

# DEBRA AUSTRALIA

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ANNUAL IMPACT REPORT, 2021



# CONTENTS

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Supporters	.....3
Our Vision	.....4
Words from our community	.....5
Program expenditure	.....6
Chair's report	.....7
DEBRA team	.....9
Family support program	.....10
EB Grants	.....12
EB Services	.....13
Marketing and Fundraising	.....14
DEBRA International	.....15
Research and Education	.....16
Finances	.....18

# SUPPORTERS



MELBOURNE MARKETS

## Major Supporters

Andrew Brains

Michael Brodie

Cathy Currie

Gremmo Homes

Intralink Wealth Management

Thelma Carr Foundation

S & J Cook Family Foundation

Department of Social Services (event grant)

Malcolm Elliot

Malcolm Gray

Jean Thyne Hedges

Peter Hatfield

Heathcote Public School

Vanessa Jones

Michael Kean

Daniel McLoughlin

J & J Marty

K & R Nixon

Quilters Guild of SA Inc

Dale Schossow

Telstra

The Board Meeting Surf Charity (Sunshine Coast Qld)

Todd Family Foundation

Toyota Material Handling Australia P/L

Valenti Golf Club

Jim Warner

West Wyalong Lions Club

Jeff Yablon

## Media Partners

Ruby Agency

# OUR VISION

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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 possible support and medical care, as well as raising awareness of EB in the community and supporting research towards effective treatments and potential cures.

## **PURPOSE**

To enable a sense of dignity, meaning and belonging and reduce suffering for Australians living with EB.

## **AIM**

- 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 and research organization.
- Compassionate: DEBRA supports EB families with compassion, respect and empathy.
- Ethical: DEBRA is a professional, responsible, honest and ethical organization.
- Accountable: DEBRA is accountable and transparent 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 for the EB community.

# WORDS FROM OUR COMMUNITY

"I've donated to your wonderful charity on behalf of my amazing sister Lisa. Keep fighting the fight!" - Andrew, Family member

"Thank you for all the wonderful work you do to support those living with EB" - Tina, Director and family member

"DEBRA relies on the support of many people, financially and their time. Thanks to everyone involved" - Malcom, Donor

"I didn't know much about Recessive Dystrophic EB until Assoc Prof Albert Mellick introduced it to me. Since then, I was drawn to be part of this project. It is less prevalent than other diseases, but the discomfort it inflicts on patients' skin should be heavily looked upon. By working with Assoc Prof Albert Mellick and David Hoang, I believe we are a step closer in finding the right treatment for RDEB patients" - Maria, Researcher.

Additionally we want to extend our heartfelt sympathy to the family and loved ones of Alexis (pictured on the right) from NSW, who sadly lost her battle with EB this year.



