

EPIDERMOLYSIS BULLOSA AWARENESS WEEK 22-26 OCTOBER 2018

This week is International Epidermolysis Bullosa (EB) Awareness Week with Thursday 25 October being EB Awareness Day. There are over 1,000 people currently living in Australia who are affected by EB, many who are infants and young children.

Professor Dedee Murrell, dermatologist with the Australasian College of Dermatologists (ACD) says: "EB is a rare inherited skin fragility disorder caused by mutations in proteins that help glue the skin together leading to blistering of the skin with minor injury. It is a genetic disease and there is currently no cure."

DEBRA Australia is a not for profit volunteer based organisation that works to support those living with EB.

Sue McKenna from DEBRA says: "Our theme for the International EB Awareness Day this year is stand up and #FIGHTEB. DEBRA organisations from over 52 countries around the globe will be working together to create awareness of EB and to influence local policy makers to create better services and support for those living with EB in our communities."

A lot has been happening in the space of EB since last year:

- A case has been published of a young Syrian refugee boy with severe junctional EB (one of the major forms of EB) and over 80% of his skin denuded from infection. He was treated in Germany with gene therapy provided with the help of teams in Italy and Austria. Stem cells from his remaining skin were grown in the laboratory after the gene defect was repaired into artificial sheets of new skin and grafted back onto his wounds. He spent eight months in the burns unit, but three years later none of these wounds have broken down and he can run on a treadmill
- Various groups presented at the DEBRA International meeting in Salzburg last year on the use of gene replacement/repair using creams, but these are yet to be tried in EB patients in a randomised trial
- International guidelines that Australia has led the way in include the management of EB patients with squamous cell skin cancer, anaemia, pregnancy and childbirth, surgery and podiatry.

Professor Murrell says: "Trials of anti-inflammatory creams have been ongoing here in Australia. In St George Hospital in Sydney, an independent non sponsored clinical trial of topical sirolimus for EB simplex is still recruiting with myself, together with Joyce Teng of Stanford University. Another trial of diacerein cream for generalised EB simplex is not currently recruiting, but is ongoing. One remaining trial is for patients with Recessive Dystrophic EB (RDEB) and junctional EB of a triterpene cream and we are still recruiting for that in Sydney and Melbourne."

ENDS

Links to further information



[DEBRA](#)

[Dermatology Trials Australia](#)

[Australasian Blistering Diseases Foundation](#)

[National Epidermolysis Bullosa Dressing Scheme](#)

[A-Z of Skin](#)

[Find a local dermatologist](#)

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About the Australasian College of Dermatologists (ACD):

The ACD is the peak medical college accredited by the Australian Medical Council for the training and professional development of medical practitioners in the specialty of dermatology. They provide authoritative information about dermatology to Government, the media, other health professionals and the general public.

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