

Table of contents

- **3** Supporters
- 4 Our vision
- 5 Words from our community
- 6 Program expenditure
- 7 Chairs report
- 9 DEBRA team
- 10 Family Support
- 13 EB grants
- 14 EB Services
- 16 Fundraising & Marketing
- 18 Research
- 20 DEBRA International
 - 21 Finance

Major supporters























Melbourne Market Authority

African Violet Society Qld **Andrew Brains** Balgownie Football Club **Barry Springfield** Burmeister family Catherine Webb City of Adelaide Concert Band Claudia Hudson Fresh State P/L Geoff Harris (in memory of Jan Harris) Green Team - Eliza's Ride Harin Karra J&J Marty Jean Thyne Hadges K & R Nixon Kiwanis Club Glenelg (SA) Long Weekend Laughs - Daniel Connell Manjula Shaw Marie Pitts

Melbourne Market Lions Club Michael Brodie National EB Dressing Scheme funded by the Australian Government Nina Azzopardi Noel Kratzmann Payne Road State School Quota Club of Wynnum Manly Qld Inc Redcliff Primary SA The Sentinel Foundation Thelma Carr Foundation Todd family **Toombul Ladies Bowls Club** Toowoomba morning tea (Lizzie Carr, Anne Howard, Rhondda Dean & Committee) Toyota Material Handling Australia P/L Up Stream Challenge Valenti Golf Club WA Billboards

Our 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. 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.

Values

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.

<u>Compassionate:</u> We support EB families with compassion, respect and empathy. <u>Ethical:</u> DEBRA is a professional, responsible, honest and ethical organization. <u>Accountable:</u> DEBRA is accountable and transparent to its members and to the wider community.

<u>Collaborative:</u> 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



"It was lovely just to be me for a few days, not mum, not wife or carer. I was able to turn off and get some desperately needed sleep and just quiet time. I learnt a lot from the other mums just in general conversation and hearing their experiences with EB."

-Attendee of our mums respite weekend

"It was fantastic having my daughter see the new specialised EB podiatrist in Brisbane. He has passed on his knowledge on home management, and she has been trying to follow this as best as possible."

-EB mum, Brisbane, Queensland

"Attending the Mum's respite break, I found that I benefited from meeting other Mums who know about EB and making me not feel alone. I have found the EB journey a very lonely journey until now. I feel I have made lifelong friends and forever grateful for that."

-Attendee of our mums respite weekend

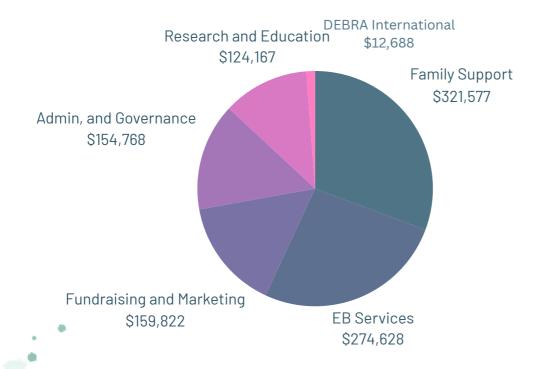
"I feel thankful that my daughter has the support and knowledge that I didn't have growing up.
I feel thankful that I have the support, through DEBRA and my health care team, that my mum didn't have on her journey."

