



Speech By  
**Mark Ryan**


**MEMBER FOR MORAYFIELD**

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Record of Proceedings, 29 October 2015

**PRIVATE MEMBER'S STATEMENT**

**Epidermolysis Bullosa**

 **Mr RYAN** (Morayfield—ALP) (2.58 pm): Earlier this year I met Ken, a good man cooking a fundraising sausage sizzle at the FoodWorks at Burpengary. Ken was fundraising for an organisation called DEBRA. DEBRA is the national Dystrophic Epidermolysis Bullosa Research Association of Australia. DEBRA is the peak national support and advocacy organisation for people who have epidermolysis bullosa and their families. Children born with EB are also known as butterfly children. EB is a very rare genetic disease that causes the skin to blister and peel with the slightest touch. Living with EB has been likened to living with third-degree burns. It is very painful and sufferers must be bandaged everyday with dressings to protect and medicate their wounds. There are around 1,000 Australians living with EB.

To be honest, before meeting Ken I had not heard of EB or DEBRA. Naturally, I asked Ken why he was involved with DEBRA. Ken informed me that a family member, Gavin, had had EB. Sadly, Gavin passed away a few years ago but, being a Burpengary boy through and through, I knew exactly who Gavin was. Everyone in Burpengary knew who Gavin was, even if they did not know his name. Every day, people would see Gavin, limbs bandaged, travelling around on his souped up motorised scooter. A few years ago, I was pleased to meet with Gavin. Gavin was an inspirational young man, and I know he is missed by many people.

Having been inspired by memories of Gavin and the fundraising efforts of Ken, I made contact with DEBRA and was pleased to meet with DEBRA's chairperson, Dr Jenny Marty, and I briefly attended this year's national EB camp and conference. Jenny outlined to me the great work being done by DEBRA every day—from providing support to people with EB and their families, to delivering awareness training for medical practitioners, supporting medical research into EB and being a strong advocate. DEBRA is fighting hard to make the lives of people with EB just that little bit better. In fact it was DEBRA's strong advocacy in 2012 that convinced the federal government to increase funding for the national EB dressing scheme and expand the scheme's eligibility criteria.

In Queensland, DEBRA provides funding to support a dedicated EB nurse at the Lady Cilento hospital. It would be remiss of me not to say that DEBRA would be eager to explore additional partnership opportunities with Queensland Health to support the EB nurse program and expand their good work. Whilst there is always more to be done, as this week is national EB Awareness Week I encourage everyone to find out more about EB and the good work of DEBRA.