

ANNUAL

Impact Report



Financial Year 2018-2019

SUPPORTERS



MAJOR SUPPORTERS

Swim for Skin
Todd Family
WA Billboards
Jean Thyne Hedges
Wnpei Dwng
Fredrick Gordon P/L
Cheryl Sheard

MEDIA PARTNERS

Ruby Agency

VISION

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, whilst 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 & OBJECTIVE

- » DEBRA aims to improve the lives of children and adults living with EB by providing necessary support services, home aids and information to individuals and their families.
- » DEBRA aims to deliver programs to support and educate families living with EB, health professionals, communities and the general public.
- » DEBRA strives to ensure that all EB families across Australia have access to specialised EB care services within hospitals and the community.
- » DEBRA will support and facilitate opportunities for EB research with the aim of finding approaches to curing and developing symptomatic therapies for EB.
- » DEBRA Australia contributes to and supports the activities of DEBRA International.
- » DEBRA aims to establish positive and sustainable partnerships to support our mission.

VALUES

Focused

DEBRA is an individual and family-focused, EB service organisation

Compassionate

DEBRA supports EB families with compassion, respect and empathy

Ethical

DEBRA is a professional, responsible, honest and ethical organisation

Accountable

DEBRA is accountable to its members and to the wider community

Collaborative

DEBRA builds partnerships and networks to collaborate with stakeholders and the wider community

Impactful

DEBRA seeks to achieve positive impacts on behalf of the EB community.

HIGHLIGHTS

AUGUST:

Inaugural Tee off For EB

SEPTEMBER:

Family Camp / Gene Therapy Round Table discussion / EB Health Professionals Symposium

DECEMBER:

Light Up the Tree

FEBRUARY:

Rare Disease Day

MAY:

PB4EB Community fundraising campaign / Replacement EB Nurse at St George Hospital Sydney

MARCH:

Third Party Fundraising events
Brighter Days, Melbourne Market
Golf Day

JUL

AUG

SEPT

OCT

NOV

DEC

JAN

FEB

MAR

APR

MAY

JUNE

JULY:

Run4EB Campaign with major running events across the country over several months / Mum's Respite Weekend / Pilot Psychology Counselling Program commenced

OCTOBER:

Inaugural Walk for Wings Melbourne and Adelaide + Fight EB Campaign / International EB Awareness Week / Partnership Event - Show Us Your Bogan

JANUARY:

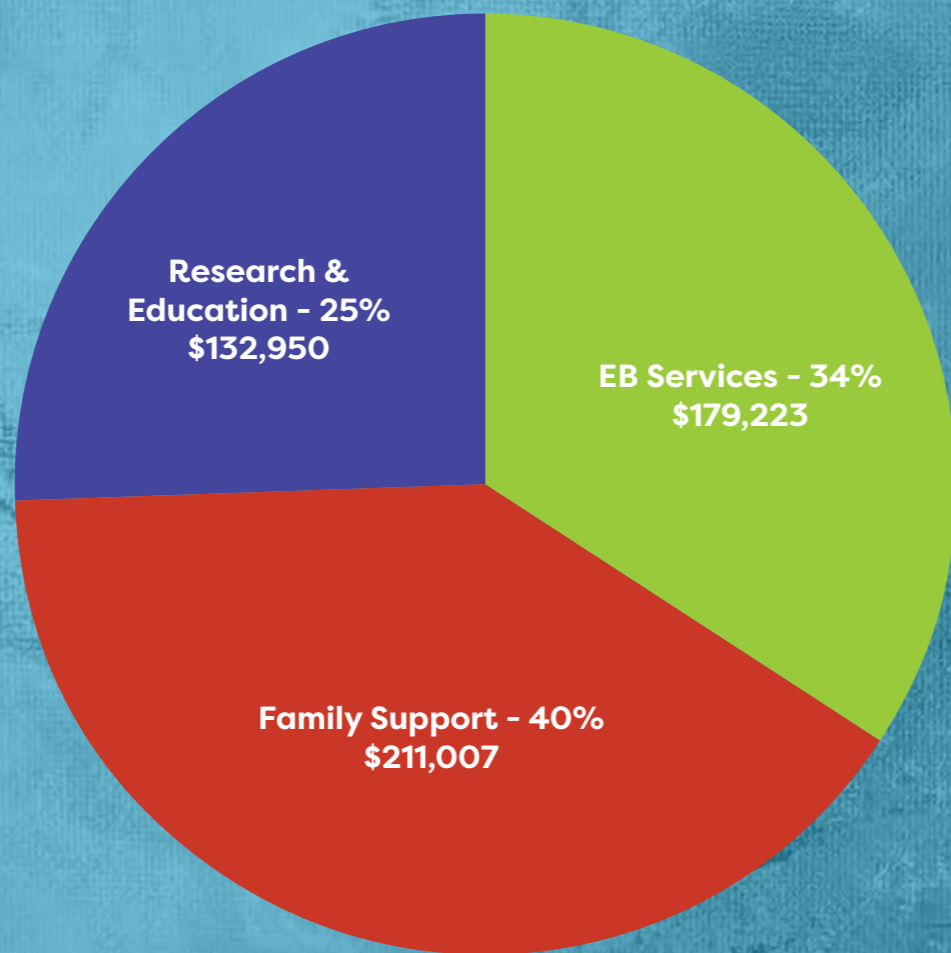
DEBRA International Conference

APRIL:

