



ANNUAL REPORT JULY 2016 - JUNE 2017



Andrew, John and Dean at the end of the Million Dollar Run event in Brisbane

Vision

A world where no one suffers from the painful genetic skin condition Epidermolysis Bullosa (EB).

Mission

To ensure that people living with EB have access to the best quality support and medical care, while also driving the effective development of treatments and cure for EB. To raise awareness and understanding of EB amongst health professionals and the general public within Australia.

Primary Objectives of the Organisation

(all of equal importance)

- EB is a rare genetic disorder causing painful internal mucosal blistering and external cutaneous blistering, likened to third degree burns.
- DEBRA is a volunteer based organisation funded by donations and grants.
- DEBRA aims to improve the lives of children and adults living with EB, a debilitating and sometimes fatal condition, by providing necessary support services, home aids and information to individuals and their families.
- DEBRAs programs support and educate families living with EB, health professionals, communities and the general public.
- DEBRA funds specialised EB Nurses in hospitals and provides in home care for families on a national basis.
- DEBRA supports and encourages EB research.
- DEBRA Australia contributes to and supports the activities of DEBRA International.

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Chair's Report 2017

The past year has been a successful one for DEBRA Australia, with several developments which have helped us to consolidate our financial position so we can continue to expand our programs for the EB community.

Financial sustainability has been a key strategic objective for the Board and we have made considerable progress towards this in the past 12 months. Our operating profit was \$146,976 and our income is more secure due to a more defined fundraising program, now that we have our Fundraising Manager in place. In particular we are grateful for the regular distributions we expect to receive over the next 3 years from The Future Generation Investment Company Limited (ASX: FGX) which is Australia's first listed company with the dual purpose of generating a social and financial benefit. This exciting philanthropic initiative resulted in a donation of \$132,218 in 2016/17 and is being used to operate hospital and in home EB nurse programs.

This year we have spent over \$160,000 to fund family support grants, in home nursing and employ our dedicated and caring Family Support Coordinator, Simone Baird.

Our EB nurses, in Brisbane, Melbourne and Sydney, continue to provide an excellent service and are continually looking at ways that we can improve things for the EB community. Early in 2017, some of our additional funds were used to appoint our first Transition Nurse, based at the Royal Melbourne, to help young people moving from the children's hospital to the adult setting. We also received notification from the Lady Cilento Children's Hospital that from July 2017, the Brisbane EB nurse position will be funded through the standard hospital budget. This is a pleasing development as it means that the hospital has recognised the value of the position, which DEBRA has funded since 2010.

We continue to support EB research in Australia. In 2016/17, 11% of our general expenditure went towards research and professional education (18% of programme expenditure). Our aim is to expand this to 15% in the next 2 years. We're looking at some exciting opportunities to strengthen links with overseas clinical and research groups to broaden the reach of our program and provide more opportunities for collaboration.

We have had some very generous donations from other groups and individuals during the year. Whilst I am not able to name them all in this short report, I want to acknowledge some of our major donors for this year: Brighter Days Foundation, Melbourne Markets Golf Day, Cotton Balls in Adelaide and Melbourne, Tough Tilly Day and the Eliza Braitling Foundation. In particular I want to give special mention to Andrew Byszczak who has undertaken a solo charity run of 3000km, from Adelaide to Brisbane, to raise funds for DEBRA. By 9 September 2017 he had raised over \$160,000 through his outstanding efforts.

On 9 September, we held our inaugural major fundraising event in Sydney, the BravE Butterfly Gala. Whilst the final financial results will not be reported until next year, I would like to acknowledge the hard work of Bianca Ciccio and her team who organised such a magnificent and successful event.

We appreciate everything our supporters do, and every donation large or small. We have taken steps to give better recognition to our donors and you can also find logos for all our corporate sponsors on our website.

Next year, we are aiming to expand our family support programs, for example by developing better psychological services, doing more to assist our young people to achieve their potential as they grapple with the challenges that are part and parcel of growing up, and working with the National Disability Insurance Scheme to optimise outcomes for our EB families.

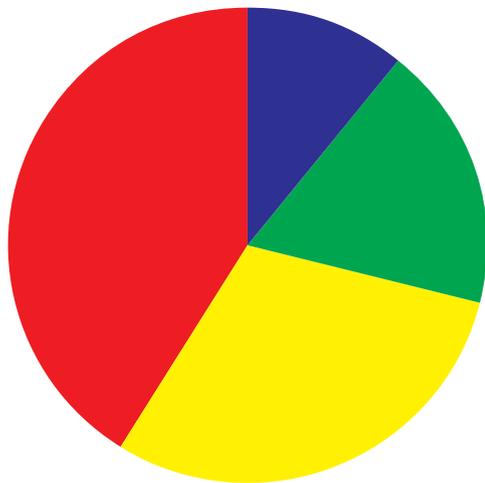
Our Board has worked together very well this year and I would like to thank all my fellow Directors and Committee members for their expertise and input. Our staff and contractors (Joanne Sturgess and Scott Macfarlane) carry a big load in implementing all of the things we want to deliver. On the administrative side Sue McKenna does an excellent job and often goes that "extra mile" in ensuring things are done in an efficient and timely manner.

