Improving Access to Medicines – Life Saving Drugs Program

The Government will strengthen the Life Saving Drugs Program (LSDP) to ensure ongoing and free access to life saving drugs for people with rare and life threatening diseases. From 1 May 2019, a new medicine, cerliponase alfa (Brineura®), will be available on the LSDP to treat Batten disease – a rare genetic disease in children. A new brand of nitisinone and a new strength of the originator brand will be available from 1 May 2019. This drug helps to treat patients with Hereditary Tyrosinaemia Type 1 (HT-1) – a rare genetic disease in infants. Under the LSDP, the Government provides fully-subsidised access to 14 very expensive, effective medicines that treat nine rare, life-threatening diseases.

Why is this important?

The LSDP is about providing hope where there often is none.

Batten disease is a rare genetic disorder in children that leads to progressive brain damage. Currently, there is no treatment that can halt or reverse the symptoms of Batten disease – it has always been fatal. Cerliponase alfa is an enzyme replacement therapy that has been shown to slow the rate at which Batten disease worsens.

Untreated, most children with HT-1 die before the age of two years but with nitisinone they can expect to live close to a normal lifespan. Worldwide, HT-1 affects about one newborn child in 100,000.

Who will benefit?

Children suffering from these rare diseases will benefit from ongoing access.

How much will this cost?

This is subject to commercial-in-confidence.