



## Social Impact Report November 2023

What we're doing &  
the impact we're creating

In partnership with



## Context

DEBRA Australia has been working to build internal capacity to ensure a sustainable organisation to continue our work into the future. In partnership with For-Purpose Evaluations, we have developed DEBRA Australia's Theory of Change model and tools to analyse, evaluate and demonstrate our impact across the EB community.

Building on this work, DEBRA Australia undertook a pilot study in October 2023 which included:

**54\***x Individual and family member surveys  
\*16% response rate



**9x** Individual and family member interviews



**24x** Health practitioner surveys



**10x** EB researcher self-reports

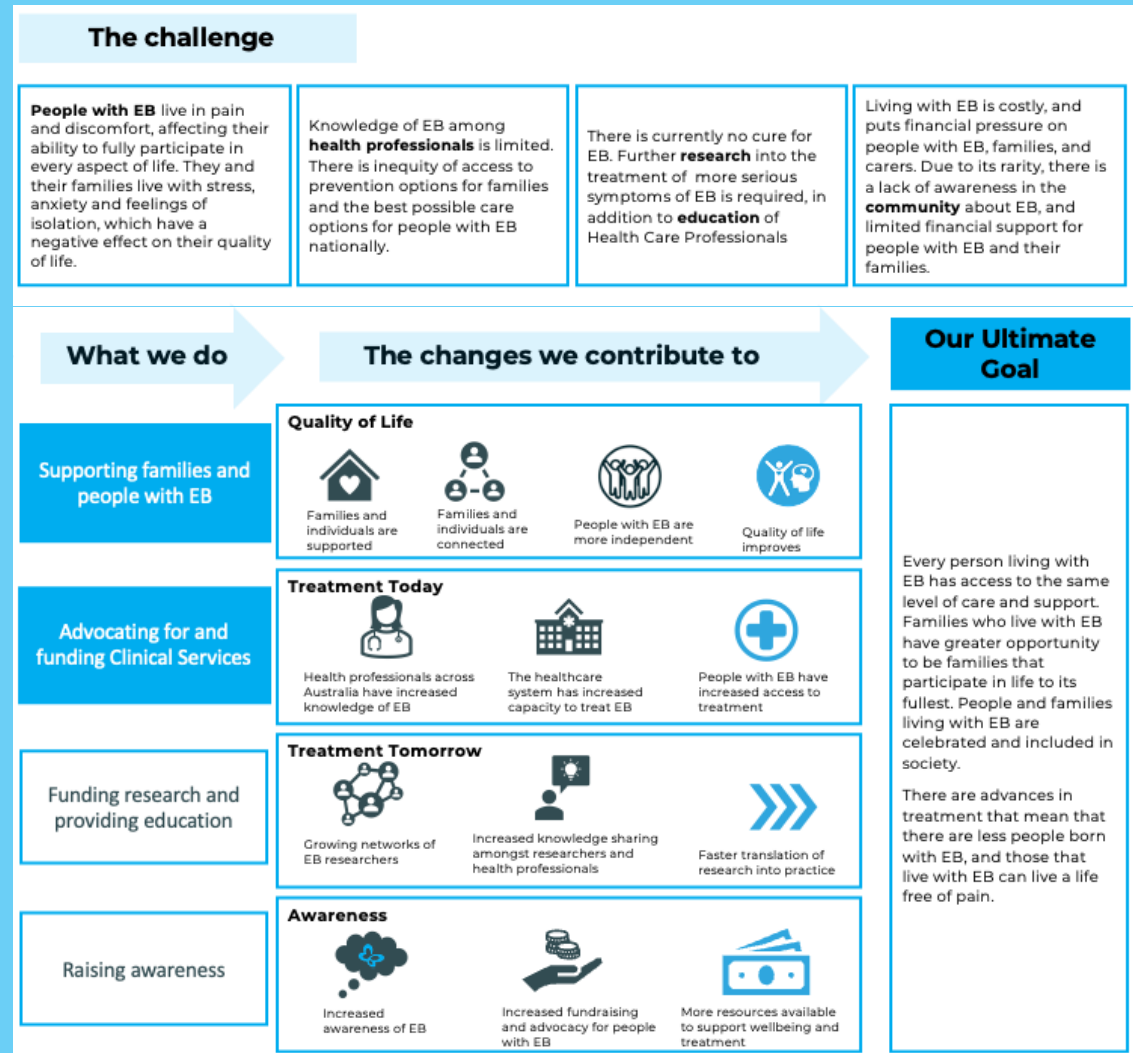


## Purpose

This report seeks to demonstrate DEBRA Australia's impact based on the data collected in the recent pilot study. By presenting this information, we are keen to:

