



ANNUAL REPORT

FINANCIAL YEAR 2017 - 2018



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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.

AIMS AND OBJECTIVES

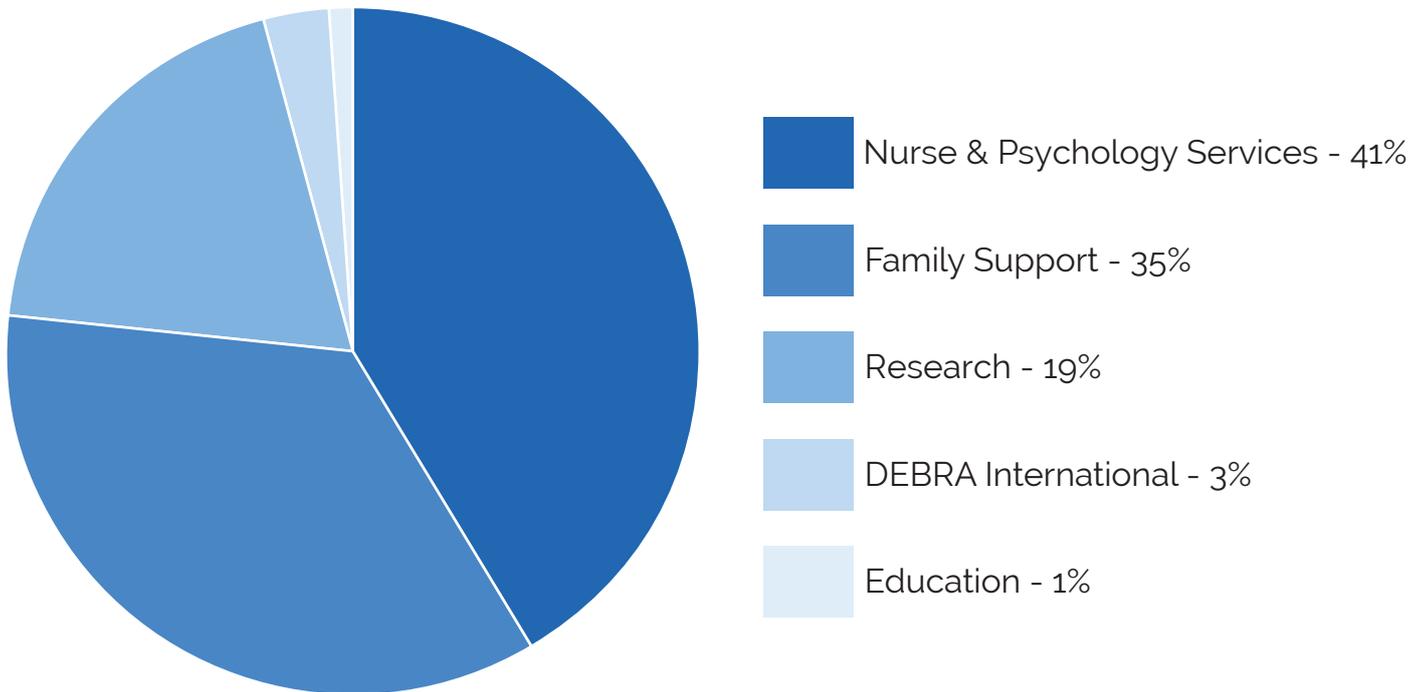
Primary Objectives of the Organisation (all of equal importance)

- 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.
- DEBRA's 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.

