working to prevent and manage pain

annual report 2011

Pain is one of the biggest health issues today – every bit as big as cancer,
 AIDS and coronary heart disease. Yet it remains one of the most
 neglected areas of health care.
 Professor Michael Cousins AM

Painaustralia Limited PO Box 770 Waverley NSW 2024 Tel: 02 9130 6086 Fax: 02 9130 6045 Email: lesley.brydon@painaustralia.org.au Website: www.painaustralia.org.au ACN 147 676 926 Publication information: Painaustralia Limited Annual Report 2011 © Painaustralia Limited 2011

CONTENTS

Chairman's Report	2
Chief Executive's Message	3
Pain in Australia	4
What is Pain?	5
Painaustralia	6
Our Board	7
Members and Partners Working Together	9
Progress with National Pain Strategy	11
The Future	15
Global Developments	16

CHAIRMAN'S REPORT

The National Pain Summit held in Canberra two years ago was the exciting beginning of what has now become a global movement to address the plight of tens of millions of people living with pain – including 3.2 million Australians.

One by one, nations around the world have begun to develop their own strategies and prestigious authorities such as the US Institute of Medicine, the International Federation of Health and Human Rights Organisations and the World Medical Association have called for urgent action.

The credit for this goes to those organisations that had the foresight, understanding and motivation to participate in the Summit and the development of the National Pain Strategy – organisations that now make up the membership of Painaustralia and our related network.

Congratulations to everyone who was involved in the long and difficult process to achieve this important step.

Whilst the progress to date is very encouraging – we are still a long way from our goal of having governments recognise pain as a heath care priority and making effective pain treatment accessible to the people who so urgently need it.

The will is certainly there, however the resources currently available to us are limited. We have a capable board and small executive team, with most of the work being done on a pro-bono basis.

We are also fortunate to have the benefit of generous financial or in-kind support which has enabled us to establish Painaustralia and begin operations. However real progress for the future, urgently requires an effective fundraising strategy as a priority, to ensure we can continue this important work.

I am proud to have the opportunity to be involved with this cause, and to work alongside people who have the skills, knowledge and passion to bring about the changes needed.

Your personal goodwill and support is important to us.

James Strong

James Strong AO Chairman

CHIEF EXECUTIVE'S MESSAGE

The executive's primary focus during 2011 has been to establish a strong foundation upon which Painaustralia can build for the future.

Whilst most of our energy has been directed at the priorities set out in our strategic plan, from time to time we were blown off course by unforeseen issues, and also opportunities, which we report on in this review.

We also report on the very important steps that have been taken to begin implementing the National Pain Strategy – however in no way do we claim credit for these.

What the National Pain Strategy process did – and what Painaustralia continues to do – is bring together the broad range of organisations and individuals who have the experience, knowledge and ability needed to create change. Input from our consumer partners, representing people living with pain, has been fundamental to this.

Gradually, significant changes are occurring: to the planning and delivery of pain services, to the education and training of health care professionals and undergraduates and to cultural attitudes – the way the community perceives and deals with people in pain.

The reality is that every individual and organisation that contributed to the National Pain Strategy shares ownership of it – and everyone one of you can play a role in its implementation.

Painaustralia remains the guardian of the National Pain Strategy – and its champion – and provides the underlying framework to bring all the various stakeholders together.

We will continue to play this facilitating role: to promote, and when necessary defend, the rights of people living with pain and all of you who seek to help and support them.

We thank all our members, our partners and supporters and the broad network of affiliated organisations that have helped achieve our goals so far.

We look forward to continuing to work with you and to an even more exciting year in 2012.

Jelly Bugton

Lesley Brydon Chief Executive

PAIN IN AUSTRALIA

Pain is one of the biggest health issues today, yet it remains one of the most neglected and poorly understood areas of health care.

A 2007 Access Economic Report, *The High Cost of Pain*, found that one in five Australians, including children and adolescents, will suffer chronic pain in their lifetime. This prevalence rises to one in three among older Australians.

However up to 80 percent of people living with chronic pain are missing out on treatment that could improve their health and quality of life.¹

Chronic pain also places a significant burden on the economy, costing an estimated \$34 billion per annum and making it the nation's third most costly health problem.

