death broke my family. My book, regrettably called *After*, chronicles the messy aftermath of my mother's death and my own journey into break down and then understanding, and peace.

"*After*" is published by Harper Collins and is available in all good book stores.

*Editorial: Professor Paul Glare explains that Nikki quite rightly has learned that attending a pain clinic, being seen by multiple practitioners, may well have given Elayn a better chance at living and coping with her pain.*

"Nikki came to me with the ABC film crew, when she was doing her Australian Story documentary," says Prof Glare. "We showed Nikki how our programs at Royal North Shore work, how a psychologist working with a doctor and a physiotherapist help define a set of activities to either complement or replace other pharmacological treatments.

"Nikki, I believe, now understands and accepts this and has become an advocate for our multi-disciplined approach to pain management. PMRI, in no way, condones euthanasia as a solution."

Copies of Nikki's book *After* may be purchased from PMRI at \$20 plus postage and handling, by calling us on (02) 9929 5566.

## UPDATE FROM OUR NEW DIRECTOR

Professor Paul Glare, Chair of Pain Medicine, University of Sydney, and Director PMRI.

I used to consider myself incredibly lucky to have had the opportunity to live in Manhattan for almost a decade while serving as the Chief of the Pain and Palliative Care Service at Memorial Sloan Kettering Cancer Center. But after being back in Sydney for 12 months and Director of PMRI, I can't believe I got that lucky twice! Certainly, Professor Michael Cousins left me with big boots to fill, but I soon came to realize what a legacy he left in terms of his academic vision, the people he assembled around him, the facilities he established, and the model for financial sustainability he provided through PMRI Ltd.



**Professor Glare addressing the Reception at Ernst & Young on 23rd March.**

It has been a very successful year for the Research Groups and the Pain Education Unit that comprise PMRI. We have identified three overarching research themes:

- reducing the suffering and disability of individuals with chronic pain;
- reducing the burden of chronic pain on society; and
- predicting and preventing acute pain becoming chronic.



In pursuing them, we have won awards, obtained competitive grants, presented our work at scientific conferences and in the media, published papers in leading journals, supervised students and enrolled candidates in our Masters program.

We have also re-launched the Discipline of Pain Medicine in the University of Sydney, as dedicated time for teaching Pain has been added to the Medical School's curriculum in 2020.

In terms of my own research, I am primarily focusing on non-pharmacological management of cancer pain. Opioids have been the cornerstone of cancer pain management for more than 30-40 years, but are ineffective for up to 30% of patients. Cancer is now a chronic illness, with most people living more than 5 years after diagnosis and cancer treatments may cause chronic pain that lasts for years. My research indicates cancer patients often have the same unhelpful thoughts and behaviours in response to their pain as people with other chronic pain. I am interested to study how ADAPT and our other self-management programs might benefit cancer patients, decreasing their reliance on prescription pain killers and all their attendant problems.

As well as having a great job, I have also met some amazing people through my role at PMRI. This includes Professor Charles Brooker and the other 70 or so clinicians, scientists, support staff and students who work at PMRI and the Michael Cousins Pain Centre; Brian Davidson and the Board Members of PMRI Limited; the marathon swimmers Barry Feyder and Kieran Kelly, and many of our other generous benefactors; and Shaan and Geoff Verco.

With their help, PMRI's aim of being "a global leader in providing comprehensive pain solutions" is achievable.

### **PAIN AT THE SCG 2017**

Sadly, we did not hold our "Walk Against Pain" at the Sydney Cricket Ground this year. However, a couple of our very supportive pharmaceutical companies represented PMRI by entering a cricket team in the Marathon Cricket event hosted by the Primary Club of Australia at the SCG on 16th and 17th February.

Congratulations firstly to the team from Mundipharma who competed on the Friday in a blind cricket match against the NSW Blind XI, and amazingly won their game by a slender margin of one run. This was played with each player wearing glasses representing different types of visual impairment, and against a team boasting two Australian representatives.

Needless to say the Blind team is keen for revenge and has thrown down the gauntlet to the 'Mundies' for a re-match!

Our other representative, Pfizer, played on the Thursday and were joint winners of the Corporate

Cup, boasting the highest net runs total in their match against Drake International.

So, a great outing for PMRI – with both of our entrants winners on their day!



*The Mundipharma cricket team (white with red trim) pictured at the SCG with the NSW Blind XI.*



That evening, players witnessed the presentation of the Sir Roden Cutler Award to the athlete with a disability who distinguishes themselves in their chosen sport and who inspires others to take on physical exercise. The winner from amongst five deserving finalists was Para-triathlete Katie Kelly from Newcastle.

*Editor's Note: The prior winner of the Sir Roden Cutler Award was Liesl Tesch, multi-Paralympian in basketball and sailing, who also happens to be an Ambassador for Painaustralia and was recently elected to the State seat of Gosford.*

Why don't you join us next summer at the SCG?



