

Pain Pals

NEWSLETTER FROM THE FRIENDS OF PMRI

MARCH 2014

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

In this issue, we highlight:

- *Chronic severe headaches – how investment in research and new clinical treatments offer many patients long-term relief.*
- *Outstanding recognition of Professor Michael Cousins AO – Minister officially names the "Michael J Cousins Pain Management and Research Centre" at Royal North Shore Hospital.*
- *Australian Olympic aerial skier, Jacqui Cooper, uses proven management techniques to overcome chronic pain from her professional sporting career.*

PAIN CENTRE NAMED TO HONOUR MICHAEL COUSINS

The New South Wales Minister for Health and Minister for Medical Research, **Jillian Skinner**, has officially renamed Royal North Shore Hospital's pain management research centre in honour of **Professor Michael Cousins AO**.

The "Michael J Cousins Pain Management and Research Centre" acknowledges the achievements of Professor Cousins as a leader in Pain Medicine and Pain Management, and the enormous impact his work has had in Australia and around the world.



Professor Cousins and Minister Skinner at the PMRC opening

Minister Skinner praised Professor Cousins for his work in the field of Pain Management and research over almost 50 years, for his leadership in development of the National Pain Strategy and advising the NSW government on its Pain Management Plan.

As a clinician Professor Cousins has directly improved the lives of countless people, through his dedication and compassion, and his willingness to try new techniques.

Sixty-one year-old **Kathleen Newton** suffered horrendous headaches following an accident in which she fractured her neck, which went undetected for almost 30 years. The fracture had healed but the bone grew against the nerve causing headaches. Kathleen was the first person in Australia to be fitted with an occipital stimulator, by Professor Cousins.



Kathleen Newton and Betty Johnson AO at the PMRC opening

"Like so many people with chronic pain, I went from doctor to doctor and tried many treatments, but nothing helped. Then Professor Cousins decided to try an occipital stimulator, inserted into my neck, and I got my life back," she said.

Reprinted with permission from Painaustralia, 20th February 2014. Photos of the event can be found on PMRI's Facebook page: www.facebook.com/pmri.ltd

PERIPHERAL NERVE STIMULATORS FOR TREATING HEADACHE

In recent years the treatment of chronic headaches has included the surgical insertion of electrical stimulation devices. These devices are based on pacemaker technology with wires placed near the nerves instead of in the heart. The wires have bare electrodes at their tip which, when stimulated by the implanted battery, create an electrical field in that part of the body.



Dr Charles Brooker

If this is close to a nerve it induces a (usually) pleasant tingling sensation in the area supplied by that nerve. It sends signals into the brain to do this which can reduce the pain signals already being experienced in that area. Sometimes the signals will be generated in one area and reduce pain in another.

The procedures require a surgical operation by either a neurosurgeon or a pain management specialist. There are surgical wounds and a risk of infection, repeat surgery to repair the wires and extra pain from the battery site. The devices are expensive for the healthcare system. If, however they can be shown to greatly reduce headaches, time off work and medication, then there would be value to wider society as well as the obvious humanitarian benefit.

Not all patients with headaches would need such a device but it has created interest in patients suffering chronic severe headaches due to migraine or cluster headache both of which can be very severe.

The research so far into such devices being used for headaches has shown a range of results with some patients obtaining excellent relief and some getting no relief and many in between. Because we often see short term responses to pain treatments that are non-specific, there is always a need to prove that such invasive and expensive treatments work better than any other treatment.

Research has been done on patients receiving stimulators comparing them with those having stimulators put in but not switched on fully. The results so far are mildly encouraging, but not good enough to justify the use of the technology on a regular basis.

One of the issues is that because the comparison group in the research studies (the so-called control group) can tell they don't have a stimulator working, then there is not a proper comparison with those feeling tingling under the skin.

Recently some other researchers have trialed low-

dose stimulation therapy in another pain condition but using the exact same technology as is used for headaches. Even with the low dose therapy (that they could not tell was switched on) this was proven to be better for pain than a device that was not switched on at all.

If this research can be applied to headache sufferers and shown to help, then the device will have been proven to work to the satisfaction of the wider medical community and governments.

Dr Charles Brooker is currently Head of Department of Pain Medicine at the Royal North Shore Hospital.

NEW PAEDIATRIC PAIN CLINIC OPENS IN THE HUNTER

The Hunter New England community has celebrated the opening of the Children's Complex Pain Service, at the John Hunter Children's Hospital in Newcastle.

The service, officially opened by NSW Minister for Health and Minister for Medical Research Jillian Skinner, will provide children with complex pain issues and their families greater access to a multidisciplinary pain management service, in a timely manner.



