debra Australia.

Annual Impact Report

2025–26



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 recognise 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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Message from **the Chair**

The 2025-26 financial year marked an important milestone for our organisation as we finalised and commenced our five-year Strategic Plan.

Through extensive consultation and careful consideration of the opportunities and challenges facing our organisation, we established a clear direction for the future built around four strategic pillars: Awareness Raising, Information and Support, Access to Care, and Research and Education. These pillars reflect our commitment to improving outcomes for the EB community we serve, and will guide our decisions, investments, and priorities over the coming years. The Board believes this strategy provides a strong foundation to strengthen our impact, enhance organisational sustainability, and ensure we remain responsive to the evolving needs of those who rely on our services. The plan has guided much of the Board's work throughout the year.

We welcomed three new Board members this year. It was appropriate to revisit our Governance accountabilities, which occurred in May 2026. The Board revisited the six ACNC standards by way of a training session and through a survey to evaluate our effectiveness. We examined the rules, regulations, policies, systems, processes and relationships and discussed any way to enhance our governance standards.

While we have made important progress against our strategic priorities, the year was characterised by significant financial challenges. The organisation recorded an operating deficit of $272,094, a result that reflects a number of factors affecting our operations and financial performance during the year. Whilst disappointing, the Board has approached these results with transparency and a clear commitment to understanding the underlying causes and implementing the actions required to strengthen our financial position.

Throughout the year, the Board worked closely with the CEO, leadership team and committees to monitor performance, manage risk, and ensure that the organisation remained focused on delivering its mission. We recognise that sustainable impact requires sustainable finances, and balancing these objectives remains a key priority for the future.

As we enter the 2026-27 fiscal year, the Board's focus will be on restoring financial sustainability, progressing initiatives across our four pillars and key strategic initiatives, and ensuring we have the capability and resources required to achieve our long-term objectives.

Whilst improving our financial performance is a key priority, we remain committed to advancing our mission and ensuring that our strategic objectives translate into meaningful outcomes and programs for the EB community.

We will continue strong governance, prudent stewardship, and maintaining the trust placed in us by our members, supporters, partners, and community.

On behalf of the Board, I would like to thank our CEO, staff, volunteers, and fellow Board members for their dedication and commitment throughout a challenging year. I also extend our sincere appreciation to our donors, partners, and supporters whose contribution makes our work possible. And, lastly a big thank you to our EB families for the trust you place in us and the work many of you do to raise awareness and funds. You are the reason we do what we do!

As we look ahead, we remain confident in our purpose, our strategy, and our ability to build a stronger and more sustainable future.

We remain committed to advancing our mission and ensuring that our strategic objectives translate into meaningful outcomes and programs for the EB community.



Judith Davis
Board Chair

CEO's Report

This year has been one of meaningful progress for DEBRA Australia. Working alongside individuals and families living with EB, we continued to strengthen support, connection, awareness, education and access to care. Guided by the experiences and needs of our community, we remained focused on advancing our strategic priorities and building a strong foundation for the future.

DEBRA Australia's FY2026–30 Strategic Plan provides a clear roadmap for our future direction and impact. This year, our focus turned to translating that vision into action and progressing the priorities and initiatives that will help deliver meaningful outcomes for the EB community.

Central to this work has been our commitment to improving the quality of life for people living with EB. Through our support services, education and community programs, alongside our work to strengthen excellence in EB care, we helped individuals and families build knowledge, access support and feel connected, while contributing to better care and future treatment opportunities.

Across our strategic priorities, we expanded opportunities for connection, support and awareness through the launch of a new online support group and community initiatives including Walk for Wings, our flagship annual community event, and the remarkable EB Butterfly Walk. We also commenced development of a new website, shaped by stakeholder feedback and designed to improve access to trusted information, resources and support for individuals and families affected by EB.

Access to care, education and research remained key areas of focus. We continued to support specialised EB nursing services and the further integration of in-hospital podiatry support, helping strengthen multidisciplinary care for our EB community. We also delivered an EB Education Forum and our annual Health Professionals EB Symposium, bringing together leading national and international clinicians and researchers to share knowledge, foster collaboration and drive progress in EB care and treatment.

Through our research grants program and the Lisa Brains PhD Scholarship, we continued to support important work in areas including including EB-related cancer detection, gastrointestinal complications of EB and vision loss associated with Junctional EB. We also strengthened relationships with industry and other partners working towards better outcomes in EB through emerging therapies, clinical advancement and enhanced support. Further highlights and outcomes across each strategic pillar are shared throughout this report.

These achievements have only been possible through the commitment of our staff, Board and volunteers, together with the generosity of our donors, partners and supporters. I would also like to acknowledge the individuals and families living with EB who continue to share their experiences, support our work, and advocate for the broader EB community. Your insights, generosity and commitment help shape our priorities, strengthen our voice and ensure we remain focused on what matters most.

Following a period of sustained growth over the preceding two years, during which DEBRA Australia achieved record income, this year marked a period of financial transition, with income returning to more typical historical levels. It also marked the conclusion of funding support from a longstanding major donor, following a change in their charitable focus areas.

Against a backdrop of broader inflationary pressures, these changes reinforced the importance of maintaining financial resilience and continuing to diversify our funding base. Building on the Fundraising Strategy developed collaboratively with stakeholders, we continued to strengthen our approach to income generation and fundraising capability. Throughout the year, our focus also remained on responsible budget management, careful allocation of resources and maintaining the programs and support that matter most to the EB community.

As we move into the year ahead, our focus will be on continuing to translate our plans into action, strengthening our organisational capacity and positioning DEBRA Australia to deliver lasting impact.

Our Strategic Plan will continue to guide this work, as we balance the needs of today with the opportunities of tomorrow, ensuring individuals and families living with EB are supported now, while contributing to advances that will improve outcomes into the future.

I am grateful for the trust, support and partnership that continue to help shape DEBRA Australia and support us in advancing our mission. Together, we are building a more connected and better-supported EB community, and I am optimistic about the opportunities that lie ahead.

> *"We balance the needs of today with the opportunities of tomorrow, ensuring individuals and families living with EB are supported."*



Mary-Jean Howard
CEO

Vision & **Impact**



With thanks to Kye and his family for being part of our Sydney Walk for Wings during EB Awareness Week.

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

5-Year Strategic Plan

Click the plan to view it online



In FY26, DEBRA Australia began implementing its FY2026–2030 Strategic Plan, setting a clear direction for the next five years and providing a framework for our continued commitment to improving the lives of people living with EB

Over this period, we will focus on strengthening connections, expanding support and ensuring the experiences and voices of individuals and families affected by EB continue to shape our priorities and guide our work.

