### PAINAUSTRALIA annual report

2021

Annual Report | admin@painaustralia.org.au | www.painaustralia.org.au

### Table of **Contents**

About Us	3
Chairman's Message	4
CEO's Message	6
Our Board	8
Our Patron & Pain Champions	10
Consumer Advisory Group	12
Governor General hosted event at Government House	14
National Strategic Action Plan for Pain Management	19
Parliamentary Friends of Pain Management Group Meeting	21
Painaustralia's Annual General Meeting 2021	22
Impact of opioid regulatory reforms Survey	23
Campaigns	24
Launch of the biography of Dr Michael J. Cousins	26
Policy & Submissions	27
Media & Communications	28

#### ABOUT PAINAUSTRALIA

### Who We Are

Painaustralia is Australia's peak pain advocacy body working to improve the quality of life of people living with pain, their families, and carers, and to minimise the social and economic burden of pain on individuals and the community. We work collaboratively with key stakeholders to integrate pain as a priority in the broader health agenda and our roadmap for achieving world-class care is the National Pain Strategy and associated National Strategic Action Plan for Pain Management.

### **Our Mission**

Pain is a recognised national health priority and all Australians living with pain or at risk of pain-related disability, their families and carers can access credible information and a world-class system of care.

Painaustralia's latest Strategic Plan 2021-2024, updated and adopted by the Board in 2021 encompasses our commitment to working with governments and key stakeholders to raise awareness and implementation of the National Strategic Action Plan for Pain Management and illustrate its benefit to decision makers, healthcare providers, community and industry and advocate.

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#### **Our Vision**

#### Painaustralia's values describe the core ethics and principles which drive our work and all our endeavours.

**Collaborative:** we will work collaboratively with the broader pain management sector, stakeholders with an interest and the general community to build partnerships and find synergies to advance our mission.

Respectful: we will value the rights and perspectives of all stakeholders.

**Courageous:** we will lead the sector by example and lead the charge for change based on achieving our mission.

**Informed:** our work will be informed by the knowledge and experience of our stakeholders, credible information, and where available, scientific evidence.

Credible: we will act ethically and professionally.

Transparent: we will be accountable to our stakeholders for our actions and outcomes.

Independent: our work will always remain unbiased and unbeholden to vested interests.



Major General (Ret'd) Duncan Lewis AO DSC CSC

#### **Chairman's Message**

I am delighted to present Painaustralia's Annual Report for 2021 – a constructive and productive year for the organisation.

As of the 18th of May 2021, I was honoured to take over the role of Chair of Painaustralia and I would like to extend my thanks to the previous Chair, Emeritus Professor Ian Chubb for his outstanding work for Painaustralia during his tenure.

As Chairman, it was particularly gratifying to see the launch and endorsement of the National Strategic Action Plan for Pain Management by the Minister for Health, the Hon Greg Hunt, at the Painaustralia Parliamentary Friends of Pain Management Group event in May. This was indeed a major achievement and milestone and was the result of years of dedicated work and extensive and comprehensive consultation led by Painaustralia. However, our work in this area is certainly not finished, and my focus moving forward is to see the goals in the National Strategic Action Plan funded and implemented throughout Australia. We need to continue our work with the new Federal Government, the governments of the states and territories and health stakeholders to ensure that more is done for the 3.4 million Australians who live with chronic pain.

As a veteran myself, it was a privilege to raise awareness and support for veterans who live with chronic pain, and I would like to thank the Governor General his Excellency the Honourable David Hurley AC DSC (Retd) and Mrs Linda Hurley for hosting an event at Government House in June 2021. We know that a significant number of veterans live with chronic pain from injuries obtained during service. Musculoskeletal pain is one of the most common reasons for medical discharge from the armed forces.

In 2021, Painaustralia celebrated its 10 year anniversary as the peak pain advocacy group with the launch of the biography of Painaustralia's founder Dr Michael J Cousins. It was also timely with our 10 year anniversary to adopt a new Strategic Plan to guide our priorities for the next three years. The plan provides the roadmap for Painaustralia to improve the quality of life of people living with pain.

Throughout the year, Painaustralia focused on developing sound evidence-based policy to inform policy makers and the community about the challenges faced by consumers with chronic pain including submissions to inform the National Medicines Policy and Australia's Primary Health Care 10-year Plan.



While there is now greater awareness of pain and pain management than ever before and a National Action Plan is in place, we need to continue to improve our understanding and responses for the benefit of the 3.4 million Australians who live with chronic pain.

Painaustralia also conducted several campaigns raising awareness of the issue of chronic pain that involved working with State and Territory governments to implement their real time prescription monitoring programs and the take home naloxone pilot with the Australian Government.

We were delighted to welcome Australian Survivor Winner 2021 and pain researcher Hayley Leake to our outstanding pain champions program. She joins a formidable group that includes our National Patron Air Chief Marshal Sir Angus Houston AK, AFC (Ret'd), ABC Medical Reporter Sophie Scott, Veteran and Invictus Games competitor. Peter Rudland . Liesl Tesch AM MP and Tara Moss, Best Selling Author. I want to thank all of our pain champions who are willing to share their personal experience, insights and demonstrate their support for those who live with chronic pain.

I would like to thank our outgoing Chief Executive Officer Carol Bennett. Carol has led our executive team for four years and has done a wonderful job in advancing our organisation in support of those living with pain. On behalf of my colleagues on the Painaustralia board I thank Carol and wish her all the best in the future. We will shortly be announcing Carol's replacement.

I would also like to thank our great executive team for their staunch support of our organisation and the aims and objectives we pursue. Their achievements have been outstanding.

I want to thank my fellow board members for their ongoing commitment and the support and advice they have given to me as Chair.

Finally, on behalf of the board and staff at Painaustralia I want to acknowledge our members, partners and consumers – it is only with your support that we are able to ensure pain management is an issue central to health policy in Australia.

Painaustralia will continue to represent and advocate for greater awareness, policy development, increased access and funding to services for the millions of Australians who live with chronic pain.

WWW 80 visits to Painaustralia's website followers @Painaustralia Facebook

ommunications

Painaustralia

followers @Painaustralia Twitter

media channels, including Facebook, Twitter and LinkedIn. Topics of conversation among engaged consumers included but was not limited to: opioids and their role in pain relief for people with chronic pain, experiences, Fibromyalgia, mental health and chronic pain, Ketamine for pain relief, and research studies across a variety of academic institutions aiming to gather first-hand information about chronic pain.