- EB mum, Melbourne, Victoria



Program expenditure

Total expenditure: \$1,047,650

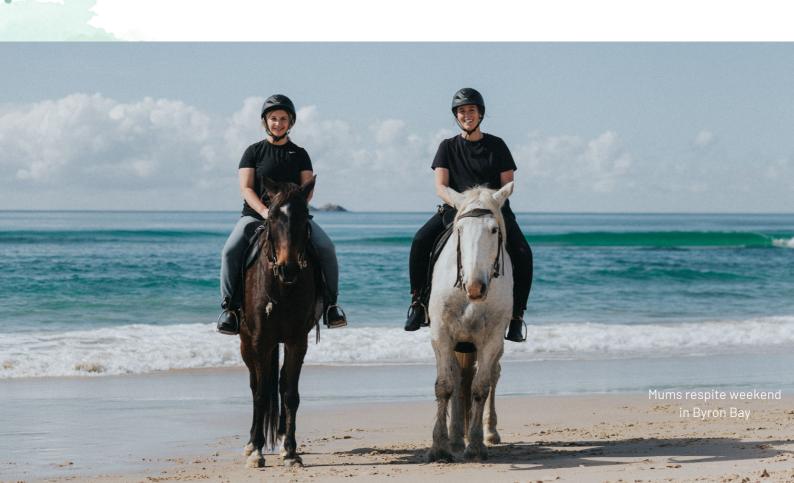


Specialist EB nurses funded

2000
Volunteer hours

6
Babies born

with EB



Chairs report

a year?

DEBRA Australia Board
Chair Judith Davis

How do we measure our success at DEBRA each year? We look due North to our Mission Statement which ultimately strives towards providing the best support possible for people living with EB.

To enable this, our organisation to be financially stable now and into the future. This year our bottom-line result was \$78,776.00 however it must be noted that this was the result of some unexpected donations in June – funds which are guarantined and to be used for specific purposes in the future. On that basis it is fair to say we came in at a break-even position which was pleasing when compared to the projected loss we had budgeted for. Unexpected larger funds from two of our major supporters namely Future Generation Australia, and Brighter Days were gratefully received and certainly made a difference as did those funds raised by the Melbourne Market Golf Day. Additionally, we were supported this year by Nicholson Ryan who we thank for their ongoing legal and financial support. There were two unexpected large donations this year the first being from Geoff Harris for \$100,000 in memory of Jan Harris for Follow Your Dreams, and from the Pope Family in memory of Darren for \$50,000 this year and an additional \$50,000 pledged for the 23/24 financial year. We thank both families very much and we know those funds will make a real difference to the families we support. By way of example, we will be able to fund 20 Butterfly Breaks in 23/24 (which is double last year) thanks to the Pope family's donation and we have no doubt the Follow Your Dream funds will make some EB children's dreams come true

During this year our Family Support has again been outstanding. Twelve new EB families with babies were supported and sadly six individuals passed away, which is never an easy time for our EB Community. Specifically, this year we lost our Ambassador Lisa Brains who was a true EB Warrior and an inspiration to all she came in contact with during her lifetime. In recognition of her contribution to the DEBRA Community we will be naming a specific research scholarship after Lisa in the 2023/24 financial year.

Our Family Support Co-ordinator has also been many families with their transition to access NDIS through assisting with plan reviews. We now have 30 families receiving NDIS Support. This coming year the EB Services Committee in conjunction with our Family Support group will conduct a feasibility study into the possibility of DEBRA Australia becoming a NDIS program co-ordinator.

Chairs report

This year, EB Services has been at the forefront of DEBRA's support offering. Our EB nurses continue to provide an excellent service to the EB community in Melbourne and Sydney hospitals. Negotiations in Brisbane have stalled regarding the establishment of a transition/adult nurse role. Our long-term objective is to have an EB specialised nurse in every state. Three families who are not supported by NDIS funding continue to be supported by DEBRA for home care, and DEBRA continues to fund dressing costs where required. The demand for psychology services has grown with 29 people using the program in the last 12 months and we have had an increased demand for our podiatry services.

In 2023, we were able to increase the size of our Australian research grants to two grants of \$50,000 each. Travel grants were awarded to nurses, clinicians, and scientists in the early stages of their careers to assist in the development of EB research and education. Guidelines have been developed during 2023 for the funding of a PhD research scholarship which will roll out in 2024.

One of our key strategic objectives is to expand the measurement and evaluation of the outcomes and impact of our programs. Thanks to Future Generation funding in 2022/23, we have been able to engage an external company (For-Purpose Evaluations) to assist us to develop suitable surveys, and then monitor the responses to better service all internal stakeholders and achieve that strategic outcome. We are in the early stages and will report back the outcomes to all relevant internal and external stakeholders in the coming months.

