debra

Impact report and financial statements

for the financial year
ended 31 March 2024

Company information

Board of Directors

Leonora Bishop

Elizabeth Collins

Colm Darling
(resigned 5 March 2024)

Fiona Duffy
(resigned 16 November 2023)

Emma Fogarty
(appointed 16 January 2024)

Valentine Fynes

Susanna Gaynor

Robert Healy

Mark Hyland

Michael O'Rourke
(appointed 5 March 2024)

Sinead Spain

Rosemarie Watson

Company secretary

Mark Hyland

Registered office

Butterfly Cottage
8 Clanwilliam Terrace
Grand Canal Quay
Dublin 2
D02 R240

Registered number

141279

Revenue Charitable Status Number

CHY 8703

Registered Charity Number

20021726

Independent Auditor

Grant Thornton
Chartered Accountants &
Statutory Audit Firm
Mill House, Henry Street
Limerick

Bankers

Allied Irish Bank
9 Terenure Road, Rathgar
Dublin 6

Bank of Ireland
St Stephen's Green, Dublin 2

Permanent TSB
St Stephen's Green, Dublin 2

Solicitors

A&L Goodbody
25/28 North Wall Quay
Dublin 1

(A company limited by guarantee and not having a share capital)

Contents

Message from our CEO

Early in 2024, the team at Debra produced a new short film – *What is tough?* We created it together with people affected by EB, and for me it embodies the spirit that connects everyone who is part of Debra. It also demonstrates why the support we receive – and the progress we inspire together – are so valuable and so badly needed.

The film shows the challenges that people affected by EB face every day and want others to see. It shows the blistering, the bandaging, the daily sacrifices and the never-ending pain. It shows the isolation of living with EB and the strain of caring for others, when the gap between the support people need and the support that's available remains so wide.

And – crucially – it also shows the strength that unites the whole EB community. It shows how people fight this cruel disease every day and refuse to let it define them. And the voiceover makes clear that Debra...

"is here to bring the boldest kind of hope, because we know what it is to be tough. Tough is every person living with EB, caring for people with EB and bereaved by EB. And they need action, not sympathy."

The film leaves me feeling more inspired every time I see it, because in just a few minutes it brings to life the determination that makes all of the progress in this report possible. On the pages that follow you can read how we got EB discussed in the Dáil and formed new connections to push groundbreaking EB research forward. You can read how we brought researchers together with members of our EB Expert Panel and supported families with everything from bespoke books to helping manage financial strain of EB. And the unifying thread across all of these stories is a refusal to accept how things are – and a certainty that life can be less tough for every person affected by EB. As the film says, we are driven by 'the boldest kind of hope'.

I feel proud every day to be CEO of Debra, and I'd like to send a heartfelt thank you to every member of staff, volunteer, medical professional, company, trust, foundation and individual supporter who chose to invest their time and money in our work in 2023/24. And I'd also like to say to every person affected by EB in Ireland, we see how tough you are, and we're right there with you, transforming the future for people living with EB

Jimmy

Jimmy Fearon
CEO

Message from our Chairs

In March 2024 I finished up my second spell as Chair of Debra. Writing this message gives me the opportunity to reflect on the extent of change which has taken place, particularly in recent years and to look forward to what the future may bring, both for our organisation and for the EB community more widely.

My overarching view is of an organisation which has transformed so much of it's operations to become far more professional, cohesive and effective in positively impacting the lives of those living with EB. The path has not always been straightforward, of course. Through the Covid-19 pandemic, for example, we faced great uncertainty and disruption, as we sought to meet the needs of everyone affected by EB in Ireland during a crisis where all of our understanding was so limited. But even in the face of great challenges, progress has continued to unfold. That progress has unquestionably been driven by the heart, inspiration and direct engagement of people living with EB and those closest to them.

Our voice as an advocacy organisation has grown far louder in recent years, and this report shows how Debra now punches well above our weight in terms of raising the profile of EB and demanding better care. Our place at the heart of the EB community ensures we know which issues trouble people the most, and we offer vital direct support to help resolve those issues while advocating to achieve long-term change.

Our research portfolio is also continuing to grow, and a sense of momentum was evident last year. Understanding and development of treatments that can ease the terrible pain of EB is definitely increasing, and though far more research is needed, it is no exaggeration to say that, without Debra's involvement, the future would seem far less hopeful.

The growth and development of Debra is created by our community – including people living with EB, clinicians, researchers, carers, volunteers and donors across Ireland. Underlying all of this we have the talent and capability of a highly motivated staff, management team and board. They work tirelessly together and with incredible commitment to make life less tough for every child and adult with skin as fragile as a butterfly wing. I feel very privileged to have been part of their journey.

I've always said that once you have engaged with Debra, Debra never leaves you. That's certainly the case for me, and I will now become an 'ordinary' Debra supporter – if such a thing as an ordinary supporter actually exists. It is fantastic to know that someone of Michael's calibre and experience will be taking Debra forward. I know he will be able to rely on wonderful support from the board and throughout the organisation and I would like to wish him and everyone connected to it all the very best for the future.

Colm Darling
Chair, November 2018 to March 2024

Though I was Chair for only one month of this report period, I want to thank Colm for his profound impact on Debra and the wider EB community. National awareness of EB has transformed in Ireland in recent years, to the extent that stories of EB now feature on prime time television. Colm has been at the heart of this progress, and at the heart of Debra's 'families first' approach, which ensures all of our work is guided by those affected by EB. It is an honour to follow Colm as Debra chair, and to be able to keep building on a period of sustained, wider-ranging progress.

Michael O'Rourke
Chair, March 2024 to present

Directors' report for the financial year ended 31 March 2024

The Directors are pleased to present their report and the audited financial statements of Debra for the year ended 31 March 2024.

Our vision, values and mission

Debra's mission is to transform the lives of people affected by epidermolysis bullosa (EB) through care, research and advocacy.

Our vision is a world where no one suffers from EB. Until that vision is realised, we will provide vital care and support for people living with EB, their families and carers, and those bereaved by EB.

We will fund pioneering research into better, more innovative treatments to enhance the wellbeing and quality of life of everyone impacted by EB. We will advocate for investment in comprehensive and appropriate services and support that meet the needs of people living with EB.

Our main activities are to:

- Provide essential services and support that meet the day-to-day needs of people living with EB and those who care for them.
- Lobby for core medical services and resources for people living with EB, and positively influence public policy in these areas.
- Strive for the development of effective, innovative, life-changing treatments and cures for EB.
- Coordinate research programmes and collaborate with other organisations capable of bringing increased value and higher chances of success.
- Encourage the development of EB support initiatives, fostering cooperation and mutual support in care and research, both nationally and through Debra International.
- Raise vital funds to perform all the above primary activities.

Our values bring us together in our work, reminding us that actions speak louder than words

- **Togetherness** – through fostering an open, fun, and encouraging culture.
- **Person-centred** – through actively listening, understanding and supporting people.
- **Boldness** – through breaking boundaries with courage, creativity and tenacity.
- **Passion** – through commitment to achieving meaningful impact for the EB community.
- **Integrity** – through delivering on our promises, demonstrating honesty, trustworthiness, transparency and appreciation at all times.