Minister Jillian Skinner & new friend at John Hunter

Dr Susie Lord, pain specialist at the Children's Complex Pain Service, says the new service is a wise investment in the future of the Hunter New England community, particularly because of the different approaches required when treating children.

"Children are very vulnerable because they are constantly

acquiring new skills, which build upon each other. Any impact, such as prolonged absences from school, can have a lasting effect on developmental and vocational opportunities," said Dr Lord.

"Minimising waiting times will mean a greater chance of helping children overcome and manage their pain, and help avoid long term disability associated with chronic pain."

The multidisciplinary service will cater to children up to the age of 18, operating two days per week with pain specialist Dr Lord, a nurse consultant, physiotherapist, clinical psychologist, and administrative assistant. An extra day each week for case management will be filled by Dr Lord and the clinical nurse consultant.

Recognising the importance of family function and wellbeing, the service will offer psychology



consultations with the parents and carers ensuring support and care for the entire family,

From next year, Telehealth consultations will also be offered for children and their families living more than 50 kilometres outside an urban zone.

Dr Lord, who has worked as a solo practitioner in paediatric pain management at the hospital since 2004, and has advocated strongly for protected funding for a multidisciplinary paediatric pain service.

"The service has been nine years in the making, and could not have happened without the support of the hospital executive, the NSW Agency for Clinical Innovation, and the NSW Pain Taskforce initiated by Minister Skinner," said Dr Lord.

There are now three paediatric pain management services in NSW, with the new service catering to children in the Northern Child Health Network, which runs from Newcastle all the way to the Queensland border.

Dr Lord is also the Chairperson of the Pain In Childhood Special Interest Group of the Australian Pain Society. Anyone interested in joining the group should contact Tracy Hallen, APS Secretariat on 02 9016 4343 or tracy@dcconferences.com.au.

MICHAEL COUSINS AO AWARDED AUSTRALIA DAY HONOUR

Painaustralia congratulates Director Professor Michael Cousins on being awarded an Officer in the Order of Australia (AO) in the Australia Day Honours.

The award recognizes his role as a leader in pain management and anaesthesia, and over 44 years of research, teaching and clinical innovation in Australia and internationally.

Professor Cousins' research has led a new understanding of chronic pain as a disease in its own right, and has revolutionised Pain Medicine and Pain Management ideology and practice, bringing hope to millions of people living with chronic pain.

Perhaps his greatest legacy is his leadership of the National Pain Summit (2010), which led to development of Australia's National Pain Strategy and the establishment of Painaustralia, and sparked a groundswell of change across the world.

As a result of these initiatives and his tireless advocacy efforts, significant reform in relation to the recognition and management of pain has begun in this country.

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FROM BEDRIDDEN TO BUSINESS-OWNER

By Karyn Markwell, Media Manager, Australian Pain Management Association



Michele Cousins with Professor Michael Cousins AO

A community healthcare organisation has assisted 51-year-old grandmother **Penny Curnow** from being bedridden to weaning herself off prescription medication and operating her own communication business.

Penny has experienced persistent pain in her lower back, hip and leg since playing a vigorous game of squash at the age of 18. She has had four operations on her lower spine and has been bedridden many times.

After Penny first heard about the Australian Pain Management Association (APMA) – a non-profit organisation which gives hope, information and life skills to people with persistent pain – she started to turn her life around.

"Before APMA, I was very isolated," recalls Penny. "I was bedridden for months at a time, seeking someone who understood my pain. APMA offered me real support and strategies that helped me to help myself."

"APMA made me feel normal, when everything around me felt like it was out of control."

With the goal of being able to walk again, free from prescription medication, Penny took charge of her health by using her mind and her determination.

"I realised that I was the only one who was going to make my life better," says Penny.

While she lay bedridden, Penny watched yoga videos and imagined that she was actually doing the exercises.

"I later discovered that this was exactly what I needed to do to stimulate the electrons in my muscles," says Penny. "Even though the electrons were not physically doing the exercises, they were still receiving the impulses."

Today, Penny is able to walk again, with the support of a walking stick, and she has successfully weaned herself off her prescription medication. To manage her pain each day, Penny uses meditation, visualisation and focussed breathing. As a result





of this positive approach, she doesn't suffer from depression, which is so common among people with persistent pain.

"My moods are generally great," says Penny. "I do have my challenging days, but I have developed some robust triggers to help me to come through them."

Penny occasionally attends APMA's community pain-support group in Mackay, to connect with other people with persistent pain who understand what she is experiencing. She also regularly visits APMA's website and Facebook page, to stay up to date with latest pain news and self-management techniques.