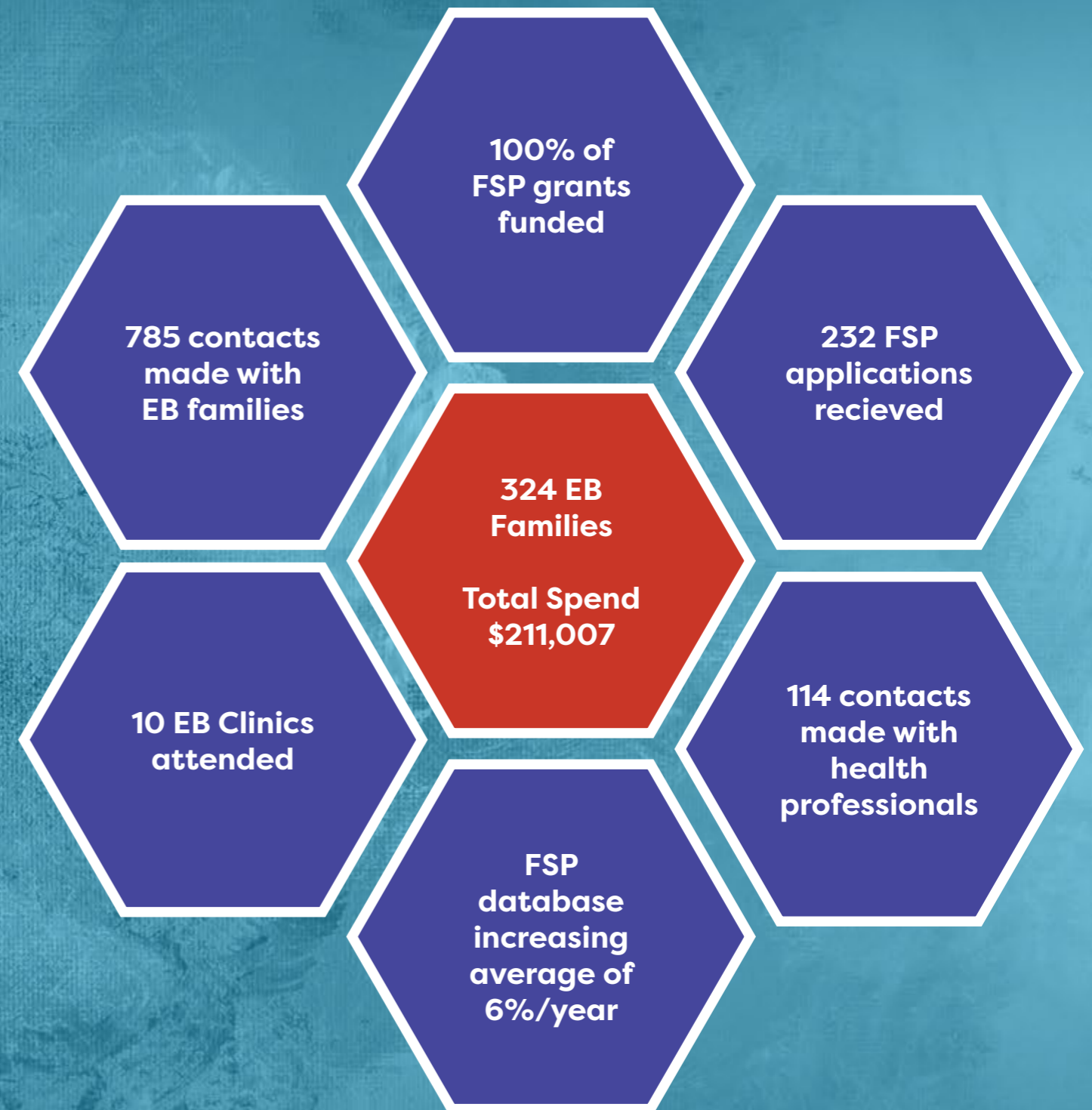
Appointment of new General Manager in Sydney

PROGRAM EXPENDITURE

**TOTAL PROGRAM SPEND:
\$523,181**



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



**IN 2018/19 THERE WERE 8 COMMITTEES WORKING ON PROGRAMS
AND PROJECTS DURING THE YEAR INVOLVING OVER 2,360
VOLUNTEER HOURS.**