When I commenced in the role of CEO of Painaustralia in July 2017, the task ahead to achieve a national approach to pain and its management with buy-in from key stakeholders seemed a daunting and distant prospect.

It was so exciting to finally see this hope become a reality when the Federal Minister for Health, the Hon Greg Hunt MP, launched the National Strategic Action Plan for Pain Management (the Action Plan). Developed by Painaustralia in collaboration with all key stakeholders and endorsed by all Australian governments (and in the midst of a pandemic too), it was officially launched at our Annual General Meeting held in May.

My thoughts are with the many Australians who live with chronic pain, who have not only had the day-to-day difficulties of accessing health care and managing their pain but have experienced extreme social isolation and increasing barriers to accessing care and support.

While Painaustralia led the development of the first National Strategy for Pain Management in 2011, the need to gain endorsement of all Australian governments was the milestone that was needed to place chronic pain on the national agenda and to provide some significant improvements in the way that pain is managed in Australia.

The Action Plan is a critical step towards improving the guality of life for the millions of Australians who live with chronic pain and every day face the challenges of accessing affordable and specialised pain treatment. However, the work to ensure that the 50 practical recommendations in the Action Plan are now implemented and funded is the challenge going forward. Some of this work has commenced and we are actively working with State and Territory governments on key activities including the implementation of Real Time Prescription Monitoring programs.

This year Painaustralia farewelled Professor Ian Chubb AC and welcomed our new Chairman, Major General (Ret'd) Duncan Lewis AO DSC CSC, who took up the role in May. It has been wonderful to have his expertise and insight to guide Painaustralia's critical work. Pain scientist, educator, physiotherapist, Professor of Clinical Neurosciences and Chair in Physiotherapy at the University of South Australia, Lorimer Moseley AO also joined our board of directors this year.

We welcomed our latest Pain Champion, Hayley Leake, who is the 2021 Australian Survivor Winner, a physiotherapist and pain researcher. Hayley joins our outstanding group of pain champions which includes best-selling author Tara Moss, Invictus Games Gold Medallist and veteran Peter Rudland, ABC national medical reporter Sophie Scott and seven-time paralympian Liesl Tesch AM MP - who all help to raise the profile of chronic pain in national conversations and among their networks.

We were honoured that the Governor General, His Excellency General the Honourable David Hurley AC DSC (Retd) and Her Excellency Mrs Linda Hurley hosted another Painaustralia event at Government House to raise awareness and support for veterans who live with chronic pain. We know that a significant number of veterans live with chronic pain from injuries obtained during service and particularly musculoskeletal pain and we are grateful to their Excellencies for their ongoing support. As the year comes to a close, we work closely with partners in the defence in dustry to prepare a response to the Royal Commission into Defence Personnel and Veterans Suicide.

2021 has seen many achievements for Painaustralia including the launch of the updated and improved National Pain Services Directory with a comprehensive listing of more than 200 private and public pain clinics. More than 100,000 people including consumers, health care professionals and GPs have used the directory.

This year marked our 10 year anniversary as the peak pain advocacy group and to celebrate we launched the biography of Painaustralia's founder Dr Michael J. Cousins. The online launch of Breaking the Pain Barrier: The Extraordinary Life of Dr Michael J Cousins by patient and author Gabriella Kelly-Davis included guest speakers from across the nation and the US to speak about the amazing contribution that Michael has made to those who live with pain.

It was timely with our 10 year anniversary to adopt a new Strategic Plan to guide our priorities for the next three years. The plan provides the roadmap for Painaustralia to improve the quality of life of people living with pain, their families and carers.

We undertook a number of awareness activities including the Take-Home Naloxone Pilot Program campaign and Painaustralia's community education and awareness project. The project has increased availability of evidence-based information on chronic pain and pain management on a single web-based platform and now includes a chatbot feature to help consumers and health care professionals navigate information on our website. Our September International Pain Awareness Month consumer-led awareness and education campaign featured a webinar, factsheets and videos and resulted in us reaching more than 130,000 people.

On the policy front, we provided around 30 government submissions to key policy reviews and inquiries including the National Medicines Policy review, response to the proposed National 10 Year Primary Healthcare Plan and 2021-22 and 2022-23 Budget Submissions.

Our Parliamentary Friends of Pain Management Group continued its valuable support for our work. I would like to thank our Co-Chairs, Senator Wendy Askew and David Smith MP, Member for Bean, for their commitment to people living with chronic pain as well as the parliamentary members of this group for giving so generously of their time. I extend this appreciation to the Minister for Health, the Hon Greg Hunt MP for championing chronic pain and bringing it to light.

Our work to raise awareness and understanding of chronic pain has strengthened with a stronger media presence than ever before. Our social media engagement has also increased with additional followers and reach to thousands of consumers every day.

Our partnership with our international colleagues has continued this year and Painaustralia participated in forums including the International Association for the Study of Pain Virtual World Congress on Pain in June and 15th Annual Pain Society of Alberta Virtual Conference, October 2021.

I believe that one of Painaustralia's greatest strengths has been its capacity to bring the lived experience of consumers to the forefront of awareness and policy decision making that makes a difference to the way we view and manage chronic pain in Australia. A heartfelt thanks to Sister Mary-Lynne Cochrane and our incredible Consumer Advisory Group who so courageously share their voice.

I have been privileged to work with the pain community over the last four and half years. A special thanks to former Chairs Robert Regan and Professor Ian Chubb as well as our current Chairman, Duncan Lewis and my staff team, in particular Nick Nguyen who has worked alongside me for more than four years.

Painaustralia is well served by its outstanding board, national patron, Sir Angus Houston AK AFC, our incredible Pain Champions, Parliamentary Friends of Pain Management Group, the Consumer Advisory Group, the Communication and Awareness Reference Group, health professionals, our members and sponsors.

2021 was another tough year and my thoughts are with the many Australians who live with chronic pain, who have not only had the day-to-day difficulties of accessing health care and managing their pain but have experienced extreme social isolation and increasing barriers to accessing care and support during the pandemic.