*The Pfizer team with skipper Andrew Endicott holding the trophy.*



**Katie Kelly (left) receiving the Sir Roden Cutler Award plate from Liesl Tesch.**

## NEW RESEARCH INTO CANNABIS MEDICINES FOR NEUROPATHIC PAIN

*Dr Chris Vaughan, Head of Cellular Research, Pain Management Research Institute, University of Sydney.*

Damage to the nervous system through injury and disease often leads to the problematic condition of neuropathic pain, an extremely disabling chronic syndrome. It has a relatively high prevalence which will only increase in the future as the population ages. Unfortunately, current medications are not always effective, and in many cases they produce

side-effects which stop patients from continuing their treatment. A major challenge in pain research is, therefore, to find new drugs which relieve neuropathic pain AND produce fewer side-effects. The use of cannabis for the treatment of a number of chronic conditions is receiving a lot of media and political attention. Indeed, there is a lot of anecdotal evidence that cannabis is effective in reducing the abnormal pain associated with chronic pain. There is some clinical evidence to support the use of cannabis for chronic neuropathic pain, but there are concerns over its side-effects, including disruption of movement and cognition, and the potential link to psychological problems.

To date, most clinical studies into chronic pain have focused on whole raw cannabis, or its major psychoactive constituent THC. Cannabis, however, contains over 100 ingredients which may have medicinal properties and/or side-effects. The use of whole cannabis is therefore problematic because it contains variable amounts of many chemicals



**The Cellular Team: Patrick Seow, V Hyo-Jin Jeong, Jessica Falon, Dr Vaughan.**

## Reception at Ernst & Young 23rd March

hosted by  
Senior Partner Rowan Macdonald





with unknown effects. Therefore, it is important to examine the actions of known quantities of specific cannabis ingredients. We know that like Cannabis, THC produces pain relief. Unfortunately, THC also produces all of the side-effects commonly



Vanessa Mitchell, Sherelle Casey, Nicholas Atwal and Bryony Winters.

associated with cannabis use. We believe that the clinical use of THC is problematic because of the inability to separate the good from the bad. Very little is known about the 'other ingredients' in Cannabis. The Cellular Research Group at PMRI, headed by Dr Chris Vaughan, has been exploring the actions of these cannabis ingredients. The members of this group, including Bryony Winters, Hyo-Jin Jeong, Vanessa Mitchell, Sherelle Casey and Nicholas Atwal, have been spearheading this research.

We are asking whether these other ingredients relieve chronic pain, and how do they do this? This research is being examined in a basic science model. This is an important first step before we test these ingredients in people. So far we have found some ingredients have the potential to relieve chronic neuropathic pain. Interestingly,

these ingredients do not produce the well-known cannabis-like side-effects. While these studies are ongoing, we hope that in the future these new drugs might be examined in clinical studies.

*Editor's Note: We are pleased to advise that most of this particular research effort is funded by one of PMRI's private benefactors.*

## FREE PAIN MANAGEMENT PROGRAM IN CANTONESE

NSW Health in association with the NSW Agency for Clinical Innovation is offering a free pain management program in Sydney for Cantonese speaking people.

The program will be delivered in Cantonese in May and June this year and will consist of two hours every week over six weeks. It is aimed at adults aged 18 and over who live with chronic pain.

A questionnaire will need to be completed prior to participation to determine suitability for the course. For a copy of the questionnaire please contact Theresa Chow on 02 8759 4120 (Monday, Thursday, Friday).

Source: [www.painaustralia.org.au](http://www.painaustralia.org.au)



## AUSTRALIAN PAIN SOCIETY

#auspain2017

The Australian Pain Society's Annual Scientific Meeting Expanding Horizons held in Adelaide 9-12 April was a resounding success, attracting around 600 participants.

Now in its 37th year, it provides a unique opportunity for pain researchers and clinicians to improve their knowledge and expand their networks.

As always there was an impressive line-up of speakers, including three international speakers Professor Stephen Hunt from University College in London, Professor Judith Turner from the University of Washington and Dr Sean Mackey from Stanford University.

For those unable to attend #auspain2017, you can obtain copies of recorded sessions from [www.everttechnology.com](http://www.everttechnology.com).

Source: [www.apsoc.org.au](http://www.apsoc.org.au)

## PLACEBO EFFECTS SYMPOSIUM

*Dr Duncan Sanders, Senior Lecturer, Academic Coordinator, Pain Education, PMRI*

Over the last decade, there has been a lot of media coverage about the effects of placebo tablets (often called 'sugar pills') and placebo effects. Unfortunately, there appears to be some confusion and, at times, negativity in the medical and non-medical world around placebos and placebo effects.