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 organisation
2. **Compassionate** • DEBRA supports EB families with compassion, respect and empathy
3. **Ethical** • DEBRA is a professional, responsible, honest and ethical organisation
4. **Accountable** • DEBRA is accountable to its members and to the wider community
5. **Collaborative** • DEBRA builds partnerships and networks to collaborate with internal and external stakeholders as well as the wider community

1. **Impactful** • DEBRA seeks to achieve positive impacts on behalf of 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.

DEBRA Australia's Theory of Change

The challenges we face	What we do	The change we contribute to	Our Ultimate Goal
People with EB live in pain and discomfort, affecting their ability to fully participate in every aspect of life. They and their families are burdened with stress and anxiety and feelings of isolation, which have a negative effect on their wellbeing.	Provide support for families living with EB including helping with access to services and providing opportunities for respite and connection with others in similar situations.	**Wellbeing** Families feel supported Families feel connected People with EB feel more independent **Wellbeing increases**	**Every person living with EB has access to the same level of holistic care and support. Families who live with EB have greater opportunity to be families and participate in life to its fullest. People living with EB are celebrated and included in society.** **There are advances in treatment and prevention that mean there are less people born with EB, and those that live with EB can live a life free of pain and itching.**
Knowledge of EB among **health professionals** is limited. There is inequity of access to the best possible care for people with EB.	Providing funding and advocating for clinical services. Providing opportunities for health professionals to share knowledge.	**Treatment Today** Health professionals have increased knowledge of EB The healthcare system has increased capacity to treat EB **People with EB have increased access to treatment**	
There is currently no cure for EB, and further **research** into prevention, and treating the more serious symptoms of EB, is required.	Providing funding for research, and opportunities for collaboration.	**Treatment Tomorrow** Increased knowledge sharing amongst researchers and health professionals Growing networks of EB researchers **Faster translation of research into practice**	
Living with EB is costly, and puts financial pressure on people with EB, families and carers. Due to its rarity, there is a lack of awareness in the **community** about EB, and limited financial support for people with EB and their families.	Raising awareness of EB through fundraising and advocacy activities.	**Awareness** Increased awareness of EB Increased funding 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:

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

Pictured from top to bottom are members of our EB Community accessing respite programs, at Walk for Wings in Melbourne, and EB Researcher A/Prof Albert Mellick with students.



"Connecting with other EB mums, feeling understood without having to justify or explain is irreplaceable."

EB mum, on the value of the DEBRA Australia EB community

"I am very grateful for DEBRA's support and support of other health professionals working in the EB community, which has directly enhanced my clinical practice and improved outcomes for the individuals and families I work with."

EB healthcare professional



"I came away with new friendships, a stronger support network and a renewed appreciation that while every EB journey is unique, there is a special bond between all of us that are walking this path together."

EB dad, speaking about DEBRA Australia's Dad's Respite Weekend



"DEBRA Australia is truly making a difference for the EB community to healthcare professionals, families and patients who are involved in EB."

EB professional

Financial Summary & **Outlook**



DEBRA Australia on stage to raise awareness of EB at Brighter Days Festival in March 2026.

Finance & Risk
Committee Overview

In the 2025-26 financial year, the first year of our five-year Strategic Plan, total income was $1,058,095, compared with $1,550,421 in 2024-25. A detailed breakdown of revenue and other income is provided in Explanatory Notes 2 and 3 of the financial audit report. Expenditure decreased from $1,528,317 to $1,330,190. Explanatory Note 4 provides further detail on the reasons for this change.

Total comprehensive income for the year was a deficit of $272,094, compared with a surplus of $22,104 in 2024-25. While disappointing, this result reflects a number of significant challenges experienced during the year.

For the 2025-26 financial year, the Committee recommended drawing on equity to fund all current programs and minimise the impact on the families we serve.

The Committee notes that income was adversely affected by the loss of a major donor approximately 18 months ago. In addition, economic uncertainty resulted in reduced contributions from several important donors, while no significant one-off restricted donations were received during the year. Despite the considerable efforts of staff, volunteers, and supporters, the organisation was unable to fully close the resulting revenue gap. The timing of several donations also affected the final result for the financial year. Lower income was further impacted by the loss of some long-standing fundraising activities, increased demand for family support and hospital services, and a challenging fundraising environment. Collectively, these factors had a significant impact on DEBRA Australia's financial performance during the year.

The Finance and Risk Committee regularly monitored the budget and provided recommendations and support to the Board throughout the year. Despite reduced revenue, the Committee continued to support the funding of programs following the six-month review, recognising the importance of maintaining services for the EB community. The Family Support Program was in line with the budget expectations, and the prior year varience was due to one off expenditure in 2024-25.

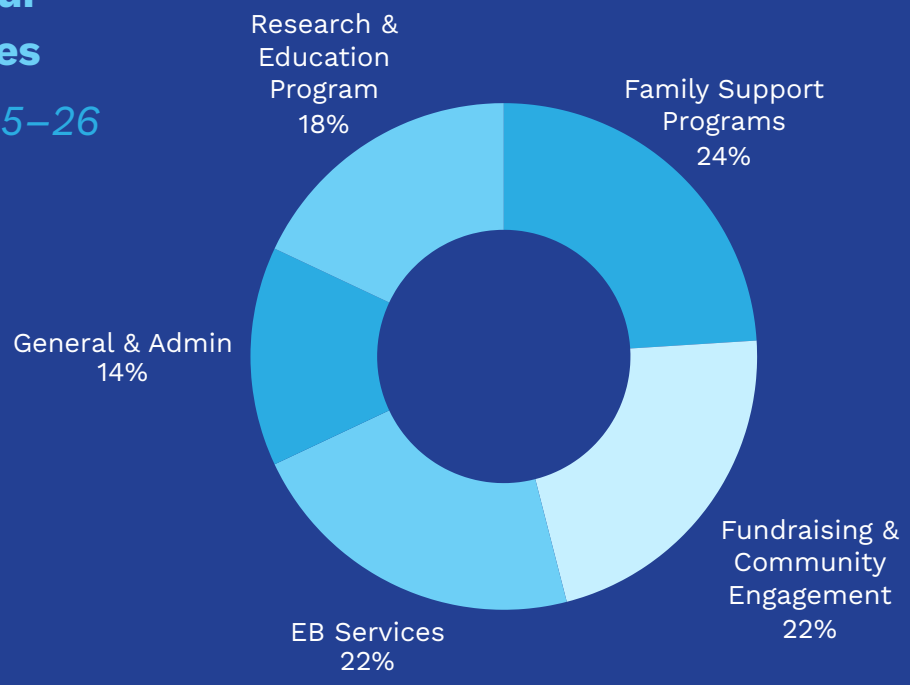
From a governance perspective, the Committee noted and recommended to the Board that the trend of expanding service delivery should be closely examined during the next budget cycle, and that improved fundraising and income generation outcomes will be required to ensure long-term sustainability. Despite these challenges, our financial stewardship was strengthened by solid investment returns, which provided a positive contribution during a difficult year.