It is with some sadness that I leave the role as CEO of Painaustralia but I look forward to seeing the organisation move forward on its journey of working to achieve significant and positive change in the way Australia responds to people experiencing pain.



Ian Chubb at Parliamentary Friends of Pain Management Group Meeting

Our Board directors volunteer their time to guide the direction of Painaustralia. Their expertise and knowledge spans areas including law, finance, business management, health economics, consumer advocacy, clinical excellence, and government policy.

In 2021, we welcomed our new chairman, Major General (Retd) Duncan Lewis AO DSC CSC who had recently completed his five-year term as Director General of Security and Head of the Australian Security Intelligence Service [ASIO], prior to his exceptional career of 47 years with the Australian Government, both in and out of uniform.

We wish to acknowledge and pay gratitude to our outgoing Chairman, Emeritus Professor Ian Chubb and thank him for his service to Painaustralia over the last few years.



Professor Chubb was Chief Scientist for Australia from May 2011 to January 2016.

Prior to that, Professor Chubb was

Vice-Chancellor of the Australian National University from January 2001 to March 2011; Vice-Chancellor of Flinders University of South Australia for six years and the Senior Deputy Vice-Chancellor (Provost) of Monash University for two years. While at Monash he served as Dean of the Faculty of Business and Economics for 16 months.

He was awarded the Academy Medal of the Australian Academy of Science in 2016 and was elected Fellow of the Academy in 2017. He is a member of the Council of the Academy of Science, chairs its Education Committee and is a member of its Policy Advisory Committee.

#### **Dr Will Howard**

Director (Resigned 9 June 2021)

Dr Howard became a pain medicine physician via rural general practice and anaesthesia. He has been strongly involved in the Australian Pain Society since 2004, initially as Editor of the

newsletter and later as Secretary. Will has recently retired from clinical practice but continues his involvement in research into lessening pain and disability after surgery, and he remains active in seeking system change to lessen pain and disability in the community.



#### **Professor Deborah Schofield** Director

Professor Schofield is Professor and Chair of Health Economics, Faculty of Business and Economics, Macquarie University. Her career has spanned the Australian Government public service,

academia and clinical practice and she has a national and international reputation for her work in economic modelling of the health system, health, and its impact on families and the economy.



#### Major General Duncan Lewis AO DSC CSC

Chairman (Appointed 13 May 2021)

Duncan Lewis recently completed his five year term as Director General of Security and Head of the Australian Security

intelligence Service (ASIO). This was the last appointment in a 47 year career with the Australian Government both in and out of uniform. Following Duncan's retirement from the Australian Army as a Major General. Commander of Special Operations Command, he served for 15 years in the Australian Public Service in the most senior positions including as the Secretary of the Department of Defence, National Security Advisor to two Prime Ministers, and Australian Ambassador to Belgium, Luxembourg, the European Union and NATO. During his public service Duncan served on a number of boards and committees including the board of the Australian Criminal Intelligence Council, The Council of the Order of Australia, the National Australia Day Committee and on the inaugural board establishing the National Security College at ANU. Duncan recently joined the Board of Thales Australia as a non-executive director and is a senior visiting fellow at the University of Sydney US Studies Centre.

Duncan was awarded Officer of the Order of Australia in 2005 for his service as the inaugural Special Operations Commander Australia. He is a graduate of the British Army Staff College and the United States Army War College. He is a member of the Australian Institute of Company Directors. He is fluent in Indonesian.



A/Prof Malcolm Hogg

Director and Clinical Advisor

A/Prof Hogg is a full-time specialist in Anaesthesia and Pain Medicine and Head of Pain Services, Melbourne Health He is a past president of the Australian Pain Society (APS) and fellow of Faculty

of Pain Medicine. ANZCA, and member of the International Association for the Study of Pain (IASP)

Malcolm's leadership roles include membership of external advisory groups to Victorian Dept of Health and Human Services safescript (medication monitoring system) external advisory group, Drugs of Dependence committee and Pain services clinical advisory committee. Research interests include pain outcomes following trauma and models of care for pain service delivery.



Dr Chris Hayes Director

Dr Hayes is a specialist pain medicine physician who works at John Hunter Hospital in Newcastle NSW and has been Director of Hunter Integrated Pain Service, since its foundation in

1997. He is a past Dean of the Faculty of Pain Medicine, Australian and New Zealand College of Anaesthetists. Additional roles have included co-chair of NSW Agency for Clinical Innovation's Pain Network and Chair of the Pain Management Clinical Committee of the Medicare Benefits Schedule Review. His research interests include a "whole person" approach to pain, outcome measurement and redesign of health systems to achieve greater integration between specialist pain services and primary care.

#### **Catherine Murphy** Director



Catherine holds degrees in Economics and Law from the Australian National University. She held senior positions in the Australian Public Service before joining the Prime Minister's Office

where, for several years, she was senior legal adviser to Prime Minister the Hon John Howard. Subsequently she served as Chief of Staff to Minister the Hon Dr Brendan Nelson. She was also CEO to a major industry organisation. Catherine's main interest is working with boards dealing with social and health related public policy to improve the lives and outcomes for all Australians. She is an active volunteer with OzHarvest, Legacy and a women's resource and referral centre





A/Prof Craigie is a specialist pain medicine physician working in the CALHN Pain Management Unit at the Queen

Elizabeth Hospital and Clinical Associate Professor at the University of Adelaide. She is the immediate past-Dean, Faculty of Pain Medicine of the Australian and New Zealand College of Anaesthetists (FPM). She has a Masters of Pain Medicine (Sydney University) and has fulfilled numerous roles locally and nationally as a teacher, advocate, and advisor to government, researcher and journal editor of Anaesthesia and Intensive Care as well as clinician in anaesthesia and pain medicine. Meredith is passionate about medical education, pain education for healthcare practitioners and consumers, pain at the extremes of life and the transition from acute to chronic pain.



Director Ben is a highly experienced Chartered

Accountant with over 25 years' experience in the professional services industry working within Australian and international markets. He is currently

the Canberra Assurance Leader for EY. His experience over the last 25 years includes providing of a broad range of assurance and financial advisory services to a diverse range of clients in the corporate, not-for-profit and government sectors. Ben is passionate about working with executives and Boards in supporting them improve governance, finance and risk management practices.

#### Dr Graeme Killer, AO Director



Dr Killer is a former Chief Medical Officer for the Department of Veterans' Affairs and physician to Prime ministers and Governors General.