Productivity losses are estimated at \$11.7 billion which equates to 36.5 million workdays each year. The report pointed out that half of the costs to the health system of \$7 billion, could be saved by providing effective and timely treatment.

However, access to treatment for chronic pain is a key issue, with people in regional and remote areas, and indigenous populations particularly affected.

Patients face long waiting times to access multi-disciplinary pain services in public hospitals – frequently more than one year – resulting in deterioration in quality of life and reduction in ability to return to work.²

There is a serious shortage of qualified pain medicine specialists and the education and training available for health care professionals at all levels is extremely limited.

Despite these alarming statistics, pain is not yet recognised as a health care priority.

One in five Australians will suffer chronic pain in their lifetime and up to 80 percent of people living with chronic pain are missing out on treatment that could improve their health and quality of life.
National Pain Strategy, 2010

WHAT IS PAIN?

The International Association for the Study of Pain (IASP) defines pain as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage."

All pain is an individual human experience that is entirely subjective and can only be truly appreciated by the person experiencing the pain.

Acute Pain: When pain is brief or short term (acute pain), it acts as a warning for the body to seek help. Acute pain occurs most commonly following injury or surgery and most patients can be helped with appropriate treatment.

Effective timely treatment is essential to prevent transition to chronic pain.³

Chronic Pain: Some forms of chronic pain, for example pain associated with severe osteoarthritis, may be treated with therapy which may include medication or surgery; however other types of chronic pain, such as neuropathic pain or migraine, may be far more difficult to diagnose and treat.

When pain becomes severe and continues day after day, night after night, for more than three months and does not respond to treatment, it can cause physical and psychological changes to the peripheral and central nervous system and the brain. This represents a disease in its own right.

Thus chronic pain is shown to have a distinct pathology that often worsens over time and can constitute a serious, separate disease entity.

Left untreated, chronic pain can have a devastating impact on all aspects of sufferers' lives. About 65 percent of people with chronic pain report interference with daily activities including sleep, sex, work, exercise and routine self-care, which can have a negative effect on personal relationships, social interactions and lifestyle.

Cancer Pain: Pain is one of the most feared aspects of cancer. It can occur in patients with both early stage and advanced disease, and in cancer survivors as a severe and debilitating side-effect of treatment.

My post-op recovery for breast cancer was uneventful except for my level of discomfort which began to intensify when I began my chemotherapy treatment. There was nothing to identify the cause of my pain. The pain became so incapacitating that I could not walk to the bathroom without excruciating pain reverberating in my chest.

Painaustralia



- Promote awareness of the National Pain Strategy and build policy support with State and Federal Governments;
- Achieve Federal and State Government recognition of chronic pain as a chronic disease;
- Sustaining our organisation with effective fundraising and marketing campaigns.

We have a capable board of Directors with extensive experience in corporate governance. They include people with clinical expertise in pain, as well as community directors with backgrounds in law, health care, education and consumer advocacy.



James Strong, AO - Chairman

Mr Strong has a long career in business and law. He is currently Chairman of Woolworths Limited, Kathmandu Holdings Limited, the Australian Council for the Arts and the Organising Committee for the ICC Cricket World Cup 2015.



James Wood, AO - Director

Mr Wood is Chairman of the NSW Law Reform Commission and Deputy Chairman of the NSW Sentencing Council and a former judge of the NSW Supreme Court (1984-2005). He is currently a member of the Domestic Violence Death Review Team and a member of the Sydney Children's Hospital Network Human Research Ethics Committee.



Robert Regan - Director

Mr Regan is Partner in Charge of the Sydney Office of Corrs Chambers Westgarth, Member of the Corrs Executive Leadership Team and leader of that firm's Banking & Finance, Tax, Projects and Energy & Resources divisions, and a Director of the Australian Centre for International Commercial Arbitration.



Geoffrey Applebee - Director and Treasurer

Mr Applebee is a highly experienced professional adviser to professional services firms and their partners. He has served on a diverse group of board and audit committees since retiring from an International Accounting Firm in 2009.



Kieren Perkins, OAM - Director

Well known as one of the greatest swimmers of all time, Mr Perkins is Head of Private Clients and Business Development QLD National Australia Bank Private Wealth and a Director of the Starlight Children's Foundation. He is also a dedicated and compassionate carer for his wife Symantha and son Harry who both live with chronic pain.