- Identify areas where DEBRA Australia can learn, strengthen, and evolve our impact;
- Outline DEBRA Australia's impact so far to current funders and EB community members;
- Attract new, sustainable funding sources to support our important work.

## DEBRA Australia's Theory of Change



# Quality of Life

Supporting families and people with EB



Families and individuals are supported



Families and individuals are connected



People with EB are more independent



Quality of life improves

**38%** of people with EB and their families have been our **accessing support for 10 years or more.**



**82%** of people with EB agree that DEBRA Australia has **helped them be aware of what support is available.**



**“** DEBRA Australia has improved my quality of life through community, education and by providing personalised assistance. It changed my life – I can't stress that enough. **”**



**53%** of people with EB agree that DEBRA Australia has helped them **feel more independent.** The other **47% were neutral.**



**69%** of agree that DEBRA Australia has helped their loved ones with EB **be more independent.**



**“** DEBRA Australia has enabled me to live independently which is something I thought I would never be able to do on my own. Because of their ongoing support I have been able to move out of home and live with my fiancé without the need of my parents' assistance. I am also able to attend more medical appointments without requiring the support of my parents. **”**



**– Individual with EB, VIC**

**63%** of people with EB and their families agree that their **overall quality of life has been improved** with DEBRA Australia's help.



**96%** of health practitioners surveyed agree that DEBRA Australia **improves the overall quality of life** of people living with EB.



**“** I work directly with patients with severe EB. DEBRA Australia has been essential to support these families. Rare conditions can be so isolating, DEBRA Australia connects knowledge, people & resources. **”**



**94%** of family members agree they feel supported by DEBRA Australia **75% strongly agree.**



## Learning point

While a sense of connection with the EB community is often referenced, only 48% of respondents agree that DEBRA Australia has helped them feel more connected with the wider community; highlighting opportunities to broaden awareness & interaction.

**78%** of respondents agree that DEBRA Australia has helped them feel **more connected with the EB community.**







“ The mum's respite made me feel normal for the first time since [my child] was born. I found my identity again and this weekend gave me a purpose of life. I have made lifelong connections with EB mums, families and DEBRA Australia that will continue to nurture to be part of our life. ”



– Family member, QLD

“ Accessing DEBRA Australia supports has definitely made it easier for me to deal with the condition and day to day life. DEBRA Australia helped me source a wheelchair which provided access to the broader community. It enabled me to have independence at school and keep up with my friends. Starting school was very nerve-wracking, but all went well because DEBRA Australia was involved with transitioning, training and education. ”



– Individual with EB, VIC



“ The family support side of things has been huge to give me the confidence and my parents to make sure I can live an independent life by myself. DEBRA Australia has provided this support to me and my family. The biggest thing is not feeling alone and that I don't have to do this by myself. The emotional and medical support provided for myself and my parents has enabled me to live a more independent life. ”



– Individual with EB, QLD



# Treatment Today

Advocating for and funding Clinical Services



Health professionals across Australia have increased knowledge of EB



The healthcare system has increased capacity to treat EB



People with EB have increased access to treatment

“DEBRA Australia has significantly impacted my family by helping us continue to provide beneficial supplements/medications and skin products for our son as well as health care services.”



“The education provided to health care staff has been a wonderful resource in improving EB knowledge throughout Australia.”



**92%** of health practitioners surveyed agree that they have **more knowledge of EB** after interacting with DEBRA Australia.



