



Annual Impact Report 2021-2022

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Supporters



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
 Ruby Agency

Our vision

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

1 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.
To enable a sense of dignity, meaning and belonging and reduce suffering for Australians living with EB.

Aim

To improve the lives of people living with EB by providing necessary support services, home aids and information to individuals and their families.
To deliver programs to support and educate families living with EB, health professionals, communities and the general public.
To ensure that all EB families across Australia have access to specialised EB care services within hospitals and the community.
To facilitate opportunities for EB research with the aim of finding approaches to curing and developing symptomatic therapies for EB.

2

Values

3

DEBRA Australia contributes to and supports the activities of DEBRA International, we aim to establish positive and sustainable partnerships to support our mission.

Focused: DEBRA is an individual and family focused, EB service and research organisation.

Compassionate: We support 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: We build 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

"My son has suffered with EB for seven years and there is little known about it in Tasmania. I have struggled through trial and error to help him with the condition and it has been frustrating and overwhelming. Since discovering DEBRA I have received so much information and support which has been amazing."

- Rebecca, Tasmania

"Being diagnosed with EB Recessive Simplex at birth with so much uncertainty about what to expect and how to manage this condition. The support I received from the EB nurse was phenomenal and has helped me significantly in the last few years. I was able to ask questions and clarify queries regarding medication. I was able to seek medical advice when needed and be able to get in touch with someone who had information regarding my condition."

- Nurbanu, Melbourne

"The EB Nurse program is fantastic. I have never felt so supported in regard to a health setting. The accessibility is second to none which is so important when dealing with a condition many practitioners haven't heard of. I hold our EB Nurse in high regard and the care from her is critical."

- EB Family member

"Given how rare EB is, most hospital based health professionals have not previously cared for patients with EB and rely heavily on the EB nurse to guide and support care. Not only is the EB nurse an invaluable resource for health professionals in the hospital, but patients with EB also depend very much on the specialist nurse."

