

Senate Community Affairs Committee

ANSWERS TO ESTIMATES QUESTIONS ON NOTICE

HEALTH PORTFOLIO

Additional Estimates 2014 - 2015, 25 February 2015

Ref No: SQ15-000100

OUTCOME: 2 - Access to Pharmaceutical Services

Topic: Pharmaceutical Benefits Scheme Listing

Type of Question: Written Question on Notice

Senator: Di Natale, Richard

Question:

With the approval of treatment for young Australians with Pompe disease [Myozyme], is it correct that there are 27 patients with Pompe who are over 18 and cannot access Myozyme?

Answer:

Under the Life Saving Drugs Programme (LSDP) Myozyme[®] is subsidised for infantile onset and juvenile late-onset Pompe Disease.

As at 9 March 2015, there were four patients currently subsidised for infantile onset Pompe disease and one patient being subsidised for juvenile late-onset Pompe disease. There are no patients over the age of 18 being subsidised through the LSDP for Pompe disease.

The Department of Health is aware through its engagement with the Australian Pompe Association that there are a number of adults with the late-onset form of Pompe Disease.

As announced by the Minister for Health, the Hon Sussan Ley MP, on 17 February 2015, the Department is working with the sponsor of Myozyme[®] to assist them in preparing a further submission to the Pharmaceutical Benefits Advisory Committee for consideration of subsidy of the drug in patients diagnosed after 18 years of age on the Pharmaceutical Benefits Scheme.

The sponsor of Myozyme[®] is providing compassionate access to some patients. This is entirely a decision for the company.

The Australian Government provides funds to the State and Territories to assist with costs of providing public hospital services. Doctors wishing to prescribe Myozyme[®] may consider making an application to a local public hospital for assistance with the cost of Myozyme[®].