Our strategic objectives 2022–2025

Our current strategy was launched in mid-2022 and commits us to working towards seven strategic objectives that will drive us to achieve the greatest possible impact for people with EB and their families. The strategy was created with extensive input from people with lived experience of EB, families, carers, medical professionals, researchers and donors, and outlines seven closely connected objectives.

The seven objectives reflect the three areas where progress must keep growing – family services, advocacy and research – and the four areas of our organisation we must strengthen to achieve our ambitions – support for our people, fundraising, communications and impact measurement.

- **Family support** – improving care for people living with EB, caring for someone with EB or bereaved by EB.
- **Research, treatments, and symptom relief** – driving, demanding and investing in research that contributes to solutions that improve the well-being and comfort of people living with EB.
- **Advocacy** – advocating for families impacted by EB, ensuring they receive the right services and support at the right time.
- **Fundraising** – securing our long-term viability through a strong, sustainable funding platform.
- **Communications** – streamlining our communications to increase awareness of EB and our work.
- **People** – being great people to work, volunteer and collaborate with.
- **Impact** – demonstrating that our activities lead to a significantly improved quality of life for people with EB.

To better understand the scope of these objectives and the extent of our ambition,

we recommend you read our *Strategic Plan 2022–2025*, downloadable on debra.ie.

Through the remainder of this report, we will explain the activities we have undertaken in the past year and those we will continue to focus on into the new year to continue to work towards achieving our strategic goals.

Our thanks

It is impossible to convey sufficiently our heartfelt thanks to everyone who supports Debra.

On behalf of the Board, we would like to thank our donors, supporters and the public for their ongoing generosity, attention and care.

We are enormously grateful to our research partners, medical and clinical support partners, professional service providers and of course to our amazing staff and volunteers. Your hard work, incredible commitment, consistent dedication and deep conviction are immense.

Above all, we wish to acknowledge and thank those of you living with EB. You play such a crucial role in Debra. You are our inspiration, motivating us day in and day out to prove the power of the butterfly effect – that seemingly small acts and forces can create the most meaningful and monumental change.

Our impact and work for the year ended 31 March 2024

Objective 1

Family support

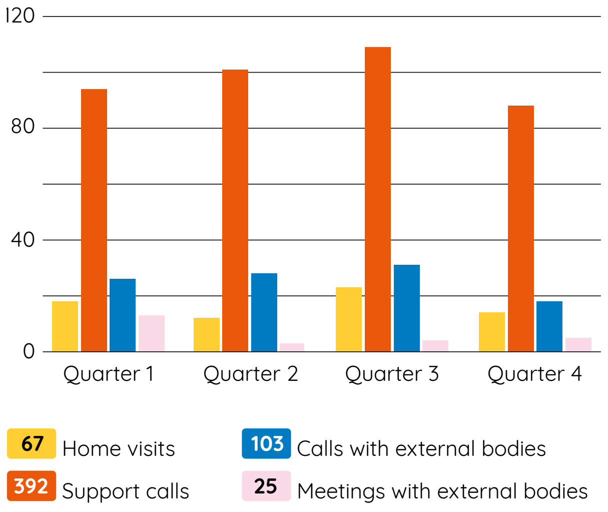
Our family support team is there for families across Ireland, taking action to empower everyone affected by EB. We provide direct support and a sense of connection, listening to what every family wants and tailoring our work in response. We are here to offer home visits, to give local, peer and clinical support, to share advice over the phone and email, and to be side-by-side with people as they connect with the HSE, hospitals, private health care providers, charities and community support services. Every day, we do everything in our power to stop families affected by EB from facing challenges alone.

Last year, we increased the amount of time we spent supporting families face-to-face and over the phone. We provided:

- 392 support phone calls
- 67 home visits
- 103 advocacy calls
- 23 advocacy meetings

We take pride in being flexible and adaptable, so however families want to engage with us, we make it happen. It's our goal to reach as many people living with EB as we possibly can.

Number of calls/visits 2023–24



Measuring our impact

In 2023, we surveyed everyone who connected with our services to make sure we are providing the support people value most. We were delighted with what people told us:

- **100%** said that they have access to the family support service when they need it.
- **86%** rated the service as exceptional or very good.
- **100%** said that have access to all the information they need.
- **38%** would like even more support in 2024/25, including more financial support, information and advice and help with personal advocacy.

Reaching people nationwide

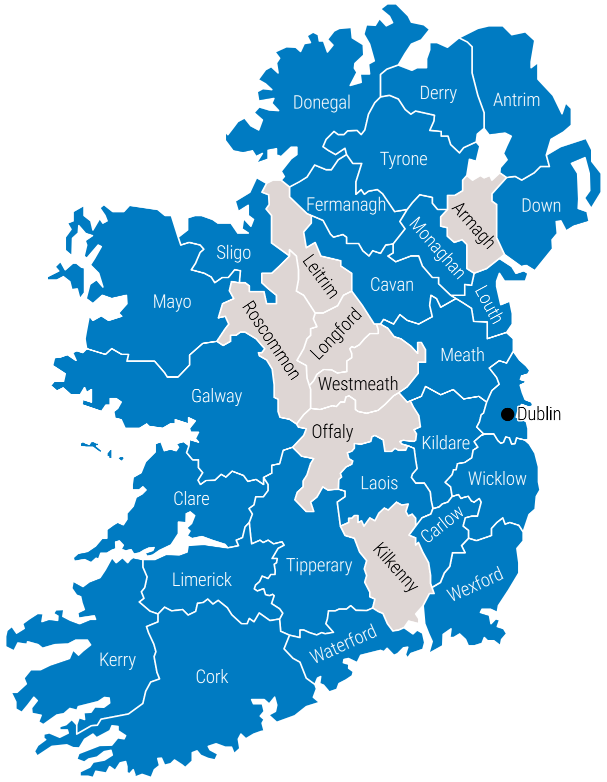
To make sure we allocate enough resources to meet the different needs of the EB community, we record the number of interactions we have with people. The map below shows the counties where we supported people impacted by EB last year (in blue).

Our family support service connected with six new families nationwide last year. Sadly, we also learnt of the death of one of our service users and responded with bereavement support adapted to the family's needs, which we will continue to offer.

