BrightSky AUSTRALIA

FACT SHEET

SHINING A LIGHT ON EPIDEMOLYSIS BULLOSA

Louise Stevens, CNC
Epidermolysis Bullosa
BrightSky Australia

Epidermolysis Bullosa (EB) is a rare genetic disorder, where protein is missing from the skin layers. It is characterised by blistering and fragility of the skin in response to minor friction or trauma. The disease varies in its severity and impact, from relatively minor disability (i.e. difficulty walking long distances due to blistering of the feet), to death in early infancy.

The most recent classification separates this condition into four sub-types:

- EB simplex (EBS)
- Junctional EB (JEB)
- Dystrophic EB (DEB)
- Kindler Syndrome

The common factor in all these types is skin blistering and fragility and/or ongoing chronic wounds.

In JEB sub-type, the internal mucosa can be affected which means that some patients suffer with corneal abrasions of the eyes, difficulty in swallowing and difficulty with passing urine. This can result in needing a gastrostomy tube to help with feeding, tracheostomy tube to help with breathing and sometimes a supa-pubic catheter to help empty the bladder.

In the recessive type of Dystrophic EB there is a high chance of developing an aggressive skin cancer before the age of 35.

Dressing the wounds is a painful, time consuming and expensive necessity.

The role of wound dressings in EB is to provide a barrier between the patient and the environment, help reduce infection, relieve pain, limit friction, protect vulnerable skin and provide an optimal healing environment. For many years these dressings were not available to many patients. There was inequality in who received dressings in Australia. Some had to self-fund basic traditional dressings while others received subsidised advanced dressings.

DEBRA Australia (Dystrophic Epidermolysis Bullosa Research Association) and other professionals spent many years lobbying for a nationally funded scheme.

DEBRA Australia is a not-for-profit organisation, established in 2005 and dedicated to supporting children and adults with EB. DEBRA allocates public donations towards providing important member services and funding research into effective treatments and ultimately a cure for EB.

For more information visit http://www.debra.org.au/

In the 2009 – 2010 Budget, the Australian Government committed $16.4m over four years to establish the National Epidermolysis Bullosa Dressing Scheme (NEBDS). The Scheme supports eligible people with Epidermolysis Bullosa by improving access to dressings and bandages.

The National EB Dressing Scheme commenced on 1 January 2010 and is administered on behalf of the Australian Government by BrightSky Australia, in consultation with the National EB Dressing Scheme Clinical Advisory Committee and the Department of Health and Ageing.

Approved applicants receive a standard order of dressings each month, as prescribed by their treating healthcare professional. To maintain eligibility, approved applicants must also attend regular reviews with their treating healthcare professional.

As part of the Scheme, a Clinical Nurse Consultant, Louise Stevens, is available to provide educational support and wound care product advice to patients and professionals. Louise also presents at conferences around Australia, educating and increasing awareness about the National Epidermolysis Bullosa Dressings Scheme.

For more information regarding eligibility guidelines, application process, the schedule of dressings, an educational resource tool and a DVD, please visit www.ebdressings.com.au. Alternatively, contact BrightSky on 1300 290 400 for more information.

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