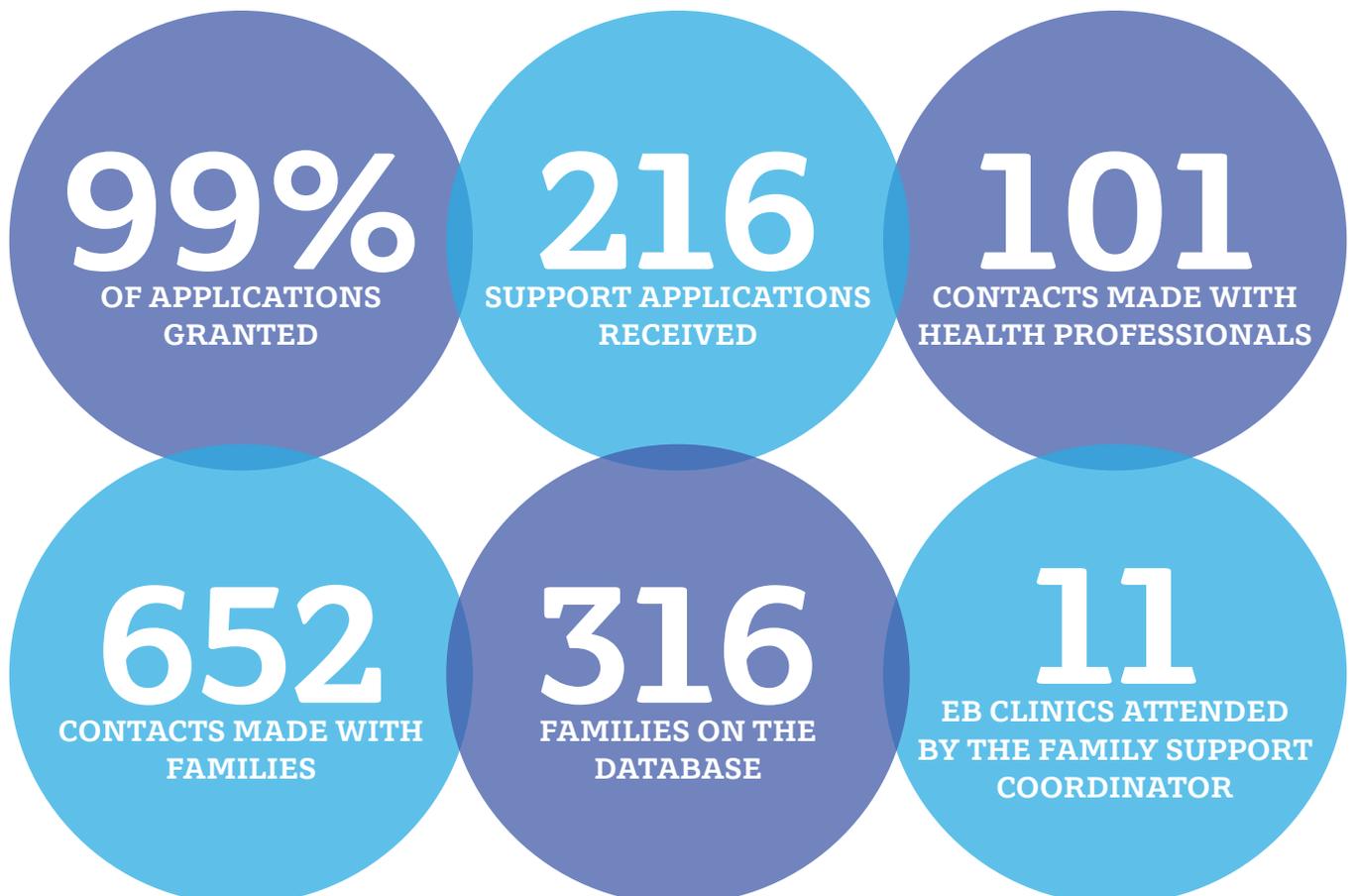
VALUES

1. **Focused:** DEBRA is an individual and family-focused, EB service organisation
2. **Compassionate:** DEBRA supports EB families with compassion, respect and empathy
3. **Ethical:** DEBRA is a professional, responsible, honest and ethical organisation
4. **Accountable:** DEBRA is accountable to its members and to the wider community
5. **Collaborative:** DEBRA builds partnerships and networks to collaborate with stakeholders and the wider community
6. **Impactful:** DEBRA seeks to achieve positive impacts on behalf of the EB community