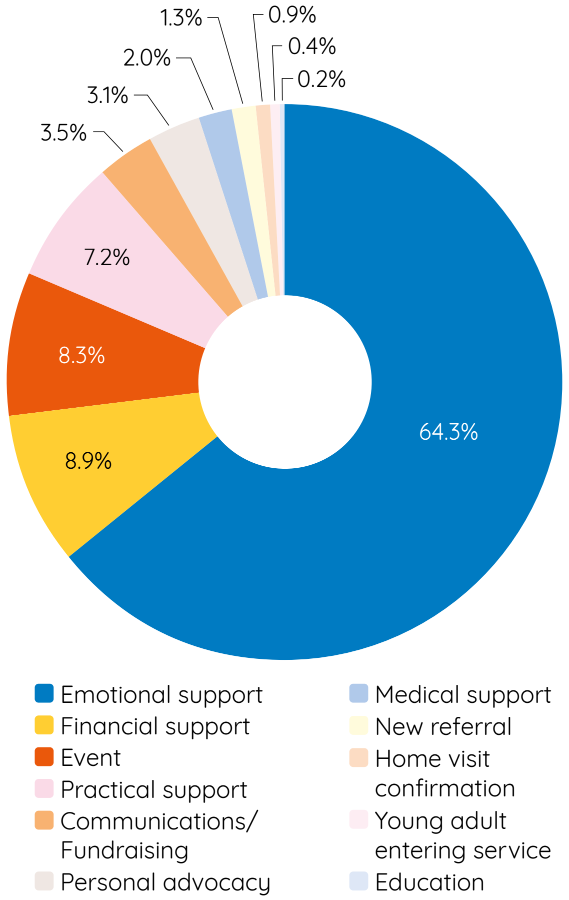
We also provided an urgent response when a child living with EB required a long stay in hospital, arranging hotel accommodation for the family on a number of occasions to ensure they were all together, and making sure a member of the Debra team was available whenever needed.

Emotional support continues to be a big focus of our calls and requests for support with personal advocacy continue to increase. Personal advocacy requests are wide-ranging and involve assistance to families in accessing medical, practical and financial supports within their community.

Counties (shaded blue) contacted by phone or visit in 2023



Primary concern for call



Easing the financial strain of EB

We offer a range of grants and support that people affected by EB can access, regardless of their financial situation. Our respite and wellness grants give people the chance to take time out for a fun activity, short break or family treat. We also offer a counselling and therapy grant. This can help people access counselling or play therapy, as we increase our focus on supporting the mental health of adults and children living with EB, as well as their families and carers.

The quotes below give a sense of what our financial grants and support meant to families across Ireland in the past year.

“The impact of receiving a grant has meant my son has had highly improved mental health since he started with his therapist.”

“With your help I was able to take a break away as it was a very tough year on us. Thank you all so, so much.”

“It’s taken financial stress out of the equation, very helpful.”

“I received a gift voucher for Christmas and I was able to get food that I would have struggled to get, and I thank Debra for helping me. Well done to all the staff that help greatly, and I appreciated the chats that helped me coping with EB Simplex. Thank you many, many times.”

“The grant is of huge benefit to us as my husband is the carer for our children. It gives us a break away in a hotel with a few days free of domestic duties. It is very much appreciated by us and we are very grateful for this.”

Filling the gaps in care packages and personal assistance

Care packages provide funding for home nursing and healthcare assistance, so families affected by EB can get help with vital tasks like bandage changes and wound care. The packages give parents much-needed respite and mean they can simply be mum or dad again, creating a crucial distinction between parents and healthcare providers.

Most of the time, care packages are funded and delivered by the HSE and its partners. But there are often gaps, so we continued to offer extra funding when it was needed, working closely with multidisciplinary HSE teams across Ireland.

It is a similar story for personal assistance for adults, which helps people to maintain a level of independence. When HSE-funded assistance doesn’t meet people’s needs, we can step in to fund extra personal assistants. In line with our strategy, we continued to advocate for everyone’s care needs to be fully met by the HSE. But when gaps remain and have a negative effect on people’s quality of life, we won’t hesitate to step in.

Reviewing our family support services

In 2023, we began a full review of our family support service to understand how demand for our services is changing and how well we are meeting people’s needs.

The overarching objective for our family support service is clear. We aim to improve care and support for people living with EB, and for their families and carers, by providing essential services and tailored support. We know that, between 2021 and 2023, the biggest request we received from families was for financial support, followed by requests for home visits, support calls and personal advocacy.

But we also know that more families are now accessing our services, and that people’s needs are changing. Families are finding it harder to access support in communities, and our family support team is therefore spending more time involved with personal advocacy. There is a growing, and often unmet, need for psychosocial support. We want to understand how well we are meeting these changing demands and this review will help us achieve that objective.

We expect to complete the review by Autumn 2024. It will include recommendations on if and how we need to adapt our services to make sure we keep delivering the best support for families across Ireland, and this will shape our service going forward.

Creating bespoke booklets for children with EB

Big life events like starting a new school can be even more challenging than normal for children with EB, because most people know very little about the condition and what its impact can be. So this year we began producing personalised, illustrated books for families, telling their child’s story in a simple, accessible way. Children with EB can then take these books to school with them to share their unique experience and let others know how they can help.

We created eight of these books in 2023/24, along with guidance for schools explaining the value of the books and how they can be used. We’ve also created a set of design guidelines for creating the books and shared these with organisations internationally that also offer EB support.

In her own personalised illustrated book called Darcee’s Story, Darcee (5) explains how she is just like any other little girl who loves drawing and stories. And even though she sometimes wears bandages, the booklet lets her new friends know that her condition is not contagious and doesn’t stop her playing games with them.

“I love my new book because it’s all about me and my special skin, and my mummy and nanny [grandmother] are in it too,” Darcee said. “I really hope my friends love my book and learn about my butterfly skin.”

Listening to our EB expert panel

Launched in 2022, the EB Expert Panel advises us on various topics related to what living with EB in Ireland is like now and what it should look like in the future. With members’ help, we can make sure we provide support in the way that matters to the EB community. As valued advisors, panel members provide advice to our Research, Advocacy and Family Support projects and initiatives.

We held two in-person EB Expert Panel events in 2023/24, listening to the group’s insights on a variety of issues related to life with EB in Ireland. Members discussed how Debra’s services could be tailored to meet the needs of the community, as well as helping to inform and shape our EB research priorities.

Our new EB emergency cards are one example of how we’re putting EB Expert Panel feedback into action. We ran a workshop to understand what people want from the cards and how they will be used. Following this input, as well as feedback from EB clinics and paramedics, we have now designed the new medical alert cards. They contain details about EB, emergency contacts and information about each person’s EB service. We are confident the cards will have a big impact during emergency and routine healthcare.

Building connections through peer support

Given the rarity of EB, our peer events are often the only chance people impacted by EB have to meet and share experiences with others who truly understand what they are going through. In 2023, as a result of feedback from our EB Expert Panel, we restarted our adult peer support groups, giving people with all types of EB and their carers a chance to get together in a social setting. We organised two events for people to come together and connect, chat and form relationships and friendships, and feedback from participants was very positive.

Bringing families together

Families from all over Ireland travelled to Barretstown for our family weekend in May 2023, with plenty of old friendships rekindled and new connections made. This year the weekend included a programme of events for adults, including holistic treatments, research talks, a stress management workshop and a peer support meeting.

Our traditional Christmas party was once again a highlight of the year. Held in Dublin, with everyone from outside the county offered accommodation for the night, our guests had lunch, caught up with friends, played games, shared gifts and enjoyed the chance to meet Santa. Events like this offer an invaluable chance for the EB community to come together, create memories and forge new friendships.

Feedback from both events was excellent and reassured us that we are sticking to our promise to place people impacted by EB at the heart of all we do.

Celebrating special siblings

Our sibling grants are fast becoming a firm favourite with families affected by EB. The idea is simple. A young person living with EB nominates their sibling for being fabulous, and we celebrate their fabulousness with a personalised certificate and a shopping voucher. With families’ consent, we also share their pictures on our social media channels, so the celebrations can spread even further.

