



## **President's Message, 16 December 2008.**

**Hornsby, NSW, Australia**

### **Apologies:**

Diana Aspinall, Board Member

Stephanie Houston, Board Member

Matt Craig, Platinum Member

Welcome to the Annual General Meeting of the Chronic Pain Association of Australia, otherwise known as 'Chronic Pain Australia'. This notice of meeting together with the AGM agenda has been circulated in accordance with the procedures required by the Incorporations Act NSW (1984). The purpose of today's meeting is to hear the Presidents report, the General Manager's report and to receive the accounts for the year ending 30.6.08. Procedurally we will then accept those reports into the record.

Two years have passed since incorporation, and we continue to work hard to build the peak body to represent Australians living with persistent pain.

During 2008 I have worked long hours to build a stronger Board so that we can benefit from the collective wisdom of many special and varied strengths. The professionalisation of the Board is vital to the development of the organisation, and can be seen as the driver behind all successful organisations whether in the not-for-profit or corporate sectors. The Board is the governing body of the organisation. Its job is to provide leadership and vision, to source funding and make sure that financial management is sound, and to ensure that the operation of the organisation complies with Australia's laws. While day-to-day decisions within Chronic Pain Australia are made by operational management, major decisions that affect the organisation are made with guidance from the Board.

In Australia, it is acknowledged that during the start-up phase of community organisations, especially in the presence of no income, building the infrastructure takes time. The Incorporations Act NSW (1984) gives us flexibility in our first couple of years of development to work with and around rules as we learn what works and what doesn't. Some rules will need to be changed. Chronic Pain Australia's constitution - duly registered during our incorporation processes with Department of Fair Trading Charities Registration Division, ASIC and ATO - is not perfect, and the Board is working behind the scenes to make the appropriate changes needed to bring it in to line with our vision and objectives. The Board as it stands has been built with carefully selected members to give us the best possible range of expertise and wisdom for our stage of development. The composition of the Board will possibly change over time as the organisation matures.

Firstly, let me spend a minute discussing my role in the organisation. I have the honour of being the President of the Board of Chronic Pain Australia. As President, my job is to develop the capacity of Chronic Pain Australia through nurturing partnerships and initiating programs that help us realise our mission and objectives. A lot of my work is behind the scenes, developing relationships with sponsors and partners. I will speak further about specific achievements in this regard later.

Many of you know that it was Lee Furlong and I who started up Chronic Pain Australia two years ago. We did this because of a growing awareness that although clinicians can do a terrific job helping people in pain take control and learn management strategies Monday to Friday during business hours, there was a huge gap not being filled for people whose pain and suffering doesn't stop outside of business hours. Opening the door for people to contact me outside of that clinical encounter revealed the depth of suffering and isolation in the community – and this I found out had the potential to lead to such enormous desperation that people in pain consider suicide. We don't know the numbers of people who have that experience, but American figures indicate that you are three times more likely to commit suicide if you live with chronic pain than if you don't. It is the passion to build a strong organisation capable of meeting the needs of people in pain and especially in crisis - reducing the suffering and isolation - that has sustained the work that I and many others have put into Chronic Pain Australia. While we have made some outstanding progress in spreading the word, raising awareness and forging good partnerships, we have a long way to go and we face many challenges.

I would like to take this opportunity to thank many individuals who have been instrumental in our progress so far.

Firstly I would like to thank the 100+ members of the organisation who have joined us as a show of good faith and will, supporting Chronic Pain Australia's vision and objectives, and understanding that Rome wasn't built in a day.

- Firstly, let me thank Lee Furlong, who initially encouraged me to act upon my conviction that things were inequitable for Australians dealing with long term pain. He continues to provide wisdom and strength to the organisation and to me personally in my most difficult and frustrating moments as I work with other volunteers to reconcile the needs of Chronic Pain Australia's members with available resources.
- For day-to-day organisational management and wisdom I would like to thank our General Manager, David Newman who goes above and beyond the call of duty – and also his wife Kylie Newman who offers support before being asked.
- For attending Board meetings to provide collective wisdom and support I would like to thank Carolyn Kerr, Luke Arthurs, Milton Cohen, Deb Kirkman, Maddie Wales, Lynette Guy, Michael Ward, Stephanie Houston, Lee Furlong, Ron Mobbs and Diana Aspinall, as well as Amanda Muggleton, one of our patrons.
- For providing office space for our day to day running of the organisation, I would like to thank Aidan and Carmel Mullan of Protone in Thornleigh.