PROGRAM EXPENDITURE

EB RESEARCH TOTAL SPEND \$139,250

- 3 EB Grants awarded totalling \$80,000
-
- 3 travel grants awarded totalling \$6,000
-
- \$35,000 grant awarded to DEBRA International research project in collaboration with an Australian researcher (\$10,000 funded in 2017/18 and \$25,000 in 2018/19)
-
- EB Symposium held in Sydney attended by 46 health professionals
-
- 18% of annual expenditure was allocated to the Research & Education Program (includes subscription and attendance at the DEBRA International conference)

MARKETING & AWARENESS

- Grant application success rate 60%
-
- Website sessions (users) 17,439
-
- Website page views 29,863
-
- Facebook organic reach 277,470

EB SERVICES TOTAL SPEND \$179,223

HOSPITAL EB NURSES

- 3 part time EB Nurses
-
- Qld Paediatric Nurse funded by government (June 2019) after DEBRA funded for 7 years
-
- 23 EB Clinics held
58 Outpatient visits
740 Family contacts made
-
- Ave time to first contact to family when baby is born with EB from being notified - 16 hours

IN HOME EB NURSES

- 6 families supported by in home EB Nurse services
-
- Families supported to transition onto the NDIS

PSYCHOLOGY PROGRAM

- Pilot Program commenced VIC
-
- Program extended to NSW

CHAIR'S REPORT

DEBRA Australia has had a solid year in 2018/19, and made some important structural moves to set us up for the future.

We began the year on a high note with our 6th family conference in Sydney attended by over 180 EB families, health professionals and researchers. Feedback from participants was very positive - they appreciated a good combination of social networking and learning opportunities, as well as an engaging and enjoyable Kids Program. Sincere thanks to all who contributed to this successful event. Our international guest speaker, Dr Peter Marinkovich, from Stanford University, USA, provided some insights into progress with trials of various protein correction (gene therapy) approaches for different types of EB. We hope that some more encouraging results will be presented at the forthcoming EB World Congress in London in January 2020.

The board took a significant decision late last year to commence recruitment for the new role of General Manager, with a view to taking DEBRA Australia to the next level in its evolution. The responsibilities of the General Manager include working with the Board to develop DEBRA's strategic direction, overseeing the delivery of all programs, managing our staff, raising awareness about DEBRA and strengthening our fundraising activities. Lise Angus was appointed to this position in April 2019 and is now getting involved in several new activities after completing her orientation period. Welcome Lise, we hope you will have many rewarding and enjoyable years with DEBRA.

Although our fundraising fell behind a little this year, leading to a modest deficit of about \$63,000, expenses were well contained and our financial position remains strong, with significant reserves. Nevertheless, the Board has recognised that we need to strengthen our income streams to ensure the future sustainability of our programs. Our Fundraising Manager, Bianca Ciccio, coordinated a successful golf day in Sydney, a new activity

for us, and continues to build relationships with new and existing donors. We appreciate all that our supporters do, and every donation large or small. Bianca and Lise are currently developing an updated fundraising strategy to guide future activities.

Our 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 and their shareholders for their generous support which amounted to over \$206,000 this year. Whilst I'm not able to mention all our major donors in this short review, I particularly would like to acknowledge the following for their fabulous ongoing support: the Brighter Days Foundation, Melbourne Markets Golf Day, & the Eliza Braitling Foundation; I would also like to give a special mention to Lisa Brains and her team who had lots of fun and successfully raised over \$11,000 at their Bogan Bash in Victoria last October. We also have some great ambassadors who have willingly represented DEBRA at several events, engaging with corporate supporters and the general community.

You can read all about the assistance that DEBRA has given our EB individuals and families in the reports you've received from each of our committees, so I will not go into a lot of detail here. Overall, we invested over \$390,000 this year (approximately 52% of our expenditure) in various support activities, including our family assistance grants, nursing programs, family conference, and staff support, especially from our dedicated and caring Family Support Coordinator, Simone Baird and our capable and well organised administrator, Sue McKenna who took the lead in coordinating the family conference.

Our Psychology program in Sydney and Melbourne is growing and its impact will be evaluated later this year. Our understanding of the NDIS has developed and improved, leading to some good outcomes for clients in recent months. Our EB nurses continue to provide an excellent service

and we have begun negotiating the setup of an EB Transition Nurse role in Brisbane.

We were also proud that Simone Baird was able to go on an EB Without Borders mission to Vietnam last year in November. This is a core initiative of DEBRA International to help patients, families and doctors in countries where there is no supporting DEBRA structure.

DEBRA Australia continues to encourage EB research and we're pleased that in the past year almost 16% of our expenditure went towards research and professional education. Our role in research funding has been recognised in a recently released international report on EB Research which we will make available to you shortly. We are continuing to monitor developments in the gene therapy area with a view to finding ways to ensure Australian patients can access these novel treatments as the early clinical data matures.