None of the achievements we have had this year would have happen without the outstanding work done by our General Manager Lise Angus and her wonderful team. I would like to specially thank Sue McKenna our Board Secretary who has done an amazing job keeping up with my many requests. We also have a marvellous Board and Committees who are all volunteers, and willingly give up their time, insights, and expertise to assist DEBRA to do what we do.

Finally, I would like to recognise Dr Jennifer Marty who is stepping down from the DEBRA Board this year. Her service and commitment to DEBRA has been nothing short of exemplary. Jenny was invited to join the Board as a Director in 2012 when the states amalgamated through Project National to become DEBRA Australia Ltd. In those early days of the new national organisation Jenny was involved with the Finance Committee as well as both the Research and EB Services Committees and will continue to be involved with the latter two into the future. Jenny is also on the Governance Committee of DEBRA International and has served as Chair of the DEBRA Australia Board since 2014. She also managed staff until we appointed a General Manager five years ago. Jenny has been a calm, pragmatic and compassionate leader who bought structure to a fledgling organisation and has always dug deep to get involved in any fundraising event.

DEBRA team



Board

Jennifer Marty (Chair) July to November (NSW)
Judith Davis – (Chair) November onwards (SA)
Tina Segulin (Deputy Chair) (VIC)
Zlatko Kopecki (Deputy Chair) (SA)
Melinda Oxford (VIC)
Belinda James (VIC)
Mary Woods – Retired from November (NSW)
Michael Kean – New Director from November (NSW)

Employees

Lise Angus (NSW) – General Manager Simone Baird (VIC) – Family Support Coordinator Bianca Ciccia (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) New Ambassadors: Renae Wood (QLD) Daniel Connell (VIC)

Family Support program

The Family Support program received 491 applications for assistance with various EB related items during the 2022/23 financial year, which is an increase of 27 applications compared to this time last year.

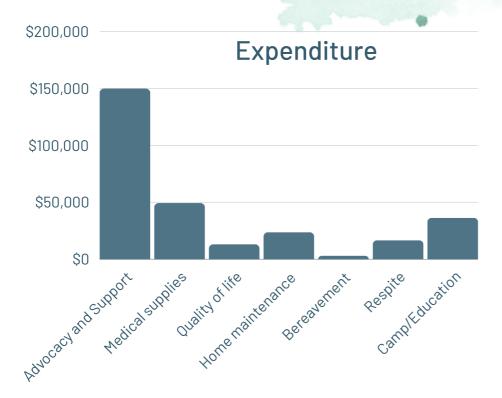
Our Family Support Coordinator, attended 192 meetings resulting in positive outcomes for individuals living with EB and has also connected with families via emails, phone calls, telehealth and zoom meetings through-out the year. Additionally, 17 EB clinics and many face-to-face meetings were held with EB families in various states, including rural areas whilst working closely with the EB multi-disciplinary teams to best support the EB community. Twelve new EB families were also supported during this time and sadly six individuals passed away, tragically two of them were newborn babies.

The Family Support Committee assisted many families, including 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.

Ten families were able to access much needed respite via the Butterfly Break program providing opportunity for restful time away enabling families to reconnect. Nine mothers of children with EB accessed the Mum's Respite Break in Byron Bay and, the Family Support program implemented a Dad's Respite pilot program reaching 17 EB fathers.



Family Support in numbers



17

EB clinics attended

491

Family support grants approved

12
New EB families

ING-No-Top spice.

UNG-No-Top spice.

Local Stage Share, season of down rear and all stage of more after the stages.

Ky North, at EB clinic in Sydney

Clinic in Sydney

GELN

THE STAGES OF THE STAG

192

Meeting with EB families

EB dads reached through our new respite program





Follow Your Dreams

Thank you to all those who have donated to the Follow Your Dreams grant account and to the Committee for helping make these special times a reality for grant recipients. A big thank you to Geoff Harris for the wonderful \$100,000 donation made in memory of his wife Jan who passed away in December 2022.

The 2022 Follow Your Dreams grant recipient was Chase, who had a dream to attend an AFL game with his idol Jonathan Brown (AFL legend and radio commentator). Chase's dream came true when he got to attend an AFL game at the MCG in Melbourne to watch from the commentary box with Jonathan. The 2023 grant recipient will be decided before the end of the financial year.

