What Can You Do?

Make a donation

DEBRA Australia relies on the generosity of our supporters to provide vital programs, services and support to individuals and families living with EB. Without recurrent government funding, every contribution helps us to continue this important work.

By becoming an EB Butterfly Warrior through regular giving, making a one-off donation, or leaving a bequest in your Will to DEBRA Australia, you can make a positive, lasting outcome for Australians living with EB.

Join in

Rally your staff, colleagues and friends to raise funds as a team at an upcoming DEBRA event.

Whether you enjoy walking in Walk for Wings, running in Run for EB, or creating your own fundraising challenge, every dollar raised helps DEBRA Australia provide vital care, support and hope to Australians living with EB.

Our team can help you create a fundraising team, provide resources and support you every step of the way.

Workplace giving

If your organisation or colleagues and friends have a workplace giving program, we'd love DEBRA Australia to be considered as a partner charity.

Regular workplace giving provides reliable funding that helps ensure Australians living with EB can access specialist care, practical support and connection when they need it most.

Scan to get involved or donate online at giving.debra.org.au
For other options please email admin@debra.org.au

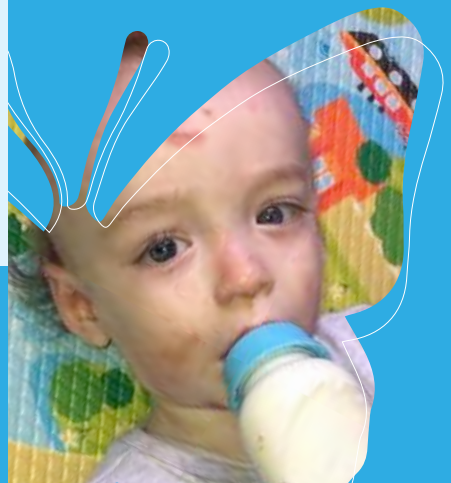
Kylan was born with Epidermolysis Bullosa (EB), a condition that makes his skin as fragile as a butterfly's wings.

When Kylan was born, he had missing skin on his forehead, nose and ears, and his right foot was fully degloved. His family soon learned just how complex and demanding life with EB can be.

DEBRA Australia has been there to support Kylan and his family with practical assistance and specialist care, helping them manage the challenges of EB and giving Kylan the best possible support as he grows.

For families living with EB, access to specialised support, expert guidance and dedicated advocacy can be life-changing.

Help DEBRA be there for children like Kylan and families living with EB across Australia.



debra Australia.

debra.org.au
admin@debra.org.au

debra Australia.

This is Kylan and he was born with a condition called Epidermolysis Bullosa (EB).

Who is DEBRA Australia?

DEBRA Australia (DEBRA) is the only national patient advocacy charity in Australia, dedicated to improving the quality of life for children, adults, and families living with Epidermolysis Bullosa (EB).

For over 20 years, DEBRA has supported the EB community, providing specialist nursing care, family support, counselling, respite, practical assistance, education and research funding.

Our programs help families navigate the physical and emotional challenges of EB and access the care and support they need. Through this work, we foster a sense of dignity, meaning and belonging while enhancing the quality of life for people living with EB.

What is EB?

Epidermolysis Bullosa (EB) is a rare genetic disease that causes the skin to blister and tear at even the slightest touch, with skin often described as being as fragile as butterfly's wings.

Living with EB has been likened to living with painful third-degree burns. Daily bandaging is required to protect and medicate wounds, manage pain, and help prevent infection. EB can also affect the mouth, throat, digestive tract and other parts of the body, requiring ongoing medical care and potentially leading to life-threatening complications.

It is estimated around 1,200 Australians and more than 500,000 people worldwide are living with EB. It affects people of all ages, genders and backgrounds.

While there is currently no cure, advances in research are bringing new hope for improved treatments and better quality of life.

EB Programs & Services

Specialist EB Nurse Program

Our specialist EB Nurses are a lifeline for families from the moment of diagnosis through every stage of life. They provide expert clinical advice, education and coordination of care, supporting hospitals, health professionals and families across Australia.

In-Home Nursing Support

When additional care is needed, DEBRA Australia provides in-home nursing support to assist with bathing, wound care and dressing changes. This service is particularly valuable for families with newborns, people experiencing complex wounds and young adults building independence.

Family Support

Our Family Support team helps individuals and families navigate the many practical and emotional challenges of living with EB. We connect families with services, advocate on their behalf and ensure they have access to government and community support, while helping fill any gaps in care when needed.

Counselling & Wellbeing

Living with EB affects the whole family. We provide access to confidential counselling and psychological support with professionals who understand the unique challenges of EB, helping individuals and carers build resilience and wellbeing.

National Conference & Family Camp

Every two to three years, DEBRA Australia brings together families, clinicians and researchers for our National EB Conference and Family Camp.

Families connect with others who truly understand life with EB, learn about the latest research and clinical care, and share experiences and practical knowledge. Children can enjoy activities and friendships, while parents benefit from connection, respite and peer support.

Research & Education

DEBRA Australia funds Australian research aimed at developing better treatments and, ultimately, a cure for EB. We also support education for health professionals through conferences, training and research grants, helping improve EB care across the country.

"Living with EB has been compared to living with third degree burns."