

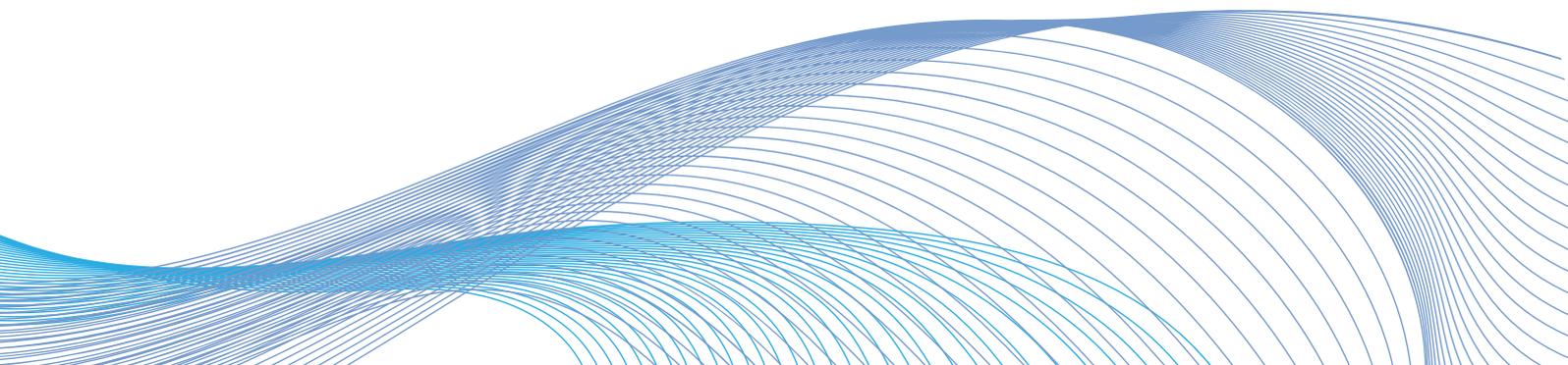
Kylan from NSW- one of the brave
butterfly children supported by
DEBRA Australia programs.



Annual Impact Report 2023-2024

Acknowledgement of Country

DEBRA Australia acknowledges the Traditional Custodians of the land on which we gather today, and we pay our respects to their Elders past, present, and emerging. We recognize their continuing connection to land, waters, and culture. We also acknowledge the continuing cultural, spiritual, and educational practices of Aboriginal and Torres Strait Islander peoples.



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Chair's Report



This year we bid a fond farewell to Lise Angus (General Manager) and Bianca Ciccia (Fundraising & Marketing Manager). I would like to welcome our new General Manager Mary-Jean Howard, and our interim Acting Fundraising and Marketing Manager, Ewan Isbister.

This is the second year of DEBRA Australia's (DEBRA) current three-year strategic plan, which is our benchmark to determine the success and impact of our programs and services, and our financial performance. Financial KPI's were met, with the organisation achieving a bottom-line profit. Our objectives to enrich the lives of families who depend on us for Family Support, EB Services, ongoing funding of EB Research, and Education and Awareness, were also achieved via the highlights in the following pages. Overall, the business is in a strong and dependable position. During our annual strategy and planning meeting in May, it was also reaffirmed that there would be no changes to our existing Vision and Mission.

Next year we will come together to formulate our new five-year Strategic Plan, which will be one of both optimism and fiscal consideration, to remain sustainable and financial in the future. We are aware of the current cost of living challenges and other external factors families face, and we will continue to focus our available resources on supporting families through these testing times.

As always, we are thankful for the ongoing support of our major sponsors, Future Generation Australia and Brighter Days Foundation. In addition, the long-term support provided by the Melbourne Market, Fresh State, The Lions Club of Melbourne Market, Valenti Golf Club, The Green Team, Intralink Wealth Management, and Nicholson and Ryan Lawyers to name a few, is greatly appreciated. This year we also thank the Classic Ladies Foundation, The Nigel and Patricia Peck Foundation, and the Pope Family who donated in memory of Darren Pope, for their generous support.

The Board's focus for 2024/25 is to:

- Ensure we offer continued support through our programs for families.
- Measure the impact of our continued programs and action all impact feedback and reports.
- Remain financial and sustainable for the future with a focus on fundraising.
- Succession planning for our Board and Committee positions and recruiting additional members across our required skill base.
- Ensure we work with a solution-based and impact decision making focus.

In addition to the significant amount of work done by our incoming General Manager on important operational and governance matters, the Finance Committee in July expanded its scope to include risk management for the Board.

