

**TO THE HONOURABLE THE SPEAKER AND MEMBERS OF  
THE HOUSE OF REPRESENTATIVES**

This petition signed by the Australian Community on behalf of Australian Citizens diagnosed with Pompe's Disease draws to the attention of the Members of the House of Representatives that:

- The life saving drug Myozyme which is funded by Governments to treat Pompe's disease in over 44 countries throughout the world has not been accepted onto the Australian Government's Life Saving Drugs Program for Juvenile and Adult onset Pompe Disease sufferers. This is despite evidence showing the drugs success in halting disease progression, prolonging and improving quality of life in Juvenile and Adult onset Pompe patients.

The high cost of Myozyme is out of reach of the average Pompe disease sufferer. The drug is currently funded by the Australian LSDP for infants only. Withholding access to this drug for Adult and Juvenile Pompe sufferers means confinement to a wheelchair and the need for permanent ventilatory support. Untreated Pompe patients require high cost medical care and die prematurely due to respiratory failure.

We therefore ask the Members of the House of Representatives to:

1. Recognize Myozyme as a life saving drug in the treatment of Adult and Juvenile onset Pompe's disease
2. Pass appropriate legislation to place Myozyme on the Australian Governments Life Saving Drugs Program
3. Allocate sufficient funding to ensure Myozyme is made available to all Australian Citizens diagnosed with Pompe's disease to bring the care offered in Australia in line with accepted International Practice.