## A MESSAGE FROM BEAU'S FAMILY

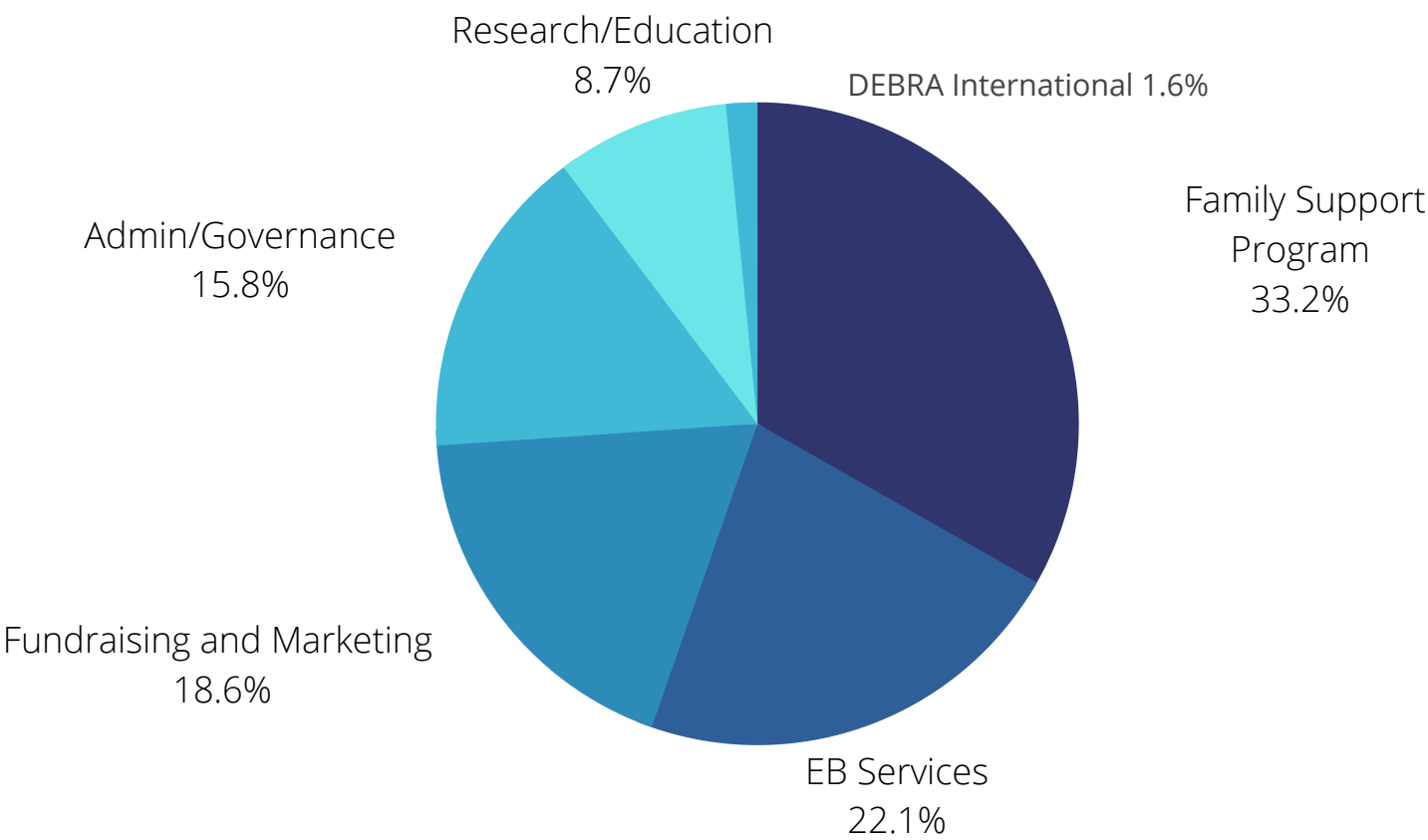
"EB causes pain in our lives both physically and mentally, there is no break from EB, it's always there. As a result, life can become draining and frustrating, and sometimes you just sit back and think "this isn't fair".

As a family we try to remain positive and look on the bright side as life is precious. Knowing we have support from DEBRA makes living with EB more bearable. We will be forever grateful for their assistance in many ways as they help to improve our quality of life."

- Melissa, Beau's Mum

# PROGRAM EXPENDITURE

Total expenditure \$813,892



A big thank you to all of our volunteers who collectively contributed over 1550 hours in 2020/21 one of whom is Laraine Frost (pictured left with Dr Zlatko Kopecki, DEBRA Australia Director in SA) who has worked with DEBRA for almost 30 years.

# CHAIR'S REPORT

DEBRA Australia has had another interesting, and sometimes challenging year, dealing with the consequences of the Covid-19 pandemic – with lockdowns, travel bans and other restrictions impacting our activities and fundraising. Despite this DEBRA has been able to continue to deliver its services, although sometimes in a modified manner.

We recorded a solid financial result, with a small operating surplus, helped by the Australian Government's stimulus packages, and keeping a careful eye on our expenses. Whilst I'm not able to mention all our major donors in this short review, there are a few I would like to highlight. A couple of our major fundraisers, Brighter Days and the Melbourne Markets Golf Day, managed to come up with alternative fundraising activities, enabling them to continue their generous support. In addition, we received a larger donation this year from Future Generation Australia, which has encouraged us to think about increasing some of our support activities. Convatec came on board as a major donor and the Eliza Braitling Foundation continues to be a generous contributor.

