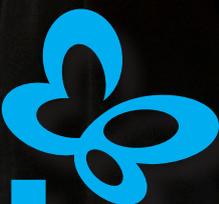


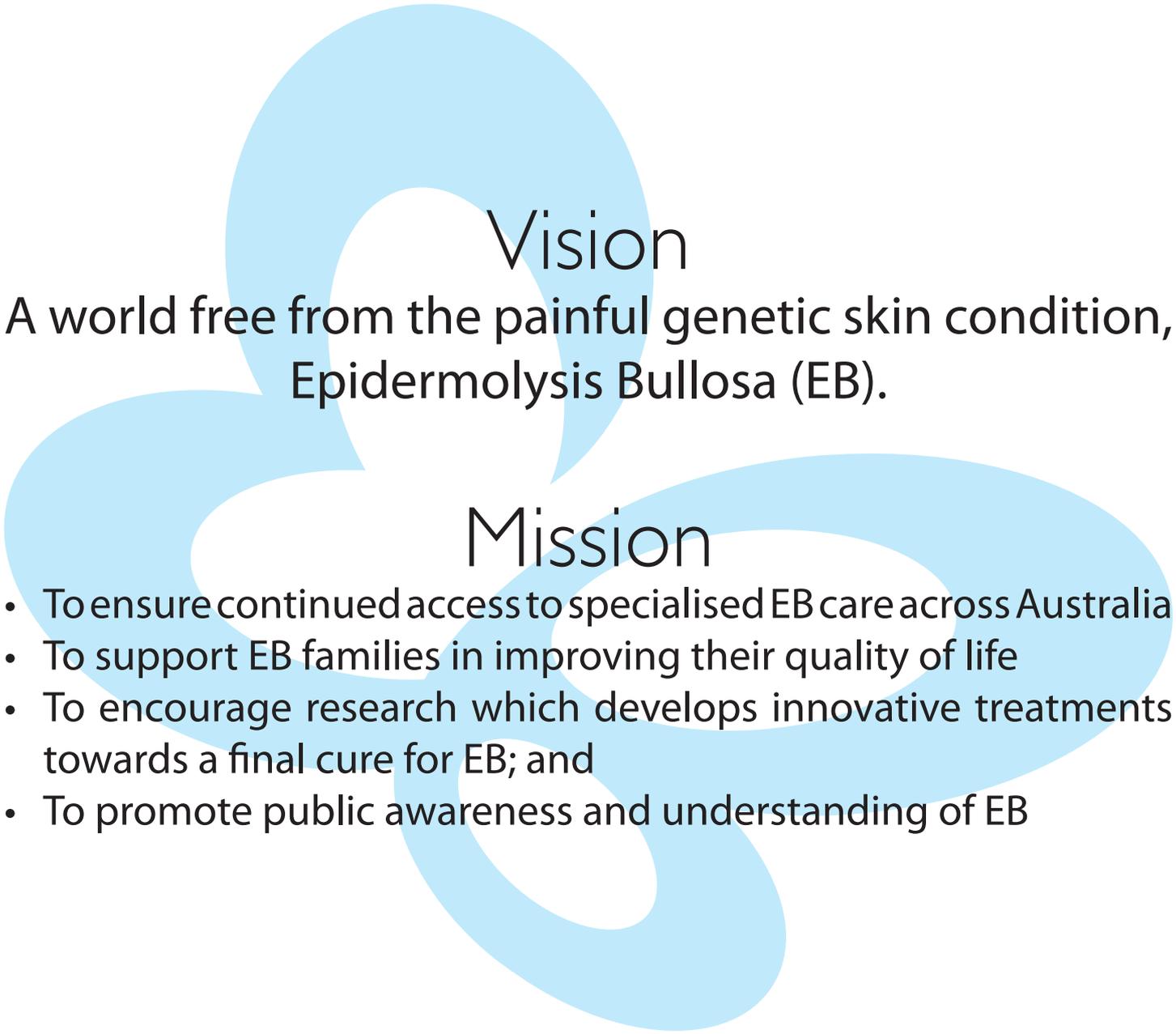
Annual Report 2015




debra
Australia.

Matt Bevilacqua (Ironman and DEBRA Australia Ambassador) and Hayden

Working for a life free of pain.



Vision

A world free from the painful genetic skin condition,
Epidermolysis Bullosa (EB).

Mission

- To ensure continued access to specialised EB care across Australia
- To support EB families in improving their quality of life
- To encourage research which develops innovative treatments towards a final cure for EB; and
- To promote public awareness and understanding of EB

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Chair's Report 2015

In this, my first year as Chair of the Board of DEBRA Australia, I am extremely proud of all that we have achieved.

