



Chronic
Illness
Alliance

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Submission on behalf of Chronic Illness Alliance

29 March 2010

Committee Secretary
Senate Community Affairs References Committee
PO Box 6100
Parliament House
Canberra ACT 2600

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RE: Consumer access to pharmaceutical benefits and the creation of new therapeutic groups through the Pharmaceutical Benefits Scheme (PBS)

The Chronic Illness Alliance is a national group representing more than 50 community-based foundations that work with people with chronic illnesses (see www.chronicillness.org.au/community.htm). The aim of the Alliance is to minimise the social impact of chronic illnesses through education and information.

Many of the people the member organisations of the Alliance represents and works, with are people who have rare, long-term and multiple illnesses. However with both clinical and social support many are still able to work and/or contribute to their communities. Medicines form an essential part of that support.

The Chronic Illness Alliance conducted research into the costs of chronic illnesses in 2004 and found that many people with chronic illnesses lived in poverty due to the costs of their illness, which in some cases exceeded more than 25% of their annual income. The greatest contributors to those costs were the co-payments related to PBS medicines. With this in mind the Alliance would argue that many people with chronic illnesses:

- Cannot afford any increase in co-payments for PBS medicines. The view that most people can absorb a small increase in a co-payment ignores the fact that there are co-payments or full payments on nearly every service they receive, from Federal, state-based and privately provided services. Out of pocket costs for health care in Australia are now some 30% of the total costs.

<http://www.chronicillness.org.au/reports.htm#costs>

- Appreciate generic medicines where they are able to switch to them without affecting their health, but would appreciate that they were substantially lower in price. The 12.5% lower cost of generic medicines barely offsets all the other additional costs.

The Alliance notes however that the Free Trade Agreement resulted in the creation of the F1 and F2 formularies which broadly separate brand name medicines into F1 and generics into F2 cutting out the interchangeability between the two in terms of pricing. While there is a mandated need for price cuts to continue for F2 medicines there are no mandatory price cuts required for medicines in the F1 category. There is now even less transparency in pricing for the Australian consumer and the PBS and its related committees grow ever more 'byzantine'.

- Have rare conditions and have access to the orphan drugs scheme. This is a great asset since most people with rare conditions would not be able to access life-saving medicines due to the sheer cost. However, in some cases further medicines are required and these are not always listed for the condition, for example gabapentin (Neurontin) is available to treat epilepsy but also has application for the treatment of neuropathic pain but anyone requiring it for this purpose must meet the full cost. Similarly sildenafil (Viagra) is available on the PBS to treat erectile dysfunction related to some conditions but not erectile dysfunction related to MS. It also has been found to have an application in primary pulmonary hypertension but people with this condition and men with MS must pay the full price.

For those people with rare conditions there is often a sense of isolation and even abandonment by the medical profession and medical research community, since they are aware that their condition attracts little research attention compared to the National Health Priorities. The Alliance notes that the US FDA is actively encouraging clinicians to sign up patients to the US Orphan Drug Scheme in order to support pharmacological and medical research in various rare conditions.

<http://online.wsj.com/article/SB10001424052748704145904575111943356541152.html>

In conclusion, the Chronic Illness Alliance notes that trade negotiations with the United States are current, and that it is likely that further deals related to pharmaceuticals will be included. Given the past history of negotiations the Pharmaceutical Benefits Scheme and its benefits to all Australians is likely to be under threat since it is seen by US pharmaceutical companies as 'price-fixing'. It is in the national interest that the PBS remain as it is, rather than being subject to change in the interests of overseas private enterprise.

The Chronic Illness Alliance requests the Senate Community Affairs Reference Committee takes these matters into consideration in its review and bases its investigations on high quality outcomes for people with chronic illnesses who may not otherwise have the opportunity to have their needs considered.

Christine Walker
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Chronic Illness Alliance