Due to the Board's policy of ensuring we have more than one year's operating expenses in the bank, we will be able to continue to operate satisfactorily in the coming year. We were planning to hold our 7th family conference in Melbourne in 2021, but recently took the difficult decision to postpone it to the end of April 22 when we hope that state borders will be open and travel restrictions relaxed.

The DEBRA International meeting, hosted by DEBRA Russia, had to be held virtually this year. There were talks on family education and support around the world as well as research updates. Several promising leads are being investigated for both symptomatic relief as well as gene correction approaches for different types of EB. We are keenly awaiting the results of the current trials and will keep you updated as they are released.

Our Australian research grants continue and, pleasingly, have provided seed funding to assist some of our local researchers to generate initial data which has enabled them to attract major grants from other bodies to continue their work. In the past year Dr Zlatko Kopecki (University of South Australia) has received a 3 year Fellowship from the Channel 7 Children's Research Foundation to study childhood wound infections in children with EB and Dr Nicholas Veldhuis (Monash Institute of Pharmaceutical Sciences) has received a 3 year grant from DEBRA International and the EB Clinical Network to study pain mechanisms and relief in dystrophic EB.

Our EB nurse, podiatry and psychology programs are funded by a grant from Future Generation Australia, which is Australia's first listed company with the dual purpose of generating a social and financial benefit. We are extremely grateful to Future Generation Australia and their shareholders for their generous support.

Due to their increased donations we have been able to expand the level of nursing support by adding a second day per week at The Royal Melbourne Hospital, and are currently negotiating with Sydney Children's Hospital to add an extra day per fortnight to the EB nurse there. Additionally we have added online chat sessions for young people with EB have with two of our ambassadors Matt Bevilacqua and Dean Clifford acting as moderators. Unfortunately our Mother's respite weekend had to be postponed due to Covid restrictions but we are expanding our respite programs by piloting a Butterfly Break scheme for family holidays over the summer.

Our staff continue to go above and beyond to assist our community. Special thanks go to our GM Lise Angus for the way she has managed the team and also, for volunteering to reduce her paid hours during the first lockdown period to reduce our expenses. Her staff, including Simone Baird, our National Family Support Coordinator and Sue McKenna our Executive Coordinator, have continued to deliver outstanding services over this challenging year, and Claudia Brooks proved to be an excellent replacement while Bianca Ciccia, our Fundraising and Marketing Manager, was on parental leave.

Our Board was able to have its first face to face meeting in May and this allowed us to start thinking about what DEBRA's needs may be in the future as we start to develop a new strategic plan. All of our Board members have helped to steer DEBRA through these troublesome times and I would like to thank them for their insights and advice.

Finally, we could not achieve what we do without fantastic support from our volunteers. A special congratulations goes to our 2021 Chair's Award winner Laraine Frost who has been an active, loyal and enthusiastic supporter of DEBRA for almost 30 years. Her heart is always with the kids and parents with EB. Her involvement began when her daughter Karen asked her to be treasurer in the first DEBRA SA support group which started in 1992. She remained on the SA DEBRA Committee and also been part of the fundraising committee and coordinator of the Kate Turner Foundation.

She was the main organiser and fundraiser for the first EB family camp (held in SA). She has held many other fundraisers along the way including with one of her friends Chinzia, used to raise funds for DEBRA by selling preloved clothes and running wellness fetes which included tarot card readers and all kinds of colourful participants. Laraine also assisted with the Rove video, many Butterfly Days and the Adelaide City Concert band afternoon fundraisers. Laraine encouraged researcher Zlatko Kopecki to join the SA group, thus beginning his involvement with DEBRA.

The biggest achievement and her biggest passion, is by far being a supporter and alongside Roger the developer of the Kate Turner Foundation. Her love of Kate and her support for Linda and the rest of the family has been unsurmountable over the years.