Creating space for bereavement

All family members are affected by EB, and the grief people feel after a death is as diverse and nuanced as the condition itself. Our team is experienced in loss and bereavement care and provides tailored bereavement support to all families, by phone and through home visits. We provide this assistance for as long as it's needed, and we also fund access to adult bereavement therapeutic services, if someone needs additional care.

This year, we held a very special memorial service in Kilashee House. The service was led by Brian Gough, Chaplin at St James's Hospital, and attendees were invited to plant bulbs in clay pots, which they could then take home after the service. We had music from a gospel choir, and everyone shared afternoon tea, creating a space for families to share stories of loved ones.

Supporting clinical teams

We continued to work closely with Children's Health Ireland and St James's Hospital in 2023/24. Our work included funding staff training to increase knowledge of EB. Partnerships like these are vital to ensure everyone living with EB receives the care they need.

Providing advocacy alongside support

There are close links between family support and advocacy, because of the gaps between what families need and what they get from national services like the HSE. So we do everything we can to make sure families are heard in decisions that affect their lives. This includes sitting on multidisciplinary teams and supporting families as they navigate through interactions with schools, county councils, community support groups and the HSE.

In 2023/24, we supported families so that they could feel comfortable sharing their experiences of EB on TV, raising awareness of what needs to change among a large audience.

We also worked closely with our advocacy colleagues to support national campaigns and shape our priorities, as well as joining an Oireachtas meeting and a presentation at the Dáil. This is covered in more detail under the section 'Objective 3 – Advocacy' on pages 19–21.

Our plans for 2024–2025

- Our focus will continue to be on delivering excellent services that put the needs and voices of those impacted by EB at the heart of all decisions.
- With Dr Jessica Gale now appointed as a consultant dermatologist, we hope to partner with SJH and Children's Health Ireland at Crumlin to make the outreach service happen. Our family support team will work closely with our advocacy colleagues to make this a priority for Debra's national campaigns.
- We will conclude the family support service review in 2024, enabling us to make strategic changes that align with what people value most.
- In response to growing demand for our family days, we're planning an event in Emerald Park for 2024, catering to a wider age range that previous family day events. Our annual Christmas party will also take place in December.
- We have two peer support meetings and two EB Expert Panels scheduled for 2024.
- We are partnering with our advocacy colleagues to support the development of the EB Butterfly Review (see Advocacy section).
- We will continue to develop our team's skills, expanding people's knowledge through external training and education and internal workshops.
- We plan to share and collaborate closely with our nearest neighbour, DEBRA UK, on initiatives including respite opportunities for families.
- Along with other colleagues from the Debra team, we will attend the DEBRA Cares Conference in Atlanta, USA in July, to meet with families and experts and share our knowledge and expertise.

Spotlight:

Sharing Katie's story to raise awareness and funds

Katie Riley was born with the most severe form of EB, in June 2004. A midwife noticed skin was missing from five of Katie's fingers, and her parents Miriam and John watched on helplessly as their newborn baby was whisked away to the hospital's intensive care unit.

"We couldn't hold her or feed her," says Miriam, who's from Dublin. "I got to hold her skin-to-skin for about two minutes, and then she was taken away. After just a few days, Katie was transferred to the Nazareth ward in Our Lady's Children's Hospital, Crumlin."

Miriam and John were devastated to find out that Katie wouldn't live for more than a few months. She passed away in August that year. "The nurse placed her in my arms and I held her close," Miriam remembers. "I didn't have to worry about hurting her anymore. She passed away in my arms a few minutes later."

Twenty years on, Miriam has shared her story with Debra because she wants more people to know the reality of life with EB. She has also turned to Debra for support for many years, and wants others to know that help is available. By sharing her story, Miriam helped us raise €160,000 in our Christmas appeal.

"Debra's support has been just brilliant," Miriam says. "I've met other families who share the hardships of EB and these are the only people that truly understand what I've gone through. They're like a second family. Debra brings people together, and in doing so they heal wounded hearts."

Objective 2
Research

There are multiple types of EB and it's a complex disease, so it's unlikely we'll find a single, universal cure. Instead, the cure for EB will likely involve a combination of treatments. At Debra, we fund pioneering studies in Ireland and internationally, support EB researchers, advocate for research funding and ensure people affected by EB are at the heart of research – because we know one day that the right combination of treatments will be found.

Being guided by our EB Expert Panel

Our EB Expert Panel was set up in November 2022. It brings together people with EB, their families and people who have lost loved ones to EB, giving people a powerful chance to shape Debra's work and make sure research is focused on the issues they care about most.

In April 2023, the expert panel came together at a session to hear directly from researchers about projects funded by Debra. The researchers then worked with panel members to understand how they could communicate their research more effectively in plain English.

This collaboration continued in September, when researchers met with the panel to understand how much people knew about gene therapy. After a lively discussion, researchers offered to give the panel a first-hand look at their work, and we put plans in place for members to visit the UCD Charles Institute of Dermatology research lab.

We will keep building understanding and accelerating progress by bringing researchers and the EB community together.

Bringing people together to prioritise research

We have agreed to co-lead a project for the James Lind Alliance (JLA) with DEBRA UK and DEBRA Canada, aiming to identify the biggest unanswered questions and uncertainties facing people affected by EB. JLA is a non-profit making initiative that brings patients, carers and clinicians together to agree on research priorities, so researchers and funders know the biggest issues facing people who will be affected by future research. This initiative will identify priorities for research that DEBRAs will focus their efforts on supporting and funding.

Collaborating on Irish and international studies

We continue to co-fund research projects with the potential to transform the future for people living with EB. In 2023/24, this included joining with DEBRA UK to fund two new research studies that aligned with priorities identified in Ireland, both based at Queen Mary University in London:

- Prof Caley QMU London: Treating JEB With Recombinant Laminin 332.
- Dr Sequeira QMU London: Identifying the cellular and molecular mechanisms underlying the oral mucosal scarring and resistance to cancer development in RDEB patients.

A number of projects we have been funding also came to a conclusion in 2023/24. Full details of all of these are available at debra.ie/eb-research/. One notable study led to a finished project called Norzite Mouth Spray, which is now available to buy. Though the product has not yet been tested specifically on people with EB, early anecdotal feedback from people with EB has been very positive.

We also continue to represent EB as a European Patient Advocacy Group (ePAG) on the ERN Skin group, alongside DEBRA Belgium. In 2023/24, our work included taking part in a panel discussion at a two-day event on rare skin diseases.

In addition, as foot pain is an issue faced by many people who live with EB, we increased our research focus on this issue when a student joined our team over the summer. She gathered all available information on the subject into a report which is available at debra.ie/news/putting-eb-foot-problems-in-focus/, and which will now guide our future studies in this area.

We also created internal guidance and recommendations for how we can support the integration of clinical staff into research initiatives for EB given the time constraints and lack of protected time for research within the HSE.

And, finally, last year we also funded a third-year graduate medical student to review and bring together existing information about eye problems affecting people with EB who were treated at CHI at Crumlin. This study is ongoing and will help determine better support services for people living with EB.