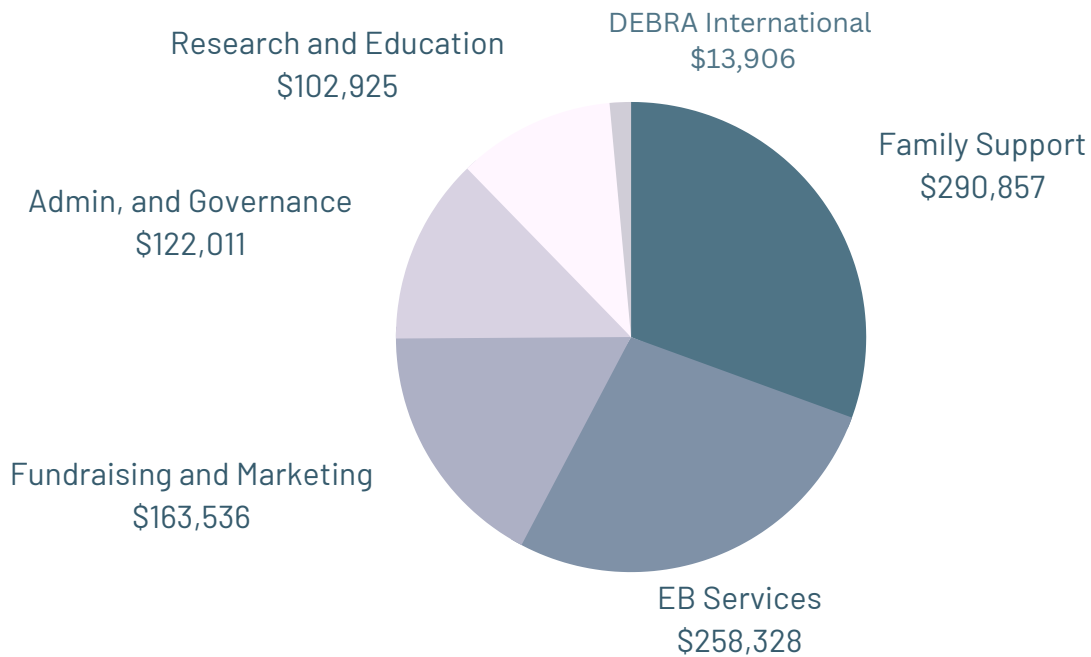
- Paediatric Specialist, Melbourne



Kyran in his 2022 halloween costume

Program expenditure

Total expenditure: \$951,563



170

**Contacts made
with health
professionals**

1550

**Volunteer
hours**

100%

**Of family support
applications
approved**



2022 EB camp in
Melbourne

Chairs report

2022 has been a very successful year for us at DEBRA Australia. We were finally (third time lucky) able to have our national conference after the delays due to the Covid pandemic. However this year did throw us some new challenges, especially due to the downturn in the global economic outlook, which is impacting our investments and influencing our plans for the next couple of years. Given this situation, our financial result for the year was reasonable, with a deficit of \$99,512. This was largely due to the lower valuation of our investments at 30 June. Revenue was higher than the 20/21 year, as was expenditure, particularly with an increase in the outlay on EB nurses, employee costs and costs associated with the national family conference. Our major donors like Brighter Days and the Melbourne Markets Golf Day were very generous with their support as well as Future Generation Australia (FGX) which has underpinned our family support and professional programs.

Our policy is always to ensure we have at least a year's operating expenses in the bank, and a defensive investment portfolio. At the moment we have sufficient reserves to be able to continue to operate in the coming year despite the current economic challenges. Our Finance Committee will be carefully reviewing our income and expenditure each quarter and making recommendations to our plans if needed.

As mentioned, our national conference and health professionals symposium held in Melbourne in April were extremely well attended and participants were delighted to have the opportunity meet again once travel restrictions were relaxed. The feedback from the families was very positive and the face-to-face interactions with old friends and new families was invaluable. The event was made possible by funding from an Australian Government Department of Social Services National Disability Conference Initiative grant and also generous donations made by FGX, Molnlycke Healthcare Ltd, Convatec, Eliza Braitling Foundation and the Todd family.

This year the board has developed a three year new strategic plan with several key objectives including:

- Continuing the focus on EB individuals and families as the principal stakeholders
- Working towards financial sustainability; and
- Expanding the measurement and evaluation of the outcomes and impact of our programs and activities

We also expanded our respite programs by piloting a Butterfly Break scheme for family holidays over the summer, which was very well received. This will be continued and expanded in 22/23.

There have been several developments with our EB nurse program this year. We have increased our support at both The Royal Melbourne Hospital and at Sydney Children's Hospital. Negotiations are continuing to set up a Transition/Adult nurse role in Brisbane. The Dermatology Department at Princess Alexandra Hospital is keen to host this position but will need approval from hospital management and Queensland Health to establish a statewide service (centre of excellence) before this can be implemented.

The value of the EB nurse program was strongly endorsed by both families and health professionals in an impact assessment survey conducted this year. The size of our Australian research grants was increased to two grants of \$40,000 this year and on the education side, apart from coordinating the successful Health Professionals Education Day, the research and education committee also looked at ways to expand the program when funds permit.

In the past 12 months DEBRA International (DI) has been very active in enabling EB families affected by the conflict in Ukraine to have access to dressings, medical needs, and nutrition. Through partnership with industry, the support of DEBRA member countries, and Red Cross Singapore, 35 EB families have been helped with settlement outside Ukraine and assistance given to 65 EB families remaining in Ukraine.

Our staff continue to do an outstanding job and special thanks go to General Manager Lise Angus and her team for everything they do. We have had fantastic support from our volunteers and our Board members willingly give their time, insights and advice to help DEBRA to deliver its activities.