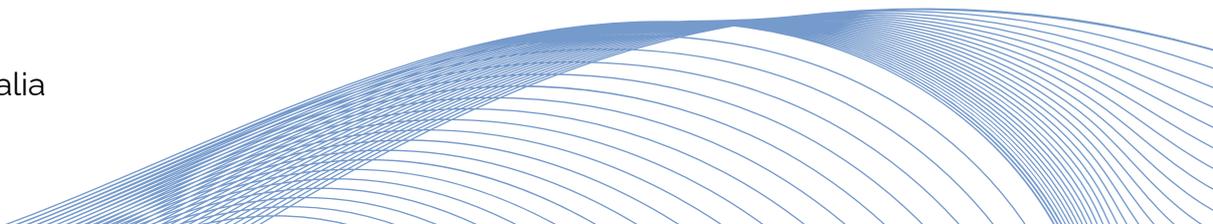
The significant social impact we have achieved this year would not have been possible without the outstanding work done by our wonderful, hardworking team at DEBRA Australia. This year they have all stepped up when required, and it has been valued and appreciated. I would like to thank Sue McKenna, who does a great job providing board support as Board Secretary in addition to her other staff duties, and our dedicated staff Mary-Jean, Simone, Jo, and our contractors, for everything you do for the entire EB community. We are also fortunate to have marvellous Board and Committee Members, all of whom are volunteers that willingly give up their time, insights, and expertise to assist DEBRA to do what we do. A big thank you from me – your support is valued and appreciated.

This year we are farewelling two of our longstanding Board members Dr Zlatko Kopecki and Melinda Oxford who have both been involved with DEBRA for many years. The first is Melinda Oxford who finished at the end of May. Melinda has had a 25-year association with DEBRA, firstly as President of the Victoria DEBRA, and on the Board and Family Support Committee for 8.5 years. We thank Mel for her amazing contribution and wish her well.

Our second farewell is for Dr Zlatko Kopecki who steps down from the DEBRA Board as of the AGM in October. Zlatko began his involvement with DEBRA in 2007 and has been able to both lead the Research and Education Committee, and represent us on the DEBRA International Board where he is currently the Treasurer. Zlatko was responsible for piloting the in-home nursing in Adelaide which later became a national program. He has also peer reviewed research grants and travel scholarship grants for health professionals. Additionally, Zlatko has organised the annual Health Professional Symposiums, the training of the next generation of scientists in EB research, and has been working with disadvantaged, or war affected EB families overseas. His service and commitment to DEBRA here and overseas has been nothing short of exemplary, and in recognition, I have awarded him the Chair's Award.

In closing, I look forward to serving you again as Board Chair, and approaching the coming twelve months with optimism and energy. We have so many opportunities ahead of us and I have no doubt we will all embrace them, together.

Judith Davis
Chair, DEBRA Australia



Our Vision

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

Mission

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

Primary Objectives

- To ensure continued access to specialised EB care across Australia
- To support EB families in improving their quality of life
- To encourage research which develops innovative treatments towards a final cure for EB
- To promote awareness and understanding of EB
- To become financially sustainable

Values

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

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

Our Impact

DEBRA Australia delivers impact across our program areas, working towards our vision of a world where no one suffers from the painful genetic skin condition Epidermolysis Bullosa (EB). Our *Theory of Change* speaks to these impact areas, highlighted through the key changes we contribute to outlined below.

Quality of Life



Families and individuals are supported



Families and individuals are connected



People with EB are more independent



Quality of life improves

Treatment Today



Health professionals across Australia have increased knowledge of EB



The healthcare system has increased capacity to treat EB



People with EB have increased access to treatment

Treatment Tomorrow



Growing networks of EB researchers



Increased knowledge sharing amongst researchers and health professionals



Awareness



Increased awareness of EB



Increased fundraising and advocacy for people with EB



More resources available to support wellbeing and treatment



Community Insights

Through our extensive programs and services developed to best support our EB community, DEBRA continues to grow engagement and track community impact across key areas including:

- The Family Support Program
- EB Services
- EB Grants
- Research and Education
- Fundraising and Community Events

78%

Of families agree DEBRA has made them feel more connected with the EB community



"Thank you from the bottom of my heart for giving my son the greatest gift ever, the opportunity to meet others like him and show him he's not alone. We had a great weekend and I learnt so much and have so much more knowledge now on my sons condition." - EB Mum

"The Butterfly Break was such a lovely time, we went to the beach every day and went for walks and just a different scenery was just lovely. We can't thank DEBRA enough for giving us this opportunity to take Ellsie away, we had the best time." - EB Mum

94%

Of families agree they feel supported by DEBRA Australia



"It was a great opportunity to get away and connect with other EB dads that I wouldn't normally have a chance to meet and get to know. And the best part was that we all understood what each other was going through." - EB Dad