He is currently involved in a case management pilot of Veterans with complex physical and mental health problems.



#### **Professor Paul Glare**

Director

Professor Glare is the Chair of Pain Medicine, Gorthern Clinical School, Faculty of Medicine & Health, University of Sydney; Head of the Specialty of Pain Medicine in the Sydney Medical School; Director, Pain Management

Research Institute (PMRI), Kolling Institute. He is also a specialist physician in pain medicine with a Clinical Academic appointment in Northern Sydney Local Health District as well as having external appointments at North Shore Private Hospital and Genesiscare at St Leonards and Macquarie University Hospital. He is also a medical advisor to Cymra Life Sciences Pty Ltd.



#### Professor Lorimer Moseley AO DSc PhD FACP FAAHMS FACP HonFFPMANZCA HonMAPA

Director (Appointed 29 July 2021)

Lorimer is a pain scientist educator and physiotherapist. He leads IIMPACT in Health at the University of South Australia, where

he is also Professor of Clinical Neurosciences & Chair in Physiotherapy. After seven years working as a physiotherapist in pain and and high performance roles, he undertook, in 1998, his PhD at the University of Sydney. Since then he has continued to work with people challenged by persistent pain and has had research posts at the University of Queensland, Oxford University and Neuroscience Research Australia. He is now an NHMRC Leadership Investigator, has authored 350 scientific articles and six books on pain and rehabilitation, including the two highest selling pain books internationally. He leads the non-profit initiative Pain Revolution and Chairs the Pain Adelaide Stakeholders' Consortium. His contribution to the science and management of pain has been recognised by honours or awards in 13 countries. His public engagement and education initiatives have also been honoured in six countries. In 2020, he was made an Officer of the Order of Australia for distinguished service to humanity at large in pain science and management, science communication and physiotherapy. He lives and works on Kaurna land in Adelaide, South Australia.



#### Sister Mary-Lynne Cochrane Director

Sister Cochrane is a Consumer Representative with the Agency for Clinical Innovation Pain Network and a member of the Executive Committee. Mary-Lynne lives with a form of arthritis and over 35 years

she has endured twenty-two surgeries, including three knee replacements, three hip replacements, three back surgeries, a shoulder replacement, pelvic bone transplants and surgeries in both feet and hands.

Mary-Lynne entered the Sisters of the Good Samaritan in 1977 after a period working with the Endeavour Foundation a facility for intellectually slow children. She has a background in Social Science with Welfare. In her current role, within the Good Samaritan Congregation Mary-Lynne conducts training programs for her sister nuns in the use of mobiles handsets and iPads to enhance communication and connect.

Last year Mary-Lynne was appointed as Wellbeing Coordinator for another religious order.

### **National Patron & Pain Champions**

Painaustralia would like to thank all our highly valued Pain Champions for their meaningful contributions throughout 2021.

In 2021 Painaustralia was delighted to appoint Hayley Leake as our newest Pain Champion this year. Hayley is a physiotherapist and pain researcher and spent 6 years working clinically before she embarked on a PhD at the University of South Australia with Professor Lorimer Moseley's research group. Hayley's research aims to optimise pain education for adolescents and adults living daily with chronic pain. Additionally, Hayley was the Australian Survivor Winner of 2021.

Hayley's goal as Painaustralia's newest Pain Champion is to "help address issues of discrimination, misunderstanding and stigmatisation in the community and to reduce the sometimes-severe impact on those living with pain, their families and carers".

In 2021 Hayley wrote a blog for Painaustralia detailing how she drew upon her 'experience working as a physiotherapist with people living with chronic pain', when she was on Survivor. She drew upon the resilience she observed when working as a physiotherapist with people living with chronic pain.

Currently based at Neuroscience Research Australia, Hayley is trialling treatments for chronic low back pain, Complex Regional Pain Syndrome as well as working alongside researchers at the Body in Mind research group at the University of South Australia.



Air Chief Marshal Sir Angus Houston AK, AFC (Ret'd) National Patron

Air Chief Marshal Sir Angus Houston AK, FC (Ret'd) continues to honour our organisation through his role as National Patron.

Sir Angus was awarded the Knight of the Order of Australia in January 2015 for extraordinary and preeminent achievement and merit in service to Australia through distinguished service in the Australian Defence Force, continued commitment to serve the nation in leadership roles, particularly the national responses to the MH370 and MH17 disasters, and in a variety of roles in the community.

Sir Angus retired from the military as Chief of the Australian Defence Force in July 2011 after serving for 41 years. In April 2017, Sir Angus was appointed Chancellor of the University of the Sunshine Coast. In addition, he chairs several boards and is the Ambassador/Patron for a number of charitable organisations.

Sir Angus accepted the role of National Patron of Painaustralia in recognition of the unfortunate fact that chronic pain is a common condition among veterans, especially those injured in conflict. Sir Angus is an exceptional Australian with a deep commitment to the Australian community.

Painaustralia is honoured that he continues to serve as our National Patron



Hayley Leake, Australian Survivor Winner 2021 Painaustralia's Newest Pain Champion

I work among a community of researchers looking to innovate, improve, and provide better access to pain therapies.



#### Tara Moss, Best Selling Author and Advocate

Tara Moss is an award-winning author, documentary producer, host and advocate. Since 1999, Tara has written 13 bestselling books, published in 19 countries and 13 languages. She is the winner of an Edna Ryan award and in 2017 was recognised as one of the Global Top 50 Diversity Figures in Public Life, for using her position in public life to make a positive impact in diversity.

In the media and through her page Tara and Wolfie, Tara brings advocacy and visibility to issues of disability and chronic pain, and the need to normalise mobility aids.



#### Sophie Scott, ABC Medical Reporter

ABC Medical Reporter, Sophie Scott lives with chronic pain as an outcome of her genetic condition of hypermobility. Sophie says: "I visited GPs, physios, rehab physicians and then a pain clinic, where I learned that taking pain-killing medication wasn't really helping. What did help me was doing a free online pain management course at Macquarie University, strength training, pacing and for flareups using a biofeedback device. What I learned is that living with pain is nothing to be ashamed of, that managing pain goes hand in hand with managing your mental health."