**79%** of health practitioners agree that DEBRA Australia **increases the overall capacity of the healthcare system to treat EB.**



**75%** of health practitioners surveyed agree that DEBRA Australia **increases access to treatment for people living with EB.**



**71%** of people with EB agree that they have **increased access to treatment** because of DEBRA Australia.



“DEBRA Australia has been critical link in helping me shape my career path, provide vital connections to other health professionals and clinicians dealing with EB. DEBRA Australia has also helped with my education (attendance to conferences) and supported my research program into EB. Without their support my career path would be in a different area of skin research.”



“The dressing scheme and being on the NDIS has enabled my day-to-day activities to increase as we don't have to worry about supplies and access which has increased the number of activities as I can go out any day anytime.”



“When we moved here, DEBRA Australia helped us get wound care and set us up with all the specialists in the EB care unit [...] and we appreciate having helpful conversations with DEBRA Australia too.”



“DEBRA Australia has assisted our Complex Care patient cohort with education on the various complexities of this condition and has provided community links with service providers.”



# Treatment Tomorrow

Funding research and providing education



Growing networks of  
EB researchers



Increased knowledge  
sharing among researchers  
& health professionals



Faster translation  
of research into  
practices

**88%** of health



practitioners agree  
that DEBRA Australia  
**helps improve EB  
knowledge sharing**  
between researchers  
& professionals.

**71%** of



health practitioners  
agree that DEBRA  
Australia contributes  
to **faster translation  
of EB research into  
practice.**

“ DEBRA Australia's focus on  
developing the next generation  
of EB scientists, researchers and  
health professionals will make a big  
difference to ensuring Australian EB  
research is at world standard. ”



– **EB Researcher**

## Thematic analysis



Researchers reported DEBRA Australia's  
impact on EB research as:

- **Supporting local and global collaboration**
- **Investing in the next generation of researchers**
- **Facilitating interactions between researchers, clinicians, patients & families**
- **Enhancing international EB networks through conferences**
- **Accelerating novel ideas & initial testing**
- **Funding towards essential research & treatment breakthroughs**
- **Supports EB researcher career entry, establishment & growth**

“ DEBRA Australia has a  
communication link within  
Australia, NZ and overseas, providing  
resources, current research/  
education & collaboration. ”



– **Health professional**

DEBRA Australia has awarded

**22 grants** valuing a total of  
**\$642,568** to EB research projects

investigating areas including assessment  
and diagnostics, treatment therapies,  
prevention & access to medical support.



“ DEBRA Australia has enabled  
me to meet EB clinicians  
and patients which has been very  
important for my research and  
work. ”



– **EB Researcher**

“ DEBRA Australia is the main  
contributor to the progression  
of knowledge, understanding and  
treatment of EB in this country. It's  
highly unlikely that any EB research  
program in Australia could be  
sustained without it. ” – **EB Researcher**



## Highlight

EB researchers identified that DEBRA  
Australia's seed funding resulted in around

**\$4.1 million** additional funding  
towards EB research projects. That's  
**6.4X** the original investment.

# Awareness

Raising awareness through fundraising & advocacy



Increased awareness of EB



Increased fundraising and advocacy for people with EB



More resources available to support wellbeing & treatment

## Media data\*

**10,880** web sessions

**8,693** new visitors

**2,241** returning visitors

**3,262** Facebook likes

**147** new Facebook page likes

**1,223** Instagram followers



## Fundraising data\*

DEBRA Australia Walk for Wings

**\$42,792**



Donations & other fundraisers

**\$1,084,063**

Total income

**\$1,126,855**

\*Based on 2022/23 period



Researchers have produced **29 publications & 59 abstracts or presentations** about EB research funded by DEBRA Australia.



DEBRA Australia funded **491 family support grants** in 2022/23



“DEBRA Australia has helped us by providing information, dressings, bandages etc. It has helped us become aware of fundraising and all that's happening in EB Community.”



“The offer of financial support with all things EB helps so much. Knowing that I have all of the creams and socks and shoes or whatever it is, takes a weight off my back when we're already strained in other ways to support our family.”



“DEBRA Australia provides not only financial support for EB research but also aids in increasing knowledge to all who have a connection with EB impacting the availability of resources.”



## Learning point

EB treatments, socks, electricity bills, physical & mental health costs are expensive. 24% of individuals and family members mentioned financial challenges in the survey (unprompted), highlighting DEBRA Australia's impact through financial support.