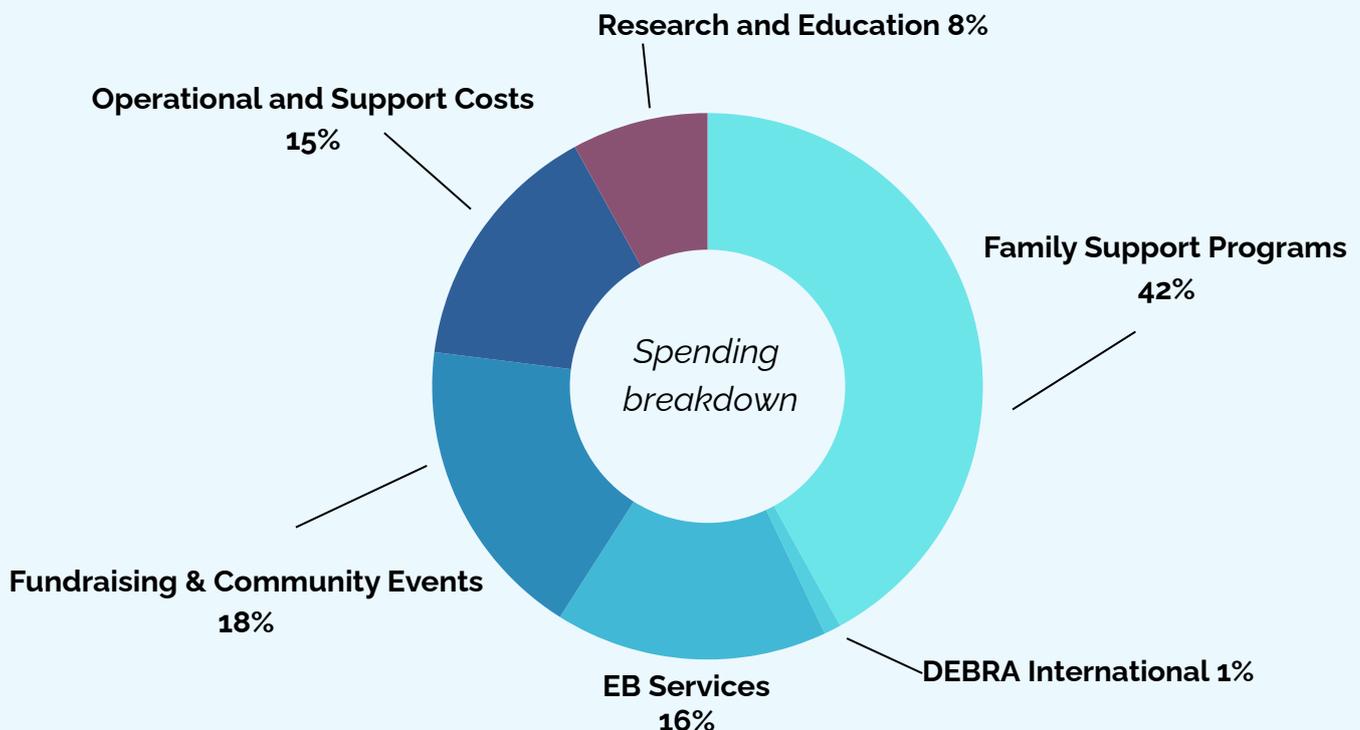
How we applied our Financial Resources

2023/2024 Financial Year Results

We are so grateful to all the donors, partners and funders that make our work possible. Thanks to this vital support, the 2023/24 financial year saw our total income come in at \$1,142,499, compared with \$1,028,804 for the 2022/23 financial year. Our improved income result was due to the continued support of our major sponsors, new donors, investment performance, and fundraising outcomes.

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

Financial Year 2023-2024 Expenditure



Investment in Our Future

2024/2025 Financial Year Planning

The 2023/24 budget projected a total income of \$1,025,700 and an expected net deficit of (\$156,415), but thanks to a welcomed uplift in revenue and prudent management of expenses, DEBRA Australia was able to end the financial year with a net surplus of \$95,351 to re-invest and support future planning.

The 2024/25 budget projects the need for an increase in revenue of up to 40% in order to continue to respond to growing support needs, and invest in further developing company resources. Noting this projected financial need calls for an unprecedented revenue growth rate within a 12-month period, a carefully considered potential net deficit for the financial year 2024/2025 has again been approved. Whilst significant deficits are not sustainable long term, it has been supported for this next financial year, with the Finance and Risk Committee closely monitoring the interest rate environment, inflation, expenditure, and the cost-of-living challenges, to make appropriate recommendations to the Board as required. This approach will ensure the continuation of existing DEBRA programs and services, and support the required incremental growth of the organisation as a whole.

In addition to the five-year business strategy planning in 2025, a new five-year Fundraising Strategy is also under development and planned for implementation in 2025. The aim of developing this robust long-term plan is to further support revenue growth and diversification of fundraising streams, as part of working towards one of DEBRA's primary objectives of being financially sustainable and future proofing for the long term.



Family Support Program

Over the past year, DEBRA's Family Support Program has seen an increase of 12% more families now known to us, meaning there are now over 360 people who are living with EB on our database. In addition to the increased numbers of families and individuals DEBRA is supporting through this program, there has been a 50% increase in requests for support in FY 2024, as many from our community face ongoing pressures amidst the cost of living crisis in Australia.

DEBRA is dedicated to addressing the increasing needs of our community, offering support services to both individuals living with EB, and their family members where required. This is delivered via the various mechanisms in place ranging from advocacy, funding medical supplies and equipment, respite programs, therapies and more.