DEBRA extends its sympathy to all those who have lost loved ones this year and assures you of our ongoing care and concern, remembering in particular Ivy Krause and Aaiden Ng. We are also working to maintain contact with bereaved families and included a small number of bereaved mothers in our mothers' respite weekend this year.

Our Board continues to work together very well, with each member contributing their skills and experience. Sincere thanks to all our Directors and Committee members, and particularly Rodney Sheaves, who is stepping down this year as a mentor on the Board. Rodney's excellent organisational and governance background have greatly assisted us over the past few years and his input will be missed. 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



Dr Jennifer Marty (DEBRA Chair) and Lise Angus (new DEBRA General Manager) visiting the Ingham Institute in Sydney

HOSPITAL BASED EB NURSES

DEBRA has funded nurse positions this year at three hospitals: St George Sydney, Royal Children's Hospital Melbourne and The Royal Melbourne Hospital. We are investigating the possibility of funding an adult nurse in Brisbane in the coming year. In addition, we have facilitated educational opportunities for all the Australian EB nurses, including those whose positions are not directly funded by DEBRA. All the EB nurses work hard to make a difference for our families and we are grateful for their support.

IN HOME EB CARE

During the year DEBRA has coordinated home care for 7 families. On average we have funded 44 hours care each week. Funding assistance has been given by the Eliza Braitling Foundation and the Little Heroes Foundation directly funds care for an additional family in South Australia.

EB DRESSING SCHEME

The EB Dressing Scheme is now administered by Independence Australia. DEBRA has developed a good relationship with the key personnel and participated in a stakeholder meeting in January 2019. We are continuing to advocate the need for a transparent, defined process for proposing changes to the list of dressings available under the scheme.

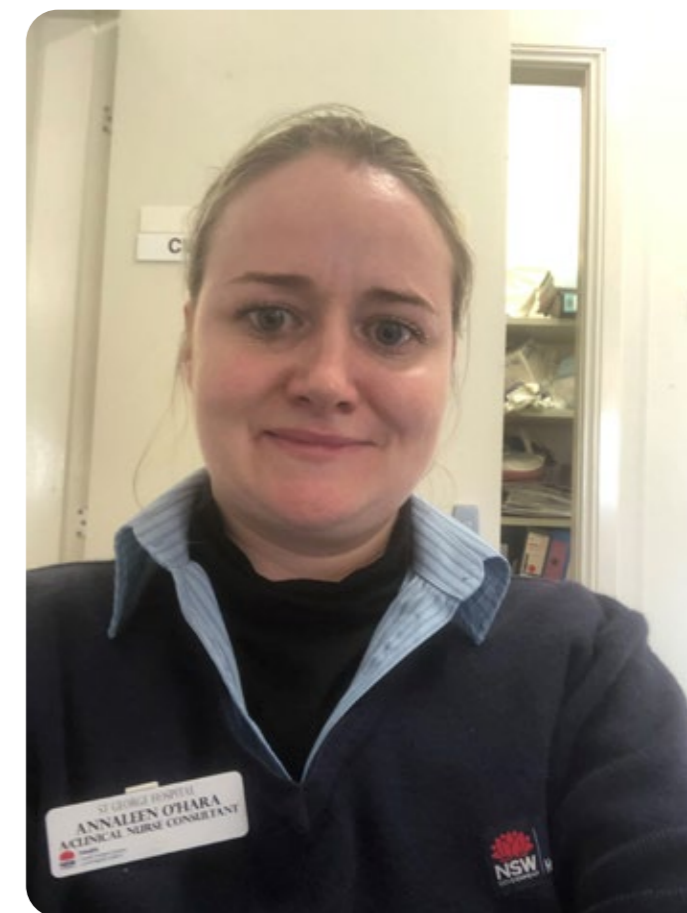
We have been advised recently that the Health Department and Independence Australia are working together to re-establish a process for the assessment of new products for possible listing on the NEBDS Dressings Schedule. They are looking to ensure that the process is as transparent as possible and presents an opportunity to consider new technologies while guaranteeing the sustainability of the Scheme. The Clinical Advisory Committee will discuss this process at its next meeting, later this year.

NDIS

This year DEBRA has assisted several families with the NDIS enrolment and review process. It is important to differentiate between needs due to disability and medical needs. Growing understanding has led to some good outcomes for clients. In the coming year we intend to determine our members' level of satisfaction with their experience of the scheme and communicate this to all stakeholders.

PSYCHOLOGICAL SUPPORT

The pilot psychology program has been accessed by 8 families to date. The impact of the program will be evaluated in the next few months to assist us to decide on the next steps, which may include improving access for regional/rural families and adding suitable EB-familiar psychologists in other states.



