



THE HON SUSSAN LEY MP

Minister for Health
Minister for Sport

MEDIA RELEASE

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Life-saving drug for Adult Pompe patients

Minister for Health Sussan Ley has approved a life-saving drug that will ensure adult Australian Pompe patients receive treatment that previously would have cost several hundred thousand dollars at no out-of-pocket cost.

Ms Ley said the Abbott Government would commit close to \$40 million over five years to list the drug Myozyme® for patients over 18 years with late-onset Pompe disease through the Life Saving Drugs Programme (LSDP) from 1 September 2015.

“Pompe disease is a rare and severe medical condition, affecting only a very small number of Australians every year,” Ms Ley said.

“However, it is a very expensive treatment – costing several hundred thousand dollars – putting it out of reach for many Australians.

“This decision will improve the lives of adult patients with late-onset Pompe disease.”

The drug has been listed on the Life Saving Drugs Programme for children with the infantile-onset form of the disease since 2010 and since February 2015 for children aged two to 18 years.

Newly diagnosed patients are required to undergo clinical assessment prior to accessing the treatment and then an annual assessment throughout their ongoing treatment to ensure the Myozyme® treatment is clinically appropriate and effective. Patients already on treatment will be immediately eligible for ongoing treatment with LSDP-subsidised Myozyme.

If patients respond to treatment they continue to receive the subsidised drug.

This approval is the result of considerable effort on behalf of the Australian Pompe Association, the sponsoring company Genzyme and officers of the Health Department to bring together the necessary evidence to support this listing.

The treatment is available now with the Government subsidy to begin from 1 September following Ms Ley’s approval of the new indication of use for the medicine.

Further details are accessible through the LSDP website: www.health.gov.au/LSDP

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