OUR BOARD



Associate Professor Milton Cohen - Director and Clinical Representative Associate Professor Cohen is a pain physician and rheumatologist on the St Vincent's Sydney Campus. He is a Fellow of the Royal Australasian College of Physicians and of its Faculty of Rehabilitation Medicine, and a past Dean of the Faculty of Pain Medicine of the Australian and New Zealand College of Anaesthetists.



Professor Stephen Gibson – Director and Clinical Representative Professor Gibson is the immediate past President of the Australian Pain Society and is an executive member of the International Association for the Study of Pain special interest group for pain in older persons. He has been involved in pain research for more than 20 years and is currently Deputy Director of the National Ageing Research Institute (NARI).



Professor Michael Cousins, AM – Director and Clinical Representative Professor Cousins is the Head of the Pain Management Research Institute of Sydney University at Royal North Shore Hospital (RNSH). He was the Chair of the National Pain Summit (Canberra, March 2010) and the International Pain Summit (Montreal, September 2010). Professor Cousins is a world-leading pain medicine specialist and is Head of the new Discipline of Pain Management at University of Sydney.



Diana Aspinall - Community Director

Ms Aspinall is the nominee of the Consumer Health Forum of Australia. She is a Director of Arthritis NSW and a Consumer Representative on the Blue Mountains GP Network Consumer Reference Group advising on Medicare Locals implementation and other consumer health issues.



Elizabeth Carrigan - Community Director

Ms Carrigan is the nominee of the Australian Pain Management Association and has a background in education and strong track record in health advocacy. She is a trained Leader of the Chronic Disease Self-Management Program, member of the Queensland General Practice Advisory Council and the Persistent Pain Statewide Steering Committee.



Lesley Brydon - Chief Executive

Ms Brydon is a former pharmacist with extensive experience in corporate communications. Formerly Executive Director of the Advertising Federation of Australia, and prior to that, Manager Corporate Communications for Austrade, she was engaged in 2010 as Executive Director of the National Pain Summit and National Pain Strategy.

MEMBERS AND PARTNERS WORKING TOGETHER

Partners: Painaustralia's membership base of consumer and health care organisations continues to grow steadily, and our strength and influence is enhanced by our extensive network – more than 150 organisations that contributed to and supported the National Pain Strategy.

We have also established valuable partnerships with professional firms – Corrs Chambers Westgarth who generously provide all of our legal services pro bono; communications agency, Morris and Partners and consultants Wildworks.

Members of the Painaustralia Collaboration – CSL Ltd/ Grunenthal Australia Ltd, Janssen-Cilag, Mundipharma and Pfizer Australia have provided very valuable funding and we are enormously grateful to them all.

The Australian and New Zealand College of Anaethetists and its Faculty of Pain Medicine (ANZCA, FPM) the Australian Pain Society and the Pain Management Research Institute, University of Sydney, Royal North Shore Hospital (PMRI) provided the base on which Painaustralia was founded.

These organisations have been integral to all stages of progress – from the National Summit, the development of the National Pain Strategy to the formation of Painaustralia, providing core funding and key personnel with expertise which is vital to our work.

Leading have played a major role and we particularly thank the Consumers Health Forum, the AustralianConsumer Pain Management Association, Chronic Pain Australia and Cancer Voices Australia for theirOrganisations: valuable contribution.

Veterans' are also important stakeholders because of the high prevalence of chronic pain among
 Organisations: veterans and serving members of the Defence Forces, the enormous need for better access to effective pain treatment and community support.

The Department of Veterans Affairs recently devoted their March 2012 issue of their magazine, *Men's Health Peer Education* to pain – to provide helpful information about pain and treatment options as well as tools to help self management of pain.⁵

Generation Our society says that you have to be tough and get on with it, especially if you're male, but the reality is that pain is a clinical problem and children in particular fall under the radar.

Kieren Perkins OAM

MEMBERS AND PARTNERS WORKING TOGETHER

ConsumerConsumer Directors, Diana Aspinall (CHF and Arthritis NSW) and Elizabeth CarriganPartnerships:(Australian Pain Management Association), together with Dr Ian Roos, (Cancer Voices Australia)initiated the formation of a Consumer Committee to act as an advisory body, reporting through
the Chair to the Painaustralia Board.