The wealth of experience and skills that Sophie brings to our organisation has been invaluable. Sophie's personal experience gives her an excellent understanding of the issues faced by people with chronic pain, and we are grateful that she is willing to share this publicly to help raise awareness about

this important issue.





Peter Rudland, Veteran and Invictus Games competitor

Veteran and Invictus Games competitor and gold medallist Peter Rudland survived a horrific Black Hawk helicopter crash while serving with the army in Afghanistan. He sustained severe injuries and lives with chronic pain.

Peter joined the Army in 1989 and was medically discharged in 2017. During his service he was deployed to Cambodia, Iraq (twice), Timor Leste (twice) and Afghanistan. It was during the Afghanistan mission in 2010 that he survived a Black Hawk helicopter crash as he and his fellow servicemen closed into a Taliban stronghold. Four people died. Peter awoke in a German hospital, with bleeding on the brain, organ damage and almost every major bone in his body broken.

Peter acknowledges just how difficult his journey has been since that crash. He was a proud competitor at the 2019 Invictus Games, competing successfully in wheelchair rugby and recumbent cycling.



Liesl Tesch AM MP

Liesl is a seven-time Paralympian and the first NSW MP to use a wheelchair. She has achieved enormous success in her personal and public life and lives with a spinal cord injury. We are extremely grateful to Liesl for her continued support of Painaustralia.

# Painaustralia's

Painaustralia aims to provide a voice to Australians living with chronic pain, and this is fundamental to informing our policy and positions on key issues.

The Consumer Advisory Group (CAG) provides Painaustralia with an opportunity for people with lived experience of chronic pain to assist in addressing strategic objectives, and help the organisation in identifying potential gaps, barriers as well as comment on topical and priority issues requiring consumer and community engagement.

CAG members assist, advise, and work together with Painaustralia to improve chronic pain management throughout Australia. Members of the group represent diverse conditions, gender, age, and geographical locations.

Deciding to expand the CAG due to its highly successful role in providing valuable feedback to goverments and stakeholders, Painaustralia put a call out in September 2021 for consumers interested in joining the group. The number of applications and high level of interest from consumers was overwhelming and we are grateful to everyone who did apply. In December 2021 after processing many applications from interested consumers, Painaustralia was delighted to announce the expansion of the CAG and alongside board director and consumer Mary-Lynne Cochrane, welcomed new members Alexandra Christie, Maria Heredia, Jason Styles, Deidre Pinto, Gabriella Kelly-Davies and Janine Monty.

Throughout 2021 the CAG was consulted in and out of session. The members of the CAG gave valuable input which helped to shape Painaustralia's policy positions and several programs and initiatives relating to pain management in Australia. Painaustralia extends a heartfelt thanks to the members of the CAG for their valued participation.

To see the profiles of all our CAG member go to www.painaustralia.org.au/ consumer-advisory-group



Mary-Lynne is a Painaustralia Board Director and Chair of the Consumer Advisory Group. She is a Consumer Representative with the Agency for Clinical Innovation Pain Network and a member of the Executive Committee. Mary-Lynne lives with a form of arthritis and for over 35 years she has endured 22 surgeries, including three knee replacements, three hip replacements, three back surgeries, a shoulder replacement, pelvic bone transplants and surgeries in both feet and hands.

Pain is a constant in my life, that is a fact which is not going to go away. I have lived with pain now for more than 42 years. For the last 6 of those vears, I have written and spoken about my pain story numerous times. In sharing my story my aim is to let others know that I found it possible to move to another space - a space where I was in control and the pain was not controlling me.



Originally from the beautiful city of Seville, Maria Heredia is an academic with a large array of experiences which had her living and working throughout Europe despite living with chronic pain, which occurred when a minor operation went bad. After living in the UK for many years, Maria returned to South Australia to be close to her daughters. Retiring a lot earlier than expected due to chronic pain, Maria now focuses her time on her voluntary efforts in mental health, chronic pain, and disability within CALD communities. She hopes to contribute and share her inside perspective and experience.



As a result of mixed connective tissue disease, a rare bone disease that causes spinal degeneration and nerve compression and peripheral neuropathy, Janine Monty has lived with chronic pain for the past 15 years, and her pain has been severe and disabling. Termed High Impact Chronic Pain, Janine also manages Poly-Cystic Ovarian Syndrome (PCOS), eosinophilic esophagitis which causes gastrointestinal pain that Janine manages with diet. Janine had a total hysterectomy to treat her pelvic pain which originated from endometriosis and adenomyosis and has had multiple joint surgeries and three levels of her lumbar spine fuse. After trying many types of treatment, Janine is a big believer of managing pain holistically, and has undertaken university level study in pain theory, behaviour change, nutrition, meditation, and mindfulness and is passionate about advocating for those living with high impact chronic pain.



Jason has experienced chronic pain for 15+ years, in this time he has tried just about everything to try and get relief from his pain. He is currently managing his pain guite well and has found a good balance in his life. The improved quality of life Jason has now did not come guickly or easily, it was and still is a constant battle to obtain the right balance in his life. Jason completed a pain management course but because he had spent a lot of his own time researching possible solutions for his pain, he now aims to help others to improve the quality of their lives through a variety of techniques and methods and enjoys being involved in Consumer Advocacy work



Gabriella is a biographer and has studied at the University of Oxford and the Australian National University and is currently a PhD student in biography at Sydney University. The President of Life Stories Australia Association, Gabriella's pain journey began when she was pushed off her bike by some thugs, triggering a lifelong struggle with occipital neuralgia and chronic migraine. After seeking a variety of pain management strategies, Gabriella has found that the concepts she learned at a multidisciplinary pain clinic has helped her manage her pain the most. She urges other people with chronic pain to never give up and to remain hopeful.



Deirdre is a woman of many achievements including three decades of experience as a government project manager, policy advisor and strategic planner. She is also the cofounder and secretary of Chronic UTI Australia Incorporated, an organisation dedicated to improving awareness, diagnosis and treatment of a condition that causes chronic bladder and pelvic pain. Regarding her own experience of chronic pain, Deirdre has lived with severe endometriosis for almost 40 years and has a strong interest in the way people unite around marginalised or stigmatised health conditions.