Funding small projects with big potential

We first launched our seed funding scheme in 2022, because so many interesting and high-quality applications focused on EB were being made to national funders such as the Health Research Board and turned down because of a lack of preliminary evidence to support their concepts.

Through the fund, we provided €20,000 to researchers in 2023 to apply their ideas and technologies to EB, in the hope their findings will lead to larger grants and eventually to EB treatments. These studies progressed through 2023 and 2024 and four out of the five projects have since generated preliminary evidence and secured larger national grants.

Advocating and communicating about research

As a member of Health Research Charities Ireland (HRCI), we continue to develop our advocacy work to push for more research and more research funding. We hope that expressing the voice of Debra and working with other research charities will bring about national changes to further support and improve health research in Ireland. In 2023/24, our work included:

- Participating in the Irish Health Research Forum on the process for biobanking skin samples for EB.
- Sponsoring the first Rare Disease Clinical Trial Network Conference – a group which has been set up to strengthen and increase clinical trials for rare diseases in Ireland.
- Contributing to the HRCI's report on getting the most social benefit from research.
- Contributing to guidance for charities, civil society organisations, researchers, research institutions and funders on creating successful research partnerships.

We also raised awareness of EB among future healthcare professionals, with presentations to students and researchers at Trinity College, University College Dublin, the Royal College of Surgeons of Ireland, Dublin City University and Maynooth University.

We made sure the experiences of people living with EB were heard at the PPI and Communications Working Group for the HSE Implementation of the National Genetic and Genomic Strategy. It is vital that the patient voice is integrated into decisions on how the strategy is implemented, to ensure the strategy meets the needs of its end users.

Finally, we were pleased to welcome Dr Emma Creagh of Trinity College to join the Debra Research Committee. Dr Creagh is an Associate Professor at the School of Biochemistry & Immunology and brings additional expertise as a scientific researcher to the committee.

Our plans for 2024/2025

- A sustained and concentrated focus on maintaining Patient and Public Involvement in our research activities.
- Supporting more EB research and expanding research capacity both in Ireland and abroad.
- We look forward to working with all our stakeholders to realise and make tangible our proposed plans.

Spotlight:

Revealing the staggering costs of EB

Timed to create maximum impact during EB Awareness Week, we published new research from the University of Limerick in October. Titled ‘Life with EB in Ireland’, it showed that the cost of caring for someone with EB in Ireland has reached €130,000 a year.

€130,000 is almost double the cost of caring for someone in the UK and well over twice the cost in Germany and Italy. That’s largely because Ireland doesn’t provide a funded bandage scheme for people with EB.

“We have been cast aside again. My daughter matters, her life matters, people with EB matter, they exist and we’re not going away,” said Liz Collins, as we launched the report. Liz’s daughter Claudia lives with recessive dystrophic EB, leaving 80% of her body covered in open wounds.

And Liz’s frustration was mirrored by Joanna Joyce, our Head of Advocacy, who added:

> **“Of the multitude of obstacles facing people with EB, access to specialised bandages is a significant issue. Bandages can cost thousands of euros each month and this disproportionately affects those without medical cards.”**

The report also found that big challenges remain in the provision of home nursing care. Too often there’s no contingency plan when nursing staff are unavailable, and there’s a lack of EB-trained nurses able to replace those who move on. By sharing groundbreaking research and direct experiences, we pushed for progress throughout 2023/24.

Objective 3

Advocacy

No one affected by EB should struggle to get the support or services they need. So, we advocate for change side-by-side with people with EB and their families, pushing for increased funding and better support, and helping awareness of EB to keep growing.

Amplifying the voices of the EB community

Throughout 2023, we made sure the voices of people with EB and their families were heard by decision makers through our advocacy campaigns. We’re grateful to everyone who shared their stories and experiences in this way, because nothing will drive change faster than increased understanding of how tough life with EB is.

Our EB Expert Panel played a vital role by helping to identify gaps in current services, such as lack of support for those with milder forms of EB and difficulty in accessing medical cards. This made sure our advocacy work was focused on the most urgent issues people are facing in Ireland today.

Building pressure for increased funding

We launched our pre-budget submission campaign – ‘Small ask, big impact’ – with a photocall outside Leinster House. Seven politicians joined us as we called for just 0.003% of the health budget to prioritise mental health support, outreach care and home care for people living with EB.

Frustratingly, the October budget did not include extra funding for EB, but Sinn Féin and the Social Democrats did include EB investment in their alternative budgets for 2024. We continued to build on this growing political support with our work during EB Awareness Week.

Subsequent to the budget announcement, we spoke to the Minister for Disability about EB funding, and submitted an enhanced business case, following up on the pre-budget submission. As a result, Debra was mentioned in the HSE National Service Plan for 2024, and more funding was made available for children’s services in the community.

Getting heard in the Dáil

We launched our new report with the University of Limerick, ‘Life with EB in Ireland,’ during EB Awareness Week in October. This led to EB being discussed multiple times in the Dáil.

The report is based on a review of studies from around the world looking at the impact of EB on quality of life and finances, and on a comparison of current support in Spain, Australia, Ireland, the UK and Austria. It highlights challenges many people with EB face, from poor mental health to limited nursing care, and provides recommendations for government action in Ireland.

The launch was hosted at Leinster House by Sinn Féin Deputies Chris Andrews and Pauline Tully. Nineteen TDs and three senators joined us or sent representatives to the event, including Anne Rabbite, Minister for Disability, Joe O'Brien, Minister for Community Development and Charities and Mary Lou McDonald, Sinn Féin leader.

Following the launch, Deputy Pauline Tully raised the first Topical Issues Debate about EB in the Dáil in November. During this landmark moment, she spoke about the impact of EB and the determined advocacy of our ambassadors Emma and Liz, as well highlighting Debra's work. Deputy Tully then asked for increased resources to be ringfenced for EB support, and the Minister for Mental Health, Mary Butler, promised to explore the issues raised. Eleven parliamentary questions were also raised about EB following the report launch.

This is the power of advocacy in action – and we're only going to keep shouting louder.

Addressing the Joint Oireachtas Committee on Health

Another consequence of our report launch was an invitation to speak at the Joint Oireachtas Committee on Health in February. We focused on two of our key asks – more home nursing care and mental health support for adults with EB.

Laying the groundwork for a ground-breaking study

Our planned EB Butterfly Review is a landmark study to identify the strengths, gaps and challenges in all EB services and support in Ireland. It will include comprehensive recommendations for a better future, along with associated costs. In 2023/24, we developed a full project brief and began meeting key stakeholders who will help to deliver the review. We hope to publish the study in 2025.

Mapping key policy stakeholders

To make sure our demands get heard and EB gets noticed, we need to keep building new connections and engaging with political champions and relevant policymakers. This will be more important than ever as we respond to the findings of the forthcoming EB Butterfly Review and try to build a better future for everyone affected by EB in Ireland.

Collaboration

In 2023/24, we once again supported Rare Disease Day, helping to raise awareness of the 300,000 people in Ireland who live with a rare disease. We continued to play an active role in a range of coalition and umbrella groups, to highlight issues affecting people who live with EB, share knowledge and build new connections. These groups include:

- DEBRA International
- Rare Diseases Ireland
- EURORDIS – Rare Diseases Europe
- Disability Federation of Ireland
- Care Alliance Ireland
- Irish Platform for Patient Organisations, Science, Industry (IPPOSI)

We also continued to participate in policy forums including the Rare Disease Forum, the Social Policy Network and the Health Research Charities Ireland (HRCI) Advocacy and Communications Committee.