PROGRAM EXPENDITURE 2017/18

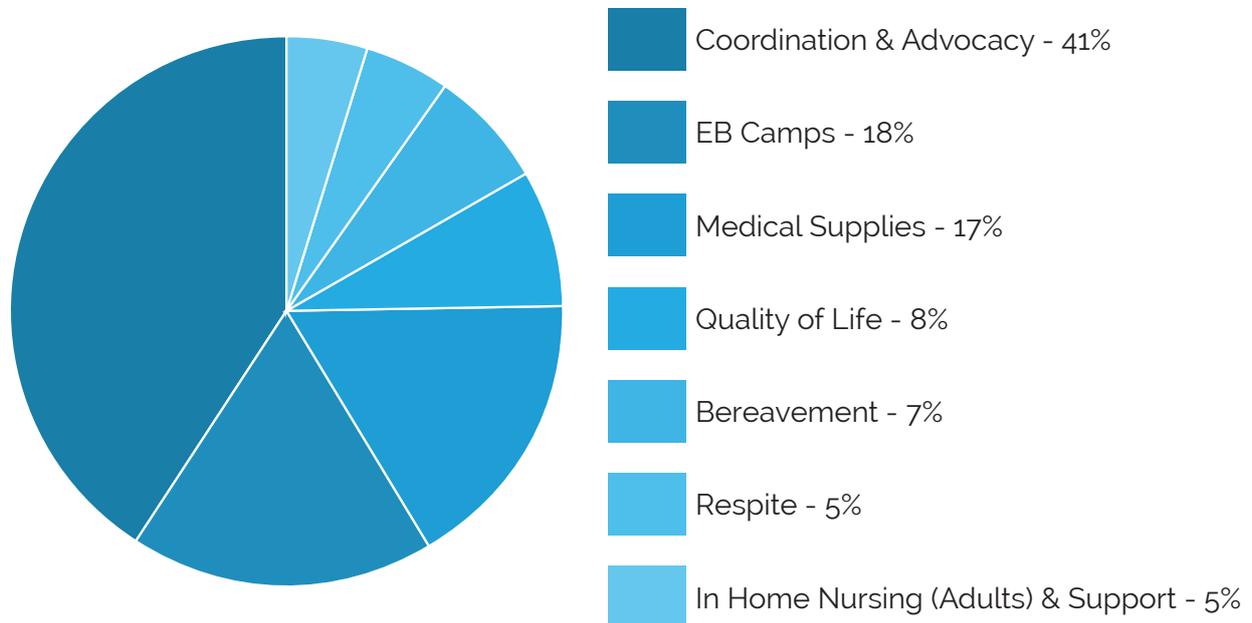


TOGETHER THIS IS THE **IMPACT** WE MADE TO LIVES OF EB FAMILIES VIA THE FAMILY SUPPORT PROGRAM



PROGRAM EXPENDITURE 2017/18

2017/18 TOTAL FAMILY SUPPORT PROGRAM EXPENDITURE - \$170,000



8 COMMITTEES AND SUBCOMMITTEES WORKING ON PROGRAMS AND PROJECTS DURING THE YEAR INVOLVING OVER 2,000 VOLUNTEER HOURS

FAMILY SUPPORT AND EB SERVICES

- \$170,000 spent on direct family support
- Mum's respite weekend attended by 10 mums of EB children in Byron Bay with very positive responses
- Specialised EB Nurses funded in 4 children and adult hospitals in QLD, NSW and VIC as well as educational support provided to a Critical Complex Care nurse in SA who looks after EB children.
- 2122 contacts made by EB Nurses to families and health professionals
- \$64,5000 - cost of nursing hours to help some families at home with dressing changes
- 16 new families welcomed into EB support programs
- Planning completed for next National Family Conference which is being held in August 2018

EB RESEARCH

- \$54,000 dollars invested into research grants
- International collaboration with EB Haus Australia established
- DEBRA Australia Inaugural Clinical Forum was held and attended by 15 guests.

AWARENESS

- Social media reach by 259,142
- Our ambassadors have been busy attending various events around Australia to create much needed awareness. Matt Bevilacqua, John Platten, Kate Moloney and Brock McLean have been long-time supporters and are now joined by new ambassadors Kevin Naiqama and Josh Aloiai who are NRL football players in Sydney.

A MESSAGE FROM THE CHAIR

I am delighted to report that DEBRA has made some great progress with its programs in 2017/18, enabled by excellent financial results over the past two years which have helped set us up for the future. Overall, we spent over \$300,000 this year on direct support, including family support grants, nursing programs, preparations for our 6th family conference, and employing our dedicated and caring Family Support Coordinator, Simone Baird. Simone's key activities this year included some new ventures - setting up pilots for our Psychology Support program in Sydney and Melbourne and working with the National Disability Insurance Authority to optimise outcomes for our EB families.