This year, our Family Support Committee welcomed Mary-Jean Howard as the new General Manager and as a committee member, whilst also farewelling Kylie Gibson after many years of service and expertise on this committee.

Throughout the year, 18 multidisciplinary clinics have been attended across the Eastern States where established clinics are in place via the public hospital sector. An ongoing focus for DEBRA Australia has been increasing our reach to more states and rural areas. This has been working well, resulting in a recent visit to Perth to meet with the health professionals looking after patients in Western Australia.



Our Family Support Coordinator Simone Baird, with EB mums on their respite weekend in Byron Bay

737

Assistance
applications

12%

Increase in
families

At DEBRA, connection, advocacy and referral to vital services remain a priority. Many of our families are accessing the National EB Dressing Scheme while others are accessing government assistance and funding through the National Disability Insurance Scheme (NDIS). Where necessary these families are assisted to apply for NDIS funding and supported with their review plans to maximise funding and care outcomes. Five new EB families were welcomed into the EB Community in this financial year and have been connected to services where appropriate.

Fourteen families were able to access much-needed respite via the Butterfly Break program, providing an opportunity for families to reconnect and refresh, away from the pressures of life with EB. The Mums' Weekend Away in Byron Bay was once again highly successful and allowed fourteen mothers of children with EB to have a much-needed break and time to network with others who share their experiences with EB or in dealing with bereavement. The Pope Family's generous donation made it possible for a new initiative to be implemented and eight EB Dads attended the inaugural Darryn Pope Dads' Weekend Away. This pilot program was well received with very positive feedback.

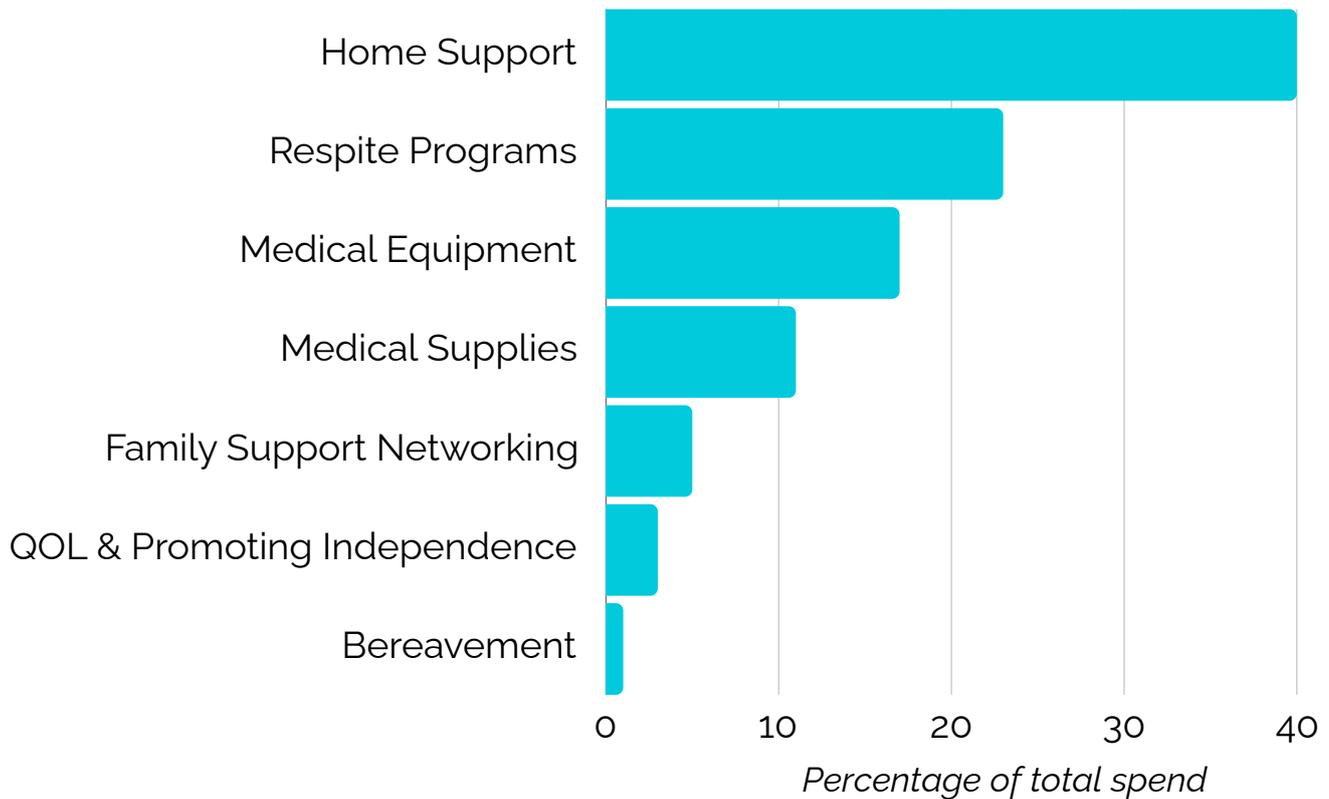
Another need identified and fulfilled over the last financial year, was to provide art, music and play therapy options for children and siblings. Feedback on this service has been overwhelmingly positive on both the individual children and their family unit.