Annaleen O'Hara - Our new St George EB Nurse

FAMILY SUPPORT PROGRAM

FAMILY SUPPORT PROGRAM

The Family Support program received 232 applications during the 2018/2019 financial year for assistance with various EB related items. Our Family Support Coordinator Simone Baird has attended 86 meetings resulting in positive outcomes for individuals living with EB and Simone also connects with families via hundreds of emails and phone calls through-out the year.

Simone has also been in attendance at 10 EB clinics in various states and worked closely with the EB multi-disciplinary team to best support the EB community. She has also engaged with many new EB families from various states during this time.

We were able to offer 10 mums of severe EB children and bereaved mums a respite weekend away so they could have time out whilst connecting with each other. We are also in the preliminary stages of developing a Youth program for adolescents and young adults living with EB.

If anyone would like to access more information regarding the Family Support Program please contact our family support coordinator at simone.baird@debra.org.au



Family Support Coordinator Simone Baird attending the EB Clinic in Adelaide and catching up with the families.

EB FAMILY CAMP & CONFERENCE 2018

EB FAMILY CAMP & CONFERENCE 2018

Over 180 families, carers, guest speakers, health professionals and volunteers attended the EB Conference and Family Camp held in Sydney NSW in September 2018. This was the sixth national EB Conference & Family Camp held and biggest one to date with attendees coming from all around Australia and New Zealand. The Novotel Brighton Le Sands was a great venue near the airport and the wonderful staff went above and beyond to make our stay memorable.

The kid's activities were non-stop with a trip to Sea Life, Wild Life and Madam Tussauds in Darling Harbour. Sunday morning included a one on one session with Matt the Australian Ironman and the magic show proved a big hit and all the kids got to learn some tricks.

While the kids were having fun the parents were listening to national and international guest speakers and learning more about dressings and podiatry in the workshops. Dressing companies were also present with their trade displays to educate guests on what products are available.

We would like to thank our major sponsor Molnlycke Healthcare P/L along with Castle Creek Pharm for helping to fund this wonderful event. It would have also not been possible without lovely donations from the Todd family, the Eliza Braitling Foundation, Merlin's Magic Wand, Kiwanis Glenelg Club SA and Mirror Booth Australia. Last but not least our volunteers who looked after the children for the weekend and the guests for coming to make it all worthwhile.

From the feedback survey 100% of attendees thought the quality of the event was excellent or very good and it was a great event that they would attend again! We only hold this event every two to three years so if you missed out this time round please be sure to keep in touch via reading our newsletter to see when the next one will be scheduled and where.

Topics and guest speakers included:

- Progress in gene therapy trials by A/Prof Peter Marinkovich (California USA)
- Wound healing therapies by Prof Dedee Murrell (Sydney NSW)
- Experiences from involvement in EB trials by Dr Susan Robertson and EB Nurse Lauren Weston (Melbourne VIC)
- Podiatry considerations in EB by Dr Tariq Khan (Sydney NSW)
- Introducing DEBRA's Psychological Support Program (Dr Katharine Hodgkinson and DEBRA Family Support Coordinator Simone Baird)
- National Disability Insurance Scheme information by Rhiannon Brodie and Richelle Arnott (Sydney NSW)
- Developing independence when you have EB by Humphrey Hanley (Wellington NZ)
- Living with EB by Matt Bevilacqua (Gold Coast QLD)
- DEBRA International Update and EB Without Borders program by Dr Zlatko Kopecki, DEBRA Australia Director and DEBRA International representative
- DEBRA Values and where to from here? by the DEBRA Chair Jenny Marty (Sydney NSW)



EB FAMILY CAMP & CONFERENCE 2018

Some of the feedback from the parents included:

- Meeting other children with the same type of EB. Feeling like they are not the only one with the condition. For siblings learning more about EB. Feeling like they are very special at the Camp.
- Our daughter had a wonderful time in the toddler room and made friends and was happy in there on her own. It was her first time left in the care of someone other than family and we thought the volunteers in the room were exceptional. They put us at ease straight away.
- Able to make friends and meet other kids with EB, which up to now he has never met anyone with EB outside our family.
- It was great for my daughter to meet other kids with EB. She does not feel “alone” anymore and made great friends. Over the last couple of weeks she already has been in touch with some of her new friends. For her mental health this camp has been great value.
- It was my daughter’s first outing on her own. She came back without a scratch. She had so much fun, she still talks about it almost every day. The volunteers and nurses surely made an impression to her and to us. We are so thankful for the opportunity.





Guest speaker Humphrey Hanley from New Zealand



John from South Australia learning some magic tricks from the magician



DEBRA Ambassador Matt Bevilacqua talking about living with EB to teens living with EB

“There are many many worthy charitable organisations in Australia today that help and support people with health, mental and circumstantial needs and issues. If anybody was looking to either monetarily support or volunteer for any one of these organisations one could not pass up the opportunity to become involved with DEBRA Australia.