Our EB nurses, continue to provide an excellent service and we are continually looking at ways we can improve things for the future. Our first Transition Nurse, Lauren Weston, is helping smooth the way for those moving from the children's hospital to the adult setting in Melbourne. She has just completed her first year in this role and we have had some great feedback about how valuable it has been.

- "As a patient I rely very heavily on Lauren's assistance and without it I believe that I would get lost in the system".
- "I look back and I think to myself how did I ever manage without Lauren?"
- "I was able to contact Lauren when I had something going wrong.....and with her help navigating the hospital system my admission was organised.... This was a dream.....she told me where to go, the ward was expecting me when I arrived.... and she was my point of contact between myself and all the medical staffso that everyone was always on the same page."

I think these quotes speak for themselves and illustrate what a significant difference this position has made. In the coming year we will be looking into the feasibility of setting up a similar one in Brisbane. The EB nurse program is funded by a grant 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. We are very grateful to FGX for their generous support which amounted to over \$198,000 this year.

DEBRA Australia continues to support EB research and we're pleased that in the past year over 12% of our general expenditure went towards research and professional education (or 23% of program expenditure). We supported members of our EB community to attend the DEBRA International worldwide meeting in New Zealand last November which included 5 nurses, 6 patients (and carers if required), 5 directors and a staff member. We're also encouraging activities to strengthen links between Australian and overseas research groups to facilitate Australian access to the latest developments and provide more opportunities for collaboration. For example, as well as our usual grants, this year we have jointly funded a new project with EB Haus, Austria and the Ingham Research Institute in Sydney related to the early detection of skin cancer in EB.

Last November we hosted our first forum of Australian clinicians to discuss some of the challenges of managing EB and in June 2018 we arranged a special lecture and roundtable discussion with Professor Michele de Luca from Modena University,

Italy, who spoke about the work of his team combining cell and gene therapy to successfully treat a young boy suffering from aggressive junctional EB. We will continue to monitor developments in the gene therapy area with a view to finding ways to access these novel treatments as more data comes to hand.

With the hard work of our Fundraising Manager, Bianca Ciccia, and the Marketing and Fundraising Committee we have broadened our fundraising approach and benefited enormously from initiatives such as the BravE Butterfly Gala and the PB4EB campaign. Our operating profit has increased over the previous year thanks to our new activities and some very generous donations and we're now much closer to achieving our key strategic objective of being financially sustainable. Whilst I'm not able to name them all in this short report, I want to acknowledge some of our major donors: Brighter Days Foundation, Melbourne Markets Golf Day, Britex Carpetcare, the Eliza Braitling Foundation and Vanessa Jones, as well as our ambassadors who have willingly represented DEBRA at several events. We appreciate everything our corporate sponsors and supporters do, and every donation large or small.

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 assures you of our ongoing care and concern. We remember in particular two special young ladies, Eliza Baird and Stevie Hislop, who taught us a lot about being resilient and getting the most out of life, even when it deals you a tough hand.

Our Board continues to work together very well, with each member using their skills and experience for the benefit of DEBRA. Sincere thanks to all our Directors and Committee members, particularly David Hanvey, who has stepped down this year as a family representative on the Board. His marketing and business input, as well as his personal insights through living with EB, have been extremely valuable.

Our staff and contractors carry a big load in implementing all the things we want to deliver. On the administrative side Sue McKenna does an excellent job and often goes that "extra mile" to get things done. Her efforts certainly paid off with our wonderful conference at the end of August in Sydney.

Finally, we couldn't achieve what we do without such a great team of staff and volunteers and I would like to finish by thanking them all on your behalf.