This year we would like to recognise Mary Woods who is stepping down from the DEBRA Board. Mary's involvement with EB began in 2002 when unexpectedly her grandson Josh was born with recessive dystrophic EB. She joined DEBRA NSW and quickly became very involved, later taking on the role of secretary. From 2003 for about 10 years Mary held an annual trivia night. This was very popular and raised many thousands of dollars to help EB families. She also raised awareness about EB, speaking at engagements and attending many cheque presentations with Kylie (and Josh in the past). After DEBRA NSW became part of the national body, DEBRA Australia, Mary became a board member, and later Deputy Chair, as well as continuing to fundraise by having a luncheon every year.

Mary knew the ins and outs of living with EB, helping her family out on many occasions with dressing changes and in times of crisis/doctors' appointments. This gave her great insight to the lives of our EB families and it was a natural fit for Mary to take on the role of Chair of the Family Support Committee. She will be continuing her involvement in this group as a family representative.

-Jennifer Marty, DEBRA Chair

DEBRA team

Ambassadors Joel Bevilacqua, Dean Clifford and Matt Bevilacqua



Board

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

Employees

Lise Angus (NSW) – General Manager
Simone Baird (VIC) – Family Support Coordinator
Bianca Ciccio (NSW) – Fundraising & Marketing Manager
Sue McKenna (QLD) – Executive Coordinator / Board Secretary
Joanne Sturgess (QLD) – Administration

Contractors

Jillian McKee (NSW) – Fundraising & Marketing
Scott Macfarlane (QLD) – Website/IT

Ambassadors

Joel Bevilacqua (NSW)
Matt Bevilacqua (QLD)
Lachlan Albert (ACT)
Dean Clifford (QLD)
Lisa Brains (VIC)

And committee members
located around Australia.

Family Support program

The Family Support program received 464 applications for assistance with various EB related items during the 2021/2022 financial year, which is an increase of 117 applications compared to this time last year.

Our National Family Support Coordinator has attended 170 meetings resulting in positive outcomes for individuals living with EB and has also connected with families on a national basis 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.

Five new EB families were also supported during this time.

The Family Support program assisted many existing and new 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. 2021 was difficult when dealing with challenges that COVID-19 threw, however we managed to provide on-going support to EB families virtually. Since borders reopened, we were able to reach more families and clinics with face-to-face presence increasing levels of support. Eight families were also able to access much needed respite via the newly implemented Butterfly Break program providing opportunity for restful time away enabling families to reconnect. Simone, National Family Support Co-ordinator, has also been involved in major fundraising activities in Melbourne and will continue to promote DEBRA whilst raising awareness for our programs.

Rest in peace

Sadly over the past year there have been three community members who are no longer with us. Our deepest condolences go out to their friends and family.