Alexandra's chronic pain journey began 14 years ago after a guad bike accident. Working as a youth worker and a wife and mother, Alexandra's life proceeded to change rapidly. She underwent six orthopaedic surgeries, attempted five times to go back to work and two times to pursue further study – all of which were unsuccessful, and her condition meant she had to stop working. Despite her challenges and whilst living in poverty, Alexandra now has a very good GP and wishes to advocate for unexplored pain management alternatives

#### Our new CAG members in 2021



This event is indeed a major achievement and milestone in policy development opportunity for pain management in our community,"

Health system reform can take approximately a decade, even when the focus of reform is established and well defined. Considering that chronic pain was a largely invisible condition in the health policy field 10 years ago, it is a great achievement to have made the progress we have.

Major General (Ret'd) Duncan Lewis

### **Governor General** hosted event at **Government House**

On 23rd June 2021, Painaustralia was honoured to have His Excellency General the Honourable David Hurley AC DSC (Ret'd) and Mrs Linda Hurley host a Painaustralia event at Government House to raise awareness for veterans who live with chronic pain. His Excellency the Governor General spoke at the event along with our Chairman Major General Duncan Lewis (Ret'd) AO DSC CSC, our National Patron Chief Marshal Sir Angus Houston AK AFC (Ret'd) and veteran and 2020 female defence leader of the year, founder and CEO of AeroPM, Mrs Emily Frizell. The event was attended by a large contingent of senior defence industry and government representatives. Major General (Ret'd) Lewis spoke about how the impact of chronic pain on veterans is often ignored despite the fact that they experience higher rates of mental health problems and musculoskeletal-related pain than the general community. Painaustralia would like to extend its thanks to everyone who attended and who spoke at the event.

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Our ex-service men and women have given much in service to their country. While our understanding continues to grow about the impact of post-traumatic stress and other mental health challenges for our veterans, we still have some way to go towards a better understanding of chronic pain and its inter-relationship with mental health.

Air Chief Marshal Sir Angus Houston AK, AFC (Ret'd), Painaustralia Patron

Living Well With Chronic Pain After Service event hosted by His Excellency General the Honourable David Hurley AC DSC (Retd) and Her Excellency Mrs Linda Hurley

(From left to right) Painaustralia CEO, Carol Bennett, Project Manager, Nick Nguyen, Senior Project Manager, Monika Boogs, AeroPM CEO, Emily Frizell, AeroPM General Manager, Adam Frizell.



We recognise that a significant number of veterans live with chronic pain from injuries obtained during service, and musculoskeletal pain is one of the most common reasons for medical discharge from the armed forces. This topic is especially relevant given the Royal Commission in Defence and Veteran Suicide which is underway and scheduled to finish by June 2023.



Australia is the first country to have a National Strategic Action Plan for Pain Management

Australia's first National Strategic Action Plan for Pain Management was launched by the Health Minister, the Hon Greg Hunt, at Painaustralia's Parliamentary Friends of Pain Management Group meeting on 18 May 2021.

The launch of the document marked the culmination of years of work for our organisation and is the result of decades of advocacy and effort throughout the sector. The plan was developed and led by Painaustralia with funding from the Australia Government Department of Health and endorsed by the Australian Government and all State and Territory governments.

Pain in Australia



Only 1 out of 100 people living with chronic pain will receive multidisciplinary care. Medications are used in close to 70 per cent of GP consultations for chronic pain management.



Suicidal behaviour is two-to three times more likely for people with chronic pain.



The national financial burden of pain is estimated to be \$144.1 billion in 2020 and will increase to \$215.6 billion by 2050.

Around **one-fifth** of all GP presentations in Australia involve chronic pain.

The Plan is a critical step towards improving the quality of life for the millions of Australians who live with chronic pain and every day face the challenges of accessing affordable and specialised pain treatment.

Emphasising the need to understand the complexity and individuality of pain, the Plan contains eight key priority areas that set out more than 50 evidence-based implementable practices that if funded will help to address chronic pain among Australians.

Painaustralia is committed to ensuring that funding is provided to realised the actions and agenda outlined in the plan to assist those who live with chronic pain.

Painaustralia would like to thank all the stakeholders, consumers and members including its founding members, the Australian and New Zealand College of Anaesthetists, the ANZCA Faculty of Pain Medicine, the Australian Pain Society and the Pain Foundation (formally known as the Pain Management Research Institute) for their work and commitment to the Plan.



Painaustralia held our Parliamentary Friends of Pain Management Group meeting in May 2021 with the launch of the National Strategic Action Plan for Pain Management and the updated National Pain Services Directory.

The meeting was attended by our Parliamentary Friends of Pain Management Group co-chairs Liberal Senator Wendy Askew and Mr David Smith MP, Labor Member for Bean.

Senator Askew launched the updated Pain Services Directory saying it allowed consumers, carers and health professionals to make informed decisions about their pain management options and pathways in their region.

The updated National Pain Services Directory provides a comprehensive list of more than 200 pain clinics who treat all types of pain conditions. It has a search function that allows the user to search via geographic location close to where they work or live to find their nearest pain specialist.

Shadow Assistant Health Minister Ged Keaney MP, also spoke at the launch urging prioritisation be given to chronic pain due to its impact and prevalence in our community. She also talked to her experience of managing chronic pain as a former nurse. While Mr Smith highlighted the importance of consumers and encouraged Painaustralia to continue its work in making sure the National Action Plan is implemented by all governments.

The meeting also heard from Pain Champion and best-selling author, Tara Moss live online from Canada in an emotional presentation where she detailed her experience with Complex Regional Pain Syndrome. "Being non-judgmental is one of the most important things we can do for people living with chronic pain. Believe them. Ask what their access needs are. Make clear that you get it, and you know pain is real even though it is invisible," said Tara Moss.

Tara's words were echoed by two other inspiring speakers with lived experience of chronic pain including Canberran Megan Kuleas and Painaustralia Board Director Mary-Lynne Cochrane.

In a heartfelt presentation Megan, 31, shared her struggle with chronic pain and spoke about the invisible nature of her condition, how pain does not discriminate and the significant impact on her life. "Chronic pain is different for each person and therefore each person's case must be treated that way and cannot be done in a one size fits all approach."

"I am very lucky to have a wonderful support system around me consisting of my loved ones and allied health team. My family and friends provide me with unwavering love and support. They listen, provide advice and perspectives, help me with daily tasks, and always encourage me to stay focused after a setback." said Megan who is a member of the Painaustralia Consumer Advisory Group.