We couldn't achieve what we do without such a great team and also the generous volunteers and supporters.

Jennifer Marty (Chair, DEBRA Australia)

Major Program Expenditure

2016/17 - \$432K



- Family Support Program - 41%
- Hospital EB Nurse Program - 30%
- Research Program - 18%
- In Home EB Nurse Program - 11%

DEBRA AUSTRALIA KPI FIGURES 2016/2017	RESULT	KPI
Admin costs as % total income (calculated on categories report)	9%	Less than 20 % total revenue
Staff/Contractor FTE	2.1 FTE	
Volunteer hours	2,264 hours	
Memberships	81	
Life Members	11	

EB Services

Hospital Based EB Nurses

During 2016/17 our 3 EB nurses, Samantha Hay in Brisbane, Lauren Weston in Melbourne and Margaret Norris in Sydney continued to do an outstanding job. A part-time nurse is now being funded at The Royal Melbourne Hospital to assist those in the adult setting and transitioning from the children's hospital. Lauren Weston was the successful applicant for this position. From 1 July 2017 the funding of the nurse position in Brisbane will be taken over by Qld Health. This is a pleasing outcome as it recognises the value that the EB nurse role provides in Qld. Margaret Norris has resigned her position as EB nurse at St George effective 1 September 2017. Nursing administration at the hospital is moving to advertise for a replacement as soon as possible. DEBRA has been assured it will be involved in the interview process.

Our lovely nurses have cared for 225 patients with 12 new families (including 6 newborns) in the last year. Average time to first contact from being notified is 19 hours. There have been 21 dedicated EB Clinics held on a national basis with up to 19 multidisciplinary health professionals involved per clinic. Up to 130 outpatient clinics were also held averaging nearly 2 hours per visit. The nurses have been very busy keeping in touch with families via visits, emails (429) and phone calls (399) along with emails to health professionals (1338), phone calls (242) and meetings attended (64).



EB and Dermatology Nurses attending the EB Health Symposium in Melbourne (November 2016) Left to right: Jane Buckley (SA), Sarah Hill (Brightsky NSW), Samantha Hay (QLD), Lauren Weston (VIC), Margaret Norris (NSW), Emma King (VIC), Jacqui Finnigan (NZ), Jane Widdowson (NZ), Sharon Cassidy (NZ), Anna Malden (SA). Absent from the photo Rebecca Saad (NSW).

In Home EB Care

From 1 July 2016 DEBRA took over support of home care outside South Australia and Little Heroes Foundation continued to support 2 children in South Australia. Assistance has been given by the Eliza Braitling Foundation to fund some care in NSW and remainder by FGX. Currently 7 families are receiving in home care coordinated by DEBRA.

EB Dressing Scheme

After representation to the Department of Health a consumer representative has been added to the Clinical Advisory Committee for the dressing scheme. However this group meets very infrequently. DEBRA is continuing to advocate the need for a transparent, defined process for proposing changes to the list of dressings available under the scheme. Progress is being hampered by personnel changes within the Health Department. A review of the scheme is underway and DEBRA is monitoring developments closely.

National Disability Insurance Scheme (NDIS)

DEBRA is now taking a more pro-active approach to assisting families who are starting the NDIS enrolment process. It is important to differentiate between needs due to disability and medical needs. With the assistance of Harry de Jong contact has been made with a senior NDIS administrator and we are hoping to work with them to develop a template for use and assessment of EB patients.

Psychological Support

Work is continuing to develop a psychological support program to suit our EB families. Teenagers/young adults have been identified as the first priority. Some psychologists who may be willing to work with us in Melbourne have been identified and further leads are being followed up for Sydney/Wollongong.