The committee's role is to build Painaustralia's consumer partnerships and capacity and advise the board on consumer issues and services relating to the implementation of the National Pain Strategy.

Other members of this committee include Ms Gillian Thomas (Post Polio Australia) and Ms Wendy Berkeley (MS Australia). Additional members representing national and state consumer networks and with experience in advocacy will be appointed during the coming year.

The committee has developed Terms of Reference and a Policy on Working Together (with other bodies and commercial organisations).

- **Priority Strategies:** Identify key consumer organisations concerned with pain and build Painaustralia's consumer membership base and network;
 - Survey these organisations to determine their key concerns and priorities; what resources and contacts they can bring to bear to further the Goals of the National Pain Strategy;
 - Develop a strategy to evaluate existing educational resources on pain, identify gaps and determine ways to develop any new materials needed, through appropriate partnerships.

As a chronic migraine sufferer, I not only had to fight the regular horrendous pain but also the feeling that I was a terrible wife, a failure as a mother and a worthless person because some days I gave up; the pain was too great. It is very humiliating being an unproductive member of the community.

Throughout the past year Painaustralia and members of our extended networks have achieved significant progress, in line with the goals of the National Pain Strategy and have advocated successfully with Government on behalf of people living with pain.

Three states – Queensland, New South Wales and Western Australia have taken action to implement state-wide pain plans. See page 12.

Advocacy: We successfully advocated for changes to the National Disability Support Pension (DSP) Assessment Tables to ensure that people who are disabled by chronic pain will be appropriately assessed, when applying for the DSP.

> Consequently, Painaustralia has been invited by the Federal Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) to contribute to the education and training of assessors in relation to pain. Associate Professor Milton Cohen will undertake this role.

> Painaustralia contributed to the successful campaign led by the Consumers Health Forum, to restore the integrity and independence of the Pharmaceutical Benefits Scheme (PBS) following the controversial deferral of essential medicines from the PBS. This work complemented the advocacy work of Medicines Australia.

Painaustralia participated with a number of consumer and health care groups to intervene to prevent changes to the Prosthesis List that would have seen infusion pumps used for delivery of medicines, removed from the list. The Health Department subsequently confirmed that no changes would be made without further consultation.

- Website: The Painaustralia website was developed as a resource centre, providing information and access to education and links including:
 - Painaustralia member organisations and services;
 - Pain clinics, services and programs nationally;
 - Educational resources for consumers;
 - Educational resources for health care professionals;
 - Pain Research:
 - Links to international pain bodies;
 - National and International Pain-related Events;
 - National Pain Strategy;
 - Progress Report.

The effects the injuries and the fibromyalgia have had on my life have been profound. I have lost friends and acquaintances who, when I say I can't work, look me up and down suspiciously. But the thing that hurts me most is that I can't wrestle or play sports with my boys, or run around with my daughter, or go swimming with them.

Peter

Queensland: In 2010, the Queensland Government committed \$39.1 million over 4 years to improve access to persistent pain services through implementation of a State-wide Persistent Pain Strategy. Recent progress that includes:

Recruitment of staff to the Persistent Pain Management Services (PPMS) in North Queensland, Sunshine Coast, South Brisbane and Gold Coast. Most services now conform to the minimum staffing profile that was agreed, such that each PPMS will have pain medicine specialists, physiotherapists, clinical psychologists and clinical nurse coordinators.

The strategy set out a persistent pain model of care that is holistic and patient-centred, promotes self-management and addresses the biological, psychological and social aspects of pain. Following on from this, each of the PPMS are developing service delivery plans that take into account the challenges and opportunities within their local areas and set out how the model of care will be delivered by their service.

A statewide consistent approach has been developed toward many aspects of entry and exit of PPMS. This includes a patient expectations brochure; a screening and referral guide that assists GPs to understand which patients may benefit from a referral to a persistent pain management service, and sets a minimum level of information required for a referral to a PPMS; electronic referral templates; an entry and follow-up patient questionnaire to measure clinical outcomes for patients managed by the service; a discharge planning and communication guide.