Painaustralia would like to thank everyone who attended, spoke and shared their stories at the event. We would also like to acknowledge Senator Askew and Mr Smith as the co-chairs of the parliamentary group and thank them for their support in highlighting the issues, cost and the challenges of chronic pain to their fellow parliamentarians.



Painaustralia Consumer Advisory Group member Megan Kuleas (centre) with her family

# Parliamentary Friends

of Pain Management Group Meeting





de King, Pain Counsellor - Dr Geoff Speldewinde, Pain Specialist - Sister A Mary-Lynne Cochrane, Painaustralia Board Member - Carol Bennett, Painaustralia CEO - David Smith MP, Member for Bean and Major General Duncan Lewis, Painaustralia Chairman











### **Painaustralia's Annual General Meeting**

Held on the 18th May 2021, Painaustralia presented our new constitution at our AGM.

Painaustralia sought and gained approval from our members at the AGM for the adoption of the amended constitution. The new constritution was accepted by our members and came into effect from 1 July 2021.

Changes to the constitution included creating a new individual membership category to enable individuals to become members. This means as a member of Painaustralia, individuals can grow their network of other individuals and organisations who are committed to improving the lives of people living with pain.

Painaustralia would like to thank our member Capital Pain and Rehabilitation Clinic for providing the venue to hold our 2021 AGM and our Parliamentary Friends of Pain Management Group meeting.



Painaustralia's Strategic Plan for 2021-2024 was unveiled. Within the document, our organisation's vision

In 2021

The Strategic Plan focuses on making pain recognised as a national health priority and advocates that Australians living with pain or who are at risk of entitled to credible information and a world-class system of care.

Working collaboratively with key stakeholders, Painaustralia's mission is to integrate pain as a priority in the broader health agenda in accordance with our roadmap for achieving world-class care, through the National Strategic Action Plan for Pain Management.

to read our Strategic Pan 2021-2024 go to www.painaustralia.org.au





Impact of opioid regulatory reforms on people living with chronic pain



In December 2021 Painaustralia launched its impact of opioid changes on people living with chronic pain survey. Released through our social media channels we asked consumers to give their input into how the June 2020 opioid reforms impacted them.

In June 2020, the Federal Government introduced several regulatory changes in relation to the prescribing of opioids for the management of pain. These changes applied to immediate release and sustained release versions of buprenorphine, codeine, fentanyl, hydromorphone, methadone, morphine, oxycodone, tapentadol, tramadol and included smaller pack sizes and changes to the authority required for opioids to be subsidised.

More than a year since the reforms were introduced, Painaustralia was keen to hear from consumers living with chronic pain to further understand what longer term impact these changes may have had.

The results of the survey will feature in a report to be released in 2022. It follows a previous report released by Painaustralia on a survey it conducted in late 2020. This survey recieved nearly 600 responses in 10 days with consumers reporting experiencing significant barriers to pain management.

### **Take Home Naloxone**

Painaustralia worked with the Australian Government in 2021 to support its Take-Home Naloxone Pilot. As part of the pilot program, the Australian Government made naloxone free and available to anyone who may have experienced or were at risk of an opioid overdose. Naloxone is a drug that can temporarily reverse the effects of an opioid overdose or adverse reaction and can be administered by injection or through a nasal spray. Painaustralia's role was to develop social media messages and tiles to raise awareness of the pilot to its consumer network and provide consumer feedback of their experiences of the program and naloxone to Government. Our social media campaign consisted of a total of 48 social media posts on Twitter, Facebook and LinkedIn reaching an audience of 55,000 people and 3,000 engagements including 1000 comments. Retweets of one of Painaustralia's social media posts about removing the stigma from co-prescribing naloxone reached an audience of 9,738 people.



Campaigns

### SafeScript NSW: What Real Time **Prescription** Monitoring means for you?

Painaustralia is pleased to have played an active role in the implementation of the Real Time Prescription Monitoring (RTPM) programs in NSW and the ACT in 2021. For SafeScript NSW Painaustralia was able to provide valuable feedback on the messaging from a consumer perspective through advice sought from our Consumer Advisory Group. Painaustralia's work with the NSW program SafeScript NSW involved extensive consultation with health professionals, consumers, and stakeholders testing, developing and evaluating messages. On the 29th of September 2021, Painaustralia was proud to host a webinar featuring NSW Health's Andrew Hargraves, Painaustralia Board **Director and Pain Specialist Dr Chris Hayes and** Painaustralia Consumer Advisory Group member Kim Allgood provided information on how the program would impact consumers. We also helped to develop factsheets and website content containing information for both health professionals and consumers that were non-stigmatising and focused on the safe use of medications.

### What is **Canberra Script**

Painaustralia worked with ACT Health as part of its launch and implementation of its Real Time Prescription Monitoring Program called Canberra Script. As part of the work carried out, our Consumer Advisory Group helped to develop and evaluate messages that avoided stigmatising language and included respectful communications for prescribers and dispensers when talking to consumers about their medications. Painaustralia was also a member of the advisory group overseeing the implementation of the program.

Like many of the RTPM programs rolled out across Australia, Canberra Script is a computer system that provides pharmacists and prescribers with medicine history information about a consumer's use of monitored drugs (for example, diazepam and tramadol) to ensure their medications are used safely and effectively.

Painaustralia also developed a video providing information about Canberra Script for consumers that is available on the Painaustralia and ACT Health website.



#### health.act.gov.au/canberrascript



Promotion video developed by Painaustralia

### Consumer Awareness

International Pain Awareness Month was recognised in September by Painaustralia in conjunction with the International Association for the Study of Pain (IASP) through a host of activities. These included a consumer-led awareness campaign which gave voice to individuals who manage chronic pain on a daily basis, a webinar, blog posts and two fact sheets - one in partnership with Soldier On Australia to highlight the impact of chronic pain in our veteran community.

As part of International Pain Awareness Month. Painaustralia launched it Chatbot which was developed in close consultation with consumer stakeholders. The Chatbot is designed to be an intelligent assistant to help consumers, healthcare professionals and stakeholders navigate through the information available on the Painaustralia website. Other awareness activities included our community education and awareness project. The project saw the launch of our updated website in early 2021 resulting in the increased availability of evidence-based information on chronic pain and pain management on a single web-based platform.

