



Speech by

Jack Dempsey

MEMBER FOR BUNDABERG

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EPIDERMOLYSIS BULLOSA

Mr DEMPSEY (Bundaberg—NPA) (10.16 pm): I wish to bring the attention of the House to the plight of sufferers of epidermolysis bullosa or EB. Children with EB are commonly known as cotton wool children or butterfly children. Their skin is extremely fragile, like a butterfly's wings, and painful blisters and wounds can form at the slightest touch. EB is an incurable genetic skin condition that affects all parts of the body, internally and externally. EB is also extremely rare, affecting an estimated 1,000 Australians. At its worst it can be fatal, but even in its mild forms it causes a life of pain and physical challenges. Everyday blisters must be lanced and dressed in a painful process that can take hours. Due to the rarity of this disease there is no uniform approach taken by the public health system in providing the necessary specialist support or dressings needed for these butterfly children.

The health system and this government are unable to provide the specialist services needed for EB sufferers, so the families turn for relief to the Dystrophic Epidermolysis Bullosa Research Association or DebRA. DebRA has state and national groups and is a voluntary organisation that provides support to individuals with EB and their families. DebRA currently receives no government funding for the vital work it does and relies on corporate and other funding to continue making a difference.

DebRA's goals are to raise awareness of EB, encourage understanding and compassion, develop a network of support for sufferers and their families and to provide practical support by supplying the essential items needed in the daily life of an EB sufferer. DebRA also funds international research aimed at developing successful long-term treatments and ultimately a cure. One of the major roles that DebRA fulfils is providing free dressings for members right across Australia. Last year alone DebRA spent \$50,000 on dressings. A national survey found that only 35 per cent of DebRA members were able to access dressings via the public system, despite a majority of them wishing to do so. Of the 35 per cent who were able to access dressings through public hospitals, most have had problems with the process: getting inferior dressings, a confusing or inconsistent process, delays on orders, as well as being made to feel guilty for accessing dressings from the public system on an ongoing basis.

I call on the government to implement a clear, straightforward and fair process whereby people with EB could be placed on a register and obtain suitable dressings from their public hospital without being made to feel inferior and ongoing specialist support provided to review dressing requirements annually. This would be of benefit by reducing the number of hospital admissions and the length of stays in our already strained hospitals, along with reduced use of antibiotics and medications. It would also increase the quality of life for people with EB and increased attendance and participation in schools. There is a similar system already in place in New Zealand which I would urge the health minister to look at when considering this issue, and to consult with DebRA Australia in developing a better outcome for the butterfly children.