Western Australia: WA Health was the first state Government to provide direct financial support to Painaustralia, with a grant of \$50,000 to assist in the formation of the organisation and drive implementation of the National Pain Strategy.

The WA Government has endorsed the National Pain Strategy and has incorporated a focus on pain across all its chronic health conditions Models of Care, working through WA Health Networks in order to achieve better treatment and access for people living with pain in WA. Models of Care for Spinal Pain and Inflammatory Arthritis are key features of this work.

New South Wales: Health Minister The Hon. Jillian Skinner formed a Ministerial Taskforce to determine priorities for a State Wide Pain Program to be announced in the first half of 2012. Professor Michael Cousins representing Painaustralia and Fiona Hodson from the Hunter Integrated Pain Service are members of the taskforce.

The taskforce is managed through the Chronic Disease Management Office. Its recommendations will draw significantly upon the work of the Agency for Clinical Innovation (ACI) Pain Network's three working groups which are: Pain Programs, Service Integration and Service Structure.

The Sax Institute was commissioned to undertake an evidence based review of International Models of Care for pain management. This report has informed the Taskforce report.

Painaustralia especially acknowledges the important role of three key people driving these initiatives: Ms. Jenni Johnson, Manager Pain Management Network, NSW Agency for Clinical Innovation; Dr. Kate Green, Manager Access Improvement Service, Queensland Health and Dr. Andrew Briggs, Senior Development Officer, Health Networks Branch, WA Health.

Nationally: Since the launch of Medicare Locals, Painaustralia has been engaging with the various boards to ensure that they are aware of the National Pain Strategy and include pain services in their planning agenda.

Some areas are making very positive progress, for example in the Hunter Region where the Hunter Urban Medicare Local and Hunter Integrated Pain Service are working together. One of the first outcomes of the collaboration is a five-minute educational video called **Understanding Pain: What to do about it in less than five minutes**. It can be downloaded from www.youtube.com.

Painaustralia members who are interested in getting involved in their local area are invited to contact Painaustralia to discuss this.

ProfessionalRecognising the overwhelming importance of pain education for undergraduates, the UniversityEducation:of Sydney has formed a new Discipline of Pain Medicine to provide pain managementeducation for medical and health sciences undergraduates, commencing in 2012.

In March 2012, the University presented the inaugural **Multidisciplinary Pain Symposium** for over 300 medical and health sciences students, the first program of it kind for undergraduates studying in this field.

Following on from the *MBF Foundation (now Bupa Foundation) 2007 Report - The High Cost of Pain*, conducted by Access Economics in collaboration with the Pain Management Research Institute, and its support for the National Pain Summit, Bupa Foundation has once again made a valuable contribution to improve the treatment of pain.

The 2011 Bupa Foundation Awards included a grant of \$200,000 to The Australian and New Zealand College of Anaethetists and its Faculty of Pain Medicine and the Royal Australian College of General Practitioners for development of **online pain education program** for primary health care professionals to be launched in the second half of 2012.

I was in car accident and now live life with paraplegia. However, it was easier to accept the loss of use of my legs than the ongoing extreme pain I have to endure. For more than six years I've been on very strong painkillers. At times, I've called the ambulance to get help with the pain and they come and give me an injection.

Other Initiatives: Painaustralia welcomed the ground-breaking work of the Pelvic Pain Steering Committee comprising Gynaecologist, Pain Medicine Physicians Dr Susan Evans (SA) and Professor Theirry Vancaille (Royal Women's Hospital) and Ms Deborah Bush QSM, CEO and Founder Endometriosis New Zealand, who developed the Pelvic Pain Report entitled *The \$6 Million Woman and the \$600 Million Girl*, released in November 2011. The report, which is an important adjunct to the National Pain Strategy, investigates the problem of pelvic pain in Australia and provides pragmatic solutions for implementation and integration into women's health services.

In development, are new **Cancer Pain Guidelines** and an Australian guideline and implementation strategy on pain management for people living with cancer – from diagnosis to treatment. Palliative Care and Pain Medicine Physician Dr Melanie Lovell, is coordinating the guidelines in collaboration with the Clinical Oncologists Society of Australia (COSA), Painaustralia and other relevant bodies. Painaustralia will assist with the launch and promotion of the guidelines, due for completion later in 2012.