"APMA has given me hope that someone is out lobbying for people with persistent pain and providing us with incredible information," says Penny.

For more information about the Australian Pain Management Association (APMA), visit www.painmanagement.org.au. You can join APMA's social media communities at www.facebook.com/apma4u and www.twitter.com/yourapma. APMA's Pain Link helpline: 1300 340 357

"SOARING ABOVE PAIN" THE JACQUI COOPER STORY

In July 2013, NSW Minister for Health and Medical Research Jillian Skinner MP hosted the PMRI Luncheon at Parliament House Strangers Dining Room, with 120 friends and supporters of PMRI.

Special guest speaker was world champion aerial skier **Jacqui Cooper**.

Jacqui Cooper has represented Australia in the sport of Aerial Skiing for 20 years. Her career started in 1989 at Mt Buller. Within three years she was already representing her country at the World Championships in Lake Placid New York; by 1994 she competed at the Lillehammer Winter Olympics.

In 1999, just ten years after starting her sport she became a World Champion; the next ten years would see her dominate and revolutionise her sport.

With her record five world titles, her sport is unforgiving; she has had knee, elbow, shoulder and hip reconstructions. In 2001 she broke her back in an attempt to win a record 3rd World Title; she went on and won it. In 2002 at the Salt Lake City Winter Olympics, she injured her knee and broke her leg just two days before the Olympic competition ending years of dreaming, willing and wanting.

In 2010, Jacqui competed in Vancouver after a year of intense hip and knee rehabilitation; she shocked doctors and surgeons by her will, inner strength and courage to make a brave attempt to be





Jacqui Cooper flying high at the Parliament House Luncheon

competitive at those games. She spent most of the months leading into the Olympics in a wheel chair, learning to walk again, and gaining confidence in a sport that is brutal and cruel. She stunned her rivals, coaches, and team mates when she came fifth, her best Olympic result in the 20 years.

"Jacqui Cooper is a true legend. She did not win a medal, but her performance in finishing 5th in the women's freestyle aerial event epitomised all that is so great about Australian sport." – Matt Miller, CEO Australian Sports Commission.

Professor Cousins asked Jacqui how she managed her pain during those periods when her pain must have been acute. Her answer: "I kept focusing on my higher goals, and convinced myself I wasn't hurting."

And now that she has retired, what does she do to minimise the prospect of her injury pains recurring and becoming chronic? "Exercise routinely, a modest diet, and keeping myself busy," replied Jacqui.



Jacqui's passion today is education: the education of children and teenagers about living a healthy lifestyle, making smart choices, nutrition, being young role models, dreaming BIG, being active and goal setting. Jacqui speaks to primary, secondary, and university/TAFE students. She has also travelled to remote aboriginal communities as far as Darwin and beyond, promoting all things healthy with a heavy focus on "SAY NO" to alcohol, petrol sniffing and smoking.

Jacqui's story is one of self-belief, passion, triumph, tragedy and the ability to overcome adversity.

TRIGEMINAL AUTONOMIC CEPHALAGIAS: CLUSTER AND ITS FRIENDS

"Trigeminal Autonomic Cephalalgias" is too long for anyone to say. So this interesting group of primary headaches are often referred to as "TACs headaches".

Most people will have heard of Cluster Headaches but few will be aware of its peers in this group including: Paroxysmal Hemicrania, Hemicrania Continua, SUNCT (Short-lasting Unilateral Neuralgiform headache attacks with Conjunctival Injection and Tearing) or SUNA (Short-lasting Unilateral Neuralgiform headache attacks with cranial Autonomic features). They differ in their cycling, frequency and duration of attacks



- ranging from continuous headache with Hemicrania Continua to hours of headache for Cluster Headache and only seconds to minutes of headache for SUNCT and SUNA.



They are all associated with features of excessive cranial autonomic reflex activation such as tearing of the eye, dripping of one nostril, redness or change in the pupil size of the eye, flushing or abnormal sweating of the face, swelling or drooping of one eyelid or a feeling of fullness in the ear. They are mostly unilateral headaches and can even mimic Trigeminal Neuralgia by their brief stabs in the shorter duration headaches.

Interestingly, imaging (such as an MRI scan of the brain) and blood tests are recommended in this group since there is a higher incidence than usual of structural brain abnormalities, particularly pituitary adenomas.

Differentiating between the different headaches in the TACs group is important in choosing the treatment of choice. For example, Paroxysmal Hemicrania and Hemicrania Continua are exquisitely responsive to Indomethacin (but not other non-steroidal anti-inflammatory medications). There is a range of nerve stabilizing medications such as antiepileptic medications, high flow oxygen, triptans (such as Imigran) and interventions such as Greater Occipital Nerve Injections that can be considered once the diagnosis is determined.