We acknowledge the outstanding fundraising efforts of Deanna Pope, whose Melbourne to Adelaide walk raised more than $78,000, as well as the success of the Butterflies and Bubbles event.

Our equity decreased by $272,093 from $2.051 million to $1.779 million. Despite this reduction, the organisation remains in a relatively strong financial position, with reserves continuing to exceed the Board's minimum reserve requirement of $1 million. The Finance and Risk Committee has recommended to the Board that the organisation target a balanced Income and Expenditure result in 2026-27 and work towards gradually rebuilding equity over the next four years.

How we applied our Financial Resources

Financial Year 2025–26 Expenditure



Funds were directed towards key areas, including program delivery, capacity building, community outreach, and support services. This enabled us to provide support where it was needed most. The largest investments were made in Family Support, EB Services, and Research and Education, reflecting our commitment to excellence in care for people living with EB. Resources also supported fundraising, engagement, and core operations to sustain and grow our impact.

Risk management activities continued throughout the year, with strategic, operational, financial, and compliance risks monitored through the organisation's detailed risk register. We thank Mary-Jean Howard and Sue McKenna for their excellent work in supporting the organisation's risk management framework and financial management.

The audit process proceeded smoothly, and the Committee recommends the reappointment of Hooper Accountants as auditors for the 2026-27 financial year.

The Finance and Risk Committee has recommended to the Board that a strong focus on fundraising remain a priority in 2026-27.

This includes continued investment in activities that drive fundraising outcomes, including marketing, education, brand awareness, networking, and the effective use of our lean resources. While it may take several years to recover this year's deficit, the Committee remains committed to supporting the Board and staff in achieving sustainable financial outcomes whilst continuing to ensure programs continue.

Along with the Board, we thank our donors, partners, sponsors, and funders for their continued financial support, which remains critical to sustaining our work and delivering meaningful impact within the community we proudly serve.

Many thanks to the Finance and Risk Committee for their dedication and contribution throughout the year, and to Tony Baum and Intralink for providing financial services to the organisation.

Judith Davis - Chair,
Finance and Risk Committee

For further details, please view our full Financial Statements and Audit Reports online.

Family Support **Program**



EB Families get together at a picnic in the park in Brisbane, organised through our Family Support Program.

Family Support **Program**

DEBRA Australia's Family Support Program continues to deliver responsive, person-centred support to individuals and families living with EB, while adapting to service demand and ensuring resources are directed where they are needed most. The program maintained a strong focus on providing timely financial assistance, psychosocial support, advocacy and care coordination, ensuring families remained connected to essential services during periods of significant medical, social and financial stress.

In addition to direct family support, the program provided a valued respite program, strengthened collaboration with multidisciplinary health teams, and expanded advocacy for families navigating complex government and service systems, including the NDIS and child and family services. It also supported fundraising and awareness initiatives while continuing to identify opportunities to improve program sustainability and service delivery.

Program Activity & Outcomes (2025/26)

675 Family Support applications were approved during the year, representing 97% of all requests received and ensuring support reached families when they needed it most.

Key Family Support Impact Areas:

- **Household Assistance** 31%
- **Butterfly Breaks and Respite Support** 25%
- **Medical & Pharmaceuticals** 11%
- **Quality of Life Support** 9%
- **Electricity Reimbursements** 8%
- **Linen & Apparel** 8%
- **Home Modifications & Maintenance** 4%
- **Home Services** 4%

Funding decisions prioritise essential needs and are assessed against program guidelines and available resources.

Mum's Respite

"It is the one weekend of the year that I can connect with other mums who I don't have to explain anything to."







Our popular respite weekends for EB mums remain very well received, with positive feedback and strong demand to continue providing opportunities to connect and unwind.

Dad's Respite

Positive responses from previous attendees meant that we continued to offer EB dads and primary carers the chance to get together and get away from it all with our Dad's Respite weekend in Byron Bay.





> ***Living with EB can sometimes feel like you are in your own bubble, so being able to spend time with other dads who genuinely understand the challenges, emotions and experiences that come with it was incredibly valuable.***

Family Engagement, Advocacy & Care Coordination

Maintaining strong relationships with families and health professionals remains central to the Family Support Program. These relationships help ensure families feel supported, informed, and connected, while also enabling the program to provide advocacy for those experiencing complex social and medical challenges. As changes to the NDIS continue to evolve, DEBRA Australia remains committed to supporting families to navigate these changes and access the services and supports they require.

There has been a noticeable increase in the complexity of presentations among individuals and families living with EB compared with previous years, requiring greater levels of support, advocacy and collaboration, including increased involvement in multidisciplinary planning and ongoing engagement with treating teams. We have also continued to review and refine our support application processes to ensure they remain responsive to community needs and changing circumstances.

During the 2025/26 year:

- Support was provided across 18 multidisciplinary EB clinics, connecting with approximately 145 families.
- Many children and adults required hospital admissions for EB treatment and management of secondary complications. The program responded by providing psychosocial support and financial assistance to reduce the financial burden associated with extended admissions.
- More than 200 individual meetings were attended to provide advocacy, care coordination, social/emotional support, and assistance navigating health, disability, and community services.
- Continued to provide valuable education to community organisations supporting Australian children living with EB, including school readiness and inclusion support.

Family **Retreats**



Above: Our EB community enjoying the Bright Family Retreat

Bright Retreat

The Bright Retreat continues to provide valuable opportunities for families to rest, reconnect, and step away from the demands of ongoing medical care. During 2025–26, the retreat welcomed nine families living with EB and one EB health professional.

We extend our sincere thanks to the Geldarts for generously supporting the Bright retreat, and to the many happy visitors who shared their retreat experiences through DEBRA Australia's social media platforms, helping to raise awareness of EB and showcase the positive impact of the program.



> ***We are forever grateful for these memories you make possible for us and all of the other beautiful EB families.***

Butterfly Breaks

Ten Butterfly Breaks were funded during the financial year, providing families with opportunities to spend quality time together away from medical appointments and daily care demands.

