

PRIVATE MEMBERS' BUSINESS (Epidermolysis Bullosa) – 15th September 2008

Mrs VALE (Hughes) (9:21 PM) —I warmly congratulate the member for Cook for raising this important issue of epidermolysis bullosa, highlighting the many challenges faced by Australian families who have a family member suffering from this unusual condition. I support the moving of this motion. Children with epidermolysis bullosa, or simply EB, are commonly known as 'cotton wool children' or 'butterfly children'. EB is a rare genetic skin disorder marked by fine, fragile skin, as fragile as a butterfly's wings, which forms painful blisters either spontaneously or following minor bumps or knocks, often as a result of the slightest touch. This is the reality for people living with EB, which can affect all parts of the body both externally and internally. EB can appear in varying degrees of intensity and type. EB at its worst can be fatal and, even in its mildest form, it causes a life of pain and physical challenges. Some people spend hours every day dealing with blisters, wounds and destructive scarring by bandaging the affected areas with protective coverings.

This matter was brought to my attention last year by a family in my electorate. The Gibson family have a five-year-old little boy called Joshua who suffers from this condition and needs the constant care and support of his mother and father. Every day, or in some cases every second day, children like Joshua and adults with EB need their blisters pierced, drained and dressed in a routine that lasts up to three hours a day in the most severe cases. The visible wounds on the skin are sometimes only the outside manifestation of this rare condition, because even the eating of solid food can have a devastating effect on the mouth and oesophagus. As a result, many EB sufferers take their food, medication and painkillers through a feeding tube directly into their stomach.

In most cases, the care of the person living with EB falls to the parents, especially the mother. This can be a 24-hour-a-day, seven-day-a-week job, with little or no support options available to many families. This has a significant impact on families, with many living in isolation, as they can often become disconnected from their friends and community. Add to this the ongoing financial burden of medication, most particularly wound dressings and bandages, and it is no surprise that the resultant stress can lead to relationship breakdown within some of those families.

There are significant lifestyle changes required, with at least one parent needing to give up paid employment to take on the role of full-time carer. Children also need support with access to education, with many needing to attend school with a teacher's aide. Parents are always on call if needed and must spend large amounts of time assisting children to catch up on missed learning opportunities and assisting school care to adapt to the children's needs.

The National Dystrophic Epidermolysis Bullosa Research Association of Australia, otherwise known as DebRA, and its member state branches are seeking the support of the federal government to fund and implement a national dressings supply scheme for around 229 children and adults on the national EB register in Australia. This will ensure that all Australians have access to care which is medically accepted as current best practice and addresses current inequities, because the present healthcare system does not have a clear strategy to deal with patients with EB. No government funding is provided to any of the DebRA groups, including the national body. It is only through community awareness and support, as well as funding from corporate Australia and other charitable organisations, that DebRA can make a difference.

DebRA proposes that the national scheme be set up with an indexed budget of \$5 million, whereby dressings are made available to eligible patients. DebRA is willing to coordinate and assist with the administration of the scheme. This would also bring Australia into line with countries such as New Zealand, the United Kingdom and other developed countries, which have long-established national schemes. The scheme would provide an equitable framework to make dressings available and it would improve the quality of life of individuals and families through improved rates of healing, reduced pain during dressing changes and a reduction in the use of other medications. It would result in greater patient compliance, fewer hospital admissions and cost savings through economy of scale. There would be greater economic productivity through increased school attendance and work participation. It would also reduce the financial burden on families already struggling with the added cost of caring for a person with a major medical condition. It would be a reliable system that is not constantly at risk of review, change or termination and it would allow improved social and community involvement for the families. It was inspiring to meet with Gavin O'Brien this afternoon. I commend this motion to the House.