In fact, there is growing evidence that placebo effects are very real and an important component of every health care interaction (even without administration of a placebo) (Wager & Atlas,

2015; Finniss et al., 2011). That is, the outcome of any given treatment we get is the combined effect from the specific treatment and the psychological and social (therapeutic) context in which the treatment is given (placebo effects/mechanisms).

Equally importantly are negative effects in the therapeutic context, whereby painful or unpleasant experiences can be activated. These have been called "nocebo" effects and can actually lead to worse outcomes.

Placebo and nocebo mechanisms are known to operate at both a physical (neurobiological) and a psychological level and they have been demonstrated to be present in routine health care. They have the ability to significantly influence the outcomes of current and future therapies (either positively or negatively). It is not difficult to see that all health care providers could stand to benefit by improving their understanding of the mechanisms underlying these effects and explore ways of using (or harnessing) this knowledge to promote better outcomes in clinical practice. The recent developments in research on placebo effects represent an exciting advance and offer clinicians (and their patients) relatively simple ways of improving clinical outcomes in both pharmaceutical and non-pharmaceutical treatments.

The Pain Management Research Institute (PMRI) and the Placebo Special Interest Group from the International Association for the Study of Pain (IASP) are excited to be holding the first international symposium devoted solely to describing these developments in placebo research and their potential clinical applications, not just for pain management, but other areas of health care as well. We have joined forces to invite several leading international and national experts in this field to this world first event at the Novotel in Manly, Sydney, in November 2017 to share their research findings and ideas with a broad range of clinicians and researchers from all over Australia (and beyond). For more information, please visit:

<http://sydney.edu.au/medicine/pmri/education/continuing/symposia.php>

*Editor's Note: It is an event such as this which enhances the reputation of PMRI as a global leader in pain research and education.*



"It's our new method for determining who we should treat first. We take people in order of how loud they scream."

## PAIN PALS

"Pain Pals" is edited by Shaan Verco on behalf of the "Friends of PMRI". We welcome your feedback and contributions. It is designed for easy reading about matters of concern to supporters of PMRI.

Membership is open to all people who care about finding new and improved ways of helping 4 million Australians who suffer from chronic or persistent pain.



In 2017/18 we need to find \$1.5m from private sources to help grow the Institute with a critical mass of highly qualified researchers and clinicians. That is \$1.5m beyond what we hope to receive in grants from Federal and State Government organisations.

To become, and to continue as, a Member of "Friends of PMRI", simply make a donation each year of \$60, or more. All donations over \$2 are tax deductible. Several options appear on our website, [www.painmgtresearch.com](http://www.painmgtresearch.com), or simply mail a cheque to 'PMRI'.

Remember "membership" is not a one-time only action; it needs constant renewal of commitment to ensure the results are achieved.

- Website: [www.painmgtresearch.com](http://www.painmgtresearch.com)
- Email: [pmri.info@painmgtresearch.com](mailto:pmri.info@painmgtresearch.com)

## CORPORATE SUPPORT

In recent years, PMRI has enjoyed a new relationship with several corporate entities who have donated time and resources to PMRI to allow us to promote our research and education to our growing community of private benefactors.

We are most grateful to the Macquarie Group, Dimensional Fund Advisors, Resimac Ltd and most recently Ernst & Young, who have all hosted functions for PMRI in their Board Rooms or Conference Rooms.

At the Ernst & Young function on 23rd March, in their new offices overlooking Circular Quay and Sydney Harbour, Senior Partner Rowan Macdonald and our Board Members hosted a reception for 60 friends to hear Professor Glare speak on three current research initiatives:

- The cannabinoid study under Dr Chris Vaughan's leadership, whereby we are assessing the properties of marijuana, as to which elements alleviate pain with minimal side-effects.
- The neurophysiology study led by Dr Paul Wrigley, where we develop a novel nerve test to detect partially preserved sensory pathways in people following spinal cord injury, improving mobility and reducing pain.
- The Workplace Injury Screening and Early Intervention ("WISE") Study, led by Professor Michael Nicholas, and being introduced progressively to enterprises managing return-to-work programs for injured employees.

Professor Glare then introduced journalist and author Nikki Gemmell and interviewed her about her mother's sad journey through chronic pain. See the article on page 1 of this newsletter.

With our need for more support from private corporations, trusts and individuals, you may be inspired to invite your employer or business partners



*Prof Glare with Ernst & Young representatives Caitlin Francis and Craig Oakes, and Shaan Verco.*

to consider hosting a similar event. Please contact Shaan on (02) 9929 5566 for more details about how your organisation can help.

## PAINAUSTRALIA KEEPS US "IN THE KNOW"

National advocacy body, Painaustralia, maintains an active website [www.painaustralia.org.au](http://www.painaustralia.org.au) developed as a resource centre, providing latest news and information about pain management services and programs nationally, the latest pain research findings, and up-to-date progress on the National Pain Strategy.

