



Chronic  
Illness  
Alliance

## Chronic Illness Alliance Inc

Ph: 9805 9126

E-mail: [christine@chronicillness.org.au](mailto:christine@chronicillness.org.au)

### Newsletter September 2006

**The Chronic Illness Alliance** undertakes a range of educational and information projects aimed at minimising the social impact of chronic illness by developing a better focus in health policy and health services. We rely on the participation of our members in our activities to help achieve our goals. This newsletter presents some of the current work that is being undertaken in this manner.

#### **CIA membership renewals**

As you will realise your membership is important to us. Thank you to all those who renewed their memberships. We appreciate your support and look forward to providing services such as forums and information throughout the year. If you are late with renewing, we are still very happy to receive them!

#### **Work, Welfare, Wills:**



#### **A plain English web guide to legal issues around health and life changes.**

We launched this new resource on 6<sup>th</sup> July, with splendid hospitality at the Victoria Law Foundation Offices. It was created for people whose health forces them to reconsider their life options including whether they stay in the paid workforce. If you have clients or, you are a client, and the following are issues:

- Need to explore alternative income especially Centrelink and superannuation entitlements?
- Plan for future financial, medical and lifestyle decisions?
- Want to know more about health privacy rights?
- Who has to be told and who doesn't?

We strongly recommend you make a link to this resource on your website.

[www.chronicillness.org.au/workwelfarewills](http://www.chronicillness.org.au/workwelfarewills)

### **Utilit Ease Forum 19 October**

The Chronic Illness Alliance ran community forums in Bendigo and Geelong to give regional people information about their gas, electricity and water supplies now supplied through private companies. On 19 October, we will run a similar forum in Melbourne, in association with the Chronic Disease Self-Management Special Interest Group. This forum will feature information on the recent changes to Energy Relief Grants from the Department of Human Services in Victoria. Details about speakers, venue etc will be provided on email shortly.

Some of this information is available on our webpages UtilitEase [www.chronicillness.org.au/utilitease](http://www.chronicillness.org.au/utilitease)

Refer your clients to these pages and use them as a reference to help clients who are having financial difficulties.

### **Joint Medicines Policy Conference 13-14 July 2006**

Robert Pask, from MS Australia, who represents the Chronic Illness Alliance on the Victorian Medicines Advisory Committee, also represented the Chronic Illness Alliance at the Joint Medicines Policy Conference in July. Below is his report:

Approximately 200 participants attended the inaugural Joint Medicines Policy Conference in Sydney on 13-14 July this year.

With a large number of Australian speakers as well as some from overseas, the conference addressed

- Long-term Pharmaceutical Benefits Scheme sustainability & access to medicines.
- Quality use of medicines
- Medical technology assessment
- Biologicals and vaccines.

Keynote speakers included:

Dr Jill Sanders - President & CEO, Canadian Agency for Drugs & Technologies in Health (CADTH)

Prof Ron Akehurst - Health Economics, University of Sheffield

Emeritus Prof Lloyd Sansom - Chair, Pharmaceutical Benefits Advisory Committee (PBAC)

Mr John Young - Chairman, Medicines Australia

A full list of keynote speakers can be downloaded from

<http://www.medicinesaustralia.com.au/pages/index.asp>

Interesting comments included the following:

John Young of Medicines Australia advocated the identification of solutions and the cultivation of appropriate policy around access to PBS medicines, while Philip Davis from the Department of Health and Ageing, spoke about the quality use of medicines.

Internationally, most delegates advocated collaboration in research and the development of time frames with more certainty & lower costs.

In response to the comment that we are left to the discretion of the drug companies regarding those drugs are submitted to the TGA for addition to the PBS, it was highlighted that health professionals should listen to consumers in regard to the nature and type of drugs the consumer needs.

The mechanism to get proven drugs onto the PBS needs to recognise that affordable drugs enable people to be more productive for longer periods of time.

Comment was also made that consumers see drugs as a cost not a value. Consumers have to be educated more about the quality of life benefits certain drugs deliver.

Additional points in this debate included

- Benefits need to be taken into account and
- the PBAC has to be more transparent
- there has to be more collaboration between the drug companies and the consumer and
- cost effectiveness is a high priority for Medicines Australia.

Quality Use of Medicines (QUM) was also discussed in the light of a bigger challenge around how QUM can work to engage stake holders in working groups. At present, there is no government member on the QUM panel.

Data linkage was highlighted as an issue that has to be addressed. In fact lack of data has to be fixed and was one of the main problems the conference highlighted.

