



THE HON SUSSAN LEY MP

Minister for Health
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MEDIA RELEASE

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Government to continue Inborn Error of Metabolism Programme

Over the past month I have been speaking with patients, parents, representatives and my parliamentary colleagues about the Inborn Error of Metabolism programme.

Through these conversations, particularly those patients with Inborn Error of Metabolism and their families, I have become aware of the difficulties associated in managing these conditions. These conversations have highlighted the importance of strict low protein products and the costs associated and the work involved in food preparation.

The initial evidence relied upon by my department, including that of the Metabolic Dietary Disorders Association's own dietary handbook, pointed to patients having cheaper supermarket options and having access to a range of new medicines being available on Pharmaceutical Benefits Scheme since the programme's introduction in 2001.

The decision to finish the programme on 31 December 2015 was based on this evidence from my department available at the time. We now have additional evidence.

Both my office and I have had conversations with patients, parents and their representatives. It has become clear to me that unlike other food-related illnesses or allergies, this condition cannot be managed using food alternatives you can buy in the supermarket.

I have listened to and considered this advice following the 2015/16 Federal Budget. I heard directly from those affected and the overwhelming feedback and evidence is that each metabolic condition is different and requires a strict special diet.

As a result of these discussions with patients, parents, parliamentary colleagues and representatives, I have decided that those patients on the Inborn Error of Metabolism programme should continue to have access to the government subsidy into the future.

As this is a Budget decision I must reiterate that nothing comes off the table without something of equal value going on. To offer patients peace of mind as soon as possible I have made the announcement and I am currently in the process of identifying the \$11.7 million over the forward estimates to offset the decision to continue this programme.

I will have more to say on this in the future. I would like to thank everyone who provided input and allowed us to review the programme and its benefit to those with Inborn Error of Metabolism.

ENDS

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