Jennifer Marty, Chair, DEBRA Australia

# DEBRA TEAM

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## Board

- Jennifer Marty (Chair) (NSW)
- Mary Woods (Deputy Chair) (NSW)
- Zlatko Kopecki (SA)
- Judith Davis (SA)
- Melinda Oxford (VIC)
- Tina Segulin (VIC)
- Belinda James (VIC)

## Employees

- Lise Angus (NSW) – General Manager
- Simone Baird (VIC) – National Family Support Coordinator
- Bianca Ciccia (NSW) – Fundraising & Marketing Manager
- Sue McKenna (QLD) – Executive Coordinator / Board Secretary

## Contractors

- Joanne Sturgess (QLD) – Administration
- Claudia Brooks (NSW) – Fundraising & Marketing
- Scott Macfarlane (QLD) – Website/IT

## Ambassadors

- Joel Bevilacqua (NSW)
- Matt Bevilacqua (QLD)
- John Platten (SA)
- Lachlan Albert (ACT)
- Dean Clifford (QLD)

# FAMILY SUPPORT PROGRAM

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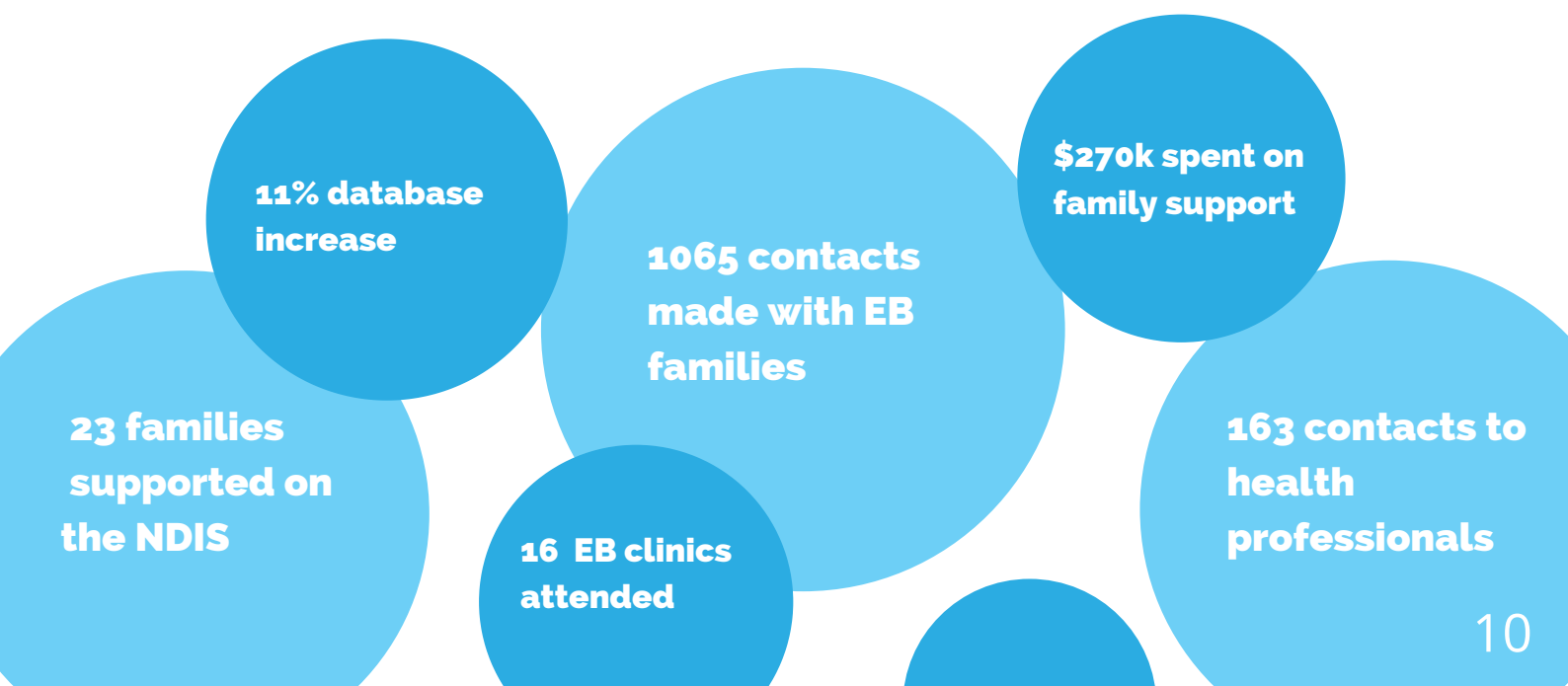
The Family Support Program received 347 applications for assistance with various EB related items during the 2020/2021 financial year, which is an increase of 65 applications compared to this time last year.