Feedback continues to demonstrate the significant positive impact these experiences have on family wellbeing.

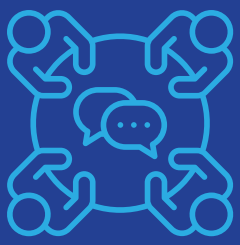


Butterfly Break recipients enjoying time away with their loved ones

Family Support
Our Impact



675
Support applications granted



200+
Family Support Program meetings attended



145
Families connected with at EB clinics



18
EB Clinics attended



13%
More individuals and families connected to DEBRA



10
Butterfly Breaks funded



10
Opportunities for respite at Bright Retreat

"DEBRA Australia has given financial and emotional support for many years. They have also given us ideas for problems that have come our way"

EB family member

EB Services & **Community Grants**



EB nurses Lauren Weston and Erin Sullivan (EB Training Fellowship Nurse), based at The Royal Children's Hospital, Melbourne

Delivering a **Difference**

At Sydney Children's Hospital DEBRA Australia has a massive impact on quality of life of children and their families

Throughout 2025–26, DEBRA Australia continued to ensure people living with EB had access to the specialist care, support and resources they need, helping to address gaps in care and improve quality of life.

Hospital-based EB Nurse Program

The hospital-based EB Nurse Program remains central to specialised EB care across Australia. Through dedicated funding, **DEBRA Australia continues to support access to specialist EB nursing care and care coordination.** While hospital budget pressures continue to present challenges in sustaining some EB nurse positions, we work closely with hospital partners to advocate for and support these essential roles. In addition, Simone Baird, DEBRA Australia's Family Support Coordinator, regularly attends clinics, strengthening collaboration between families and treating teams.

Program Developments

Ongoing two-year funding was confirmed for a part-time EB nurse at Royal Melbourne Hospital and St George Hospital. DEBRA Australia also funded a position for two days per week at Queensland Children's Hospital to support coverage during parental leave until April 2026. Funding for the EB nurse at Sydney Children's Hospital was increased from May 2026, enabling the role to be undertaken in a full-time capacity and better respond to growing demand. In Queensland, adult patients continued to access a nurse-coordinated clinic at Princess Alexandra Hospital, highlighting the importance of ongoing specialist nursing support for adults living with EB.

We were pleased to extend our first **EB Training Fellowship** at the Royal Children's Hospital Melbourne for a second year, further strengthening specialist expertise in EB care.

The fellowship nurse also received training in the UK to support the delivery of emerging EB therapies, including B-VEC (VYJUVEK), a gene therapy for dystrophic EB that is becoming available in a growing number of countries internationally. It is hoped that an application for Australian regulatory approval will be submitted later this year, alongside ongoing efforts to improve access to other emerging EB therapies.



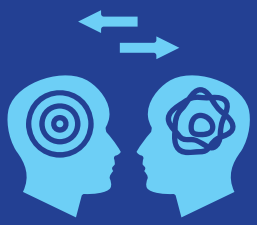
5

Specialised EB Nurses funded



2

EB babies born this year



29

People supported in our psychology/counselling program

In home EB care

Many individuals and families are now supported through the NDIS to access in-home nursing and support workers. Where gaps in support existed, DEBRA Australia coordinated home care for four individuals during the year, ensuring access to essential care and assistance.

EB Dressing Scheme (NEBDS)

As a vital service to the EB community, the schedule of dressings for the scheme continues to be reviewed as new products become available and other products are discontinued. Following the expansion of her role at Sydney Children's Hospital, Rebecca Saad concluded her involvement with the scheme during the year. We thank Rebecca for her valued contribution and ongoing commitment to the EB community. We are pleased to welcome Lara Munns from Queensland Children's Hospital as the new EB Specialist Nurse for the scheme.

NDIS assistance

Strong support for families eligible for the NDIS has continued, with 33 community members receiving assistance in 2025/26. The impact on EB families of any changes to the operation of the scheme with the passing of the new legislation by the Federal Government is being closely monitored. Families are strongly encouraged to discuss their situation with DEBRA Australia's National Family Support Coordinator before engaging in negotiations with the NDIA.

Psychology & Counselling Program

Strong demand for psychology consultations continued, with 29 individuals accessing the service during the year. Access to the service continues to be monitored to support equitable and sustainable delivery. A quarterly online group forum was also introduced to facilitate connection and support among individuals and family members, which has been well received.

Podiatry & Genetics Programs

Feedback continues to be positive about the regular podiatry clinics in Queensland, NSW and Victoria. A quarterly Queensland Children's Clinic has also now been established at the Children's Hospital, with an adult clinic continuing twice yearly.

While demand for the genetics program was low during 2025–26, this important service remains available to the EB community.

> ***"The continued support from DEBRA Australia has been greatly beneficial, both emotionally and financially. They have provided me with so much education about the disease and how to treat and manage blisters, especially with dressing wounds."***

33

Individuals and families supported by the NDIS

> ***"DEBRA Australia has impacted us through access medical supplies, EB clinic and providing an allowance for specialised shoes."***



Pictured above: Dr Tariq Khan providing podiatry care to members of the EB community

EB Community **Grants**

It is a joy to see the smiling faces when we receive photos from successful applicants fulfilling their dreams.

Follow Your Dreams

DEBRA Australia is grateful for another $20,000 donation from the Harris Family, which has further increased the funds available to dispense as Follow Your Dreams Grants. These increased funds have allowed us to grant two applications in the 2025-26 year.

A review and update of the Policy governing the Committee's function was accepted by the DEBRA Australia Board for ratification.

2025/26 Grants

Ruby (from Queensland) · Ruby's dream was to stay at the Jamala Wildlife Lodge in Canberra and spend time with the giraffes. Ruby fulfilled her dream and spent a night in the Giraffe treehouse to get up close and personal with her favourite animals.

