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Minister for Health and Ageing

MEDIA RELEASE

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Life-saving drug to help people with Hunter Syndrome

Eligible patients suffering from the rare, life-threatening Hunter Syndrome will have access to a subsidised medicine to treat their illness, thanks to the Government's Life Saving Drugs Program.

The drug would ordinarily cost families up to half a million dollars each year.

Hunter Syndrome is an extremely rare and life-threatening condition, and Elaprase® (idursulfase-rhu) will significantly improve quality of life for patients who suffer from it, and could add years to their lives.

Around 11 people are expected to receive Government-funded Elaprase® during 2008-09. It is expected that around 2 new patients will commence treatment in each future year.

The drug will be listed on the program from 1 December 2008, subject to finalising appropriate risk-sharing arrangements with the pharmaceutical company.

Hunter Syndrome is the common name for Mucopolysaccharidosis type II (MPS II), a rare genetic disease caused by insufficient levels of the enzyme I2S. It affects multiple organ systems and tissues. It is progressive, debilitating and life threatening.

Hunter Syndrome slows growth and causes skeletal deformities, coarse facial features, upper airway obstruction, recurrent airway and ear infections and deformities in the joints. If left untreated, Hunter Syndrome leads to a very poor quality of life and early death.

The addition of Elaprase® will add around \$29.3 million to the program expenditure over the four years ending 2011-12.

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