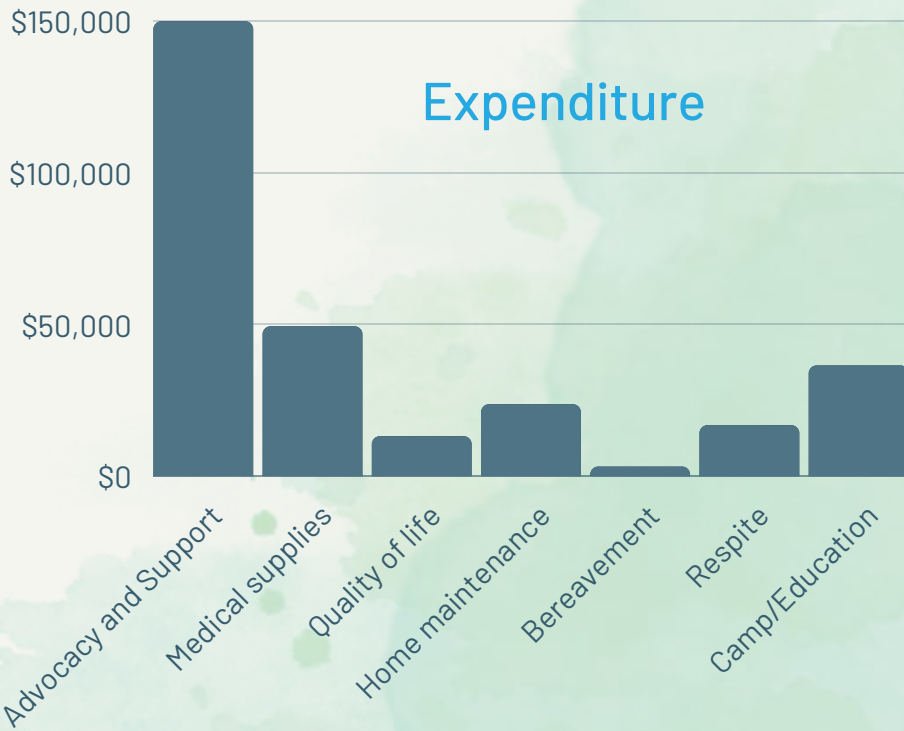
Nikki Howe (pictured right)– July 2021

Zeelan Hussaini – October 2021

Richard Frost – April 2022



Family support in numbers



17

EB clinics attended

464

Family support grants approved

29

Families supported for NDIS

1000

Contacts made with EB families

170

Contacts made with health professionals



Simone attending the Sydney EB Clinic where she met up with the Azny family.

EB camp

The Seventh National DEBRA Australia EB Conference & Children's Camp was finally held in April 2022 after two postponements due to Covid restrictions. The successful three day event went ahead at the Pullman Melbourne on the Park and was attended by 40 families. 160 people were involved overall, which was a great outcome considering the NZ families were not able attend due to travel restrictions being lifted just prior to the event going ahead.

The feedback and comments from the families was very positive via the survey results. The face-to-face interaction of old friends meeting up and new friendships being formed was invaluable. Interesting educational EB topics were on offer for the parents and some much needed respite with the children's program in place. The children had lots of fun and entertainment on and off site, with a dedicated team of volunteers looking after them.

The hands-on workshops were very well received with the dressings/wounds topic being the most popular. Feedback survey results also outlined that 92% of attendees would be extremely like to attend another event and 8% would be very likely to attend one.

Funding the event was made possible by receiving an Australian Government Department of Social Services National Disability Conference Initiative grant and also generous donations made by FGX, Convatec, Molyntycke Healthcare Ltd, Eliza Braitling Foundation and the Todd family.

Work has already commenced on the next event which is planned for 2024 in Queensland.



Central Victorian Trike Tours & Joy Rides provided fun activities on the day



Parents and carers attending the EB Dressing Workshop





EB grants

Follow your dreams

The successful 2021 grant recipient was Riordon from NSW. His dream was to meet the cast and crew of his favourite show Hamilton. Unfortunately this has not yet come to fruition due to strict Covid rules and is still a work in progress. As is the case for the 2020 grant allocated to Marie to go on a cruise ship holiday (with the Follow Your Dreams grant helping to support the cost with a \$1,170 grant). Alternative options are being looked into for both grants.

Kate Turner fund

The major focus for this year was to reprint the Boy who Dared book which originated in NZ to raise awareness and understanding in the school community. Generous donations were received from S LePoidevin and McLaren Vale Podiatry which allowed for this project to be completed. IVE Group in Melbourne generously provided free printing of the updated version. These new books have now been shared with families and community groups throughout Australia. A successful fundraising and donation year was had with \$6,780 in income received. A key contributor Laraine Frost continues to keep heavily involved, in spite of the sad loss of her lifelong partner and husband Richard. The continuous and unanimous support of the committee makes this a very satisfying fund to be involved with.



Crowds hit the beach during
Walk for Wings 2021

EB services

Hospital based services

There have been several developments regarding our EB nurses this year to assist them to meet growing workloads. DEBRA has increased its support at The Royal Melbourne Hospital (RMH) from 1 to 2 days/week and enabled the hospital-funded EB nurse at Sydney Children's Hospital (SCH), Rebecca Saad, to increase her work by an additional day per fortnight, bringing her position to 3 days every week. Rebecca is using this extra time to document Care Coordination Plans for children attending the EB clinics at SCH.