Painaustralia was also a member of the Accessible Product Design Alliance which advocated to the government and packaging industry to design and make more products accessible to consumers.



Fact sheets were developed by Painaustralia during International Pain Month Awareness

### Launch of the biography of Painaustralia's Founder Dr Michael J. Cousins



On Sunday 25, 2021, Painaustralia hosted the online launch of the biography about our founder, Dr Michael Cousins as part of our 10 year anniversary.

Entitled "Breaking the Pain Barrier: The Extraordinary Life or Dr Michael J Cousins", the book was written by his patient, Gabriella Kelly-Davies.

Over 130 individuals including consumers, health professionals and pain specialists from Australia and all around the world were in attendance to honour the pain medicine pioneer.

Through almost 50 years of research, Dr Cousins advanced pain treatment which included epidural analgesia and spinal cord stimulation to help relieve lower back pain.

Dr Cousin's work genuinely changed the way that Australia responded to pain, through his commitment to advocate for chronic pain to be understood as a condition and he helped make access to pain management a fundamental human right. His work brought visibility to a condition at a time when the medical profession was not yet ready to accept pain medicine as a legitimate field of medical practice.

Dr Cousin designed Australia's National Pain Strategy which several other countries replicated, and he was the driving force behind the creation of Painaustralia. Our organisation now proudly works with governments and stakeholders to implement the world-first National Strategic Action Plan for Pain Management.

The launch of Dr Cousin's biography was an opportunity to not only highlight the book and all his work, but also for the panellists to reflect on how his work has influenced them both as professionals and as individuals.

### Policy & Submissions



Painaustralia continued to advocate to all governments and work with key health stakeholders to make positive changes on issues impacting consumers who live with chronic pain. During 2021 Painaustralia provided submissions to a broad range of consultations and

inquiries including a submission to the National Medicines Policy in October, a submission regarding Australia's Primary Health Care 10 Year Plan in November and a submission to the Federal Budget in December.

In addition, CEO Carol Bennett appeared before the House of Representatives Parliamentary Inquiry on approval processes for new drugs and novel medical technologies at Parliament House in Canberra in April 2021.

Giving evidence to the Inquiry, Ms Bennett told parliamentarians that there was a need for meaningful consumer consultation when approving new medications and devices.

"There must be a better way to consult consumers throughout the regulatory process as the current process is leaving consumers disappointed and berefit of hope. Consumer input needs to be considered, valued and adopted when making decisions that have a real impact on the quality of life of those living with pain and other health conditions."

To read Painaustralia's submissions go to www.painaustralia.org.au/submissions-reports



#### Other submissions made by Painaustralia throughout the year included:

- Submission to the 2021-22 Federal Budget Working together to address chronic pain, January 2021.
- Submission to the Potential Reforms to the Medicinal Cannabis Manufacturing, Labelling and Packaging Requirements Consultation Paper, January 2021.
- Submission to the Regulation to support Real Time Prescription Monitoring (RTPM), March 2021.
- Submission to the review and update of the Guiding Principles for Medication Management in the Community and Guiding Principles for Medication Management in Residential Aged Care Facilities, April 2021.
- Submission to the Draft National Preventative Health Strategy Consultation, April 2021.
- Submission to the Post-market Review of Opiate Dependence Treatment Program (ODTP) Medicines, April 2021.
- Submission to The Australian Medical Research Future Fund Strategies and Priorities, June 2021.
- Submission to the Use of Cannabis in Victoria, August 2021.
- Submission to the National Medicines Policy, October 2021.
- Submission to the Australian and New Zealand College of Anaesthetists Faculty of Pain Medicine position statement on the use of ketamine in the management of chronic non-cancer pain, November 2021.
- Future Focussed Primary Healthcare: Australia's Primary Health Care 10-year Plan 2022-2032, November 2021.
- Submission to the 2022-23 Federal Budget A Better Future for People Living with Chronic Pain, December 2021.



#### To read all of Painaustralia's blogs go to www.painaustralia.org.au/blogs

In 2021 Painaustralia produced over 34 blogs outlining timely issues impacting people living with chronic pain, as well as eight newsletters.

Topics which were covered included: our Consumer Advisory Group, Therapeutic Goods Administration updates, drug and medicine updates, Pain Awareness Month, medicinal cannabis, Defence and Veteran Suicide Roya Commission survey, Accessible Product Design Alliance, Pain Champion, membership updates, National Pain Week, National Action Plan, Naloxone and stigma, Migraine management, National Pain Services Directory, Parliamentary Friends of Pain Management Meeting and budget submissions.

#### Painaustralia in the news.

In 2021 Painaustralia appeared in the news over 28 times, on platforms including ABC News, The Medical Republic, The Sydney Morning Herald, ABC Radio, Channel 9, The Australian, ABC PM, The Australian Women's Weekly, HerCanberra, WIN News, ABC Every Day, Body + Soul, Global Accessibility News, Short Black with Sandra Sully, Australian Pharmacist and CNN World.

## Media **Communications**

awareness of chronic pain.

On Friday 11th June 2021, Painaustralia was honoured to speak at the International Association for the Study of Pain Virtual World Congress on Pain. Our CEO's topic was the 'Australian National Pain Strategy: a 10-year challenge'. The Congress was an informative day and convened by Dr Sean Mackey from the United States of America, strategic themes surrounding health were discussed and there was much collaboration.

Painaustralia also spoke as a panellist at the 15th Annual Pain Society of Alberta Conference in October 2021. Entitled 'Leading the Way: Provincial, National and International Pain', the panel engaged with the audience to hear updates and to work together to build a better future for all people living with persistent pain.

# Engagement



Throughout 2021 Painaustralia attended various conferences and summits to further increase the



David Ali CEO of Motor Neurone Disease Australia Gethin Thomas, Executive Director Research at Motor Neurone Disease Australia and Carol Bennett, Painaustralia CEO at the House of Representatives Standing Committee on Health, Aged Care and Sport Inquiry into the Approval processes for new drugs and novel medical technologies in Australia

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The National Strategic Action Plan is a critical step towards improving the quality of life for the millions of Australians who live with chronic pain and every day face the challenges of accessing affordable and specialised pain treatment.

Carol Bennett, Painaustralia CEO 2021

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