Research and Education

Research Grants

Two awards of \$30,000 each were given for the following projects:

1. Project Title: Characterization and utilization of new mouse models for Dominant Dystrophic Epidermolysis Bullosa (DDEB). Applicant: Dr Ken Pang, Murdoch Children's Research Institute, Melbourne
2. Project Title: Combating blister infection one step at the time. Applicant: Dr Zlatko Kopecki, University of South Australia, Adelaide



Dr Ken Pang



Dr Zlatko Kopecki

Travel Grants

This year the focus for DEBRA's travel grants has been to assist young researchers to present information about their EB research by attending the September 2017 EB Research Conference in Austria and the November 2017 Debra International (DI) Meeting in New Zealand. Blake Smith, a PhD student with Dr Ken Pang, Murdoch Institute Melbourne, will attend the Salzburg meeting. Dr Adam Harris, a Dermatology registrar, is planning to attend the DI meeting in Wellington in November. Seven EB nurses have been offered grants to assist them to attend the DEBRA International meeting.

Health Professional Education

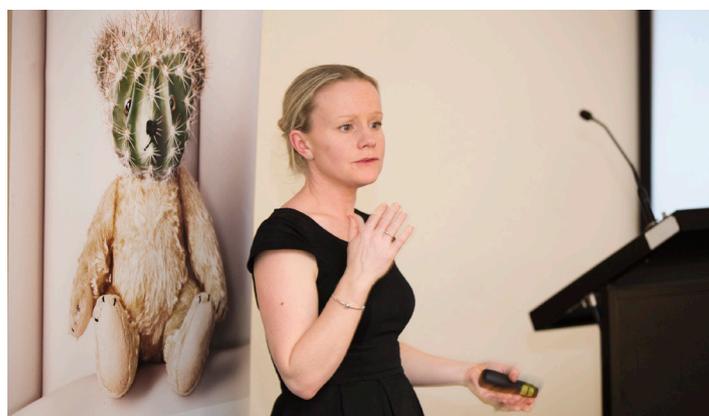
In November 2016 a successful visit was arranged for Dr Jemima Mellerio, from St Thomas' Hospital London, who spoke about Skin Cancer Management Guidelines at a Health Professional symposium, as well as visiting hospitals in Sydney & Melbourne. A family/carer session on skin cancer management was also held in Melbourne and was webcast and recorded for later viewing by those interstate. Nurses also had the opportunity to attend a training session entitled "The Accidental Counsellor" provided by a Lifeline trainer.



Dr Jemima Mellerio speaking in Melbourne



Prof Dedee Murrell and Dr Jemima Mellerio meeting up with Nikki from Sydney



Samantha Hill conducting the Accidental Counsellor course to EB Health Professionals and DEBRA staff

Medical Forum

DEBRA is working with Drs Tom Connell and Lachlan Warren to arrange an inaugural medical forum in November 2017. We hope this will facilitate greater dialogue and sharing of ideas between clinicians interested in EB.

Family Support Program

2016/17 has been a very productive and busy year 214 applications being funded for a huge range of requests from medical supplies, in home nursing, aids and equipment amongst other things, outlaying nearly \$113,000 in grant applications.

There were 18 new families in the 2016/17 year ranging from adults, children and new babies. Simone the Family Support Coordinator has attended over 50 meetings with our EB families and attended 13 EB clinics in the various states. Besides that there are hundreds of email and phone conversations liaising with families and various organisations arranging for our clients support. Simone has also attended various fundraising events, promoting DEBRA Australia and raising awareness.

The Eliza Braitling Foundation continue to help with funding essential requests to meet medical requirements. Cockrams Building Constructions have also generously donated their skills and labour to create a backyard made over for a family with a young child. They have also provided home improvements for another family to improve their home care and quality of life.

An annual Mum's Respite Weekend away for 10 mothers of very severe children and adults living with EB was again organised to provide much needed time out and networking opportunities. The Mum's were all surveyed after the weekend away at Byron Bay with 100% finding the experience very positive. One comment included:

"The strength, warmth and solitude that we get off each other as EB Mums is so vital and nurturing. The benefits of being able to bond and relate to other Mums that are going through and totally understand your feelings of what you are experiencing is so important and so needed. It is important that we do not feel left out and know that there are other people who are dealing with the same issues you are is actually very assuring. We can talk and vent without being judged and the bond we have all formed is amazing and we all know we are there for one another which is one of the most important things that came out of this weekend".

In August last year 7 adolescents living with severe EB and their dedicated carers were funded to attend an EB Camp in New Zealand to promote independence and provide networking opportunities. Everyone enjoyed the experience enormously and a big thankyou to DEBRA New Zealand for inviting families from Australia.

An EB Camp will be held the end of August 2018 in Sydney and further details will be circulated in the New Year via the newsletter. We encourage families to attend as it is a wonderful opportunity to meet other families, network and learn the latest in EB care. The children's activities will be loads of fun and they will be looked after by dedicated nurses and volunteers.