DEBRA is somewhat unique in that it supports a small number of people in Australia that are afflicted with a rare and sometimes fatal internal and external skin condition called Epidermolysis Bullosa (EB). DEBRA is also unique in that it donates virtually all of its fundraising to the people, often children that are afflicted. It does not have expensive office spaces and operates as a volunteer based organisation with minimal staff.

The wonderful aspect of the organisation is that it supports the most amazingly positive array of EB families that in many cases have defied their mortality by many years, quite possibly because of their attitude, and the help of DEBRA.

DEBRA well and truly “punches above its weight” against other better funded and longer, established charities because it commits it’s all!

MIKE KENNEDY

General Manager of Wolff Design and new DEBRA Committee mentor

EB GRANTS

The following grants were established to help support individuals living with EB to improve their quality of life.

The Follow Your Dreams annual grant (which closes each year on the 31st May) commenced in 2009 in memory of Carmel Harris from Perth. The Kate Turner Fund was established in 2013 in memory of Kate Turner from Adelaide.

Both Carmel and Kate were great supporters for DEBRA always flying the EB banner. Their legacy now lives on helping others living with EB via the grant programs and their supporting families and friends.

More information on the grant applications processes and prior successful recipients can be seen via debra.org.au/kate-turner-fund and debra.org.au/follow-your-dreams.

KATE TURNER FUND

The Kate Turner Fund has allocated one grant in the 2018/19 period which included:

A \$4,500 grant was allocated to help contribute to Lisa Brains (Adult EB individual) from Melbourne to go on a dream Cruise ship holiday in Australia with her family.

FOLLOW YOUR DREAMS GRANT

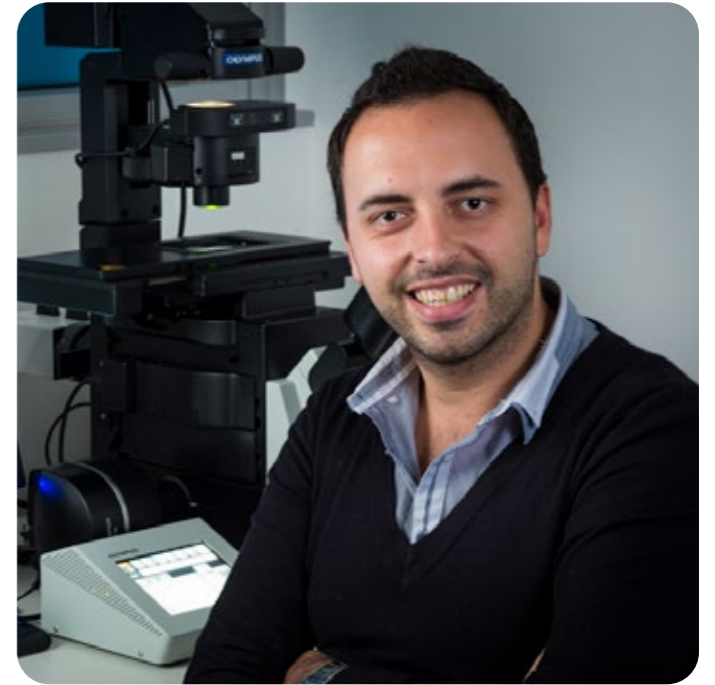
A \$2,000 grant was allocated to contribute towards Dean Clifford's (Adult EB individual) lifelong dream of travelling to Las Vegas to celebrate his 40th birthday with his family.



RESEARCH GRANTS

The following grants were awarded in 2019:

- Assoc Prof Albert Mellick, Ingham Institute for Applied Medical Research NSW: Establishment of a non-invasive protocol for early detection of malignant carcinoma in RDEB (\$40,000).
- Dr Zlatko Kopecki, Prof Krasimir Vasilev, Prof Allison Cowin, University of SA, and David Ogunniyi, Adelaide University SA: Safe and intelligent dressings for the treatment of infected blister wounds (\$40,000).
- Professor Dedee Murrell received \$10,000 held over from last year's grant round to enable the purchase of additional sirolimus medication to complete her study assessing safety and efficacy of topical Sirolimus 2% in the treatment of plantar blistering in patients with Epidermolysis Bullosa Simplex.



Dr Zlatko Kopecki

TRAVEL GRANTS

The following travel grants have been awarded to assist applicants to attend the January 2020 Global Congress on EB in London:

- Lauren Weston, EB nurse, Royal Children's Hospital (\$3,000)
- Moksha Shah, Medical student & research associate, Ingham Institute (\$2,000)
- Blake Smith, PhD student, Murdoch Children's Research Institute (\$1,000)

HEALTH PROFESSIONALS' SYMPOSIUM & FAMILY CONFERENCE 2018

The symposium and conference program went well with good feedback about the presentations and some useful suggestions for future topics. The international guest speaker Dr Peter Marinkovich also gave a lecture at the Walter and Eliza Hall Institute, Melbourne and visited Prof Dedee Murrell's clinic with a representative from Krystal Bio for discussions about a future EB clinical trial.