It has also been negotiated to increase the cover at The Royal Children's Hospital Melbourne from 2 to 3 days/week, with DEBRA funding two days and the hospital funding one. Lauren Weston resigned from the RMH position and was replaced by Sylvia Tsang, Sylvia has since resigned and recruitment of a new nurse is in progress. There was also a change at St George Hospital Sydney with Annaleen O'Hara replaced by Michelle McKinlay in March.

Negotiations are continuing regarding the establishment of a transition adult nurse role in Brisbane. The dermatology department at Princess Alexandra Hospital is keen to host this position but will need approval from hospital management and Queensland Health to establish a state wide service (centre of excellence) before this can be implemented.

Evaluation of nurse program

The impact of the nurse program was evaluated late in 2021, with input from our families and several health professionals. Several suggestions for improvement were received and are being implemented where possible.

Patients ranked most highly the following support provided by nurses:

- getting access to dressings and dressing scheme
- helping professionals to better understand and respond to the needs of EB patients
- helping to develop or understand care plans
- providing practical advice on how to deal with issues/manage care.

Health care professionals valued most highly:

- assisting access to dressings scheme
- providing input into NDIS applications
- helping patients/families to develop or understand care plans

Pictured left: EB Nurses Lauren Weston, Michelle McKinlay and Rebecca Saad



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 3 families not receiving NDIS funding.

EB dressing scheme

The process for adding new products to the list of products available via the national EB dressing scheme has now been implemented. This operates in line with the Federal Government's budget cycles in May and November. New product applications are considered in line with these cycles at the Department of Health and Aged Care's discretion. A slightly simpler process is available for replacement of products being discontinued. DEBRA liaises with the program administrator where necessary to address any questions or difficulties experienced by our clients.

NDIS

We continue to help individuals and families access NDIS support plans and also assist with plan reviews. In the past year we have achieved some good outcomes, with 29 clients currently receiving NDIS packages. Families are strongly encouraged to discuss their situation with our National Family Support Coordinator, Simone Baird, before engaging in negotiations with the NDIS representatives.

Psychology program

Consultation options in Sydney and Melbourne were expanded during the pandemic. Nine people are using program at present with telehealth consultations being used when appropriate.

Podiatry

Podiatrist Dr Tariq Khan holds a regular clinic at St George Hospital Sydney and negotiations to set up a program in Brisbane are moving forward in consultation with Professor Debbie Turner. Dr Khan has also been involved in establishing training with the Australian Podiatry Association.

Genetics

A small group has been formed to work on documenting the services available in different states for genetic testing and counselling regarding the various types of EB for pregnancy and family planning purposes. Some information will be included on the website and a future newsletter and individuals may contact DEBRA in confidence if extra help is required.

8

\$290,857

14

New babies born

Providing life changing services to EB Families



Marketing & fundraising

The Marketing and Fundraising committee has continued it's momentum this year. Coming out of Covid-19 lockdown, the focus has moved from a purely strong online presence to also now including in person fundraising and marketing opportunities. We have continued with a key focus on awareness and ensured a strong presence on our social media platforms Facebook, Instagram and heightened presence on LinkedIn, to successfully grow this platform and form of communication.

Fundraising

The committee has worked on continuing to manage and support third party fundraisers. This year DEBRA was successful in becoming a selected charity of the Upstream Challenge which is a 25km and 50km walk around the Donvale area in Melbourne run by the Upstream Foundation. DEBRA had a strong team of participants including corporate partner Intralink and overall DEBRA received a donation of \$28,401.46 (donation received in following financial year). The event received great feedback from our participants and also provided an opportunity for our volunteers to get involved.

