



Senate Finance and Public Administration Committees
PO Box 6100
Parliament House
Canberra ACT 2600
Australia

Dear Senator Ryan,

For more than 25 years, the Mental Illness Fellowship of Australia (MIFA) and its member organisations have been national leaders in defining and delivering recovery-based services in Australia. We know recovery of a better quality of life is possible. With carers and consumers as our 'grassroots', we advocate strongly and inform policy by highlighting relevant issues and recommending changes to current practices at local, state and national levels with governments, clinical services and individuals.

Our specific issue within the terms of reference of this inquiry relate to the process which saw the deferral of PBS listing of the anti-psychotic preparation paliperidone palmitate (proprietary name Invega Sustenna) which we have followed with close interest through the last couple of years in its final stages of approval. This medication has a number of features that we believe will make it a first-line choice for many people with schizophrenia, and yet it's PBS listing is currently deferred as part of the budget measures. While MIFA supports the ongoing program of monitoring efficacy and side effects, this approved medication holds great hope for people with schizophrenia and offers a wide range of benefits.

Recently, our colleagues at SANE Australia, Consumer Health Forum and the MIFA member organisation, Schizophrenia Fellowship of NSW have referred publicly to the advantages to people living with mental illness and those who care for them as well as to the Government:

MIFA members:

Mental Illness Fellowship of Nth Queensland Inc

Mental Illness Fellowship Victoria

Mental Illness Fellowship of South Australia Inc

Mental Illness Fellowship of Western Australia Inc

Mental Illness Fellowship of Queensland Inc

Schizophrenia Fellowship of New South Wales Inc

Mental Health Carers (ARAFMI) NT

Association of Relatives and Friends of the Mentally Ill (Tas)

1. The monthly injection cycle available with paliperidone palmitate has many advantages to the consumer such as :
 - reduction in clinic attendances required
 - injection site being more comfortable and less intrusive
 - reduction in side effects such as weight gain
 - no need for refrigeration and therefore no requirement for cold chain—especially in rural and remote areas
2. This medication offers a much-needed alternative for those people who have not been able to gain relief from their symptoms with current available PBS listed medication. The reduction in the cycle of injections assists people to feel more able to maintain the regime and thereby gain the greatest benefit from the medication.
3. The advantages to the health system should not be under-estimated, including a reduction in clinic visits, together with the expected reduction in hospital visits and occupied bed days due to increased efficacy and reduced side-effects.

MIFA would like to draw the attention of the Committee to the PEARL (Paliperidone Palmitate Effectiveness Assessment Registry) being conducted across Australia, where paliperidone palmitate is being provided to consumers under continuous monitoring for a period of 12 months. 20 sites have been invited to participate, and we have had contact with Glenside Hospital site in South Australia where consumers are registering an interest at a greater rate than the study can support. The consumer experience reported to has been overwhelmingly positive, particularly the ease and comfort perspective, with no reports of either weight gain or sedation as side effects. This trial is limited to those who are able to get a position on the program.

With regard to the process of approval and listing, MIFA holds the same position as the Consumer Health Forum. Their Chief Executive Carol Bennett, in a recent press release on 23rd June 2011, asked for clarification on several key points about the process for listing medications for PBS subsidy:

1. *We seek to understand the criteria and advice being provided to Federal Cabinet in order to make decisions on which medicines should be subsidised by the PBS.*
2. *Whether that information is in addition to that being given to the experts on the PBAC*
3. *We also seek to understand what financial impact this new process will have on the Federal Budget and whether Cabinet is taking into account the potential savings to the health budget that new medicines bring to the sick and chronically ill by allowing them to avoid more expensive hospital or GP visits.*

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