

21 May 2007

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

Dear Secretary,

**Re: Patient Assisted Travel Scheme**

**Members**

AIDS Housing Action Group  
Arthritis Victoria  
Asthma Victoria  
Australian Crohn's and  
Colitis Association  
Australian Kidney Foundation  
Australian Leukodystrophy  
Support Group Inc.  
Bendigo Community  
Health Service  
Brain Foundation Victoria  
Cancer Council Victoria  
Cardiomyopathy Association  
of Australia Ltd  
Cystic Fibrosis Victoria  
DEBRAA Victoria  
Diabetes Australia - Victoria  
Epilepsy Foundation  
of Victoria  
Green Triangle Injured  
Persons Support Group Inc.  
Haemophilia Foundation  
of Victoria  
Hepatitis C Council  
of Victoria  
The IN Group  
The Leukaemia Foundation  
Lymphoedema Association  
of Victoria  
Me/CFS Society of Victoria  
Ménière's Support Group  
of Victoria  
Multiple Sclerosis Society  
of Victoria  
Myeloma Victoria Inc.  
NiDKIDS Support Group Ltd  
Palliative Care Victoria  
PASS, Barwon Health  
Pharmacy Guild  
Positive Women  
Pro-ability Consultancy  
Service  
Royal District Nursing Service  
Thalassaemia Society  
of Victoria  
Thyroid Australia  
Victorian AIDS Council

The Chronic Illness Alliance is a-not-for-profit organisation that commenced in 1994. Its aim is to build a better focus in health policy and health services for all people with chronic illness, their families and carers. The Alliance represents 39 member organisations that provide services to people with chronic illness, and 18 individual members.

The following submission will argue that chronic illness causes substantial financial distress, often reducing incomes to below the poverty line and that it is therefore important to develop policies and services that alleviate this distress. Transport is a major cost incurred in accessing health care. While getting to health services is an important part of managing long term illness, currently the cost even with assistance schemes, can act as a barrier with consumers either reducing the number of visits or only accessing health services in emergency situations.

In 2003 the Alliance researched the financial costs incurred by rural and regional households that had one or more members with a chronic illness. We conducted a comprehensive survey of 381 households and held public forums in Geelong, Bendigo and Moe. The purpose of the survey and the forums was to collect both quantitative and qualitative data about the true cost of chronic illness and how these costs impacted on the management of their illness.

The results showed that rural and regional households caring for people with chronic illnesses experience considerable hardship and distress. For example, households with incomes of \$36,400 or less spent 14-27.5% of this income on health-related expenses such as medical and PBS co-payments, unlisted medications, hospital bills, medical equipment and aids, additional heating and power, telephone bills and transport. Budgets were stretched beyond reasonable limits and a great deal of stress was experienced. In addition to high levels of outgoings, chronic illness contributed to poverty through reducing income. Many of the households were reduced to part-time work or no work at all because of illness. In some cases it was the person with the illness that had been forced to leave work, in others it was the carer, and in some, it was both.

Another way in which chronic illness contributes to financial distress is that it is invariably progressive and life long. Nearly all households will experience financial stress at various stages: recent purchase of a house, school fees, while a parent stays home to raise young children etc. but all these stages are passed through and relief eventually comes. In the case of illness the financial stress is ongoing and usually gets worse not better.

The following are a summary of the key points raised in the survey and the forums:

- Having a city-centric health service created repeated trips to Melbourne. Of the 381 households surveyed, 57% traveled regularly to Melbourne for appointments or treatment. Most made six visits a year or less but others traveled fortnightly or more often with one household reporting 75 visits in a year.
- In addition to traveling to Melbourne, thousands of miles were regularly traveled to regional medical centres, to the nearest doctors and into towns to attend appointments and to collect scripts and medications. These trips incurred petrol costs of around \$39 on average per month and parking of around \$7, but many people paid much higher amounts particularly for petrol (and prices have increased dramatically since this survey), and parking near the city hospitals which often cost \$18 or more per day.
- Meal costs added substantially to direct transport costs especially where the whole family traveled to take a sick child to Melbourne. Even stopping for coffee breaks along the way or at a destination added \$10 -20 to a basic trip for a driver and passenger. Our survey showed that on average, food and beverages cost \$26 per trip, but again, many trips cost far more than this.
- It is common practice for hospitals and other health services to often schedule tests for first thing in the morning requiring an overnight stay for both the patient and the driver incurring substantial accommodation and meal costs.
- For those without their own transport there were very few options other than being dependent on family and friends.

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### Key points from the survey and forums directly related to VPTAS

- The reimbursement amount offered by the Victorian Patient Transport Assistance Scheme (VPTAS) was so poor that going through the laborious application procedure and delayed payments negated the benefit of the reimbursement. Consequently, entitlements were frequently forgone. (This criticism has been documented by cancer patients in a transport study conducted in 2000 by the Cancer Council of Victoria. It would seem that despite modifications made to the forms since that time they are still a barrier to take-up of the Assistance Scheme.)
- Lack of awareness of the Scheme's existence was common. (This was also a frequent theme from the cancer study).
- VPTAS does not take into account frequency of travel so assistance was not given to multiple shorter distance trips, only long distance trips despite the same total distance being covered.

For a copy of the full report on costs of chronic illness in rural and regional Victoria go to:  
[www.chronicillness.org.au/reports.htm](http://www.chronicillness.org.au/reports.htm)

Chronic illness by definition means long term medical care and invariably, financial disadvantage. Cost and distance are barriers to good health care for people living in regional, rural and remote regions of Australia. The Chronic Illness Alliance congratulates the Senate Community Affairs Committee on its review of the Patient Assisted Travel Scheme and requests that in particular, the following aspects are investigated thoroughly:

- The level of assistance provided as presently in Victoria it is grossly inadequate to the point of being irrelevant.
- The process for reimbursement which continues to act as a disincentive to the genuinely needy.
- The reasons for the low level of usage so that targeted measures can effectively ensure awareness of the scheme's existence.

We would also strongly recommend that the types of service that qualify for assistance are extended to include many more allied and dental services. These services are often as critical as medical visits in maintaining good health particularly for people with chronic diseases such as diabetes, cystic fibrosis and multiple sclerosis, to name a few.

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Should the Committee require further information or assistance from the Chronic Illness Alliance please contact either Dr Christine Walker [ [cwalker@chronicillness.org.au](mailto:cwalker@chronicillness.org.au) ] or Jo-Anne Tamlyn [ [jtamlyn@chronicillness.org.au](mailto:jtamlyn@chronicillness.org.au) ] either by email or by phone (03) 9805 9126. We would be only too pleased to give a more comprehensive explanation of the difficulties experienced by people with chronic illnesses.

Yours sincerely

Jo-Anne Tamlyn  
Project Co-ordinator.  
On behalf of the Chronic Illness Alliance