Golfing at our inaugural
Darryn Pope's Dads
Weekend Away in Byron Bay

Family Support

Impact in numbers



18

EB Clinics
attended



14

Mums attended
respite weekend



50%

Increase in support
applications



43

New people joined
the DEBRA
community





Chartotte during her Butterfly Break in QLD



DEBRA Ambassador Dean Clifford using his Follow Your Dreams grant in Las Vegas



Brighter Days 2024

EB Services

Hospital based services

DEBRA Australia continues to fund the National EB Nurse Program, in partnership with hospitals in key areas of need across Australia. This essential program assists in providing specialised healthcare services and resources to those living with EB, and their families.

In 2024 we welcome some new faces to our EB nurse team, with Holly Ferguson taking over the role at the Royal Melbourne Hospital in January 2024, and Bianca Mirco commencing at St George Hospital in July. From September 2024, highly experienced nurse Bonnie McNeill takes on the role of main EB Service nurse at the Brisbane Children's Hospital, with Samantha Hay farewelled and warmly thanked for her many years of dedication to this role.

In home EB care and NEBDS

Many EB families are now being supported via the NDIS for in home nursing or support workers. During the year DEBRA has coordinated home care for three families not receiving NDIS funding. DEBRA also continues to liaise with Independence Australia, the current National Epidermolysis Bullosa Dressing Scheme (NEBDS) administrator, to address any EB community questions, and help facilitate access.

Psychology Program

Demand for psychology and counselling services has continued to grow this year, with an increase in utilisation of 400% since program inception, and 37 people now accessing the program. Future budget planning to further support the growing demand for access to this program, has been put in place for FY 2024/25 accordingly.

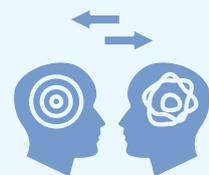
5

EB babies born
this year



37

People involved in
our psychology
program



National Disability Insurance Scheme

DEBRA continues to provide valuable support to eligible individuals and families living with EB, regarding gaining access to the scheme, and with regular NDIS package reviews. Families are, therefore, strongly encouraged to discuss their situation with our National Family Support Coordinator, before engaging in negotiations with the NDIS.

In 2024, a feasibility study was conducted to investigate the possibility of DEBRA becoming an NDIS Program Co-ordinator. Feedback was sought from DEBRA families and a few external organisations. When taking into consideration the current interest within the DEBRA community for such a service, the likely income together with costs, and the feasibility of employing an NDIS Program co-ordinator, it was concluded that it would not be viable to establish such a role at this stage. Changes by the Federal Government to the operation of the scheme are expected in the next year and the impact of any changes affecting EB families will be closely monitored.

31

Clients
supported by
the NDIS



Podiatry

Feedback has been very positive about the quarterly clinic being held by Dr Tariq Khan in Brisbane, with the cooperation of QUT. Dr Khan also holds a regular clinic at St George Hospital Sydney, and hospital-sponsored clinics are held regularly at Royal Children's Hospital Melbourne, and Sydney Children's Hospital. This year, funds were also donated by DEBRA Australia, to enable the children's hospitals in Sydney and Melbourne to purchase nail drills for their clinics.

Genetics Program

The Genetic Support Program is experiencing a growing interest, with many young families experiencing gaps in the funding available for genetic testing. To support these families with their assisted pregnancy planning, DEBRA Australia has provided some financial assistance to help cover the costs of this vital testing.



EB Grants

Follow Your Dreams

In 2024, DEBRA Australia lost a much-loved and dedicated member of the Follow Your Dreams (FYD) Sub-Committee, Geoff Harris. Geoff is a family member of Carmel Harris, of whom this grant is dedicated. In Geoff's absence, Carmel's sister Delvene and her husband Nick have joined the committee to continue representing the Harris family. As the current General Manager of DEBRA Australia, Mary-Jean Howard has also joined the committee replacing Lise Angus, who the committee thank for her contribution during her time as General Manager at DEBRA.

During the past year, the committee have worked to increase the funds available for FYD grants, and are looking to extend grants to more applicants in 2024-2025. The most recent FYD grant recipient is Ryan Hoffman, from Victoria. Ryan and his family were able to fulfill his dream and head to Darwin for a crocodile encounter he had long desired. The family had a wonderful time, and we were so pleased to make this happen for them, through the support of this grant.

Kate Turner Fund

The Kate Turner Fund (KTF) has existed now for over 11 years, championed by Laraine Frost and in memory of DEBRA Australia foundation member, Kate Turner. This financial year, the committee was thrilled to award the KTF grant to three applicants, totalling just under \$5,000 being awarded. These grants were awarded across three different states:

- Dean Clifford in Queensland, DEBRA Australia's ambassador
- The Azny family in New South Wales
- Hannah Burmeister in Victoria

Each grant was awarded for different and worthy purposes, within the funds criteria.