The site also provides access to educational resources for consumers and healthcare professionals.

## TIMOTHY HOLDEN RETIRES

In late November, we received advice that our Chairman of PMRI Ltd since March 2009 had tendered his resignation effective at that time. Timothy Holden had served as a Member of the Board since 2003 and felt the need to resign due to ill-health.

In her letter to Mr Holden, former NSW Minister for health, Jillian Skinner said:

"Under your chairmanship, we have witnessed some exciting breakthroughs in pain research and education. Such as the closed-loop spinal cord stimulation technology and the status with which PMRI's post-graduate degree courses are now regarded internationally. This of course has been made possible through your pragmatic approach to fund-raising for important research programs, and to forming collaborative associations, such as Painaustralia, to ensure higher priority is given in public policy debates about chronic pain as a disease."



We join with Mrs Skinner in thanking Tim for his devotion to the cause and his many successes with Professor Cousins and the Institute over the last 14 years.

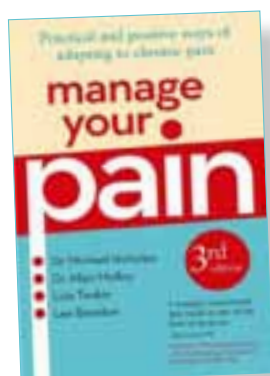
We sincerely hope to see Tim and wife Elizabeth in the months ahead at one or other of the PMRI Awareness events. In the meantime, we wish him well for a steady and full recovery.

Succeeding Mr Holden as Chair of PMRI Ltd is Mr Brian Davidson, who has served on the Board since 1996.

### MANAGE YOUR PAIN: 3RD EDITION

In Manage Your Pain, members of the Pain Education Unit have drawn on the latest scientific research and their extensive clinical experience to show you how to live with pain. Manage Your Pain will help you and your family to gain a better understanding of your pain and minimise the impact it has on your life.

Manage Your Pain is a self-help book, but it can be used as part of a program worked out with your doctor, clinical psychologist and/or therapist.



Good news! Friends of PMRI can now order a copy of this excellent guide online via our website at the discounted rate of \$24.95 per copy, or call us on (02) 9929 5566.



### TALENTED NEW RESEARCHER HELPS KICKS OFF SPINAL CORD STIMULATOR TRIAL

The PMRI research team lead by Dr Paul Wrigley (Pain Medicine Specialist) are excited to welcome Anna Marcuzzi who started work in January 2017.

Anna has come with an impressive academic record, achieving outstanding results in her undergraduate science (BS, University of Parma, Italy) and physiotherapy degrees (MPhysTher, University of Pisa, Italy) and more recently her doctoral thesis examining risk indicators for chronic low back pain (PhD, Macquarie University).

She practiced as a physiotherapist in Italy prior to undertaking her doctoral research in Australia.

Since joining the PMRI she has enabled the commencement of an important treatment trial examining the long-term effects of spinal cord stimulation on nerve function in people with low back pain.



Her previous research in low back pain, her clinical trials experience, her expertise in research analysis and previous formal training in sensory testing (Germany, 2014) have made her particularly suited for this position and an asset to the team. We wish her all the very best over the year.

*The funding of Anna's role in this important project has been provided by one of our private benefactor organisations, for which we are most grateful.*

### MICHAEL COUSINS ANNOUNCED AS PATRON OF PAIN MANAGEMENT RESEARCH INSTITUTE

Many readers will know Professor Michael Cousins AO, who was our Director until April last year, when he retired and was succeeded by Professor Paul Glare.

Chairman of PMRI Ltd, Mr Brian Davidson, said following the May Board Meeting: "I am delighted to announce that Professor Michael J Cousins AO has accepted the appointment of Patron of PMRI. Professor Cousins inspired the formation of PMRI 27 years ago as a joint venture between the University of Sydney and the Royal North Shore Hospital, and has grown the scope and reputation of PMRI globally. Since his retirement last year, Michael continues as a Board Member, and now Patron, of PMRI Ltd providing guidance on all matters relating to new research and education initiatives in chronic pain.



Professor Michael Cousins has worked in the field of persistent pain for over 40 years as a clinician, researcher, educator, administrator and community advocate. Professor Cousins was chair of the Executive Committee for the Australian National Pain Strategy. He is currently a director of PainAustralia, a network of healthcare, consumer and other organisations formed to facilitate the implementation of the National Pain Strategy.

In August 2010, Professor Cousins chaired the first International Pain Summit in conjunction with the World Congress on Pain in Montreal, Canada. An important outcome of this Summit was the "Declaration of Montreal" which called for "Access to Pain Management as a Fundamental Human Right".