Our Family Support Coordinator Simone Baird has attended 170 meetings resulting in positive outcomes for individuals living with EB and has also connected with families via hundreds of emails, phone calls, telehealth and zoom meetings through-out the year. Additionally, she attended 16 EB clinics via telehealth and / or face to face meetings in various states and worked closely with the EB multi-disciplinary team to best support the EB community. Nine new EB families from various states were also supported during this time.

The Family Support committee assisted many families as they have either transitioned or gone through plan reviews with the National Disability Insurance Scheme and continues to work closely with the NDIA.

The past twelve months have been difficult when dealing with challenges that COVID-19 has thrown us, but we have managed to increase our on-line support with meetings to provide on-going support to EB families. Simone has also been involved in remote major fundraising activities in Melbourne and will continue to promote DEBRA whilst raising awareness for our programs.

Together this is the impact we made to the lives of families living with EB via the Family Support Program.

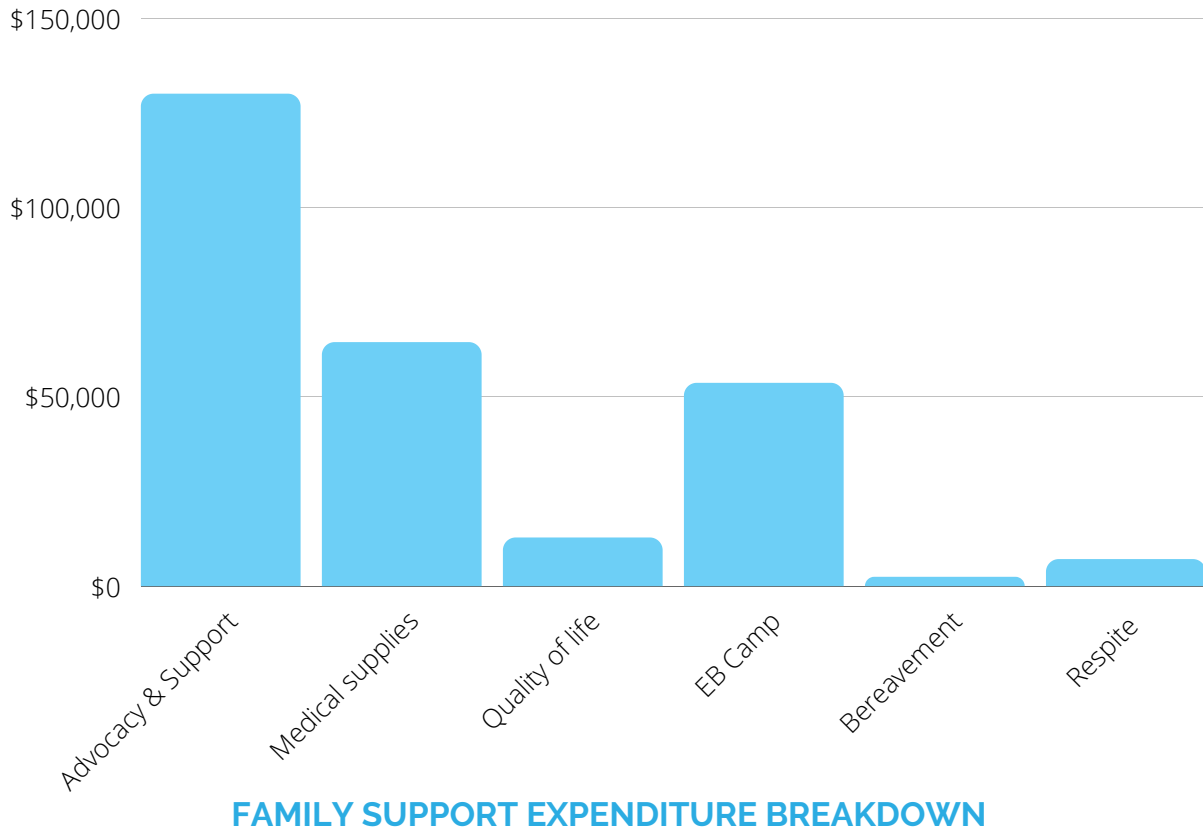




**Alessio in Perth has not let living with Recessive Dystrophic EB get in the road of achieving a major goal of getting his licence and is now more mobile in his new car**



**Simone Baird (DEBRA National Family Support Co-ordinator) visiting the Azny family in Sydney**



# EB GRANTS

## Follow Your Dreams

The successful 2021 grant recipient was Riordon who has a dream to meet the Hamilton Show crew and cast. A \$750 grant has been allocated to help make Riordon's dream come true.