Dr Allan Molloy, Pain Management Research Centre; The Hon Jillian Skinner NSW Minister for Health and Minister for Medical Research; Ms Lesley Brydon, Painaustralia.

Whilst Painaustralia will continue to play a leadership role, the ultimate success of our efforts will require a groundswell of support from the community and the media, effective partnerships with state and Federal Governments, health care professionals and consumer advocacy groups representing the millions of people living with pain.

Building those partnerships remains a clear priority and attracting the funding and support to underpin these efforts will be paramount.

We welcome your support for this work and urge all of you who care about the plight of people who live with pain, to contribute to this important cause in any way you can.



Health system costs for chronic pain represent \$7 billion. This cost could be halved by providing effective and timely treatment.

The High Price of Pain: The economic impact of persistent pain in Australia. November 2007. Prepared by Access Economics for MBF Foundation (now Bupa Australia Foundation) in collaboration with University of Sydney, Royal North Shore Hospital Pain Management Research Institute.

GLOBAL DEVELOPMENTS

Australia led the world with the first National Pain Summit held in Canberra in March 2010. Since then, there has been a groundswell of events and activities globally, which call for urgent action to address this very neglected area of health care. Key events include:

The International Pain Summit – Montreal September 2010, attended by over 120 countries. The summit released two important manifestos:

- The Declaration of Montreal calling for access to pain management as a fundamental human right
- A Statement of **Desirable Characteristics of National Pain Strategies**, which drew extensively upon the Australia National Pain Strategy

A meeting of the European Chapters of the International Association for the Study of Pain in Brussels May 2011, where the National Pain Summit was presented. The meeting endorsed a **"Road Map for the development of Pain Services"** for all European countries.

In mid 2011, the prestigious US Institute of Medicine of the National Academy of Sciences released the report **Relieving Pain in America – A Blueprint for Transforming Prevention, Care, Education and Research**. Its recommendations are closely aligned with the National Pain Strategy.

At its General Assembly in Montevideo in 2011, the **World Medical Association** adopted a resolution urging for an end to unnecessary pain for millions of people. The resolution states that "People facing pain have a right to appropriate pain management, including effective medications such as morphine. Denial of pain treatment violates the right to health and might be medically unethical."

In a very significant call to action, the WMA urges all countries to provide resources for the development and implementation of a national pain treatments plan, including a responsive monitoring mechanism for receiving complaints when pain is inadequately treated.

This position has been strongly supported by the **International Federation of Health and Human Rights Organisations.**

Every nation should have policies on the management of pain that describe the burden of pain, its impact, and what should be done in terms of policy interventions to reduce these problems.

Desirable Characteristics of National Pain Strategies: Recommendations by the International Association for the Study of Pain, 2011

Acknowledgements: We acknowledge and thank the following organisations for pro bono services:

- Deloitte Touche Tomatsu for Painaustralia audit
- Moore Stephens Sydney for taxation advice
- Financial Reporting Specialists (FRS) for preparation of financial statements
- Morris & Partners for graphic design work

References: 1 MBF Foundation 2007. The high price of pain: The economic impact of chronic pain in Australia in 2007. Report conducted by Access Economics in collaboration with the University of Sydney University of Sydney Pain Management Research Institute. Australia, November.

- 2 Australian Pain Society Waiting in Pain, 2010
- 3 Macintyre PE, Schug SA, Scott DA, Visser EJ, Walker SM; APM:SE Working Group of the Australian and New Zealand College of Anaesthetists and Faculty of Pain Medicine (2010), Acute Pain Management: Scientific Evidence. Third edition. Australian and New Zealand College of Anaesthetists and Faculty of Pain Medicine, Melbourne.
- 4 Siddall PJ and Cousins MJ, 2004. Persistent pain as a disease entity: Implications for clinical management. Anesth Analg 99:510-520.
- 5 The Department of Veteran's Affairs Men's Health Peer Education Vol 11. No.1 March 2012 (http://www.dva.gov.au/health_and_wellbeing/physical_health/mhpe/mag/Documents/MHPE_Vol11_1.pdf)