Kate Turner Fund

The main focus for the fund this year was to contribute towards the purchase of a young man's first car in South Australia. Another grant was also funded to help fill a gap and support natural therapies needed for a young patient in New South Wales. We are very thankful once again to The City of Adelaide Concert Band, who donated \$750 from their event this year; also the Walkely Heights Bowls Club for their support and other donors through the efforts of Laraine Frost. Overall donations received totalled \$1,268.30 for the year and once again, we are indebted to Laraine for her untiring efforts in promoting most of our fundraising each year.

Our board lost two of our committee members this year, Michael Fitzpatrick and Mary Woods. On the up-side, we now have as replacements, Kate Turner's sister Claire Guinan, plus Tina Segulin as the new Board member on the committee. It is now 10 years since the Kate Turner Fund began and I have been honoured to chair the committee since then. It is always very satisfying to be able to meet members' needs by way of this commemorative fund set up in the name of our late and loved SA member Kate Turner. We look forward to another year of support for DEBRA Australia members who are in need and qualify under the terms of this fund.

EBServices

Hospital based services

Our EB nurses continue to provide an excellent service for the EB community. Our incredible EB nurses continued to work hard throughout the year. Nurse Lucy Macleish was recruited to replace Sylvia Tsang at The Royal Melbourne Hospital but has decided to move to another role towards the end of 2023, so recruitment is underway for a replacement. Unfortunately negotiations have stalled regarding the establishment of a Transition/Adult nurse role in Brisbane. The Dermatology Department at Princess Alexandra Hospital had offered to host this position and wanted to implement a statewide service (centre of excellence) for EB funded by DEBRA, but hospital management and Queensland Health were not in favour due to budgetary concerns.

Genetics program

Services available in different states for genetic testing and counselling regarding the various types of EB for pregnancy and family planning purposes have been documented and Simone Baird, National Family Support Coordinator may be contacted in confidence for information. Funding assistance for all of these programs by Future Generation Australia and the Eliza Braitling Foundation is gratefully acknowledged.

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 three families not receiving NDIS funding.

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.



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 30 clients currently receiving NDIS support. Families are strongly encouraged to discuss their situation with our National Family Support Coordinator, Simone Baird, before engaging in negotiations with the NDIA. Those using the scheme were recently invited to complete a survey to explore their experiences and any suggestions for improvement. About three quarters of the 44% who responded had positive experiences with the scheme and felt their needs were being met. Several commented that DEBRA's help with the application and review process was greatly appreciated. A few indicated that they had problems in accessing a suitable program coordinator, though others were more positive. All respondents indicated that they would be interested in considering the use of DEBRA as a program coordinator if this was offered. Given this response, the committee proposes to investigate the feasibility of offering this service and report findings to the Board, who would need to make the final decision.

Pyschology program

Consultation options in Sydney and Melbourne have been expanded to meet current needs with telehealth consultations being used when appropriate. 29 people have used the program during the past 12 months and 12 individuals are currently engaging in appointments.

Fundraising & marketing

Our Marketing and Fundraising team has been dedicated to expanding reach through strategic social media efforts and targeted campaigns this year. By prioritising these initiatives, we aimed to increase awareness which generated more participation in third-party events. Excitingly, DEBRA Australia was chosen to collaborate with the University of Technology Sydney (UTS) Shopfront project and the talented studio Kaleidoscope, created valuable content for us to incorporate into our marketing endeavours.

Fundraising

The team successfully managed our third-party fundraisers including a heartwarming surprise from comedian Daniel Connell, who had previously performed for our families at our family camp in Melbourne. Daniel was deeply moved by our EB families and wanted to organize a comedy night in Melbourne to raise awareness and funds for our cause. He enlisted an amazing line-up of comedians and the Comedy Lounge generously supported the event, resulting in an impressive donation of over \$14,000 for DEBRA. We are incredibly grateful for the ongoing support from Future Generation Australia, who have generously funded several of our EB Services. This funding has not only allowed us to continue providing these crucial services, but also expand into other areas of need, such as podiatry and counselling services. We would also like to express our deep appreciation for the ongoing support of Brighter Days and the Melbourne Market Golf Day, both of which took place in 2023. The Brighter Days event continues to be a highly anticipated gathering for many of our supporters, while the Melbourne Market Golf Day has once again proven to be a tremendously successful event. One of our most important campaigns and events for DEBRA is Walk for Wings, which takes place during EB awareness week in October each year. This year hundreds of families showed unwavering support by raising over \$36,000.



