

Senate Community Affairs Committee

ANSWERS TO ESTIMATES QUESTIONS ON NOTICE

HEALTH PORTFOLIO

Budget Estimates 2014 - 2015, 2/3 June 2014

Ref No: SQ14-000496

OUTCOME: 2 - Access to Pharmaceutical Services

Topic: Kalydeco

Type of Question: Written Question on Notice

Senator: Xenophon, Nick

Question:

I have been contacted by my constituent Leah Johnston regarding the stalemate between the Government and the manufacturer of the Cystic Fibrosis (CF) drug Kalydeco. I have also written to the Minister about this matter.

- a) Is the Department aware of any sufferers of the G551D mutation who have passed away or whose conditions have rapidly deteriorated as a result of not having access to this medicine?
- b) In the response I received from the Health Minister, it states it may be possible for the treating doctors of patients with the G551D Mutation to make applications to local public hospitals for assistance with the cost of Kalydeco.
 - i) Is the Department aware of any applications that have been granted from public hospitals for assistance with the cost of Kalydeco? If so, how many?
 - ii) Is there any assistance available from the Federal Government that could assist patients and their families with the cost?

Answer:

- a) No.
- b) i) No.
 - ii) As stated by the Minister, there are special arrangements available through public hospitals, where the Australian Government provides funding to states and territories (states) to assist with the cost of providing public hospital services, including medicines.

Under the National Health Reform Agreement, states are required and funded to provide pharmaceuticals for public and private admitted patients, and for public non-admitted patients in public hospitals.

In addition, there are a range of other medicines available on the Pharmaceutical Benefits Scheme (PBS) for patients with cystic fibrosis. These include dornase alfa (Pulmozyme[®]); pancreatic extract (Creon Micro[®]); pancrelipase (Panzytrat 25000[®]); tobramycin sulphate (Tobi[®]); and mannitol (Bronchitol[®]).

In 2012-13, Government expenditure under the PBS and Repatriation Pharmaceutical Benefits Scheme on medicines for the treatment of cystic fibrosis was over \$35 million.