Our plans for 2024/2025

- In 2024/25, we'll keep building our capacity as an advocacy organisation to make sure we can meet our long-term objectives.
- We will focus on delivering the EB Butterfly Review and putting its recommendations into practice.
- We will work to make sure everyone who's part of our new Advocacy, Research and Policy team has the skills and support to thrive.

Spotlight:
Campaigning for EB care in Ireland

For the second consecutive year, we urged the Government to invest in EB care as part of Budget 2024. Our 'Small ask, big impact' Pre-Budget Submission asked the Government for €810,000 to be invested in mental health support, home nursing care, and outreach care for people with EB in Budget 2024 – an investment that would amount to less than 0.003% of the current health budget.

Joanna Joyce, our Head of Advocacy, emphasised that this request represented a mere 0.003% of the €23 billion health budget. Yet, it would make a monumental difference in the lives of those affected by EB. Despite its invisibility, EB has a profound negative impact, often leaving individuals struggling to access vital services.

The stories of individuals like Aoife Murdock and Emma Fogarty highlighted the relentless challenges posed by EB. Aoife described the condition as "really draining," affecting every aspect of her life. Emma recounts the unbearable pain and the emotional toll on her and her family due to inadequate support.

As a result of our campaign, the issue of EB funding was raised in the Dáil. While we are pleased with the attention EB has received, our work is far from over. We will continue to push for the necessary funding and resources to ensure those living with EB in Ireland receive the support they desperately need.

Objective 4

People

Over the past year, we made sure we incorporated our staff's feedback to achieve our ambition to make Debra a great organisation to work at, to volunteer for and to collaborate with.

We prioritised showing our appreciation for our team's hard work. Through activities such as team away days, we continually developed the relationships that keep the team strong and help Debra deliver on our collective goals.

We rolled out a new Employee Assistance Programme, giving all staff the opportunity to access various types of support, confidentially, through a third-party service provider.

We identified the values that characterise Debra, holding training to discuss their meaning and to help staff put them into practice every day. And we used an annual staff survey to identify and prioritise areas where additional input and resources are needed.

Our plans for 2024/2025

- We will continue to invest and grow our team.
- We will focus on delivering training to meet the needs identified by our team, including external training and education and internal workshops delivered to the Debra team.
- We will bring in a range of new initiatives that recognise and reward people's efforts, support their wellbeing and help people develop in their roles.
- We will continue to listen closely to the needs of each individual.
- We will conduct an annual staff survey.

Objective 5

Fundraising

About 1% of Debra's income in 2023/24 came from government funding. Or, to put it another way, our work simply wouldn't be possible without the support of our incredible donors. We'd like to take this chance to say a huge thank you to everyone who gives a regular gift to Debra and everyone who donates to our appeals. We'd like to send an enormous thank you to our corporate partners and the philanthropic foundations and trusts who support us. And we'd like to say a gigantic thank you to our unstoppable event participants. You make Debra what it is.

Thanks to all these supporters, we raised just over €1.7m in 2023/24, and when government grants of €23k and in-kind support valued at €31k are included, our total fundraised income amounted to €1.78m.

Reaching more people in more ways

Gifts from individuals accounted for 37% of our income this year, totalling €700k. These gifts are vital because they provide Debra with a secure, sustainable foundation, and enable us both to deliver the very best care and support to families affected by EB now and to invest in pioneering research as we keep searching for new, more effective treatments.

We worked in a range of new ways to keep these gifts growing in 2023/24. We developed our donor communications and focused on delivering more integrated appeals across printed media, email, online and in the press. And as we focused on delivering our new donor engagement program, we experimented with radio advertising and train advertising for the first time. This led to an increase in the number of new donors who support our work and to an increase in monthly direct debits being set up.

Celebrating our fantastic fundraisers

We're constantly amazed by the commitment and determination of our brilliant supporters. The Debra community will take on any challenge to raise funds to make life better for people with EB – from bake sales to coffee mornings, marathons to football tournaments and mountain climbs to golf competitions.

Two of many highlights in 2023/24 were a group of *Star Wars* Storm Troopers (and one Chewbacca!) fundraising in their local shopping centre, and an entire community coming together to make and sell over 1,900 St Bridget's Crosses.

Supporters ran incredible events for Debra throughout the year too. Ken Carraher once again hosted his now famous Halloween extravaganza, raising over €11,000. And 2023 ended with a beautiful evening of Christmas music, generously organised by Massey Bros Funeral Homes and raising over €20,000. In total, supporters who organised events for Debra raised over €120,000 in 2023/24. We are hugely grateful to each and every one of you.

Finally, we must also thank the unstoppable participants who made this year's Kerry Challenge the biggest and best ever. This achievement wouldn't have been possible without the support of our key sponsors, Perry and Sandy. The event raised over €156,000 for Debra. And we would like to say a special thank you to Ross Lewis in Chapter One Restaurant, who hosted a beautiful afternoon event, raising over €40,000. People with EB are able to live better, fuller lives because of all of your generosity.

Recognising the impact of philanthropy

The support of Ireland's business and philanthropic community is crucial to the work we do. And, in 2023/24, leaders in business who are as passionate about supporting people with EB as we are helped our corporate and philanthropic income to keep on growing.

We welcomed a new corporate partner, Wild Rover Tours, and we are planning our next collaboration as we work towards achieving our mission together.

SMBC Aviation Capital continued its multi-year support of Debra. It's generous funding enabled the Debra team to keep responding to people's specific needs throughout the year, and a team of SMBC employees also showed their support by participating in our Kerry Challenge 2023.

Renault Trucks continued and increased its support for Debra in 2023, once again making a vital difference as we seek to make sure no one in Ireland faces EB alone.

We would like to thank Enfer Medical, KPMG, the Bewley Foundation and the Hospital Saturday Fund for funding the specific care needs of people with EB this year. Thanks to your support, Debra is improving the care for people with EB, in hospitals and in the community.

We also want to mention that 2023 ended with incredible commitment from a host of new and existing supporters at the Debra Abseil Croke Park challenge, where €30,000 was raised. We would like to say a huge thank you to ICON Plc, Manna Drone Delivery, Equinix, Renault Trucks, Enfer Medical, ATA and All Human, as well as every individual who took on this challenge and made the event a huge success.

We would like to thank everyone who has given their time, passion and funding to our shared cause.

Finally, we also want to thank the members of our Development Committee, who continue to give their time, contacts and resources to Debra. This dedication to our work leads to additional support for Debra from across the business and philanthropic community. We look forward to building on of all our relationships into the new year, as together we keep working to transform the future for everyone with skin as fragile as a butterfly wing.