Jennifer Marty
(Chair, DEBRA Australia)

EB SERVICES

HOSPITAL BASED EB NURSES

DEBRA has funded nurse positions this year at three hospitals, St George Sydney, Royal Children's Hospital Melbourne and a new position at The Royal Melbourne Hospital. In its first year, the number of adults attending the clinic at Royal Melbourne rose from 9 to 23, indicating the need for this new initiative. From 1 July 2017 the funding of the paediatric nurse position in Brisbane was taken over by QLD Health. We have decided to evaluate the need for an adult nurse in Brisbane in the coming year. Margaret Norris resigned her position as EB nurse at St George from September 2017, and was replaced by Andrea Matisan in March 2018. We thank Margaret for all her efforts. In addition, we have facilitated educational opportunities for all the Australian EB nurses, including those whose positions are not directly funded by DEBRA. We wish to thank all the nurses who have made a difference for our families in the past year.



EB Nurse Lauren Weston from Melbourne Royal Children's Hospital with patient Zoe

IN HOME EB CARE

During the year DEBRA has coordinated home care for 7 families. On average we have funded 38 hours of home care each week. Assistance has been given by the Eliza Baitling Foundation to fund some of this care in NSW and the Little Heroes Foundation directly funds care for 2 additional families in South Australia.

EB DRESSING SCHEME

As of 1 July 2018, following a Department Health tender process, administration of the EB Dressing Scheme has transitioned from Bright Sky to Independence Australia. DEBRA is liaising closely with Independence Australia to ensure a high quality service is delivered. We are continuing to advocate the need for a transparent, defined process for proposing changes to the list of dressings available under the scheme. This matter will be discussed further with the Health Department now that the transition has occurred.

NATIONAL DISABILITY INSURANCE SCHEME (NDIS)

DEBRA is now taking a more pro-active approach to assisting families who are starting the NDIS enrolment process. Introductory information has been provided to families and posted on our website. It is important to differentiate between needs due to disability and medical needs. With the assistance of Harry de Jong, an EB briefing template outlining disability needs of people with different types of EB at different ages was provided to a senior NDIA administrator for reference by their assessors.

DEBRA has also requested to be utilised as a point of reference for the NDIA on matters related to the disability impacts of EB. We now have a strong line of communication which will be beneficial in helping to resolve contentious cases. We also recently wrote to the NDIA suggesting some modifications to the current definitions used in the NDIS Operating Guidelines to describe Epidermolysis Bullosa (EB) in its most severe forms to bring the terminology up to date.

PSYCHOLOGICAL SUPPORT

A pilot Psychological Support program designed to suit our EB families has now been established in Melbourne and Sydney, involving a small number of psychologists with experience in dealing with individuals with chronic diseases. Background training about EB and its challenges has been provided and the program introduced to families. The service has begun with 2 families, one in each state. A couple of others who have expressed interest may start in the next few months.

RESEARCH & EDUCATION

RESEARCH GRANTS

The following grants were awarded for 2018:

- Dr Zlatko Kopecki (University SA): "Development of simple, effective and pain-free diagnostic tool for patients with mild EB" (\$30,000);
- Dr Ken Pang (Murdoch Children's Research institute) "Development of animal models for Epidermolysis Bullosa-related pain" (\$20,000).

In addition it was decided to encourage more collaboration between Australia and international researchers to broaden the EB research base supported by Australia. To start this off, a sum of \$35,000 was set aside to fund an international collaboration between EB Haus in Austria and the Ingham Institute in Sydney for an EB skin cancer project. A PhD student from Austria has spent approximately 6 weeks working with Professor Albert Mellick at the Ingham Institute and will be returning to Austria to continue the next phase of the work. Further collaborative activities are being planned.



Dr Zlatko Kopecki

Dr Ken Pang

TRAVEL GRANTS

Seven Australian EB nurses were offered grants to assist them to attend the DI meeting in Wellington in November 2017. Blake Smith, a PhD student with Dr Ken Pang, Murdoch Institute Melbourne, presented a poster on his work at the Salzburg EB Research Meeting in September 2017 and Dr Adam Harris, a Dermatology registrar, presented the results of his work about surgery in EB patients at the DI meeting in Wellington.

In the 2018 grant round, Emma King, Dermatology Nurse Practitioner from the Royal Children's Hospital was awarded a grant to attend the Health Professionals EB Symposium Sydney (31/8/18) and medical student Brendon Lee was awarded \$3,000 to attend an international conference to present the research he has been doing about ocular complications of EB in conjunction with Professor Dedee Murrell and Professor Minas Coroneo.

