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Epidermolysis Bullosa Dressing Scheme

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Media Statement - 26th October 2009



This week, 26-31 October, is International Epidermolysis Bullosa Awareness Week.

Epidermolysis Bullosa (EB) is a rare, debilitating genetic disease characterised by extremely fragile skin and blisters, which occur spontaneously or following even slight contact or friction.

EB most commonly affects children, and treatment involves the constant management of wounds and blisters and protection of the fragile skin from trauma or infections.

Nicola Roxon This requires using very expensive, specialised dressings and bandages which, in some instances, can cost up to \$5,000 per month.

Apart from the pain and difficulty experienced by sufferers every day - the impact of EB on families can be financially devastating.

That's why the Rudd Government committed \$16.4 million over four years in this year's Budget to establish the National Epidermolysis Bullosa Dressing Scheme.

As well as supporting people with EB and their families in meeting the cost of these clinically necessary dressings, the scheme will help improve access to them.

The dressings reduce infections, complications and unnecessary hospitalisations and improve quality of life.

The scheme will commence on 1 January 2010, and the Department of Health and Ageing is currently finalising the selection of the organisation to undertake the scheme's administration.

Under the scheme, a month's supply of dressings will be delivered to eligible patients' homes for a fee equivalent to one Pharmaceutical Benefits Scheme co-payment.

A Clinical Advisory Committee of health professionals with expert knowledge, skills and experience in EB will be established, and it will make clinically-based recommendations to the Department of Health and Ageing to ensure best treatment practice for those registered under the scheme.

The scheme will complement the services provided to people with EB for treatment during public hospital care, and ease the burden on not-for-profit organisations that presently provide financial assistance through community fund-raising to obtain the necessary dressings.

The Government appreciates the significant work that Dystrophic Epidermolysis Bullosa Research Association (DebRA) has contributed to the development of the scheme. My department will continue to work with key stakeholders, including DebRA, to ensure the scheme meets the needs of people with EB.

Application forms will be available by commencement of the scheme. Further information will be available through www.health.gov.au.

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