The conference was informative and a good start as far as Medicines Australia involving their peers and consumers. However there were some negatives.

One facilitator commented at the start of the first day that consumers were biased in their opinions as they were in the pockets of the drug companies, something I and other consumers took offence to.

The lack of data collaboration was, as I have said, a major issue that has resulted in a severe lack of information about the real costs of supplying drugs to the public. I indicated that, the Multiple Sclerosis Society - a member of the Chronic Illness Alliance - had an Access Economics report that highlighted the ongoing cost of MS drugs and how their use had contributed more to government coffers by offsetting costs in terms of taxes, productivity and enabling people with MS to stay in the work force longer.

I also asked a question on getting drugs onto the PBS when the drug companies will not submit the drugs for certain chronic and other conditions. This question was a positive as the panel gave answers. Included on the panel was the chair of the PBAC Emeritus Professor Lloyd Sansom who I was lucky enough to continue speaking with about this issue during the lunch break. This enabled me to meet privately with him to discuss how we might get additional drugs onto the PBS.

Another positive was that research is now at the stage that vaccines are coming out for chronic illnesses such cervical cancer, meningococcal, hepatitis as well as advanced research on other illnesses.

In conclusion, this conference was a good start but it has a long way to go to become a more effective forum for the advancement of policy around the supply of drugs for chronic illnesses.

**Robert Pask**

### **New Resource from National Health and Medical Research Council (NHMRC)**

*Making decisions about tests and treatments: principles for better communication between healthcare consumers and healthcare professionals* is a new resource available from the NHMRC website: [www.nhmrc.gov.au](http://www.nhmrc.gov.au)

People with chronic illnesses will have had some experience of the problems related to poor communications and will be aware that communication on both sides can be improved. When consumers need to make important decisions about their care and treatment, good communication will assist them. This toolkit spells out the principles of communication and provides exercises to help both healthcare professionals and consumers develop their skills. While the best results will be achieved if both parties undertake to improve their skills, a great deal can still be achieved if consumers are prepared to work independently on their own skills.

At the Chronic Disease Self-Management Special Interest Group recently, Dr Peter Greenberg (who was Chair of the committee that developed this resource) and Christine Walker presented the principles of communication and some of the exercises to an enthusiastic group of healthcare professionals and consumers. Another workshop is planned for later this year in a regional area.

### **National Medicines Symposium June 2006**

Christine Walker attended this conference with sponsorship from the National Prescribing Service. The conference focused on themes about balancing beliefs and behaviours about medicines, balancing the benefits and harms of medicines and balancing systems and settings.

Some of the highlights were:

A presentation on the challenges relating to indigenous populations in remote locations where there was no pharmacist available. It meant that new ways of delivering medicines was needed such as a standardized drug list to ensure people got medications consistently and had consistent information about them.

A presentation on complementary therapies which explained that they were generally approved by the TGA as safe, but not necessarily effective; that \$1.8 billion per year was spent on them; that more women than men used them; that the Pan Pharmaceuticals crisis has not had a permanent effect on their usage.

A presentation on the multicultural perspective which looked at some of the barriers and enablers to Quality Use of Medicines, including the programs developed by NPS to address them. This includes the development of worksheets for AMES and a partnership with FECCA.

Another presentation looked at the evaluation of the Adverse Medicines Line. Although the evaluation has shown it to be an important community service to all Australians it is no longer funded and ceased work on 30 June this year.

There were many more great presentations over the two days. More exciting is the amount of work being undertaken to ensure that medication safety is of a very high order.

***REMEMBER THIS UPCOMING DATE! VISIT the website below and check out the range of services available.***

**[Ask Your Pharmacist Week](#)**

25–30 September 2006

Ask Your Pharmacist Week 2006 is designed to raise awareness of service provided by your local pharmacist.

**SAVE MEDIBANK UPDATE**

From Stephen Jones, *Save Medibank* / CPSU National Secretary  
12 September 2006

Under increasing pressure from policy holders, unions, media, doctors, community groups and health academics - it appears that the Government may be postponing its plans to sell Medibank Private.

In explaining the apparent change, some in the Government are claiming it would have been too difficult to sell Telstra T3 share and Medibank at the same time.

However recent opinion polls - and our own Save Medibank Alliance survey results - indicate the sale of Medibank has the potential to cost the Government politically ahead of an election in 2007.

The Save Medibank Alliance will continue campaigning to ensure Medibank members and staff are treated fairly and have the opportunity to have their say.

Thanks for you support and please continue to send us you ideas and feedback.

<<mailto:savemedibank@cpsu.org.au?subject=feedback>> Have your say