Ambassadors

DEBRA Australia has maintained strong and enduring relationships with our amazing ambassadors, who have been instrumental in spreading our message far and wide. We are grateful to have the support of Matt Bevilacqua, the inspiring Ironman, Dean Clifford, the brave EB Warrior and motivational speaker, Joel Bevilacqua, the talented Bondi Rescue lifeguard and journalist, and Lachlan Albert, the talented Rugby Union player. This year, we were thrilled to welcome our newest female ambassador, Renae Woods, another courageous EB Warrior, as well as the hilarious comedian Daniel Connell. We were deeply saddened by the loss of our incredible ambassador, Lisa Brains, who was not only an EB Warrior but also a self-confessed bogan. She worked tirelessly to spread her magic wherever she went, and her impact will always be remembered. Our ambassadors have graciously represented DEBRA at numerous events throughout the year and we are truly grateful for their dedication and support.

Public Relations

During the last financial year, we achieved an extensive reach through media, with a total of 31 media pieces featured in various online and print platforms. As a result, our PR and media efforts potentially reached over 10 million people around the globe. Notable accomplishments include coverage in major health industry news outlets regarding the successful launch of our new podiatry clinic in Queensland. Additionally, we secured media coverage in some of the country's most read platforms including News.com.au, 7News, Kidspot, Daily Telegraph, and Mamamia.

Marketing

We have dedicated significant efforts to enhance our marketing strategies and expand our online presence, especially through social media platforms. In addition, we have successfully executed the UTS shopfront project, which has provided DEBRA with exciting new branded content and resources. These materials have been seamlessly integrated into our social media platforms, website, brochures, and other marketing materials, resulting in a unified and rejuvenated appearance for our organisation. We are focussed on continuing the evolution of our marketing initiatives and the positive impact they have on our brand.





Research & education

In the last 12 months the focus of the Research and Education committee has been centered around how we can best support early career researchers in their journey working with EB. In alignment with our strategic plan, we implemented a process to better support early career by diversifying our research grants to focus on specifically funding early career researchers as well as established researchers. Additionally, we developed guidelines for funding of a PhD scholarship which we will roll out in 2024. This is on top of our continual support for education of health professionals, nurses, scientists, and clinicians using our Research Travel Grant scheme.

Our main activity also included a very successful Health Professionals Symposium which was seen as the most successful one to date in terms of breadth of topics covered and quality of presentations. This years event also had highest attendance of supported nurses who dedicate their careers to EB and highest attendance of industry partners as we actively expand our engagement with industry. Now, we are focusing on planning our next Health Professionals Symposium which will take place in conjunction with our EB Camp in Brisbane in 2024. Additionally, we have also submitted a Health Technology Assessment report to the Government advising on future EB therapies that are currently coming onto the market in USA and Europe. We continue to work with relevant stakeholders to ensure access is available to Australian EB patients in the future.





Research & education cont.

Research Grants

The following grant of \$50,000 was awarded to Applicant: Dr Zlatko Kopecki, Dr Hanif Haidari, Prof Allison Cowin, Prof David Lancaster, Ms Tahlia Kennewell. For a project to be undertaken in 2023 looking at: "Photo Antibody Therapeutic platform for the treatment of infected wounds in EB". We look forward to the outcome of this research grant and updates at our future Health Professional Days.

Travel Grants

Three travel grants were awarded to nurses, clinicians and scientists in early stages of their careers to support their development of EB research and education. These include:

Awarded \$1,000 to Ms Danielle Paea – Nurse application (CNC Dermatology Department – The Royal Children's Hospital Melbourne) to attend the DEBRA EB Health Professionals Symposium in Sydney (26 May).