We are extremely grateful for the continued support FGX in funding several of our EB Services. The generous funding has allowed us to not only continue with these critical services, but to expand into other areas of need, including podiatry and counselling services.

We also greatly appreciate the continued support of Brighter Days and the Melbourne Market Golf Day, which both went ahead in 2022. The Brighter Days event once again was the highlight of many supporters' calendars and the Melbourne Market golf day returning post Covid also had a great attendance.



Walk for Wings, 2022 in Adelaide



Brighter Days 2022
cheque presentation

Our key highlight was our DEBRA Walk for Wings this year which pivoted to have a selection of options so ALL states could be involved in the activity. We introduced an online trivia evening which was very well received and a virtual walk component for states that were still unable to gather to be part of the walk in their own way. Only two live walks were able to take place where there were no restrictions.

Ambassadors

DEBRA has continued strong partnerships with our ambassadors Matt Bevilacqua (Ironman), Dean Clifford (EB Warrior and motivational speaker), Joel Bevilacqua (Bondi Rescue and Journalist), Lachie Gilbert (Rugby Union) and this year we welcomed a new female ambassador Lisa Brains (EB Warrior and self-confessed Bogan). Our ambassadors Matt Bevilacqua and Dean Clifford have continued to lead our 'EB Youth Crew' initiative and all ambassadors have continued to assist in our events and social media activations.

PR

The last financial year saw a big media buzz with 15 pieces across a range of online and print. Collectively, the PR efforts from this financial year would have exceeded a potential 20 million eyeball reach. Some key PR highlights included, 7News, 9 News, Kidspot, Mamamia & Men's Health.

Our PR campaigns were a mix of EB case studies and DEBRA fundraising campaigns. For the new financial year, we have built a strategy to ensure that media coverage spans across three key pillars; DEBRA fundraising campaigns and the impact those campaigns have on EB patients, medical research and breakthroughs locally and internationally as well as EB case studies sharing their stories.

DEBRA Australia continues to feature across aligned-organisations websites and newsletters, including; Wounds Australia, Australasian College of Dermatologists, Rare Voices Australia, DEBRA International and more.



The Intralink team at the 2022
Upstream Challenge



Participants at the 2022
Melbourne Market Golf Day

Research & education

In the last 12 months the main focus of the research and education committee included exploring avenues of how we can expand the program, increase awareness and education of health professionals and dissemination of Clinical Practice Guidelines based on the feedback received from our membership. The committee came up with a number of suggestions which helped the DEBRA Board develop their next strategic plan. We also welcomed A/Prof Albert Mellick to the committee and a patient representative Mrs Nina Azzopardi. Having a patient voice at our committee will be invaluable to help us ensure our activities are always focused on patient needs.

Our main activity also included a very successful Health Professional day in conjunction with Family Camp, this event was biggest to date and had a significantly increased number of industry representatives allowing great networking and interactions. The talks covered topics from nutrition to cardiac involvement, latest approaches in therapy development, wound management, infection prevention and skin cancer from both international and national speakers. Forum also included a talk by Ms Nurbanu Istar who lives with EB and shared her experience in developing independence. Overall, we really enjoyed face-to-face interaction and we hope to be able to organise more educational events on an annual basis moving forward.

The 2022 Health Professionals
Symposium in Melbourne





Research & education cont.

Research Grants

The following grants of \$40,00 each were awarded for projects to be undertaken in 2022.

“Identification of effective cannabinoid analgesics for Dystrophic Epidermolysis Bullosa”

Applicants: Dr N Veldhuis, Associate Professor Kenneth Pang, Associate Professor Johannes Kern, Dr. Blake Smith, Professor Iain McGregor, Dr. Elizabeth Cairns

·“Role of granzymes in itch”

Applicants: Dr C Turner & Professor Allison Cowin, University of South Australia (pictured above).

We look forward to outcomes of these research grants and updates at our future Health Professional Days.