A/P Dr Albert Mellick

GENE THERAPY DISCUSSIONS

There is considerable interest in the future potential of gene therapy in EB. A second round table discussion was held in September 2018 to coincide with the visit of gene therapy researcher, Professor Peter Marincovich, and a Stem Cell Think Tank meeting for scientists and clinicians was held in May 2019, to discuss ways of developing readiness as the field develops. Assoc Prof Megan Munsie from Stem Cells Australia presented at the May meeting and there was also discussion about the Biogrid system for hosting Australian disease registries. Participants considered that a one-size-fits all approach was unlikely and that different types of therapies may be more suited to different EB subtypes and genetic profiles. It will be important to get updated data on the numbers and types of EB patients in Australia and to develop a better national collaborative approach. Data from some new trials underway overseas is expected to be presented at the EB 2020 congress.



Gene therapy meeting Melbourne

AUSTRALASIAN COLLEGE OF DERMATOLOGISTS (ACD)

Simone Baird gave a very well-received presentation at the May ACD meeting and also attended a stakeholder meeting where plans for development of a white paper about dermatology care were discussed. DEBRA has offered to contribute a case study to this document.



Gene therapy meeting Sydney

MARKETING & FUNDRAISING

MARKETING & FUNDRAISING

The Marketing and Fundraising Committee have focused strongly on both fundraising and increasing brand awareness of DEBRA Australia. This is evident by our increased number of media articles and news stories, many of which you can read on our website. We are confident that having a stronger media profile for our campaigns and shared EB stories with the general population, will translate into increased funding outcomes.

In addition to our regular campaigns the highlights for last 12 months were:

- PB4EB community fundraising event urging supporters to set a 'personal best' goal and fundraise while doing it in the month of May. In Sydney we had four gyms participate in an outdoor fitness event coming together as a community to collaboratively raise funds for the cause.
- A very successful 'Tee Off For EB' Golf event which achieved double the forecasted income. This key initiative is now scheduled as a signature biannual event.
- Our Christmas campaign – 'Light up the tree' – highlighted our need for support and family stories. The campaign gained traction and has been adopted by other DEBRA organisations internationally.
- An inaugural 'Walk for Wings' community walk campaign was held in Melbourne and Adelaide bringing our EB families and supporters together to raise funds and connect. The campaign was well received and it has been decided to expand it to two other major cities and include it as an annual national event to engage community fundraisers and our EB community.
- During International EB awareness week in the last week of October each year we have implemented a strong #FIGHTEB campaign which highlights the different faces of EB in Australia. Our main focus during this campaign is to get as much media coverage and social media reach as possible to raise awareness.

We have made a strong effort to significantly grow our regular giving donors and will continue to increase our pool of donors, supporters and corporate partners with a strategic marketing and fundraising plan. We would very much like to thank our major donors Future Generation Australia (FGX) for their ongoing support in funding our EB Services Program. We are also very grateful to the Eliza Braitling Foundation and our third party and partnership events, in particular the Brighter Days Festival and Melbourne Markets Golf Day for all their support which enables us to deliver our programs. Our community fundraisers also play an integral part in raising funds for DEBRA and we will continue to manage these relationships for further growth.

One important development for our committee was having Lise Angus, our General Manager join and chair the committee moving forward. Lise brings a wealth of experience in marketing, fundraising and corporate relationships and we look forward to her input in our strategic fundraising approaches and targeted campaigns which will have a major focus a lot on corporate partnerships in coming years.



Run4EB



Tee Off For EB



When not busy flying the DEBRA flag Lisa took the opportunity to go on her first motorbike ride with Ken at the Brighter Days event. Ken generously donated all of the ride takings to the event.



Brighter Days committee members Steve, Paul and Rosco presenting John with his new motorised car.



Walk For Wings



Simone (DEBRA Family Support Coordinator) in front of Team Brescia.
Left to right: Ang, Hudo, Jason, Gerard and Joe Amalfi (MMGD Executive committee)