The successful 2020 grant recipient was Marrie from QLD who has Junctional EB. Marrie will be supported to fulfil her dream of going on a cruise ship holiday off the QLD coast. Due to COVID issues, unfortunately Marrie's holiday has had to be put on hold. The \$1,170 Follow Your Dreams grant will contribute towards the funds required to make the holiday happen, when it can finally go ahead.

## Kate Turner Fund

2021 has meant the 7th year of the Kate Turner fund, and this year we were able to provide grants for all three applicants, Jessika (pictured bottom left) from VIC and her family enjoying a much needed holiday on the Gold Coast visiting Movie World. The Kate Turner Fund supported the family to make the long trip to Qld.

John (pictured bottom right) from rural SA with his new iPhone 11 that was purchased by DEBRA and the Kate Turner Fund to help John stay up to date and connected with friends and family. The third applicant was Karen, from SA who had soft shoes and orthotics provided.

Our total grant money distributed was just under half our permissible limit per year, so we are open to more requests in the coming year, particularly as our Fund account now stands at just under \$60,000.

- Roger Trevor (Committee Chairman).



# EB SERVICES

## Hospital Based EB Nurses

This year DEBRA has facilitated nurse positions at three hospitals: St George Sydney, Royal Children's Hospital Melbourne and The Royal Melbourne Hospital, with support from the Future Generation Australia. During the year nurse Lauren Weston resigned from the Royal Melbourne position and has been replaced by Sylvia Tsang. The Royal Melbourne hospital position is being increased to two days/week from September and negotiations are underway for DEBRA to support the state-funded EB nurse at Sydney Children's Hospital, Rebecca Saad, for an additional day per fortnight.



## In Home EB Care

A lot of our families are now being supported via the NDIS for in home nursing or support workers. During the year DEBRA has coordinated home care for 4 families for 21 hours per week on average. Funding assistance has been given by the Eliza Baitling Foundation and Future Generation Australia.

## EB Dressing Scheme

A process for adding new products to the National EB Dressing Scheme has been published. Applications for listing may be made twice yearly by manufacturers. To date no new products have been added to the scheme except for a few replacements where products have been discontinued. News about determinations regarding new products is awaited after the November budget update.

## National Disability Insurance Scheme (NDIS)

We continue to help individuals and families access NDIS support plans and also assist when existing plans are being reviewed. In the past year we have achieved some good outcomes, assisting 21 individuals with plan reviews and 2 new applications pending approval.

## Psychological Support

Extra psychologists were recruited to assist the initial two psychologists, due to their workload constraints largely due to the pandemic. We now have 4 options in Sydney and 4 in Melbourne. Uptake has been lower than expected with some families obtaining NDIS funding or consulting local practitioners. Fifteen people have utilised the program over the past year.

## Podiatry

Podiatrist Dr Tariq Khan (pictured above) is now holding a regular clinic at St George Hospital Sydney to improve access to podiatry services for young people and adults in NSW. This may be of particular benefit to individuals with EB simplex who often experience foot problems. We hope to expand this to Brisbane in the coming year and Dr Khan is now involved in establishing training with the Australian Podiatry Association.

# MARKETING AND FUNDRAISING

The Marketing and Fundraising Committee has continued with momentum this year focusing heavily on both EB awareness, developing and building upon DEBRA Australia's presence through a variety of key PR, marketing & communications campaigns and initiatives, whilst continuing to pivot fundraising activities in the midst of COVID-19 and it's ensuing challenges.

## Brand Awareness

Over the past twelve months we have continued a focus on brand awareness by increasing our social media presence and more frequent email marketing to both our donors and families.