Travel Grants

Three travel grants were awarded to young researchers to support their development in EB research and education by attendance of national/international conferences. The Following recipients received grants to present their EB research at prestigious conferences and we look forward to their reports post event:

Dr Hanif Haidari from University of South Australia received \$2,205 to attend Australasian Wounds and Tissue Repair Society Conference and Wounds Australia Conference in Sydney 12-17th September 2022

Dr Christopher Turner from Monash University received \$1,200 to attend Australasian Wounds and Tissue Repair Society Conference and Wounds Australia Conference in Sydney 12-17th September 2022

Ms Kathryn Chen from Western University Sydney received \$3,500 to attend a Matrix Biology Europe Conference in Florence Italy, 28-30th September 2022

DEBRA international & EB without borders

In the last 12 months DEBRA International (DI) has mainly focused on activities centred around supporting EB families affected by conflict in Ukraine to have access to dressings, medical needs, and nutrition. Through partnership with industry, and with support of DEBRA member countries and Red Cross Singapore we have to date assisted with over 68,000 euro to meet these needs. Additionally, we have helped with settlement of 35 EB families outside Ukraine who are fleeing conflict by providing transport, medical needs, accommodation, portable air conditioners, mattresses, as well as providing assistance to 65 EB families still remaining in Ukraine.

Dr Kopecki continues in his role as the Treasurer at the DI Executive Board and Dr Marty continues to be an essential member of the Governance committee. Our General Manager Lise Angus is continuing to develop important networks with other DEBRA General Managers globally. EB Without Borders program has slowed down due to COVID, and missions are now starting again with plans in next 12 months to support patients and health professionals in Sri Lanka and Hong Kong where new DEBRA members groups are formed. 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 several strategic plan items to ensure sustainability and improved fundraising and communications to continue to serve the global EB population.

- Report by Zlatko Kopecki (DEBRA International Representative)



A Ukrainian EB family pictured
above with their thank you
messages

Finances

Operating Report

This year our total income was \$852,349.91 compared with \$900,962.64 in the previous financial year. Whilst income was down the continuation of excellent support from our sponsors resulted in a deficit bottom line result of \$99,212.58 rather than the projected \$220,126.00 which was pleasing. DEBRA received unexpected additional larger funds from our supporters namely FGX and an anonymous donor to Brighter Days. Minor and website platform fundraising was stronger than the previous financial year and above budget. Reduced revenue from some of our longer-term investments and low interest rates on our term deposit investments. Annual expenses were tightly controlled with total expenses being held at \$951,562.49 in 2020/21 compared to \$813,892.66. Previously cancelled DEBRA events such as the bi-annual DEBRA family camp, Mum's Respite Weekend, additional EB Services support, and staffing costs saw an increase in expenditure.

Balance Sheet

Compared with the previous year, total assets decreased from to \$2,033,518.57 to \$1,971,240.28 and total liabilities increased from \$79,585.14 to \$116,519.43. Total equity was down from \$1,953,933.43 to \$1,854,720.85 at year end. The organisation's financial position is still strong, and reserves are above the Board's target minimum of \$800,000.

Budget

The 2022/23 budget projects a total income of \$852,000.00, and expenses of \$1,130,781.00 with a net deficit of \$278,781.00. This projected outcome provides additional support to both EB Services, Family Support and our Research and Education Programs. Results can also be affected by the timings of donations. Whilst a deficit of this size can be absorbed this year, we know that amounts of this size cannot be sustained indefinitely. Therefore, the Board supported by the Finance Committee will continue to place equal importance on fundraising and managing expenditure and walk the fine balance of minimising costs and providing support to families. This approach will ensure the sustainability of DEBRA Australia.

Auditor

The audit process went smoothly, and it is recommended that Hooper Accountants be appointed as auditors for 2022/23.

Investments

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

[Financial statements and our audit report can be viewed online here.](#)

Judith Davis

Finance Committee Chair



We thank you
for your continued
support
**of our life changing
programs**