MEDICAL FORUM

DEBRA's inaugural medical forum was held in November 2017 at the Royal Children's Hospital, Melbourne. Drs Tom Connell and Lachlan Warren assisted in developing the program and identifying potential invitees. This first meeting was attended by 10 clinicians and two nurses. There was considerable discussion of various challenging clinical topics. All agreed that it was a useful forum to facilitate greater dialogue and sharing of ideas between clinicians interested in EB and further meetings will be planned for the future.

GENE THERAPY DISCUSSIONS

Prof Michele De Luca, University of Modena, Italy, presented a public lecture about his ground-breaking gene therapy work in EB in Melbourne on 24 June 2018, attended by over 20 participants. After the lecture 15 invited guests participated in a round table discussion about how DEBRA Australia can facilitate bringing this type of therapy to patients in Australia.

This is viewed as a long range project, with various pieces of information and technologies needed to facilitate the implementation. Further discussions will take place in September 2018 when another gene therapy researcher, Professor Peter Marinkovich, from Stanford University, USA, visits Australia to speak at our 2018 EB conference. Following that DEBRA will consider how best to move forward.

AUSTRALASIAN COLLEGE OF DERMATOLOGISTS (ACD)

Sue McKenna, Dean and Jenny Clifford attended the ACD annual meeting in Qld in May 2018. As well as having a display table and answering questions about DEBRA and EB, Sue and Dean attended a round table discussion for support groups to give input on DEBRA's behalf.



Dean and Jenny Clifford at the ACD Conference 2018

FAMILY SUPPORT PROGRAM

The Family Support program received 216 applications during the 2017/18 financial year for various EB related items. Our Family Support Coordinator Simone Baird has been very busy attending 85 meetings resulting in positive outcomes for individuals living with EB. Simone also connects with families via hundreds of emails and phone calls through-out the year.

Part of her role also includes attending EB clinics in various states and worked closely with the EB multidisciplinary team to best support the EB community. Simone has also engaged with 16 new EB families from various states during this time.



Stevie with her new lap top funded by DEBRA to help promote independence and improve quality of life



Simone Baird (DEBRA Family Support Coordinator back row) with Lauren (EB Nurse), daughter Eliza, and EB Mum Jess at a family networking picnic in Melbourne

Families across Australia have also been supported as they have moved onto the National Disability Insurance Scheme (NDIS) and Simone continues to work closely with the National Disability Insurance Agency (NDIA).

Another successful Mum's Respite weekend was held in June 2017 in Qld with 9 mums of EB patients attending to have much needed respite so they could have time out whilst connecting with each other.



Nikki (who receives dressings funded by DEBRA not available on the EB Dressing Scheme) with her bunny Dusty

EB SUPPORT GRANTS

KATE TURNER FUND

The Kate Turner Fund has allocated three grants in the 2017/18 period which included:

- \$1,500 contributed to purchase a motorised scooter for an EB patient in Adelaide to improve their mobility
- Special mittens from the UK purchased for new babies born around Australia
- \$3,000 was contributed in conjunction with a Follow Your Dreams wish for a family to go to Darwin.



Tara on her new mobility scooter

In Tara's words: "I've named her Silver by the way — that means freedom to me! I can get out the house, every single day if I want, and I don't have to worry about hurting my feet. I don't have a car so the scooter is how I run errands and do my shopping. But it's so much more than a practical object, it's become a part of my identity too, it's how I connect with nature and community. Without it I'd be shut-in. Nothing makes me happier than getting out in the sunshine and fresh air to see what's happening in the neighbourhood and see who's about, smell the flowers in bloom and the freshly cut grass, and smile at every stranger I see—heaven. I've spent precious years seeing doctors and specialists and being on wait lists and filling in forms and gathering documents and speaking with legal aids and psychologists and politicians—exhausting! All done to try and access support and then I found DEBRA. It was a surprise, after all that, to receive such fast, generous and compassionate assistance from you all. Thank you so much."

FOLLOW YOUR DREAMS GRANT

After much planning, the correct season to go and some additional funding, the 2017 successful grant recipient John from South Australia was able to follow his dreams and see all things crocodile in Darwin in 2018. Funds were topped up by the Kate Turner Fund and DEBRA's Family Support program. John and his parents had a wonderful trip which lived up to all expectations. He even got to drive one of the tour boats and feed the crocodiles!