Cluster headache is one of the most severe forms of headache, usually lasting hours with autonomic features, and causes marked agitation in many patients. Whilst finding the right combination of management options for each individual can be challenging, it is well worthwhile to stop the extreme suffering experienced by some patients with these headaches.



Neurologist **Dr Bronwyn Jenkins** was one of the speakers featured at last October's PMRI Symposium "Understanding Headaches." She is currently Visiting Medical Officer at Hornsby Hospital, with private rooms at Epping.

- Volunteers Wanted! -

The Pain Management Research Institute and Department of Gastroenterology, Royal North Shore Hospital are undertaking a study aiming to improve the assessment of pain in people with Irritable Bowel Syndrome (IBS) or Chronic Low Back Pain (CLBP).

Healthy volunteers and people with IBS or CLBP are invited to take part in a three hour study involving non-invasive testing of sensation.

\$120 is offered as partial reimbursement for time and travel. If you have any questions please feel free to contact Dr Paul Wrigley at drpaulwrigley@gmail.com or call 02 9926 4960.

WALK AGAINST PAIN 2014

Against the backdrop of Marathon Cricket at the Sydney Cricket Ground, 96 Walkers enjoyed a spectacular afternoon participating in PMRI's fourth "Walk Against Pain" in January.

Once again, Professor Michael Cousins and PMRI staff joined the Walkers in the celebration.

The Walkers helped raise over \$5,800 to assist pain management research, as they clicked over laps of the grand arena.

Many thanks to the Walkers, their sponsors and our corporate supporters on the day - **Medtronic**, **St Jude Medical** and **Novartis**. Also to the **Rotary Club of North Ryde**, who provided a team of marshals to watch out for low-flying cricket balls!

Alan Davison AM MBE greeted the Walkers as they finished and thanked them for their demonstration of support for 4 million Australians living with chronic pain. Minister Skinner sent a message of apology, reassuring the gathering that she was committed to seeing that NSW takes the lead on delivering better pain management services.





More photos of the event can be found on PMRI's Facebook page: www.facebook.com/pmri.ltd

Following the Walk, supporters were invited to witness the Primary Club's Battle of the Codes Twenty/20 cricket match, pitching the Legends of Rugby Union against their League counterparts. Ryan Cross once again top-scored with 64 runs for the League team, but to little avail as the Union team won in the final over, with opener Robbie Deans scoring a respectable 53.



Alan Davidson greeting Battle of Codes players, Phil Waugh and Matt Dunning, at the SCG.

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

In 2011, we reported that PMRI was selected by the ASX Thomson Reuters Charity Foundation, representing many of Australia's top corporate organisations, as a 'partner charity' for that Foundation's fund-raising drive.

PMRI is sharing with another 23 registered charities such as Wheelchair Sports, Autism Spectrum and Foodbank in a 'pot' of \$1.2m, resulting from our active participation in their Art Union, Yachting Regatta, Golf Day and Dinner. Special thanks to **Nigel Stewart, Diana Brown, Phil Prakash, Tony Kingsford-Smith, Tim Holden, Jeff Bennett and Shaan and Geoff Verco** for volunteering at these major events. And to **Paul Clitheroe** for entering Balance in the Regatta last October on behalf of PMRI.

Applications are now open for yachts and crews to compete in the next Sydney Harbour Regatta on Friday 24th October. If you have a good friend who's a "yachteer" or you are one yourself, please contact the PMRI office for entry details.

Help us keep the pain management message out there by supporting these events.

For more information about the Friends of PMRI, or if you would like to volunteer at any one of these various functions, please contact Shaan on (02) 9929 5566, or visit our website www.sydney.edu.au/medicine/pmri.

PAIN MANAGEMENT MULTIDISCIPLINARY WORKSHOP 2014

This two week workshop, organised by our Pain Education Unit, was held in February at Royal North Shore Hospital with fifty attendees representing a wide range of healthcare professionals – such as nurses, doctors, psychologists, dentists and physiotherapists.

Participants praised the organisers on the breadth of content, designed for professionals with an interest in learning about current views and approaches to the assessment and management of pain. Over 30 faculty members contributed during the two weeks. **Professor Michael Nicholas** advised that given the success of the workshop, more will be planned in concert with the Unit's range of Webinars and Postgraduate courses in months and years ahead.

For information about these events, costs and how to join them, call (02) 9926 7386 or email: paineducation@sydney.edu.au.