Kylan (from rural NSW) · It was Kylan's dream to enjoy a family holiday in Yarrawonga, Victoria, and we were so touched to have the opportunity to help make this happen for him and his family



"My favourite part was having my morning coffee on the balcony while watching the giraffes start their day. The experience that Jamala Wildlife Lodge provides is truly one of a kind. From the delicious banquet meals, to the personal tours of the zoo, the incredible animal encounters, and the superb customer service from every staff member, everything exceeded my expectations. I felt so welcomed and cared for throughout my stay. Thank you to Jamala Wildlife Lodge and the Follow Your Dreams grant via DEBRA for helping make this experience so special and unforgettable." **Ruby**



"I just wanted to say we had such a wonderful time and are incredibly grateful to have been given the opportunity! We mostly relaxed and did our own thing at our own pace, but it was so nice to be able to do so without the stress of school and appointments that generally are priorities for us. We went to the cinema twice... On the way home, Kylan said, "this was a really fun holiday mum" and it was, so thank you for the Follow Your Dreams funding and DEBRA for granting this for us 💙" **Kylan's Mum**

Kate Turner Fund

Thanks to donations from the community this unique fund continues to grow. These contributions are paramount to maintaining the grant allocation of up to $5,000 per year and our team is delighted that it is continually being used to such good effect by the EB community. The Fund's committee acknowledges the ongoing and long-standing support of Laraine Frost.

The late Kate Turner, to whom this fund is attributed, would be pleased that it is providing such wellbeing value to successful applicants. We are certain that her family would agree.

In 2025/26 three new grants were approved for eligible applicants. Those grants included a holiday for an individual living with EB plus support, a parent/carer to have much needed respite and a child to attend equine therapy.

Anyone living with EB who meets the Fund criteria may apply for a grant.



Thanks to the Kate Turner Fund, Yakub could attend equine therapy.

> *This therapy has helped Yakub build strength, improve mobility, and enhance his overall quality of life. He loves spending time with his pony Rosie, and feels confident, connected, and supported while living with his condition. We are deeply grateful to DEBRA and the Kate Turner Fund for their support to our son & family.*
>
> **Yakub's mum, Kath**

Research & **Education**



Together at the Health Professionals EB Symposium: Dr Zlatko Kopecki, Prof Cristina Has (Keynote speaker - Uni of Freiburg Germany) and A/Prof Vanessa Morgan (guest speaker - Head of Dermatology at the Royal Melbourne Hospital, and Chair of the Victorian Faculty of Dermatologists)

Research & **Education**





Pictured above: EB and dermatology nurses attending the Melbourne Health Professionals EB Symposium, and further above Dr Zlatko Kopecki (Research & Education Comm. Chair), Mary-Jean Howard (DEBRA CEO) and internationally renowned guest speaker Prof Amy Paller at the EB Education Forum.

Our Research and Education Program has continued to champion innovation, knowledge, and connection across the EB community. We supported both emerging and established researchers through targeted grants, and created opportunities for health professionals to learn and collaborate, fostering vital knowledge exchange and EB education.

In September 2025 DEBRA Australia hosted the **Health Professionals EB Symposium** in Melbourne, following a successful symposium the previous year in Brisbane. The event was well attended, with over 70 delegates ranging from health professionals to researchers from Australia and New Zealand.

> *As an OT working with children, adults and families affected by EB, DEBRA Australia has had a significant impact on my professional development, knowledge and intervention I provide*

The symposium program brought together diverse clinical and research themes, from novel therapies and gene editing to infection, itch, skin cancer, eye care, and the DEBRA International Occupational Therapy Guidelines for EB. **Professor Cristina Has** (University of Freiburg, Germany) contributed valuable insights into clinical therapy development and her experience applying gene therapy in EB care. The feedback was very positive on a range of topics. The revised format included a multidisciplinary panel which was well received and will be considered for future events.

As part of EB Awareness Week, in October, our **EB Education Forum** with Wounds Australia featured **Professor Amy Paller**, who presented insights on clinical trials, gene therapies and skin inflammation. The forum was delivered in a hybrid (in-person/online) format and was open to researchers and EB family members.

Research Grants

Grants were awarded for EB research projects commencing in 2026, with outcomes to be presented at future Health Professional events.

- **A/Prof Daniel Poole** (Monash Institute of Pharmaceutical Services) awarded $50,000 established researcher grant. Project title: *Gut dysfunction in mouse models of dystrophic epidermolysis bullosa.*
- **Jasmine Zhou** (University of Sydney) awarded $30,000 early career researcher grant. Project title: *Integrating machine learning with a blood draw for development of a minimally invasive, and rapid cancer diagnostic for patients with Recessive Dystrophic EB (RDEB)*

DEBRA Supported Study

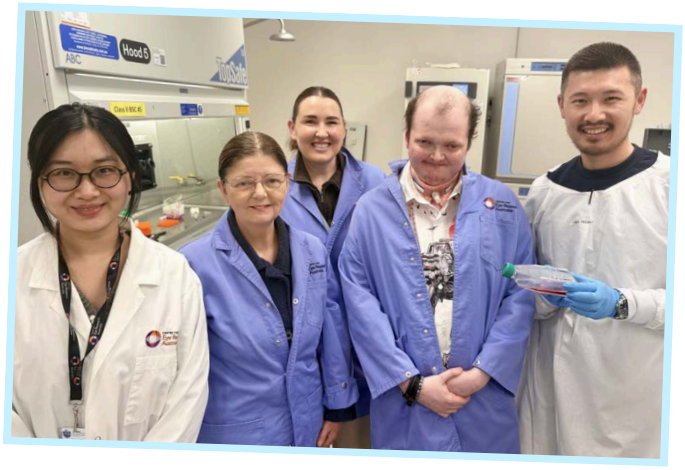
DEBRA Australia was pleased to have supported a study, published this year and co-authored by our Research and Education Chair, **Dr Zlatko Kopecki**: *The lived experience and supportive care needs of Australian parents caring for children with Epidermolysis Bullosa: a qualitative descriptive analysis* https://link.springer.com/article/10.1186/s13023-025-04159-4.

This study will provide a valuable reference for the EB community and help inform our ongoing work as an organisation.

PhD Scholarship

We are pleased to report that the inaugural Lisa Brains Scholarship was awarded to **Haiming Li**, student at the Centre for Eye Research Australia and Melbourne University.

Lisa Brains was a great advocate and fundraiser for DEBRA. Sadly Lisa lost her battle with EB, in her honour, the DEBRA Australia Lisa Brains PhD Scholarship was established in 2024 to support early-career researchers studying EB.



Haiming Li (left) and Dr Gink Yang (right) meet with Bree and Connor Fitzpatrick (centre) at the CERA laboratory.