Our plans for 2024/2025

- Armed with valuable insights gained from our fundraising review, we will streamline our calendar of appeals and asks to make sure donors feel appreciated and loved for their generous support.
- We will explore new opportunities, engage more with our stakeholders and strengthen our fundraising efforts.
- We will continue to grow our individual giver programme even further. We want to continue to expand our direct mail programme with appeals and impact newsletters throughout the year to existing and new supporters.
- We will also be expanding our tax-back and legacy programmes, to ensure the growth we have established in these areas is both sustained and expanded in future years.
- We will continue to deliver the best supporter care we can, by investing in our donor database and supporter care programme. This will help strengthen our bond with supporters, ensuring people remain loyal to Debra and are aware how important their support is for people living with EB in Ireland.
- We will do everything we can to make sure our corporate partnerships and philanthropic relationships continue to flourish. We already have various events and projects underway to help deliver on this goal.

Objective 6
Communications

Over the past year, we've updated our brand, our website and how we speak, and we've experimented with new approaches to raise awareness of EB and our work. Taken together, all of this work has helped bring people closer to Debra and made it clearer why extra support for people affected by EB is so badly needed.

2023 was a very successful year for our communications – online and offline. We built awareness and increased engagement among the EB community and improved our communications to supporters, members, staff and those affected by the disease. Guided by our communications strategy, now in its second year and designed to help us reach more people and create the highest level of impact, we kept developing an ongoing dialogue with our audience, explaining our impact more clearly and showing the importance of our services, support, research and advocacy. The effect was to galvanise our supporters and donors.

Our main achievement was successfully refreshing our brand. Co-created by people impacted by EB, the new brand reflects our past and who we want to be in the future. We have updated our key colours and our logo, while keeping many elements that help to define us – such as the butterfly icon. It symbolises the softness and gentleness that is required to care for someone with EB, as well as the fragility of their skin. The new brand also aligns us more closely with other DEBRAs internationally, because greater recognition and coordination will help to strengthen us all.

We also produced clear guidance on the language we use and how to speak with one voice. When people affected by EB come into contact with us now – on our website, on our social media and face to face – they know straightaway that we understand and we are with them. We don't judge. We don't ask people to explain. We don't tilt our head sadly to the side as people talk to us. Instead, we listen. We offer support. We push for change. We're side by side with people affected by EB, doing everything in our power to make their lives better. Our approach is no nonsense. We're human and compassionate, but we're not afraid to challenge. We know a better future is possible. And our bold, confident approach now has to come across in every word we use.

Sharpening the focus of our communications

We swiftly introduced our new visual style and language on our relaunched website, debra.ie. And we also took the chance to shift the balance of content at the site. Where there used to be mostly fundraising-related information, visitors can now find much more information about our work and the support we offer. The site also makes clear that we support people with all types of EB. This is achieved both through written content and the imagery at the site. The content is also targeted more clearly at people who care for others with EB and those who have been bereaved, as well as at people who live with EB. And our research focus is much clearer than it used to be, because – as our brand proposition states – 'without research there is no cure, without a cure there is no hope'.

To further strengthen our digital presence, we worked with a consultant to produce a five-year framework designed to identify our key audiences and the channels and tactics we should use to engage with them. Following this, we increased the quality and frequency of our social media communications to keep our members and supporters informed and engaged with our work. And we used organic and paid social media to support our appeals, share stories and build local awareness of our stories and to encourage people to take part in our events. Ultimately, we want to keep using digital channels in a strategic way to help achieve our organisational goals and build a strong, recognisable and trusted brand online.

Our print communications became more focused and compelling last year too. To help strengthen the sense of community created by our Family Support Team, we launched our EB newsletter, *Kaleidoscope*. This quarterly magazine now provides key organisational updates aimed at everyone connected with Debra. It includes information on healthcare, research, support, events and ways to get involved.

With the kind support of our ambassador, Colin Farrell, we also produced our first organisational video – *What is tough?* – and recorded a radio advert that aired across Ireland. And we secured a grant from Global Advertising via Irish Rail, which enabled us to have a video advert played on all major train stations in Dublin. Having such a recognisable figure supporting Debra has the potential to help huge numbers of people find out about us and learn more about EB.

We used Rare Disease Day in February to launch our first cross-channel, integrated online and offline campaign, helping more people to connect Debra, EB and butterfly skin.

And our teams pulled out all the stops to increase media coverage of Debra and EB too. We were featured in over 850 articles across print, online, TV and radio, reaching more than seven million people. The majority of this coverage focused on the lived experience of people with EB, showing exactly how tough life with EB can be, and why we have to create a better future together.

Our plans for 2024/2025

- Implement year two of our digital strategy, focusing on stronger stewardship journeys and emails.
- Set up an involvement network for people in the EB community, encouraging members to get involved in communications and media activities, be a representative, play a part in campaigns for EB support and funding, steer our fundraising, review our EB information and communications, and influence what we do.
- Focus our marketing and communications more than ever on empowering and engaging our communities, lobbying government and creating greater awareness of EB. This will help ensure there is understanding for those living with the condition, as well as more widespread EB expertise and funding for essential EB research and care.
- Create compelling communications to illustrate the impact of our work and showcase the inspirational stories from our EB community. This will help us connect with our supporters and build a community working towards a shared, urgent goal.
- Inform our staff and Board about EB, building knowledge and understanding of our work and increasing people's confidence to become advocates for Debra, including on social media.

Spotlight:

Fighting stigma and changing attitudes

To build knowledge of EB and help people be more supportive and understanding, we're sharing more experiences of living with the condition. Kate Cogan was one of many people who told their story to Debra in 2023/24. Now 18, Kate looked back on her childhood and how her classmates would react to her blistered skin.

"My primary school teacher explained EB to the class when I was relatively young, so everyone knew," Kate remembered. "And the older kids knew because my sister was in the school for a while as well. The thing that bothered me most was that they were told to be more careful with me. I know they were trying to protect me but as a five-year-old, I was like. 'I don't like this. I don't like being treated differently.'

“I remember when I was seven or eight. I fell in the yard. The teachers surrounded me because they knew I had EB. Whereas, if another child fell, it would have been just one teacher [helping them]. But everyone was so concerned about me and I was like, 'Oh, there's obviously something different here.'”

Even as a child, Kate remembers preferring how children would react to her to adults' usual responses. "Because kids are littler, they don't really understand. They'd see the marks on my skin and would say, 'What's that?'" Kate said.