PAIN MANAGEMENT SYMPOSIUMS

PMRI's Pain Education Unit also holds a series of Symposia, open to all healthcare professionals.

During 2013, we staged the "PAIN IN PALLIATIVE CARE" Symposium and the "UNDERSTANDING HEADACHE" Symposium at the Kolling Auditorium, at which national experts in these fields contributed.

From February to May this year, a series of two-day "PAIN EDUCATION UPDATE" Symposia are being conducted in several cities around Australia. With funding assistance from the federal Department of Health, via PainAustralia, the courses are being promoted by the Australian Medicare Local Alliance (AMLA) and PMRI.

Dates and venues are as follows:

- Sydney – 21/22 February
- Brisbane – 7/8 March
- Melbourne – 11/12 April
- Perth – 23/24 May

Each day concludes with a case presentation and discussion.

For more information, contact Carol Vickers at AMLA on cvickers@amlalliance.com.au or (02) 6228 0823.

MANAGE YOUR PAIN: 3RD EDITION

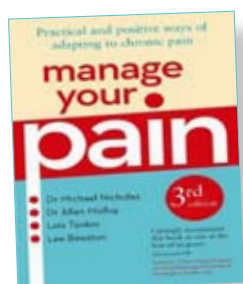
In MANAGE YOUR PAIN, members of the Pain Education Unit have drawn on the latest scientific research and their extensive clinical experience



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! You can now order a copy of this excellent guide online via our website at \$34.95 per copy, or call us on (02) 9929 5566.



BEHAVIOURAL TREATMENT FOR MIGRAINE HEADACHE

Behavioural treatment is effective for both migraine and tension-type headache but few who need it will receive it!

It has been estimated that globally, the percentages of the adult population with an active headache disorder are 46% for headache in general, 11% for migraine, 42% for tension-type headache, and 3% for chronic daily headache. On the ranking of causes of disability of the World Health Organisation, this brings headache disorders into the 10 most disabling conditions for the two genders, and the 5 most disabling conditions for women. Headache accounts for approximately 20% of lost work days. The Global Burden of Disease Study 2010 showed that headache is a problem from Western Europe to East Asia and from North America to sub-Saharan Africa, and that disability from both migraine and tension-type headache increased significantly between 1990 and 2010.

Recently, an Editorial was published in all three specialist headache journals, commenting on the findings of the Global Burden of Disease Study in which the authors wrote, with clear frustration, "But for what conceivable reason do headache disorders remain among these ignominious top 10 (causes of disability) when they are largely treatable?"

One response to this question is that behavioural treatment is effective for both migraine and tension-type headache, but of the millions of people around the world who suffer from disabling headache disorders, very few will have access to a psychologist for behavioural treatment. Meta-analytic reviews for behavioural treatment of migraine and tension-type headache have concluded that average improvement ranged from 33% to 55%, compared with 2% to 5% for no-treatment controls. In our most recent study of behavioural treatment for migraine and tension-type headache, treatment was associated with: (i) average decrease in headaches of 68% post-treatment, and 77% at 12-month follow-up; and (ii) average decrease in medication of 70% post-treatment. These percentage change figures

compare with a reported 27% headache reduction with amitriptyline, an established headache prophylactic medication. In addition to reducing headaches and medication consumption, behavioural treatments are typically associated with a number of positive changes including decreases in negative



Professor Paul R Martin

moods such as depression and anxiety, and enhanced quality of life, in contrast to pharmacological approaches that are associated with adverse side effects, and high medication overuse potential.

It has been estimated that 98% of medical management of headaches takes place in general practice. When studies have looked at the referral practices of GPs to specialists with respect to patients with headache disorders, referral rates to psychologists have been so low that they have not been reported. We are currently trying to get funding to adapt behavioural interventions so that they can be integrated into the primary care setting.

Professor Martin was one of the speakers featured at last October's PMRI Symposium "Understanding Headaches." He is head of the School of Applied Physiology at Griffith University QLD.

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 Professor Cousins and his colleagues at the Institute.

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.

To become, and to continue as, a Member of "Friends of PMRI", simply make a donation each year of \$50 or more. Please use the form downloadable from our website www.sydney.edu.au/medicine/pmri, or sign up online at www.trybooking.com/MXJ or mail a cheque to "PMRI", Douglas Building, Royal North Shore Hospital, St Leonards NSW 2065.

Significant additional funds are required to complete milestones in 2014 for several research projects in areas such as Spinal Cord Injury Pain, Lower Back Pain, Irritable Bowel Syndrome, and Cancer Pain - all moving into crucial clinical trial phases, and expected to result in improved treatments for patients living with these conditions.

Donations over \$2 are tax-deductible.