Awarded \$2,800 to Dr Kathryn Chen – Research Medical Student / Trainee Dermatologist from Western Sydney University to attend the 25th World Congress of Dermatology in Singapore (3 – 8 July) and present abstract.

Awarded \$2,800 to Ms Amy (Chen) Wang – Research Assistant/Honours Student at University of NSW to attend the 25th World Congress of Dermatology in Singapore (3 – 8 July).

All awardees submitted post conference reports that we shared with our members via the newsletter. This highlighted the benefits of these grants to our junior investigators. Our second round of travel grant calls for 2023 was advertised in October for travel between Jan – June 2024 and we strongly encourage nurse applicants to put forward applications.

DEBRA International

The focus for DEBRA International this year has been executing our recently developed strategic plan. As part of this plan we hosted the DEBRA International Round Table of companies initiative (DIRC) and hosted a symposium at the World Congress of Dermatology in Singapore. The DIRC, saw 19 DEBRA member states come together, with DEBRA Australia representative Dr Zlatko Kopecki chairing the meetings. All 19 member states stayed on for the World Congress of Dermatology where we worked with EB patients and patient advocates to raise awareness for EB. Dr Kopecki continues in his role as the Treasurer on 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.

Dr Kopecki attended an EB Congress in Hong Kong where all regional Asia Pacific EB groups got together to help DEBRA Hong Kong excel to the next level in their growth. Collaborations between DEBRA member groups in Asia Pacific region were also explored and helped to understand how we can better support EB patients globally especially in low economic countries. 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. This includes the release of new clinical practice guidelines and the soon to be expansion of our team of staff, to help us support and deliver the strategic mission in the next two-three years. We are also assisting with planning of the DEBRA International Congress which is scheduled to take place in Cairo, Egypt in April 2024.



Finances

Operating Report

The 2022/23 financial year saw our total income come in at \$1,028,804 compared with \$892,270 in the previous financial year. Our improved income result was due to the continued support of our major sponsors, new donors, investment performance and fundraising outcomes. Unexpected larger funds were received from two of our supporters namely Future Generation Australia and Brighter Days. Improved revenue from some of our longer-term investments and higher interest rates on our term deposit investments was in line with the market conditions. Annual expenses were tightly controlled with total expenses increasing to \$1,047,650 in 2022/23 compared to \$951,562 in the previous financial year. Additional Family Support needs, EB Services support and staffing costs saw an increase in expenditure. The numbers of families supported through the NDIS has increased this year meaning some of our EB expenditure decreased. We also took the opportunity in late June to make venue deposit payments for our bi-annual camp to be held In Brisbane in August 2024. Further funding for the camp will occur in the 2023/24 financial year. Whilst our bottom-line result indicates a profit of \$78,776, it must be noted that due to a quarantined donation which is to be used for a specific purpose we in fact came in at a break-even position. We are so thankful to all our major supporters and our grassroots supporters who made this year so successful for us at DEBRA.

Balance Sheet

Compared with the previous year, total assets increased to \$2,034,038 against the 2021/22 final figure of \$1,971,240.28 and total liabilities decreased from the 2021/22 figure of \$116,519.43 to \$100,541 in 2022/23. Total equity slightly improved from last financial year's figure of \$1.854,721 to \$1,933,497 at year end. The organisation's financial position remains solid with reserves held are above the Board's minimum target of \$800,000.

Budget

The 2023/24 budget projects a total income of \$1,025,700 and expenses of \$1,182,115 and a net deficit of (\$156,415). This projected outcome provides additional support to both EB Services, Family Support and our Research and Education Programs. However our Fundraising and Marketing team will look for new supporters and donors so our income flow can possibly become more balanced. Whilst a deficit of this size can be absorbed this year, we know that going forward we must work towards holding income and expenditure at an even level. The Finance Committee will closely monitor the budget given the volatile interest rate environment and unknown headwinds due to inflation and the cost-of-living challenges and make appropriate recommendations to the Board when required. 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 2023/24.

Investments

Many thanks to the Committee for their input and commitment and to Tony Baum (CEO Intralink) for again offering this service on a pro bono basis.

Judith Davis (Finance Committee Chair)

Financial statements and our audit report can be viewed online here.

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