Travel Grants

The following travel fellowships were awarded this financial year to support professionals attending EB-related events and opportunities for development. All recipients submitted post-conference reports, with selected highlights shared, underscoring the value of these grants, especially for junior investigators. We continue to encourage nurse applicants to apply for future travel grant opportunities:

- **Corrine Browne** (Sydney Children's Hospital): *$855 to attend DEBRA Australia's Health Professionals Symposium 2025 in Melbourne, Victoria.*
- **Kristin Ham** (Murdoch University Perth): *$1,000 to attend DEBRA Australia's Health Professionals Symposium 2025 in Melbourne, Victoria.*
- **Anna Antipov** (Future Industries Institute, University of South Australia): *$2,500 partial funding to present at the European Tissue Repair Society (ETRS) in Cardiff, Wales.*
- **Jasmine Zhou** (Sydney University Westmead): *$1,000 partial funding, to attend the ESMO AI & Digital Oncology Annual Conference, Berlin, Germany and also attend the DEBRA Symposium.*
- **Dhanya Shanmuganathan** (Monash Biomedicine Discovery Institute): *$3,500 to attend the EB2026 Brazil International Congress in January 2026.*

Fundraising & **Marketing**



Comedians Daniel Connell and Kitty Flanagan backstage at the Trivia Spectacular with Simone Baird, DEBRA Australia Family Support Coordinator

Fundraising & **Marketing**

DEBRA is truly making a difference for the EB community... Most people who have never heard of EB would be lost, not knowing what to do, how to help or how to hold their child without hurting them







Every dollar raised, every partnership formed, and every awareness activity delivered helps create a stronger future for Australians living with Epidermolysis Bullosa (EB).

During the year, DEBRA Australia focused on growing awareness, strengthening engagement, expanding partnerships and enhancing fundraising capability, helping to broaden our reach and generate vital funding for programs, services and advocacy. We thank the donors, fundraisers, volunteers, partners and supporters whose generosity made this work possible.

Incredible fundraising activities – top to bottom: Bubbles & Butterflies; Brighter Days Festival; DEBRA Australia Ambassador Deanna Pope's EB Butterfly Walk

Annual Fundraising Campaigns

DEBRA Australia's annual fundraising campaigns provided meaningful opportunities for supporters to make a difference in the lives of people living with EB. The **Christmas Appeal** featured gorgeous little Ella, whose resilience in the face of the daily challenges associated with EB inspired many, helping to shine a light on the vital role of our National EB Nurse Program.

Run for EB, championed by Jo Bradshaw and her family, continued to generate valuable funds while raising awareness of EB and the challenges faced by individuals and families living with the condition.

We are grateful to the families who generously share their stories with the wider community. By doing so, they help raise awareness of DEBRA Australia and deepen understanding of the challenges of living with EB.

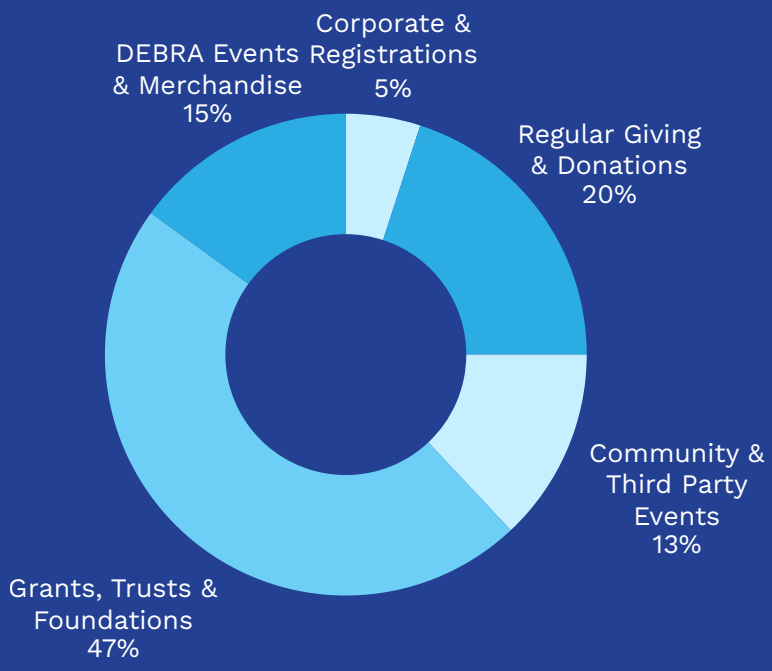


Pictured: Ella with her family, generously sharing their story with our community

Walk for Wings once again brought together individuals, families and supporters from across Australia, raising $21,965 while strengthening connections within the EB community and increasing awareness of the condition. Participants joined events in Hobart, Brisbane, Melbourne and Sydney, alongside virtual participants from Canberra, Perth, Townsville, the Sunshine Coast and South Australia, demonstrating the collective commitment of communities nationwide to supporting our EB community. The campaign was further complemented by EB Awareness Week, including promotion of the global #InsideOutforEB initiative, helping to further raise awareness and understanding of EB.

Our **End of Financial Year Appeal** raised more than $32,000, delivering one of the organisation's strongest EOFY results in recent years.

Fundraising Revenue Overview FY2026





Families and individuals came together across Australia to Walk for Wings in October 2025.

walk FOR wings















Third-Party Fundraisers, Grants, and Foundations

The **Brighter Days Foundation** was once again a significant contributor, with support from the **Green Team** helping to generate a combined donation of **$177,437** during the financial year, in support of the EB community. The 2026 Brighter Days Festival attracted approximately 5,000 attendees and provided valuable opportunities to increase awareness of EB and expand DEBRA Australia's reach through event promotion and media engagement. We are deeply grateful to the Brighter Days Foundation and the Green Team for their longstanding and invaluable support.

The second annual **Bubbles and Butterflies** luncheon was another outstanding success, with 137 tickets sold and over **$48,000** in net income raised, up from $38,000 the previous year. The event's success was driven by the dedication of DEBRA Ambassador and Board Member Deanna Pope, together with the generosity of attendees, sponsors and donors.

Building on this momentum, Deanna also led the remarkable **EB Butterfly Walk**, walking more than 700 kilometres from Melbourne to Adelaide over three weeks to raise both awareness and funds for people living with EB. The campaign raised just over an incredible **$78,000**, and generated significant community and media engagement. DEBRA Australia extends its sincere thanks to Deanna and the many supporters who contributed to the campaign, including Deanna's family and friends, event sponsors, donors, and our National Family Support Co-ordinator, Simone Baird, who joined the walk for seven days.







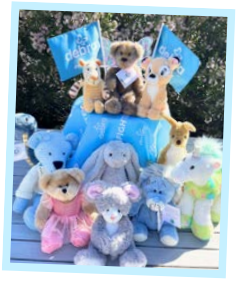


Pictured top to bottom: Deanna Pope, EB Nurses, Family member and Mary-Jean Howard at Bubbles and Butterflies; the Green Team ahead of Brighter Days Festival; Valenti Golf Club hosting a day for EB awareness.