I would like to begin by thanking all who have contributed to DEBRA this year. This includes our sponsors, donors, volunteers, those who have held or supported fund-raising events, several trusts and foundations, and those who have left DEBRA a gift in their wills, not to mention our passionate and dedicated staff and Board members.

In 2014/15, with all of these generous contributions, we have been able to expand and improve our family support services and our nursing program, as well as increase our research grant awards. More information about these is provided in the reports from each area which follow.

Some of the highlights have included:

- 92 family support grants were awarded in the 2014/15 year, helping individuals and their families with medical supplies, support services, aids, equipment and items to improve quality of life. This is a 62% increase over the previous year in grants processed and over 100% increase in funds that have been spent.
- We negotiated an agreement with St George Hospital, Sydney, to fund a part-time EB nurse to assist with teenage and adult care. Together with our paediatric nurses in Brisbane and Melbourne, this means we are now funding 3 EB nurses in major hospitals.
- We awarded three competitive Research Grants, totalling \$46,000, and four international travel grants to assist early career researchers and health professionals to travel overseas for training and to present their work at international meetings.
- We continue to be grateful to the Little Heroes Foundation, which has supported our home-care activities by providing funds to support in home nurses/carers for 21 individuals to date, as well as the Eliza Braitling Foundation which has also supported this program.
- We welcomed three new DEBRA ambassadors to our team. These people have helped to raise awareness and support for the EB community and we look forward to working with them again in the coming year.

It is always sad when one of our EB family passes on, whether a young baby, child or adult. DEBRA extends its sympathy to all those who have lost loved ones this year and wants to assure you of our ongoing care and concern.

We are extremely grateful for all the financial support we have received during the year. In particular, the Melbourne Cotton Ball team did a fabulous job in holding another successful event in March 2015. This Ball was a major contributor to our fundraising last year, accounting for over half of our income. It is that success that has enabled us to extend and continue our programs. We are pleased that a group in Adelaide has started planning a Cotton Ball of their own for 2016.

However, the Board has identified that ensuring financial sustainability should be a key strategic objective for the next few years. We need to have a good mix of fundraising activities planned for each year, so that we are less dependent on one major event every few years, and can work towards a more predictable annual budget. To assist with this we are planning to appoint a part-time person to focus on marketing and fundraising in the coming year.

I would like to take this opportunity to thank all my fellow directors and particularly acknowledge the contributions of those retiring from the Board this year. Donna Whiffin, who retired mid-year, is an integral part of the Cotton Ball Committee and also contributed to several other areas.

John Bacon, Samantha Drake and Karen Frost have made significant contributions to DEBRA in their roles as directors and have provided guidance and support through their committee membership. Our new director and mentor, Rodney Sheaves, adds additional financial and administrative expertise, and is well connected with the dermatology community, through his past role with the Australasian College of Dermatologists.

Jennifer Marty, September 2015

Family Support Program

Family Support Committee: Simone Baird (employee), Shay Zulpo (chair), Mary Woods, Karen Frost, Melinda Oxford

The DEBRA Family Support Program (FSP) is now two years old and has supported many EB families along the way. Over the past 12 months the program has received 114 requests for support, 108 which have been financially funded through the Family Support Program's budget. The FSP has sourced external support from various councils and funding bodies which has also contributed to supporting families living with EB.

During the past 12 months, the DEBRA FSP has continued to maintain professional external working relationships with Young Care Australia, the Department of Family & Community Service NSW, Keune Foundation and the Eliza Braitling Foundation which has provided significant financial savings to DEBRA and has supported 6 individuals with In Home Nursing Care & Medical Supplies.

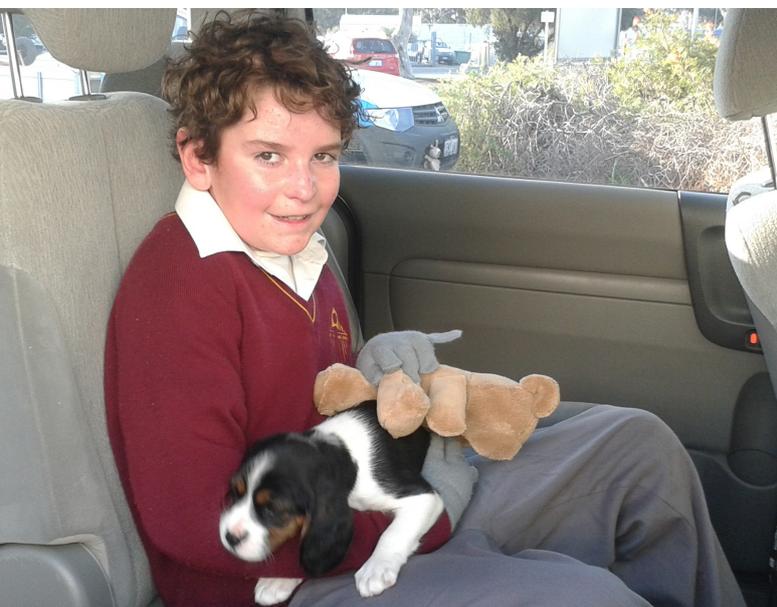
The DEBRA FSP has maintained an ongoing working relationship with the SA Little Heroes Foundation who support severe EB families (under the age of 25) with In Home Nursing. They have accepted 3 new families onto the program & extended the level of support for these families due to the severity of the newborns EB.