The KTF is now able to record a healthy \$57,477, plus a \$2,000 donation secured by Laraine Frost. On top of this, the account has earned interest of \$2,500, which represents 50% of its annual maximum grant allowance. The future goal of the KTF committee is that this interest will soon be able to cover the maximum grant payments. The Sub-Committee Chair, Roger Trevor, thanks all committee members for their ongoing support, paying special tribute to Laraine Frost for her efforts in continually promoting donations for the KTF.

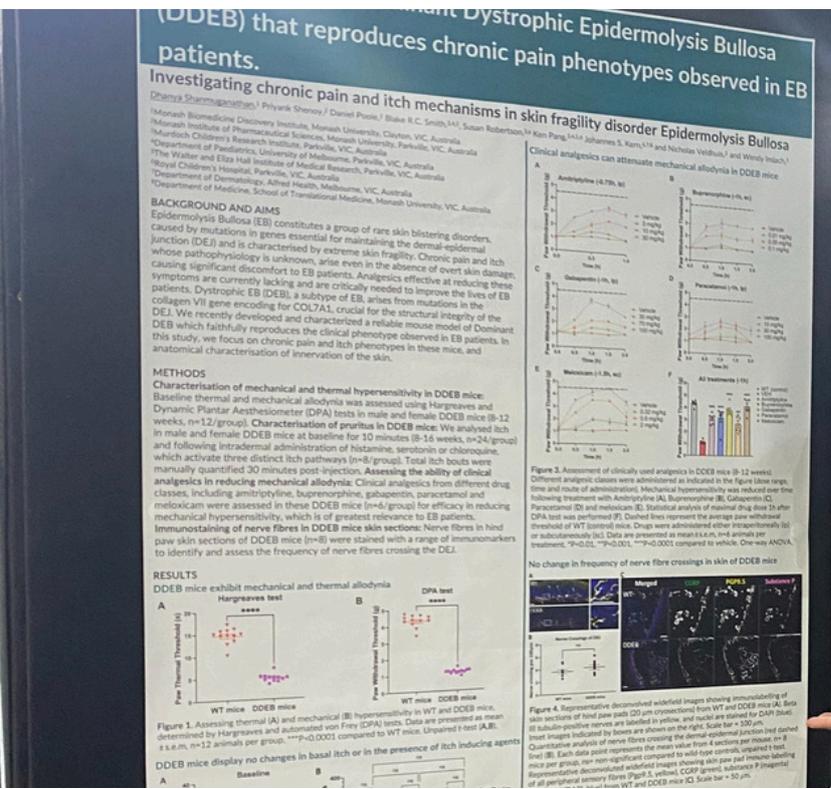
Research & Education

Over the last year, the focus of our Research and Education Committee included supporting early carer researchers with research and travel grants, organising a health professional symposium, and exploring how DEBRA Australia can partner with international DEBRA groups, to better support research activities in Australia.

The highly successful 2024 Health Professional Symposium hosted an esteemed keynote speaker from Stanford University, Professor Peter Marinkovich, who provided the latest updates on gene therapy approaches for EB. An exciting program was also developed, which included a number of clinical and research topics spanning from novel therapies, to gene editing, infection, skin cancer, and eye care, while also discussing palliative care guidelines developed by DEBRA International, and support needs required for families living with EB.

During 2024, DEBRA succeeded in securing a Global Skin grant. This grant enabled the delivery of a workshop on skin cancer awareness for individuals with EB, held at our 2024 EB Family Camp and Conference, and facilitated by Dr Susan Robinson.

DEBRA continues to collaborate with relevant stakeholders to provide access to the latest treatments, therapies, research, and educational resources for all Australian EB patients and health professionals, now and in the future.



Dr Dhanya Shanmuganathan from Monash University who received one of our 2024 research grants

Research Grants

The following grants were awarded for EB research projects to be undertaken in 2024:

Awardee- Dr Nicholas Veldhuis, \$50,000

Project Title- *“High resolution imaging to characterise a unique mouse model of Dystrophic Epidermolysis Bullosa (DEB).”*

Awardees- Dr Hanif Haidari, Dr Zlatko Kopecki, and Professor Krasimir Vasilev, \$30,000

Project Title- *“Development of biodegradable multilayered microneedle patch for targeted treatment of deep infection in EB patients.”*

Awardee- Kathryn Chen, \$30,000

Project Title- *“An RNA fingerprint of Malignant Squamous Cell Carcinoma in Recessive Dystrophic Epidermolysis Bullosa.”*

Travel Grants

The following travel grants were awarded in FY 2024:

Awardee- Dr Dhanya Shanmuganathan, \$1,000, Monash University, Melbourne Vic
Poster presentation at the Australian Pain Society 44th Annual Scientific Meeting (Darwin – April 2024)

Awardee- Dr Hanif Haidari, \$2,000, University of South Australia, Adelaide SA
Presentation at the 12th World Biomaterial Congress (South Korea – May 2024)

Awardee- Jasmine Zhou, \$2,100, Ingham Institute, Sydney NSW
Brisbane Symposium (August) and EB Clinet Conference in Vienna and visit EB Haus – Austria.

