



MEDIA RELEASE

For immediate release October 2017

**“Help Butterfly Children Get Their Wings”
by Donating to DEBRA-Australia for
International EB Awareness Week - October 25th – 31st 2017
International EB Awareness Day 25th October 2017**

It’s unfathomable, but over 1000 of children in Australia and many more worldwide live with excruciating pain 24/7. They are called Butterfly Children as their skin is as fragile as butterfly wings and blisters spontaneously. October 25th -31st, 2017 marks the International EB (Epidermolysis Bullosa) Awareness Week.

Epidermolysis Bullosa (EB), is a debilitating disease which causes the skin to blister. In severe cases, up to 70% of the body and internal linings can be covered in sores and blistered wounds that can be compared to severe 3rd degree burns.

This condition disables young children as they undergo daily rituals of dressing changes and bandaging while their illness is often life threatening due to high incidence of wound infections, skin cancer and kidney failure.

It is these challenges, and many more emotional and physical hurdles affiliated with this condition that affect the Butterfly Children and their families, that make it essential for continued research into a cure and the provision of specialised nursing care Australia wide.

Debra Australia is a non-for profit charity, a patient organization focused on providing assistance to patients and families living with EB by ensuring that Butterfly children have

- access to wound dressing and medical supplies not covered by the National EB Dressing Scheme
- access to In-home and hospital nursing by specialized EB nurses
- access to support services as these children require 24hrs/7days a week care

Our Family Support Program Coordinator, Ms Simone Baird, who is also a mum of the child with EB says, “I am extremely proud to be part of the DEBRA family, and work for this exceptional volunteer charity organization, dedicated to children and families affected by Epidermolysis Bullosa (EB).”

“Like any parent with an EB child, my greatest wish is for a cure and through research programs supported by DEBRA Australia we can hope to achieve that one day. Our everyday lives have been greatly touched by support we receive from DEBRA Australia programs, including assistance with nursing and family support, and this could only be achieved by donations they receive from the public.”

“So for this year’s EB Awareness Week, which runs from the 23rd to the 29th of October, I will participate in DEBRA Australia’s ‘Dine and Donate’ campaign by pulling together a group of big-hearted mums and bubs to help raise money and awareness. Over the next few weeks, I really hope there are many more groups of like-minded people who can do the same.”

Whether it is a BBQ, a high tea, breakfast or dinner party, EB Awareness Week is the ideal opportunity to get your family and friends together to help raise much-needed funds for DEBRA Australia.

All you need to do is host an event, ask your guests for a donation and enjoy bringing everyone together for a fantastic cause.

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For further information or for interview opportunities please contact:

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For further information on Dine and Donate please visit

<http://www.debra.org.au/dineanddonate/>