John learning all things crocodile on his Darwin trip

MARKETING & AWARENESS

The Marketing and Fundraising Committee has had another busy and successful year reaching the fundraising target for two years in a row. With a great team in place the inaugural Brave Butterfly Ball was held in Sydney raising much needed funds. More ambassadors have also come on board to help out with campaigns. Increased social media presence and campaigns has also created more awareness for DEBRA.

We are also very grateful to our third party and partnership events like the Brighter Days Festival, Melbourne Markets Golf Day and The Million Dollar Run for all their support. We are also very grateful to the Future Generations Fund (FGX) and Wilson Asset Management for their ongoing support in funding several EB Services.



Andrew Byszczak, John (South Australia) and Dean (Queensland) at the end of the Million Dollar Run event in Brisbane



DEBRA team at The Million Dollar Run end event



Stevie and her partner Dean attending the Brave Butterfly Ball

Once again we had a successful campaign with marathon events across the country as well as our new PB4EB event which was an amazing success. We are also working hard on a DEBRA Golf Event which will take place in Sydney in October and we are sure it will be a great event. We have also engaged in more PR opportunities with a significant amount of work and effort going into raising the profile of EB in the community. Having a stronger media presence for our events has translated into increased funding outcomes. Lastly, we have made a strong effort to significantly grow our regular giving donors and have had great success.

MARKETING & AWARENESS



Brighter Days cheque presentation 2018



John Platten and team players at the Melbourne Markets Golf Day 2018



Melbourne Markets Golf Day cheque presentation 2018



Ambassadors Josh and Kevin with Linda and Lisa in Sydney

More information is available via debra.org.au for all the upcoming events.

Our DEBRA Ambassadors continue to help spread the word about DEBRA and EB and we thank them for their time and dedication.



Matt Bevilacqua DEBRA ambassador and Louise Walsh from FGX

DEBRA INTERNATIONAL

DEBRA Australia has been well represented within DEBRA International and we have made a significant contribution in helping DEBRA NZ organise the 2017 DEBRA International Congress.

Dr Zlatko Kopecki, DEBRA International Representative from Australia was a part of the organising committee who volunteered to help make the event such a success. 17 families, health professionals, board members and a staff member were supported to attend the congress to network and provide an educational opportunity. It was a good experience for everyone to have an understanding of the challenges of some DEBRA countries in the Asia-Pacific region and how lucky we are with the support we can offer in Australia.

Dr Zlatko Kopecki continues to serve as the Australian representative on the DEBRA International Executive Committee and has contributed significantly to the EB Without Borders program and Small Grant committee of DEBRA International. This year our Chair Dr Jenny Marty joined the governance committee of DEBRA International.

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. For more info please keep an eye out on our website as well as the DEBRA International website for future updates.

DEBRA AUSTRALIA BOARD AND COMMITTEES MEMBERS

DIRECTORS	STAFF/ CONTRACTORS	COMMITTEE MEMBERS	SUB COMMITTEE MEMBERS
Dr Jennifer Marty <i>(Chair)</i> Mary Woods <i>(Deputy Chair)</i> Rodney Sheaves <i>(Deputy Chair)</i> David Hanvey Belinda James Dr Zlatko Kopecki Melinda Oxford	Simone Baird Bianca Ciccia Sue McKenna Scott Macfarlane Joanne Sturgess	Tom Connell Judith Davis Michael Fitzpatrick Laraine Frost Kylie Gibson Francis Harper Tina Segulin	Linda Turner Michelle Pickles Roger Trevor Shay Zulpo

FINANCIAL OVERVIEW

A strong end of year financial result was reported, with an increase in operating profit, to \$251,653.

Expenses have been well controlled and administration expenses are only 11% of the overall income.

The annual financials for 2017/18 were audited by Hooper Accountants. The audited reports are available for your information via the following link debra.org.au/about-us/annual-reports

MAJOR SUPPORTERS

WE THANK OUR MAJOR SUPPORTERS IN 2017/2018



Budburst