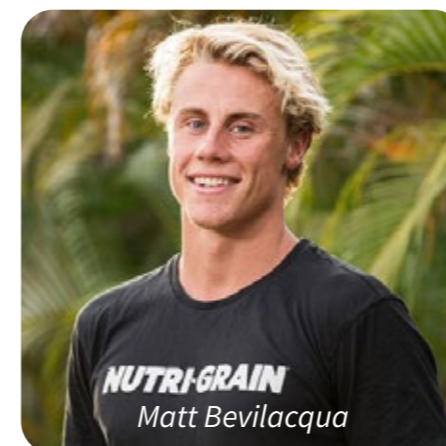
Show Us Your Bogan

DEBRA AUSTRALIA TEAM

All directors, committee and subcommittee members are voluntary positions

Directors	Staff / Contractors	Committee Members	Sub Committee Members
Jenny Marty (Chair) Mary Woods (Deputy Chair) Rodney Sheaves (Deputy Chair) Belinda James Dr Zlatko Kopecki Melinda Oxford Tina Segulin	Lise Angus Simone Baird Bianca Ciccia Sue McKenna Scott Macfarlane Joanne Sturgess	John Bacon Tony Baum Tom Connell Judith Davis Harry De Jong Krystal Evans Beth Geddes Michael Fitzpatrick Karen Frost Laraine Frost Kylie Gibson Francis Harper Mike Kennedy Mark Oliver	Delvene Harris Jan Harris Geoff Harris Michelle Pickles Roger Trevor Linda Turner Shay Zulpo

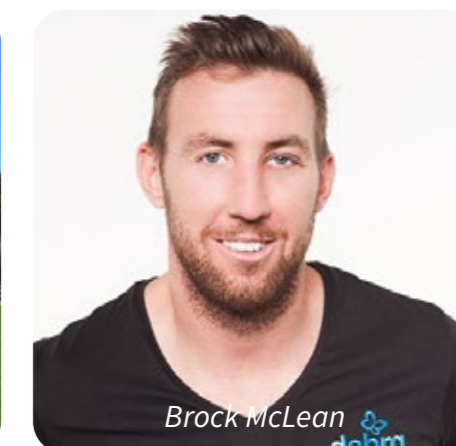
AMBASSADORS



Matt Bevilacqua



John Platten



Brock McLean



Kevin Naiqama



Josh Aloiai

DEBRA INTERNATIONAL

DEBRA Australia continues to be well represented within DEBRA International and we have made a significant contribution in the last 12 months to the number of DEBRA International initiatives. Dr Zlatko Kopecki, DEBRA International Representative from Australia is now the Treasurer for DEBRA International, whilst our chair Dr Jenny Marty continues to be an active member of the DEBRA International Governance Committee.

Dr Zlatko Kopecki is also involved in the DEBRA International program stream “EB Without Borders” and in the capacity of ambassador he has visited Cuba and facilitated establishment of DEBRA Cuba, and provided families living in Cuba with dressings and latest clinical practice guidelines for wound care in EB.

Our staff member Simone Baird has also contributed to the work of DEBRA International EB Without Borders program by visiting Vietnam and educating local families and nurses about best wound care management for EB patients. It is exciting that in a small way we can be involved in these programs and provide support to less fortunate EB patients.

In the last 12 months, DEBRA International has continued its work on producing best clinical practice guidelines including Occupational Therapy and Psychosocial guidelines, and a number of Australian patients, health professionals and nurses have been invited to participate in future clinical practice guidelines.

Dr Kopecki also continues to serve on the Small Grants committee for DEBRA International, and it is great to see that DEBRA International in the last 12 months has continued to support Australians with travel grants, training and a small research grant.

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.



Vietnam Trip 2018



2018 DEBRA International Conference delegates in Switzerland from left: Rebecca (EB Nurse Sydney RCH), Zlatko (DEBRA Australia director) and Kerry (Adelaide nurse)

FINANCES

In the 2018/19 financial year total income was \$694,484 compared with \$1,053,232 in the previous year, primarily due to a decline in fundraising, including reductions in general and on-line donations and smaller fundraising events. One expected significant donation had been held over till the next financial year.

Annual expenses were tightly controlled, being \$758,156 in 2018/19 compared with \$801,579 in the previous year. The only area which increased significantly was Staff Costs due to the recruitment and first few months of employment of the General Manager.

There was a net deficit of \$63,672 for the financial year, compared with a surplus of \$251,653 in 2017/18.

BALANCE SHEET

Compared with the previous year, total assets decreased from \$1,973,055 to \$1,901,541 and total liabilities decreased from \$67,913 to \$60,071. Total equity was \$1,841,470 at year end. The organisation's financial position is still strong and reserves are well above the Board's target minimum of \$1.2 million.

BUDGET

The 2019/20 budget projects total income of \$785,800, expenses of \$1,007,141 and a net deficit of \$221,341. Whilst a deficit of this size can be absorbed this year, it is imperative that fundraising income is increased over the next 1 to 2 years to enable desired expenditure to be maintained. DEBRA's new Strategic Plan includes objectives to achieve a surplus or break even by 2021/22. The Fundraising and Marketing team is considering some new approaches to improve this income.

AUDITOR

The audit process went smoothly and it is recommended that Hooper Accountants be appointed as auditors for 2019/20.

COMMITTEE CHAIR

Rodney Sheaves retired as Chair of the Finance Committee in May 2019. The Committee wishes to thank Rodney for his excellent leadership and contributions to this area. Jenny Marty has acted as Chair since May.

The audited report is available for your information via the following link:

[Click here to download the report.](#)