- For our logo and the associated images and designs I would like to thank Baz and Bridget Pooley, who also produced a beautiful book which we use to send our message to potential sponsors and supporters.
- For start up funding I would like to thank the Rotary Club of Thornleigh, and in particular Ron Mobbs, Frank Dunne, Rolly Crook Rolly Crook, Theo Glockemann and Aidan Mullan.
- For guidance, leadership and execution in the telephone support training program I would like to thank Ms Erica Greenop who continues to provide all round support to the organisation beyond the telephone support project.
- I would like to thank the volunteers who undertook training to become telephone supporters and who have become champions in the understanding of persistent pain and its consequences.
- Hanna deserves a bouquet for her hard work producing the newsletter which has been one of the outstanding successes of this year. I know this job goes with some frustration waiting for stories to come in, well done Hanna.
- Thanks also to Rosemarie who has contributed many times her expertise in relaxation therapy, both to the telephone support training program, and also on recordings on behalf of Chronic Pain Australia.
- We are fortunate to have as one of our volunteers, Dorothy Johnson, Dorothy Johnson who has this year helped us get our accounting system up and running, and who has produced our treasury report for tonight's meeting.
- For countless hours of energy, enthusiasm and marketing flair, I would like to thank Ms Kim Mathes who devised and executed the Pain is Not Invisible web-based project, Australia's first community commissioned prevalence study owned by Chronic Pain Australia.
- I would like to thank Janssen-Cilag and Pfizer who enabled the Pain is Not Invisible project by providing the funding for its development and marketing.
- For enthusiastically setting up and maintaining the Dee Why support group I would like to thank Margaret Knight, Suzanne Arthurs and the members of that group for attending and making it a success.
- Thanks goes to Bonnie Tosswill for donating a collection of 25 paintings ready for auction at the Ball in June 2009.
- Thank you also to the many donors of gifts for the Ball in 2009, and also for raffles to raise funds for Chronic Pain Australia.
- Thanks also goes to the volunteer performers who provided entertainment at the recent Christmas party at the Harp Hotel, including Shavaunne Newman, Kate Maclurcan, Diane Turner, Kate HL., Kate P., Industrie Standard, Swamp Woman, Mary O'Mahony, Beno the Magician and the wonderful McCoy Band as well as organiser John Gallagher.
- I would also like to thank many of those just mentioned for their personal support in my journey as President of our organisation.

- Last, but certainly not least and perhaps even most, I would like to thank my partner Peter McKinn and my children Maddie and Oliver for indulging me the time away from them that I put in to Chronic Pain Australia.

A great challenge we face is funding the many wonderful programs we have been developing. This is a difficult task in the current economic climate.

An even greater challenge however lies within our own ranks. As we are all volunteers, the stresses of dealing with our own needs versus the needs of the organisation takes its toll. We as volunteers, whether Board members or operations volunteers are constantly juggling our priorities. Teamwork is fundamental to being able to cope with these stressors and to be able to progress the organisation's objectives.

What is a team? One definition says "teamwork skills include the mix of interactive, interpersonal, problem solving and communication skills needed by a group of people working on a common task, in complementary roles, towards a common goal whose outcomes are greater than those possible by any one person working independently".

The enormity of our mission insists that we produce results which are indeed bigger than any one of us and which emphasise that we work together, pulling together, in the same direction. We have been trying to create this team over the last two years, and in a large part we have been successful. The completion of the first training program of telephone support volunteers is testament to brilliant teamwork.

However not all of our projects have been so successful, and I believe that this is because in some areas we have not succeeded in working together as a team to reach some of our agreed goals. Teamwork is fundamental to our operation. Being a team player is certainly challenging.

As President of the Board, it is my job to manage this challenge, and it appears to me that there are conflicts amongst us. These conflicts have the potential to white-ant our good work. Is this what we want? Do we want to work together or do we want to allow our automatic emotional responses to white-ant the bigger picture? I think we all want the same goal: to make a difference for our members. If that is the case then we have to work out whether we can or whether we cannot work together as a team. Only you can decide that. One thing is for sure. It won't work unless we, as a team, are bigger than each of us as individuals. I say to you, think about how you represent our organisation. Feeling frustrated can be a product of not knowing how to progress your own role within the organisation. Ask for help. Let's sort it out.

One of our objectives within the management of Chronic Pain Australia is to increase the administrative professionalism of our projects. We are seeking volunteers who feel they have the professional experience to be able to deliver the outcomes that our members deserve. We live in difficult times. "How do our members want to connect?" is a question we need to ask. Indeed this is on our agenda.