## Public Relations (PR)

This year, partnering with Ruby Agency we continued to bring EB into the spotlight through the media, in particular the EB and DEBRA Australia feature on SBS. DEBRA Australia continues to feature across aligned-organisations websites and newsletters, including; Wounds Australia, Australasian College of Dermatologists, Rare Voices Australia, and DEBRA International.

## Ambassadors

Highlights from the Ambassador program for this year include the recruitment of Brumbies player Lachie Albert as a Junior Ambassador, Joel Bevilacqua and Dean Clifford participating in key roles in our Tee off 4 EB fundraiser and Matt Bevilacqua and Dean Clifford being confirmed as the DEBRA Youth Wellbeing Program mentors for the upcoming youth focused initiative.

## 2021 Highlights

- Over \$15,000 raised for DEBRA Australia and our life changing programs at Tee off 4 EB 2021. Significantly, there were 10 pledges made to DEBRA Australia from attendees of the dinner, three of which were in excess of \$1,000.
- The Walk for Wings event was held as a virtual event giving our community a fundraising opportunity they could participate in all over the country.
- Our annual 'Light Up the Tree' Christmas campaign ensured we continued our fundraising through an appeal to support all our families at Christmas time.

Pictured: Ambassador Dean Clifford and Dr Brent Doolan (left) and (right) The Farrell Family at our Sydney Golf Day



# DEBRA INTERNATIONAL

In the last 12 months DEBRA International (DI) has focused on review of its activities, and improvements in terms of our operational processes. We are proud to have updated our website which now also includes a donate button. Our new CRM system has proved to be very useful while our monthly member updates have been highly valued by the members.

The COVID-19 pandemic has significantly affected our EB Without Borders program limiting the support we can offer to developing countries however we continue to support development of new DEBRA's globally and advocate for better support services and research aimed at finding the cure for all EB types. We were involved in updating our members by publishing "COVID-19 vaccines and EB" document with help of our medical experts. Dr Kopecki continues in his role as the Treasurer at the DI Executive Board and Dr Marty continues to be essential member of the Governance committee. Our General Manager Lise Angus is continuing to develop important networks with other DEBRA General Managers globally. This year has been challenging for all DEBRAs in terms of income stream shortfalls due to COVID and pausing a number of clinical trials. DI continues to provide patient support through release of clinical practice guidelines (both health professional and patient versions), and infographics. Additionally, the Board has been working on a number of strategic plan items to ensure sustainability and improved fundraising and communications in order to continue to serve the global EB population.

- By Zlatko Kopecki (DEBRA International Representative)

## EB WITHOUT BORDERS

DEBRA Australia received a request from EB Without Borders to help support an 18 year old student living in the Philippines with Recessive Dystrophic EB. Joyce (pictured) was no longer able to attend school until she could secure some equipment to assist with learning online due to COVID restrictions and her limited hand mobility.

Telstra in Toowoomba QLD came to the rescue donating a new iPad and iPhone (valued at \$3,000). Joyce can now continue with her schoolwork and her love of science. The new technology will enable Joyce to not only finish school but to also pursue her dream of one day having a career.



# RESEARCH AND EDUCATION

DEBRA Australia has contributed over \$518,000 to support EB related research in the past 9 years.

## **Impact of COVID-19 on our EB research community**

Our research community has faced significant hardship with a number of current DEBRA Australia research projects delayed due to COVID-19 impact (access to laboratories deemed not essential during lockdowns, delays in supply chains for research consumables, lack of government support for Universities and lack of educational opportunities to present research). Additionally, due to uncertainty in income caused by the COVID-19 pandemic the DEBRA Australia Board reduced the expenditure on the Research and Education program for the 2020/2021 financial year. Two research grants were reduced from \$40,000 to \$30,000 each for one year but these are being restored to \$40,000 for the 2021/22 period.

Due to government travel restrictions our travel grants awarded in 2020 were not realized and successful awardees were allowed to expend the grants when travel resumes. COVID-19 has also had a significant impact on DEBRA Australia's ability to provide educational content as part of the Health Professional Day which was delayed. We certainly hope we will be able to deliver an exciting educational program at a Health Professional Day in conjunction with the Family Conference in early 2022, with the date dependent on developments with the pandemic. Despite the significant impact of COVID-19 on our research community, DEBRA Australia was able to award two research grants and we hope to increase the support for EB research community in the future.