The DEBRA FSP has supported 3 families in the past 12 months who have sadly lost infants due severe EB.

The DEBRA FSP coordinated our first ever mums weekend away where 10 mums flew to QLD for much needed respite.

All EB families received a FSP survey to evaluate the program. See attached results

The FSP has considerably expanded during the 2014 – 2015 period & will continue to grow during the next financial year. It will aim to provide on-going support from within its own allocated budget & with additional accessed funding sourced from external grants & government bodies. A major focus point for the next financial year is to increase National family contact, Respite program, and Adult hospital transition. We will also evaluate the EB camp & consider alternative options for future camps.

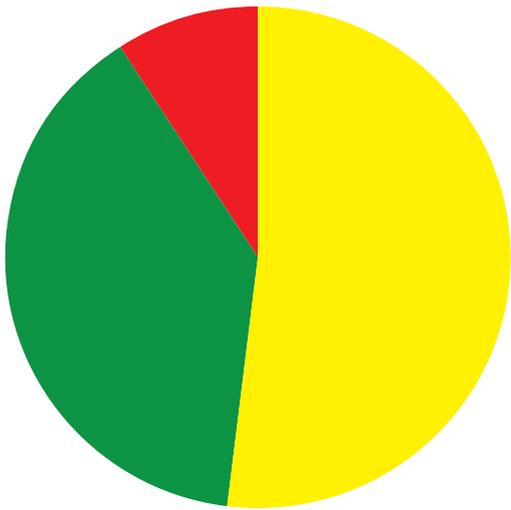


Alessio & Duchess



Deans new aircon

\$347,000 spent on 3 major programs



- Research & Education - 9%
- Hospital Nurse Program - 39%
- Family Support - 52%

Less than 15% Funds raised in 2014/15 spent on administration.
(KPI target < 20%)

DEBRA's activities are supported by 1.6 FTE staff and over 2,000 hours of volunteer time



Hannah & Ivy SA EB clinic



Lola

Nurse Programs

Hospital-Based Nurses

This year DEBRA funding was continued for our two paediatric EB nurses, Samantha Hay at the Lady Cilento Children's Hospital, Brisbane and Lauren Weston at The Royal Children's Hospital, Melbourne. They continue to do a wonderful job and the call on their expertise is growing every year, with additional clients attending the EB clinics and support needed for several births of suspected EB babies.

We were also able to extend the reach of our hospital program early in 2015 by providing funds to employ Margaret Norris at St George Hospital, Sydney, dealing primarily with adults and teenagers. DEBRA also had discussions with the Women's and Children's Hospital, Adelaide regarding the potential funding of an EB nurse for South Australia.

This has not proceeded as the Hospital advised that additional resource was not required at the moment. However we are providing some educational support for the Complex Care nurse at the hospital who sees EB patients. The current program costs about \$140,000 per year to run. The possibility of expansion is reviewed annually depending on available funds.

Home-Based Care

In the past year DEBRA has continued its program of funding home-based nursing/carer visits for dressing changes, bathing and other essential activities for some high need families and adults. Since the program began, the Little Heroes Foundation has funded home care for 21 individuals.

We are very grateful for their ongoing support for this important service. We continue to monitor the progress of the roll out of the National Disability Insurance Scheme, as this may gradually provide more assistance in this area of need.



EB Nurses from Australia and New Zealand - taken during the EB Health Professionals Day 2015

Photo by Lindsey Collier - left to right - Back row: Margaret Norris (EB Nurse St George Hospital Sydney), Samantha Hay (EB Nurse Lady Cilento Hospital Brisbane) Jacqui Finnigan (EB Nurse), Sharon Cassidy (EB Nurse NZ), Lea Prujean (DEBRA NZ Coordinator)

Front row: Lauren Weston (EB Nurse Melbourne Royal Children's Hospital), Cassie Dujmovic (Wound Clinical Practice Consultant Adelaide Women's & Children's Hospital), Anna Malden (Complex Care Clinical Practice Consultant - Adelaide Women's & Children's Hospital), Sarah Hill (EB Dressing Scheme Nurse BrightSky Australia)