Long-time supporters **Valenti Golf Club** hosted another successful Valenti Golf Day, welcoming more than 60 attendees and raising over **$21,000** for families living with EB, while also introducing new supporters to DEBRA Australia's mission.

The DEBRA Australia **Trivia Spectacular**, featuring **Daniel Connell** and **Kitty Flanagan**, delivered not only plenty of laughs but also brought supporters together for an evening of fundraising and awareness. The annual **Long Weekend Laughs** event was another calendar highlight, with the two events raising a combined **$19,765** in support of DEBRA Australia's vital work throughout the year.

Collectively, these efforts were strengthened by the generosity of **individual donors, charitable trusts, foundations and philanthropic partners**, whose contributions remained critical to our work. Complementing the fundraising outcomes highlighted above, DEBRA Australia received **more than $260,000** in grant and philanthropic funding during the year, including support from both new and existing funding partners.



Growing Awareness and Engagement

A major focus during the year was growing awareness of EB and expanding DEBRA Australia's network of community and sector partnerships. New partnerships included **Soft Love**, an Australian business that generously donates at least 10% of proceeds from the sale of pre-loved toys to DEBRA Australia, and **Wounds Australia**, with whom we delivered a joint education forum ahead of EB Awareness Week and a subsequent live webinar that extended our reach among healthcare professionals and the broader community. **Chiesi Australia** also joined DEBRA Australia as a supporter of our nursing program.

Social and Communications

Across **Facebook**, **Instagram**, and **LinkedIn**, we achieved a combined 502,800 post views — an average of 1,377 daily views — to increase our brand and cause awareness. FY26 saw continued growth across all social media platforms compared with FY25, with Instagram and LinkedIn strongest for follower increases.

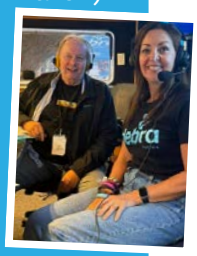
Community stories remained our most engaging content, demonstrating the power of lived experience to educate, inspire and foster connection. During the year, DEBRA Australia achieved first-page **Google** rankings for "Epidermolysis Bullosa" and related search terms, significantly increasing online visibility and helping more people access trusted information and support. As planning commenced for a comprehensive website redevelopment, we continued to refine and enhance the existing website, resulting in a 50% increase in page views during the year.

Media Highlights

Media coverage throughout the year helped increase public understanding of EB and raise awareness of DEBRA Australia's work. Family stories, fundraising initiatives and ambassador-led campaigns secured exposure across television, radio, podcasts and print media, helping bring greater visibility to the EB community. A standout example was the **EB Butterfly Walk**, which generated strong media interest while raising both funds and awareness for people living with EB.

EB Butterfly Walk

- Racing.com (24 March)
- Channel 7 *The Bright Side* (18 March)
- Channel 9 *News* (19 March)
- 3AW Radio (24 March)
- 5MU *Breakfast Show with Adam and Jennie* (7 April)
- The Murray Valley Standard (9 April)
- Channel 10 News *SA and VIC* (30 March)
- Adelaide event supported by AFL greats Robert "Dipper" DiPierdomenico and John Platten



Community Voices

- *Delving with Des* podcast featuring long term supporter David Golledge, founding member of the Green Team/Eliza's Ride.
- *Missing Schools* podcast featuring DEBRA Australia's Family Support Coordinator, sharing insights drawn from both lived experience and her ongoing work supporting the EB community.
- Simone Baird pictured above right at Brighter Days with the 3AW radio show.

32,465
Website visits



5,797
Social media followers



Our Supporters

DEBRA Australia is deeply appreciative to all of our incredible donors and partners for supporting us in 2025/26, joining us as change makers for the EB Community.

- D & T Geldart
- Flora & Frank Leith Charitable Trust
- Valenti Golf Club
- Daniel Connell
- Mercer family (Follow Your Dreams)
- Nigel & Patricia Peck Foundation
- The National Epidermolysis Bullosa Dressing Scheme (Funded by the Australian Government)

Program Supporter

Partnerships

DEBRA Australia are proud members of



Long-term supporters Sutherland Medical, with DEBRA Australia Staff members Sue McKenna and Mary-Jean Howard, at the Melbourne Health Professionals EB Symposium

Ambassadors & Volunteers

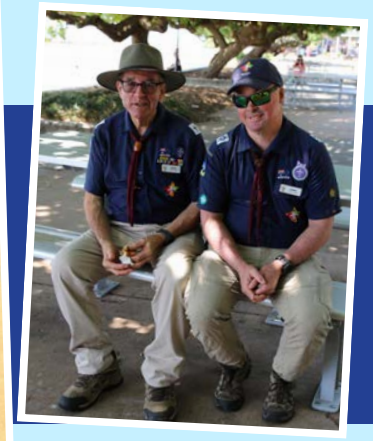
Our valued Ambassadors and Volunteers help to raise awareness and deepen community understanding of the challenges that EB presents. Thank you.



Above: Iron Man champion and DEBRA Australia Ambassador Matt Bevilacqua with baby Beau

Below: DEBRA Life members Kathy & David Hagan from Toowoomba walking in memory of their son Mitchell with Sue McKenna from DEBRA Australia





Above: Bracken Ridge Scout Leaders Keith & Jeff running the BBQ at the Brisbane Walk for Wings.

3,170

Hours dedicated by our amazing volunteers!



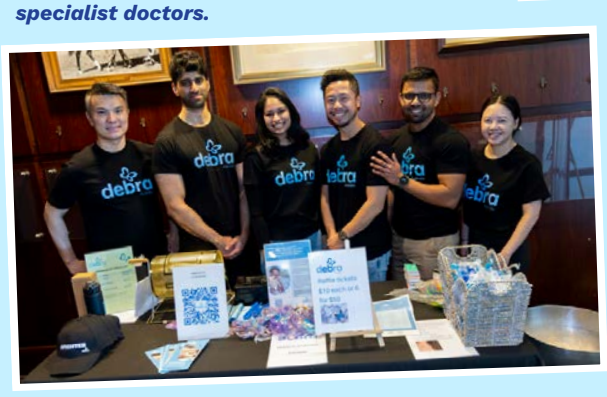
DEBRA Australia Ambassador Dean Clifford with parents Jenny and Peter



