



Cystic Fibrosis Australia

ABN: 73 104 285 136

Address: PO Box 254 North Ryde NSW 1670

Street Address: 21 Manning Road, North Ryde NSW 2113

Telephone (02) 9878 5250 Facsimile (02) 9878 5058

Email general@cysticfibrosisaustralia.org.au

Website www.cysticfibrosis.org.au

14 July 2011.

Cystic Fibrosis Australia's Submission to the Senate on the; The Government administration of the Pharmaceutical Benefits Scheme (PBS)

Dear Senate Committee Enquiry,

I write this letter on behalf of the 3000 young Australians affected by Cystic Fibrosis (CF) which is the most common life-threatening, recessive genetic condition affecting Australian children, with one child being born every 4 days.

CF affects primarily the lungs and digestive system, however with improved medication and treatment life expectancy has been extended considerably. Things have continued to improve with new medicines and this will continue as further new medicines will be developed.

Over the past 8 years or so very few new medicines have been put up before the PBAC to be used for the treatment of CF. So the CF community have needed to rely on older medicines that are now looking at being superseded as a number of new CF medicines are in the pipeline. Within the March '11 PBAC meeting 3 new CF medicines went up for assessment, but only 1 was accepted and we have no problem with that as it went through a true and correct process, which we accept. We do have a problem with what occurred following approval, a number of medicines being approved by the PBAC which included "tobi" a new drug for CF being held back by the Australian Government and sent to Cabinet rather than being handed over to the PBS by the Minister for Health. This is a major concern to us as a well accepted process that has been in place for many years and has worked extremely well has now been changed.

Following much pressure from various peak bodies, including Cystic Fibrosis Australia, consumer organisations and individuals, the Government's decision to refer it to Cabinet was reversed and those drugs that were being held back were released to be handed to the Health Minister to pass onto the PBS for listing in September '11. A very good satisfying outcome, but now another barrier has emerged, that being a Senate enquiry into 'the listings of medicines on the PBS that have been recommended by the PBAC'.

We as an organisation see no point in this new exercise by the Government to delay/defer new drugs, as the original system that we have in place has worked without problems over a number of years, the system is applauded the world over.

So now we are looking at the possibility of 20 or so politicians deciding whether consumers will have access to the best affordable medicines, this is not being decided by experts. A decision like this may actually end up costing tax payers more money because sick people may have to seek other more expensive treatments, go into hospital for care and stop taking part in the workforce. This is not only a cost and loss in income to both the person and the tax dept, but it has a deflating affect on the person's emotions and state of mind.

Australia can afford these new medicines **NOW**. People with chronic illnesses like Cystic Fibrosis should not have to suffer continued delays in access to new medicines because of the Government's very short term budgetary goals.

Our goal and it would be the goal of all other conditions to have new medicines go through the vigorous assessment by the PBAC and if approved, continue with the original guidelines that new approved medicines under \$10 million dollars being passed onto the PBS for listing as soon as possible by the Health Minister. Further if a new medicine is approved by the PBAC and is over \$10 million dollars, again using the original procedure, this would go before the cabinet for approval and passed onto the PBS.

This is a tried and tested system that has worked successfully, don't change it'.

We fear a backlog of medicines caught in the Cabinet process as more and more new necessary medicines face indefinite deferral. We should not be playing with people's lives this way, we have a very fair and just system that most people totally support, don't change it. Give people less fortunate than most a 'Fair Go'.

Yours sincerely,

Terry Stewart
Chief Executive Officer