In 2009 we will be asking our members what they want us to do to help them become less isolated in the community. The research indicates that people in pain find it hard to leave their homes. There is research that shows that *virtual* support is important. If you are having a hard time at 3am it might be the case that you want to talk to others who are awake and in a flare up You might not be able to wait until Sunday, and hope you are having a good enough day to get to the support group. Support may not be possible unless there is an online option. There are clearly many ways we can deliver the ability for people to connect, and it is not up to us to simply decide how this takes place. 2009 will be a time for consulting our members nationally to find out what would or could work for them.

### **Our Achievements**

Firstly, let me review our fundamental purpose.

**Our vision** remains that no Australian living with persistent pain should suffer alone or without access to resources and information which help them effectively manage their pain in a manner promoting dignity and self respect, regardless of age, socio-economic or compensation status

**Our mission** is to reduce the suffering and isolation caused by chronic pain in the Australian community

**Our objectives are as follows:**

1. To establish Chronic Pain Australia as the viable peak body to advocate for consumers of pain management services in the Australian community.
2. To prevent suicide - provide support and connection for people living with pain through the development of a telephone support and information service accessible by all Australians.
3. To promote supported self-management – enable self control for people currently living in fear of pain, and suffering silently in isolation through a national support network.
4. Provide support for families and carers of people living with disability due to persistent pain.
5. Reduce community mis-information and thus unhelpful attitudes / social discrimination in relation to chronic pain through education and research.

### **Progress towards our objectives during the last year**

In establishing Chronic Pain Australia as the peak body of advocacy we need to focus on infrastructure. Infrastructure involves putting into place the elements fundamental to an organisation: the skeleton, if you like, on which we can build the vital activities of Chronic Pain Australia. These elements are to do with staffing, space, and of course funding.

## **1. Staffing**

At this point in our development all staff, Board and National Advisory Panel membership is on a voluntary basis.

### **A. Board**

- Carolyn Kerr (Treasurer)
- Luke Arthurs
- Deb Kirkman
- Maddie Wales
- Diana Aspinall
- Stephanie Houston
- Lynette Guy
- Michael Ward
- Milton Cohen
- Lee Furlong
- Coralie Wales (President)

### **B. Subcommittees of the Board and Operations**

The function of the subcommittees is to provide special interest area working groups, which connect through to operational volunteers and provide support for the work happening on the front line.

- **Media, Technology and IT**

Lee Furlong  
Maddie Wales  
David Newman

- **Youth**

Maddie Wales  
Michael Ward  
Diana Aspinall

- **Finance and Compliance**

Carolyn Kerr  
Dorothy Johnson  
David Newman

- **Services**

Luke Arthurs  
Lynette Guy  
Erica Greenop  
Diana Aspinall  
Margaret Knight  
Suzanne Arthurs  
David Newman  
Deb Kirkman

- **Fundraising**

Coralie Wales  
Milton Cohen  
Diana Aspinall

### **C. Volunteers**

- **General Manager**

David Newman

- **Telephone Training Manager**

Erica Greenop

- **Support Group Manager**

Margaret Knight

- **Newsletter Editor**

Hanna

- **Accountant**

Dorothy Johnson

### **D. National Advisory Panel**

In response to requests for the organisation to give advice on materials for consumers, a National Advisory Panel consisting of consumers, clinicians and academics was selected to discuss issues relevant to consumers. The National Advisory Panel has been involved in several projects in 2008. One project that has been completed has resulted in the production of an excellent pain management resource sponsored by Janssen-Cilag, "*Coping with Persistent Pain*". Hard copies of this book are available from the office. We have also commented on other materials from other organisations and continue to take the opportunity to put forward a consumer perspective where in the past only a clinical viewpoint was propagated.

## **2. Space**

We have been fortunate in having been provided an office by Aidan and Carmel Mullan of Protone in Thornleigh. This allows us, particularly David Newman, to contact our members, work on our membership services, receive and send emails and conduct the operations of our organisation from a central point.

## **3. Funding**

As mentioned earlier this is a key challenge for our organisation. There are several ways we can attract funding to the organisation. One is through direct application to organisations who have an interest in helping community groups like ours.

### ***A. Direct applications for funding grants***

Early in 2008 management identified the need to seek substantial external funding in order to advance with the Phone Support training program. David Newman, then Manager of this project, set to work writing a number of grant applications. Each of these applications covered slightly different aspects of the project. After a number of rejected applications we finally received exciting news. Asquith Leagues advised that our application to them had been successful as part of the CDSE funding Program. Shortly after Hornsby RSL club came on board with further CDSE funding, and finally ADRA (Adventist Development and Relief) advised that they were able to provide funding. Even with this sponsorship we were not fully able to meet our expenses, but they went a long way to meeting the operational costs associated with the program.