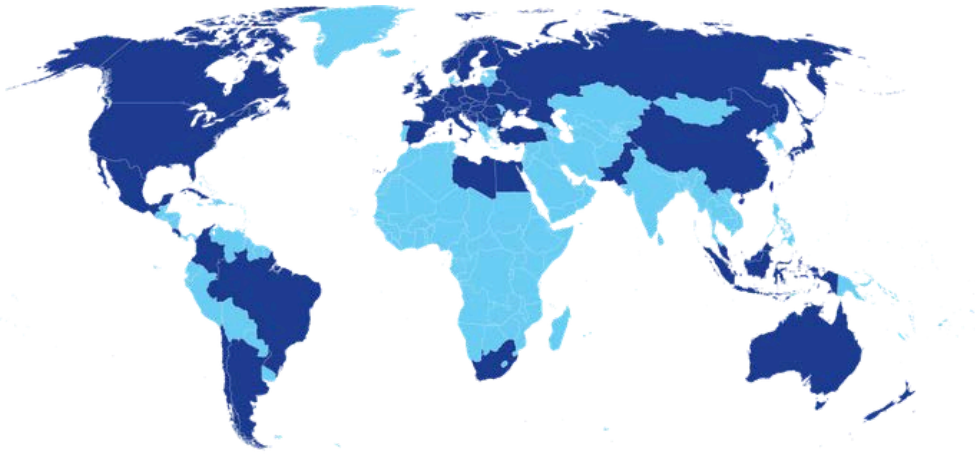
Above: Brighter Days 2026 Volunteers, including Simone Baird and RCHM EB specialist doctors.



DEBRA Australia Ambassador Renae Wood with her family



Left: Corporate volunteers from ANZ supporting the Bubbles & Butterflies luncheon



DEBRA now has a presence in nearly 50 countries worldwide

DEBRA International

DEBRA Australia continued to strengthen its connection with the global EB community through its active membership and involvement with DEBRA International.

During **EB Awareness Week**, DEBRA Australia participated in the global rollout of the **#InsideOutForEB** campaign, contributing to a coordinated international effort to raise awareness of EB and amplify the voices of people living with the condition. Following its success globally, plans are already underway to further expand the campaign in coming years.

Following the completion of Dr Zlatko Kopecki's term on the DEBRA International Executive Committee in November 2025, CEO Mary-Jean Howard was elected as **DEBRA Australia's representative**, an appointment welcomed by DEBRA Australia, helping to ensure ongoing Australian participation in global EB initiatives.

The **DEBRA International Round Table of Companies** continues to be an important forum for collaboration between DEBRA organisations, industry and the EB community, with a successful meeting held in Munich, Germany, in November 2025.

In January 2026, Australian researchers, clinicians and nurses were strongly represented at the highly successful DEBRA International EB Congress in Brazil. Several Australians presented research and shared expertise, including Dr Zlatko Kopecki, who attended with support from DEBRA International and DEBRA Australia as an invited speaker and session chair, and Dr Albert Mellick, who also presented his research. Travel grants jointly funded by DEBRA International and DEBRA Research supported the attendance of two Australian delegates, while DEBRA Australia also provided support for a PhD student through its travel grant program. The congress attracted more than 520 participants from over 35 countries, strengthening international collaboration and knowledge exchange.

DEBRA International also welcomed a **new Executive Director, Mariangela Pellegrini**, in January 2026 and launched its new **five-year strategy** and **Global Network Declaration**. DEBRA Australia contributed to consultation and planning activities to help represent Australian priorities and perspectives. The strategy outlines a range of initiatives to strengthen global collaboration, advocacy, research opportunities and organisational capability across the EB community, including future priorities such as a Global EB Registry and Biobank. DEBRA Australia continues to work closely with DEBRA International as it progresses its 2026-2030 strategic priorities aimed at improving the wellbeing of people living with EB through a more coordinated global approach.

DEBRA Australia **Team**

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

Board

- Judith Davis (SA) · Chair
- Tina Segulin (VIC) · Deputy Chair
- Michael Kean (NSW)
- Tony Baum (VIC)
- Deanna Pope (VIC)
- Dr Tariq Khan (NSW)
- Professor Ingrid Winship AO (VIC)
- Assoc/Prof Albert Mellick (NSW)

Committee Chairs

- Judith Davis · Finance & Risk
- Tina Segulin · Family Support Program
- Dr Zlatko Kopecki · Research & Education
- Dr Jenny Marty · EB Services

Employees

Full-Time

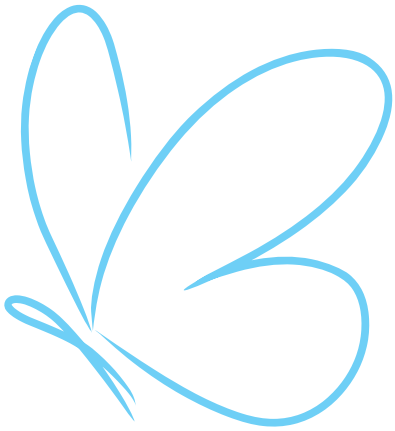
- Mary-Jean Howard (NSW) · Chief Executive Officer

Part-Time

- Simone Baird (VIC) · National Family Support Coordinator
- Sue McKenna (QLD) · Executive Coordinator/Board Secretary
- Joanne Sturgess (QLD) · Administration Assistant

Welcome to and Retiring Board Members

Welcome to Prof Ingrid Winship, Assoc/Prof Albert Melllick and Dr Tariq Khan, who joined the Board in December 2025. A warm farewell to Belinda James (Aug 2025) for her valued service on the Board and continued dedication on the Family Support Committee.



Key Contractors *(Part-Time)*

- Sarah Thyssen (VIC) · Fundraising & Communications
- Mark Cox (QLD/UK) · Marketing & Communications
- Scott Macfarlane (QLD) · Website & IT
- Anne Paton (VIC) · Philanthropy Manager (concluded November 2025)
- Rhian Mathias (NSW) · Fundraising & Marketing (concluded March 2026; we wish them well during this new family chapter)

Ambassadors

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

debra Australia.

Thank you

DEBRA Australia relies on the generosity, commitment, and support of our community to provide life-changing programs and services for people living with EB and their carers.

Every donation, every volunteer hour, and every partnership helps transform the lives of EB families across the country. All donations are tax-deductible, and your support directly enables vital care, research, and community programs.

To contribute or explore ways to get involved, visit debra.org.au or contact us today. Together, we are building a stronger, more connected, and resilient EB community.

w: debra.org.au
e: admin@debra.org.au
p: (07) 4693 7003

REGISTERED CHARITY
acnc.gov.au/charityregister

FIA ORGANISATIONAL MEMBER CODE COMPLIANT