92%

Of health practitioners surveyed agree they have more knowledge of EB after interacting with DEBRA



96%

Of health professionals agreed DEBRA improves quality of life for people with EB



Our Supporters

DEBRA Australia is deeply appreciative to all of our incredible donors and partners for supporting us in 2023-2024, joining us as change makers for the EB Community.



sutherland medical



- Co- Group
- Blackwood Capital
- Valenti Golf Club
- Tony & Dot Geldart - LITE guard Safety Solutions
- Long Weekend Laughs - Daniel Connell
- Green Team - Eliza Ride
- Quota Club of Wynnum Manly Qld Inc
- Redcliff Secondary College (SA)
- The Nigel and Patricia Peck Foundation
- Thelma Carr Foundation
- Toombul Ladies Bowls Club
- WA Billboards
- Mary Woods
- Balgownie Football Club (NSW)
- EB Dressing Scheme funded by the Australian Government
- J Thyne Hedges
- J & J Marty

Fundraising & Marketing

Our Fundraising and Marketing (F&M) team continued to grow fundraising and awareness-building activities for DEBRA Australia over the past financial year, and is now looking to the future with the pending finalisation of a 5-year Strategic Fundraising Plan, for inception by early 2025. Over the past year, we saw an increase in revenue from fundraising activities of 11% with a total income of \$1,142,499, which was a great result above budget.

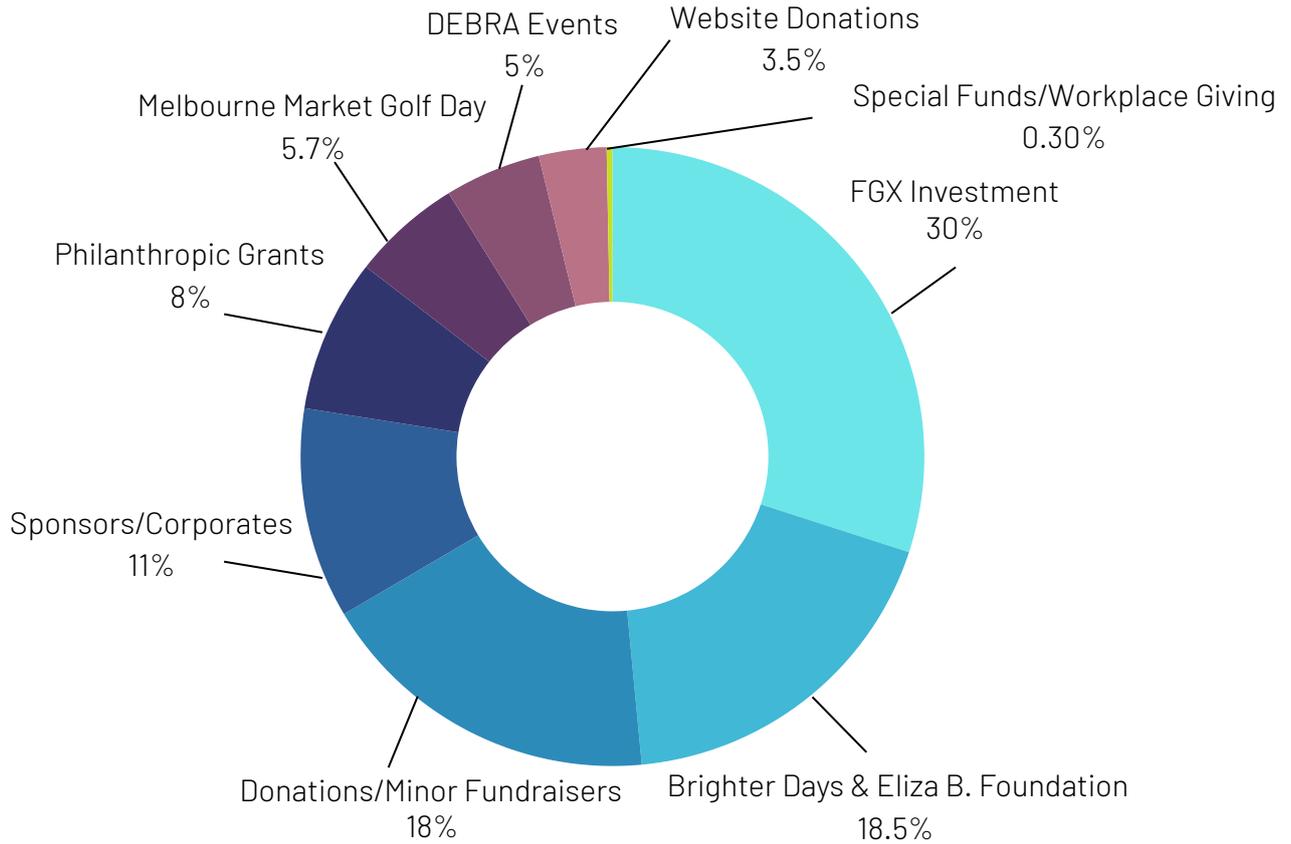
Annual Fundraising Campaigns

Annual fundraising campaigns also played a significant role in revenue generation, such as Walk for Wings (\$35K raised), and the FY24 Tax Appeal (\$9.5K raised online and \$5K thanks to the Lions Club of Melbourne Markets).