### ***B. Capacity building***

Another fundamental principle to attract funding for our services and infrastructure is through building capacity, and this means building relationships. Relationships that have the potential to nurture Chronic Pain Australia involve potential sponsors and other organisations who stand to benefit from our services or who wish to be associated with us as they believe in our mission values. One of my key roles in the organisation is to seek out and nurture these appropriate relationships.

## **4. Capacity Building activities**

**A. Arthritis NSW**

You may be aware that Arthritis NSW is a member of Chronic Pain Australia, and we are involved in ongoing discussions in relation to support for our telephone support line technology needs. Arthritis NSW has recently surveyed members and found that one of their main issues is unmanaged pain. We therefore have a role to play in assisting them with this aspect of the needs of their members.

**B. Pain Management and Research Institute (PMRI)**

Discussions are ongoing between the PMRI and Chronic Pain Australia. PMRI is interested in better understanding the needs of our members. I will be meeting Professor Cousins of the PMRI tomorrow. We have in-principle agreement from their marketing professionals that they would like to fund the technology costs of the telephone service. Their marketing team are initiating discussions with Telstra on our behalf, in relation to our technology needs for the phone service.

**C. Pfizer Australia**

We have a very positive and supportive relationship with Pfizer Australia. This year Pfizer kindly provided funding to create a pain management module which links in with the Moving On program developed by Arthritis NSW. This program is being written at present and will be ready for road-testing early in 2009. This program will be available to our members for access to easy-to-understand pain management tools.

**D. Janssen-Cilag**

Representatives of Janssen-Cilag approached us after I delivered a paper at the Australian Pain Society Conference in Perth this last April. That has led to our involvement in a booklet which has been distributed nationally through their network. The feedback from doctors about this tool has been very pleasing, and we are discussing a number of projects coming up in the near future involving Janssen-Cilag's support.

**E. The Australian Pain Society (APSoc)**

In April 2008 I spoke at the Scientific Meeting in Perth. The APSoc then asked if I would write a piece for their monthly newsletter. Chronic Pain Australia will be co-hosting with Arthritis NSW a public forum which will precede the next Scientific Meeting in Sydney, Australia in April 2009.



## **5. Special events to promote awareness of persistent pain in Australia**

- A. In September we initiated 'Pain Awareness Week' to spotlight the experience of living with chronic pain. The week included a Community Forum at the NSW Art Gallery on Sunday. This was a pilot project exploring how we communicate important messages about chronic pain to the broader community. It was well supported by both clinicians and consumers and along the way we learned several lessons about marketing our messages. In 2009 Pain Awareness Week will take place in the second week of September, and this has been registered with the *Life. Be in It* calendar.
- B. Our longer term aim clearly is to celebrate this week all around Australia. We now have a national network and will be working with our national friends to explore whether we can organise events across the nation to coordinate with this special week in September.

## **6. Conference papers**

It is important that as an organisation we promote our objectives broadly. To that extent we have written and presented a number of papers during the last 12 months at a variety of conferences.

- A. April 2008, Perth: Australian Pain Conference Annual Scientific meeting *"Introducing Chronic Pain Australia"*
- B. September 2008, Sydney: Address to National Sales Force Janssen-Cilag, Park Hyatt, Sydney: *"Who is Chronic Pain Australia and what is the Pain is Not Invisible project?"*
- C. November 2008: Sydney University Post Graduate Conference - Leura Blue Mountains NSW: *"The Chronic Pain Puzzle: Implications for Health professionals – paradigm shift in research – paradigm shift in approach"*
- D. November 2008 Adelaide: Better Choices Better Health Conference which was held from Monday 24<sup>th</sup> – Wednesday 26<sup>th</sup> November 2008 at the Adelaide Convention Centre: *"Community Based Rehabilitation in the Face of Compo Distrust Syndrome"*. This paper is a work in progress. Prof Elizabeth Kenny and Assoc. Prof Milton Cohen have agreed to be my co-authors to write this paper which we propose will provide a rationale for why governments and others should invest in consumer driven organisations like Chronic Pain Australia, to minimise the disability due to chronic pain in the community.

I hope I have given a sufficiently broad overview of the activities I have been engaged with in representing Chronic Pain Australia. I respectfully submit this report for acceptance into the record as my report for 2008.

Sincerely

**Coralie Wales**

President

Chronic Pain Australia