EB Nurse Lauren with Eliza and Jess at the Meet And Greet in Melbourne at the Botanical Gardens



Simone Baird Family Support Coordinator (second from left) and Andrew Biszczak (fourth from left) visiting the Adelaide EB Clinic and families

Follow Your Dreams Grant

The 2016/17 FYD grant contributed towards a NSW applicant purchasing his first car (second hand) which he learned to drive and he has now got his licence. Connor was very happy to receive the grant and the car which provided him with more independence and learning a new set of skills.



Kate Turner Fund

Two early requests for funding were received by our sub-committee this year, resulting in \$1,500 being approved to Connor (NSW) as part payment for his car and Alessio (WA) for a new gaming station. Team Kids Adelaide was supported which in turn will benefit EB patients Australia-wide.

Marketing and Fundraising

Welcome to Bianca Ciccia who is our dedicated Marketing and Fundraising Manager. Bianca has hit the ground running to launch new event campaigns as well as support third party fundraisers. Ongoing support and funds received from Melbourne Golf Day, Tough Tilly Day, Cotton Balls (in both Melbourne and Adelaide) and FGX have again made this year a successful one making a huge difference to our programs.



Brighter Days



Melbourne Golf Day



Cotton Ball Adelaide

This year we have again had a successful number of fun runs across the country, however one event that stood out this year is a third party fundraiser by Andrew Biszczak who ran 3,000kms raising awareness and funds for DEBRA Australia. We were happy to support Andrew on his mission to ensure maximum exposure and to organise a finale event involving local families and his running buddy John from Adelaide. The run was a great success raising over \$160K for DEBRA Australia.



Andrew with DEBRA members, family and runners at the Southbank Park Run



Run For EB Runners

The Most of this year we were busy planning and executing ideas for our inaugural Brave Butterfly Gala which took place in September 2017 and was a fantastic event.

Don't forget to check out our website debra.org.au for all the upcoming events such as Run For EB, Dine & Donate and awareness efforts during the International EB Awareness Week in October.

DEBRA Australia Ambassadors



Matt Bevilaqua



Josh Aloiai



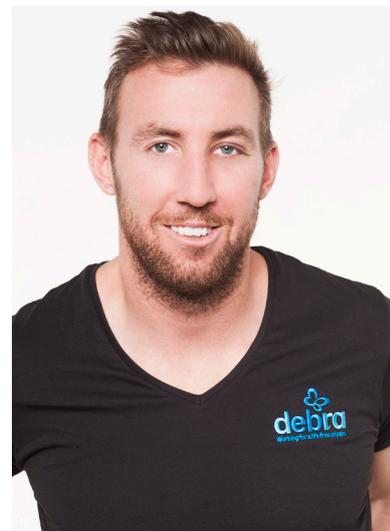
Kate Moloney



Kevin Naiqama



John Platten



Brock McLean

DEBRA International

DEBRA Australia has been well represented within DEBRA International with our representative Dr Zlatko Kopecki attending the 2016 DEBRA International Conference in Zagreb, Croatia and joining the DEBRA International Executive Committee. This has resulted in direct input on the future of how DEBRA International runs its programs and Zlatko's involvement with EB without borders program as well as one of the conveyers of the DEBRA International Conference in New Zealand which will take place in November 2017. Zlatko has been directly involved in the conference program and abstract selection ensuring the Australian researchers and clinicians are well represented. We are all looking forward to the event which will be attended by our EB nurses, DEBRA Australia Board Directors and some family members.

It is vital that DEBRA Australia maintains this level of contact with the International community as it allows us to access ideas, support and networks that benefit our national group, health professionals and most importantly our EB families. In turn other groups benefit from the contact with DEBRA Australia. Our Chair Dr Jennifer Marty is now also part of the DEBRA International governance committee, helping to streamline and shape future DEBRA International programs, as well as being involved with the research committee of DEBRA International to help our Australian researchers better integrate with laboratories overseas. Dr Jennifer Marty attended the DEBRA International Research Conference in Salzburg in September 2017 representing DEBRA Australia.



Left to right: Ritu Jain (Singapore), Brett Kopelan (USA)- Vice Treasurer, Zlatko Kopecki (Aus), Cinzia Pilo (Italy), Avril Kennan (Ireland)-Vice Secretary, Mike Jaega (UK)-President, Loreto Moore (Chile)-Vice President, Mia Werkentoft (Sweden)-Secretary, Judith Kristin Asche (Norway), Shoaib Gopalani (Canada)-Treasurer, Anna Kemble-Welch (NZ).



New DEBRA International Business Manager Olivia Mullins

DEBRA Australia 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 view our audited financial statements for DEBRA Australia [here](#) and for DEBRA Australia Ltd. [here](#).