Third-Party Fundraisers, Grants and Foundations

Third-party fundraisers, grants, and foundations continue to play a vital role in fundraising revenue generation for DEBRA Australia. This year, DEBRA welcomed the support of the Classic Ladies Foundation, at their annual Nutrien Classic event in Tamworth which raised over \$60k. It was also the second year of support from Daniel Connell, Laura Dunemann, and the Comedy Lounge, hosting the Long Weekend Laughs 2 event which raised over \$15K. Thanks to the support of organisations such as the Newman's Own Foundation and The Co-Group, grants obtained throughout the year have also greatly assisted with funding existing programs and services, education activities, and specific purchases, such as Nanobubble Hydrotherapy Devices.





Marketing and Public Relations

DEBRA Australia continues to grow its marketing and public relations activities, with the support of marketing, communications, graphic design, and public relations contractors. This has resulted in a general upwards trend in engagement across online and print publication platforms. PR firm Ruby Agency continues to work with DEBRA to raise awareness about EB and highlight the organisation's critical work. A total of 37 media pieces were featured in various online and print platforms over the FY24 period. The coverage included a mix of both planned and organic media exposure. This resulted in a potential reach of over 30 million individuals, with media highlights for the year including coverage in Kidspot and The Canberra Times.

Social Media

Across all platforms there were 492 posts published during FY24, reaching 186,141 people. This shows an increase of 50,000 from the previous year, and an average engagement rate of 9.2%. DEBRA has also achieved growth in FY24 across all online platforms from FY23, with notable increases for Instagram at 9%, and LinkedIn at 33%.

13,932

Website views



492

Social media posts



DEBRA International

In the last 12 months DEBRA International (DI) has mainly focused on activities around executing its recently developed strategic plan. This included hosting the DEBRA International Round Table of Companies (DIRC) initiative as DI engage more with industry, delivering on patient education via the online webinars, supporting the establishment of the DEBRA International Youth Council, and hosting the first Middle East and North Africa (MENA) region congress in Egypt.

Some of the highlights of this year, include DEBRA International winning the EURODIS Black Pearl Award for it's work helping EB patients in Ukraine, Syria, and Turkey, and having a strong presence at the first MENA Congress in Cairo. This congress had 326 participants from 31 countries, including three presenters from Australia who shared their clinical and research knowledge (Prof Dedee Murell, Dr Zlatko Kopecki and A/Prof Albert Mellick). Top 5 priorities of the congress to improve the patient care included: Better access to basic medical needs, learning from patients, early intervention, education programs for health professionals, and faster and accurate diagnosis globally.

Dr Zlatko Kopecki with
DEBRA Int. staff at the EB
MENA Conference



Dr Albert Mellick with
families at the EB MENA
Conference



DEBRA Australia Team

Thank you to the wonderful and talented team who were involved with us this year:

Board

Judith Davis – (Chair) (SA)
Tina Segulin (Deputy Chair) (VIC)
Zlatko Kopecki (Deputy Chair) (SA)
Melinda Oxford (VIC)
Belinda James (VIC)
Michael Kean (NSW)
Tony Baum (VIC)
Bronwyn Sacks (VIC)

Employees

Mary-Jean Howard (NSW) – General Manager
Simone Baird (VIC) – Family Support Coordinator
Sue McKenna (QLD) – Executive Coordinator/Board Secretary
Joanne Sturgess (QLD) – Administration Assistant

Employee Farewells

We extend our gratitude to the following staff for their years of dedication and contribution to the vital work of DEBRA Australia-

Lise Angus (NSW)- Outgoing General Manager
Bianca Ciccio (NSW) - Outgoing Fundraising and Marketing Manager

Contractors

Ewan Isbister (NSW) - Fundraising & Marketing
Jillian McKee (NSW) – Communications and Fundraising
Scott Macfarlane (QLD) – Website/IT

Ambassadors

Joel Bevilacqua (NSW)
Matt Bevilacqua (QLD)
Lachlan Albert (ACT)
Dean Clifford (QLD)
Rena Wood (QLD)
Daniel Connell (VIC)
Deanna Pope (VIC)



Mary-Jean Howard and Simone Baird alongside comedian Jimeoin



Get Involved

DEBRA Australia relies on the generosity of the community to continue to provide life-changing support and programs for people living with EB and their carers. You can help transform the lives of EB families across the country by making a donation at debra.org.au. Any donation over \$2 is tax deductible. Contact us today to discuss how you can get involved with DEBRA Australia in the future.



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