**The Melbourne Pain Grant Research Team Dr Blake Smith, Assoc Prof Johannes Kern, Assoc Prof Kenneth Pang, Dr Nicholas Veldhuis and Sally Davis**



## Research grants

The following grants were awarded for projects to be undertaken in 2021:

- Dr Nicholas Veldhuis and A/Prof Kenneth Pang (Monash Institute of Pharmaceutical Sciences Melbourne) were awarded \$30,000 for a project entitled "Identification of effective anti-pruritic agents in Dystrophic Epidermolysis Bullosa."
- Assoc Prof Albert Mellick (Ingham Institute, University NSW) was awarded a grant of \$30,000 for a project entitled "A minimally invasive method for early detection of malignant carcinoma in Recessive Dystrophic Epidermolysis Bullosa."

The progress of some of this work may be hampered by the impact of the Covid-19 virus in various institutions, but our researchers are endeavoring to move forward within these limitations.

## Travel Grants

Two of last year's recipients of Travel grants were not able to travel due to COVID-19 pandemic and were given extension on their travel grants so we hope they can realize their research training soon.

- Ms Annaleen O'Hara, EB CNC, St George Hospital: \$3,500 for travel to the UK for EB nurse training at Guys and St Thomas Hospital.
- Ms Hannelore Bodacion, Research Student: \$3,500 to travel from Austria to Sydney and accommodation in Sydney to continue her research project with A/Prof Albert Mellick on early detection of SCC in EB, prior to starting a PhD program.

Lastly, we welcomed new members to our Research and Education Committee including Dr Frances Henshaw, Prof Nicholas Huntington and A/Prof Pritinder Kaur and we look forward to working with them to grow the DEBRA Australia Research and Education Program. Finally, we thank Dr Jenny Marty for her hard work as the Chair of Research and Education Committee over the last 8 years. Jenny will remain on the committee as a much valued member.



**Some of the SCC in EB research team: Mr David Hoang (Medical Student University New South Wales) and Maria Evardone (Medical Student Western Sydney University) and Assoc Prof Albert Mellick.**

# FINANCES

## Operating Report

- In the 2020/21 financial year our total income was \$900,963 compared with \$840,518 in the previous financial year. The continuation of the government stimulus packages assisted the income stream momentum and gave some relief for fundraising events that were cancelled.
- DEBRA received some unexpected additional financial support from our supporters namely Future Generation Australia and Convatec, and better interest rates on some of our investments which also assisted our better-than-expected bottom line result.
- Annual expenses were tightly controlled with total expenses being held at \$813,892 in 2020/21. Unfortunately, some of our DEBRA events were cancelled or postponed which again affected the forecasted result.
- There was a net surplus of \$87,071 for the financial year. In addition to the above mentioned, receipt of government parental leave payments, and the General Manager voluntarily reducing her hours also contributed to the net surplus.
- [Audited report available here.](#)

## Balance Sheet

Compared with the previous year, total assets increased from \$1,934,046 to \$2,033,519 and total liabilities increased from increased from \$67,173 to \$79,585. Total equity was \$1,953,934 at year end. The organisation's financial position is still strong, and reserves are above the Board's target minimum of \$1.2 million.

## Budget

The 2021/22 budget projects total income of \$723,500, expenses of \$943,626 and a net deficit of \$220,126. Whilst a deficit of this size can be absorbed this year, it is important that we continue the focus on our fundraising and marketing strategies and resultant income. The Fundraising and Marketing team is looking at new and innovative approaches to hold events in the digital space due to the current environment. We will be closely monitoring the budget given the interest rate environment and making appropriate recommendations to the Board if required.

## Auditor

The audit process went smoothly and it was accepted that that Hooper Accountants be appointed as auditors for 2021/22.

## Investments

All investments now on the Intralink Wealth Management platform. Many thanks to Tony Baum (CEO Intralink Wealth Management) for offering this service on a pro bono basis.

Judith Davis, Finance Committee Chair