Research & Education

Research

The following competitive grants for research projects to be undertaken in 2015 were awarded to:

1. Dr Caroline Mahon and Associate Professor Orli Wargon : A retrospective study of the diagnostic relevance of skin biopsies taken for immunofluorescence mapping (IFM) and transmission electron microscopy (TEM) in making a diagnosis of epidermolysis bullosa (EB) subtype in newborns and infants suspected of having EB. Award \$24,700.
2. Dr Zlatko Kopecki and Prof Allison Cowin: Study to determine if improving the skins barrier function reduces susceptibility to blister wound infection. Award \$15,000 (included \$5,000 raised from donations for EB research in South Australia).
3. Dr Anna Steer & Ms Lauren Weston: Teledermatology Satisfaction in Children with Epidermolysis Bullosa. Award \$4,000.

In addition four international travel grants were awarded to assist early career researchers and health professionals to travel overseas for training and to present their work at international meetings.

1. Zlatko Kopecki, University SA: to attend the May 2015 DEBRA International Research Conference and Society of Investigative Dermatology Annual Meeting in Atlanta USA.
2. Swara Jain, University of NSW: to make an oral presentation at the 23rd World Congress of Dermatology, attend the session on Epidermolysis Bullosa and also attend sessions of the International Dermatology Patient Organization Conference in Vancouver, Canada, June 2015.
3. Lauren Weston, Royal Children's Hospital, Melbourne: awarded a scholarship to enable her to attend an EB training course in London in September 2015 and the EB Clinet and DEBRA International Meetings.

4. Emma King, Royal Children's Hospital, Melbourne: travel grant to attend the EB Clinet and DEBRA International Meetings in London in September 2015. In addition, DEBRA assisted local researchers by advertising the availability of three local EB studies to the lay EB community, using materials which had been approved by the Ethics Committees of the relevant institutions.

Education (Clinical Advisory Committee)

The DEBRA International Pain Management Guidelines, released late in 2014, were distributed to our Health Professionals mailing list. This will be a key topic for the EB Health Professionals Education Day to be held on 11 September in Brisbane, the day before the EB Family Camp.

DEBRA was represented at the March 2015 Rare Voices Summit and endorsed the proposed Summit Communique, hoping that this will assist Rare Voices in lobbying the government for better services for patients with rare diseases and implementation of a Rare Diseases National Plan for Australia.



Adam Harris, Michael Fitzpatrick, Dedee Murrell and Zlatko Kopecki attended the Triannual EB Research Conference held in May 2015 at Chateau Elan, Atlanta, USA.

Marketing and Fundraising

Communications

Our website was upgraded during the year with the assistance of Scott Macfarlane to allow completion of on-line forms, which has really streamlined our processes. A new DEBRA brochure, the "What is EB" brochure and the Health Professionals Guide have all been updated.

Marketing

Three new ambassadors have agreed to represent DEBRA this year. A big welcome to Tasma Walton, Matt Bevilacqua and Kate Moloney. Saatchi & Saatchi have also offered assistance with a short video and developing a marketing project.

Fundraising

Several successful major events were held during the year, with the help of many enthusiastic, dedicated and hardworking supporters.

The second Cotton Ball held in Melbourne in March was an outstanding success. Thanks very much to the Cotton Ball team for a fantastic effort. Planning has now started for an Adelaide function in 2016.

DEBRA organised the 5th EB Cross Country Motorcycle Ride, which was held in outback WA and NT in May/June with the help of several sponsors and supporters.

Several other wonderful events were organized by various supporters, such as the Tough Tilly Day, Brighter Days, Golf Days in Melbourne & Sydney, Dine and Donate during International EB Awareness week, and several functions in Adelaide.

There have also been many individual efforts such as those covered through Everyday Heroes activities. We are also grateful to the Little Heroes & Eliza Braitling Foundations for supporting some of our programs during the year.

Funds have been raised to set up the Kate Turner Fund and the first round of grants will be announced very soon.

A key focus for the future will be to develop a sustainable funding program. We were pleased to be invited to be one of the charities which will benefit from the newly established Future Generation Investment Fund.

Membership

As at 30 June 2015 DEBRA Australia had 52 members.



EB Cross Country 2015 Riders



Brock McLean, Ricky Roberston, Simone Baird, Rory Brockwell and Corey Wilkes at Tough Tilly Day 2015



The Cotton Ball Committee with the 2015 DEBRA Australia Chair's Award.

Financials

We are committed to ensuring our programs are delivered as effectively and efficiently as possible so that we make best use of your donations. Hence we do not produce a hard copy Annual Report. You can see how we measure up to our target Key Performance Indicators by clicking [here](#) and you can also view our audited financial statements [here](#).