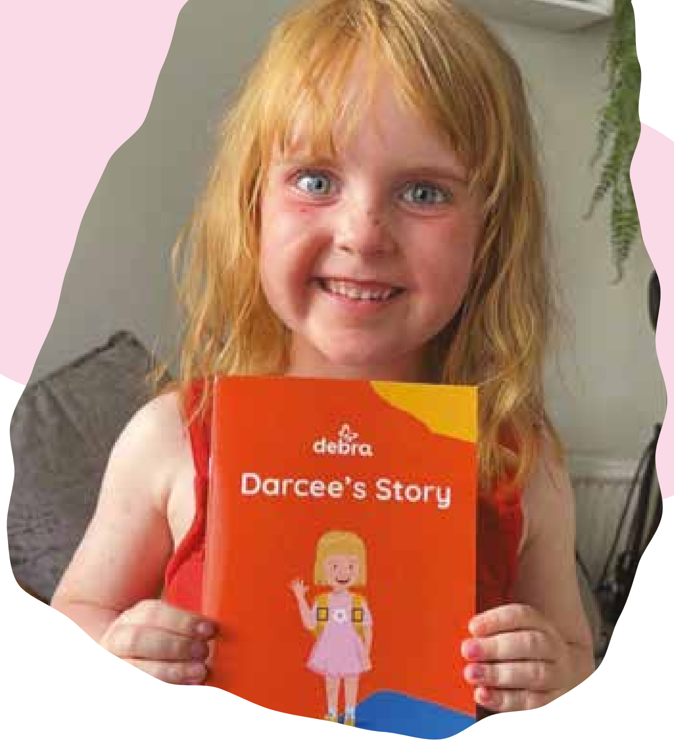
"But people stare when I'm on holidays. Because obviously, my legs are out. I'd find adults staring at me, looking at my scars, which makes me uncomfortable. I'd prefer if someone asked rather than making it obvious that they're looking at me. Because obviously, it's noticeable. I know it's noticeable. I don't mind questions at all. but I don't like the staring – just ask.”

As well as discussing people's reactions, Kate opened up about the stress and pain of dealing with EB day-to-day as an adult. "When I have a lot of cuts, I'd say changing bandages takes probably three or four hours," she said. "Normally an hour and a half in the morning and probably an hour and a half at night as well, to change everything."

And Kate was also very clear about the moment when she decided she wanted to share her story to help others. On a visit to Crumlin for a yearly check-up, she noticed a couple with a newly diagnosed baby with EB and recognised the parallels with her own parents' situation years previously.

“When I saw that baby, it made me think, 'Maybe I should be talking about EB'. I'm sure if someone my age had talked to my parents when I was six months old, they would have been less worried and less anxious about it all.”

We're so grateful to Kate and everyone else who helped us show the reality of life with EB by sharing their stories last year.



Objective 7

Impact

Over the past year, we've worked to demonstrate how our activities improve the quality of life of people impacted by EB. We have surveyed and interviewed the people who connect with the charity to identify how they perceive the quality of our service, the impact of our work and what we need to do more of. We also ask for feedback after every event and incorporate this into future plans. In this way, we continually adapt to changing needs and improve outcomes for the EB community.

We continue to keep the lived experience of EB at the core of our thinking, ensuring it informs our work and shapes our strategy. For example, people living with EB, caring for someone with EB or bereaved by EB were key participants in our EB Expert Panel, helping shape our research priorities and ways of improving our family support services. They have also continued to guide how we present Debra and how we talk about EB, and the values that guide our day-to-day activities across media.

Looking to the future, we will explore new and more effective ways to measure our impact, making sure that change is happening and taking effective action if progress is too slow. We will also identify metrics to measure our progress across family support, research, advocacy and communications.

Our plans for 2024/2025

- If we find areas where we aren't achieving as much as we hoped, we'll put in place an action plan to address this. Our goal is to continue to deliver our service and seek feedback from the families we support to ensure we remain aligned to our commitment that we are patient led.

Structure, governance and management

Legal Status

Debra Ireland, also known as Debra, is a company limited by guarantee, not having a share capital, incorporated in 1988 in Ireland and registered with the Companies Registration Office with registration number 141279.

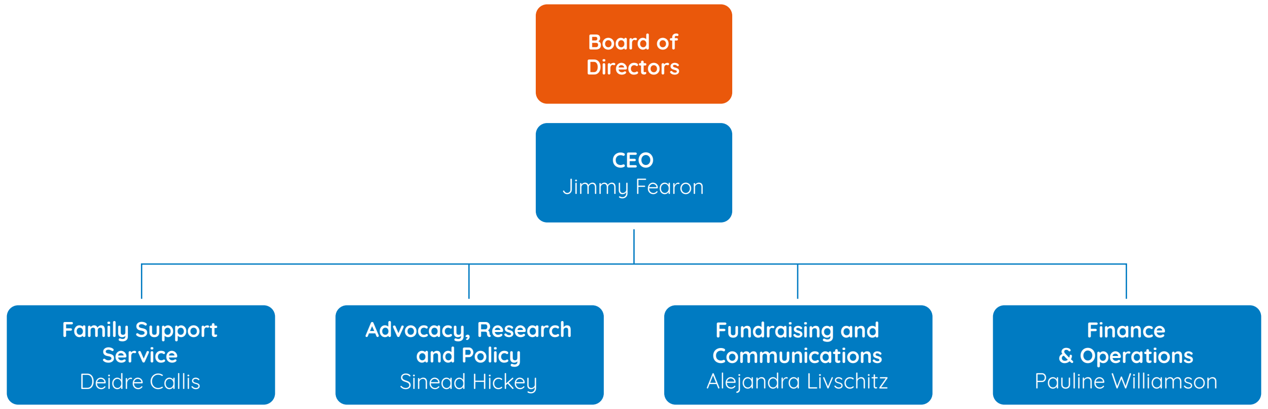
Debra is also a public benefit entity, registered as a charity with the Charities Regulator with registered charity number 20021726. Debra has been granted a charitable tax exemption under Sections 207 and 208 of the Taxes Consolidation Act 1997, reference number CHY 8703.

Debra was founded under a constitution, which establishes its objectives and powers, and it is governed under its Articles of Association. All income is applied solely towards the promotion of the company's charitable objects.

In the event of the charity being wound up, the liability of an individual member shall not exceed €1.27.

The Board of Directors is responsible for the governance, strategy, and oversight of Debra.

The Board may be comprised of a maximum of 12 non-executive directors and each director is required to be an ordinary member of the charity. Directors are expected to serve a minimum term of three years. Half of the elected directors are required to retire by rotation each year and are eligible to offer themselves for re-election.



Name	Meeting attendance April 23 – March 24	Appointed	Retired
Colm Darling (Chair)	6/6	November 2018	5 March 2024
Mark Hyland (Secretary)	6/6	February 2014	
Leonora Bishop	4/6	December 2015	
Elizabeth Collins	5/6	October 2018	
Fiona Duffy	1/4	February 2018	6 November 2023
Valentine Fynes	4/6	March 1989	
Susanna Gaynor	4/6	May 2020	
Robert Healy	1/6	September 2017	
Sinead Spain	4/6	January 2018	
Rosemarie Watson	4/6	January 2018	
Emma Fogarty	1/1	16 January 2024	
Michael O'Rourke (Chair)	0/0	5 March 2024	

The Board meets at least six times a year. As a voluntary board, members do not receive any remuneration in respect of their services to the charity. Relevant expenses, once in compliance with Debra's internal policies, are reimbursable where claimed and vouched. There were no claims for expenses from any director in the financial year under review.

The names of the persons who were directors during the financial year 1 April 2023 to 31 March 2024 are set out above. Unless indicated otherwise they served as directors for the entire year.

All directors are obliged to adhere to the Debra Code of Conduct for Board Members which all directors sign up to on nomination and further attest their ongoing compliance with the code on an annual basis.

A board Conflict of Interest and Conflict of Loyalty Policy is also in place and forms part of the Code of Conduct for Board Members. Conflicts of interest is a permanent agenda item at every board meeting. In the last financial year, no conflict of interest was notified to the Board.

The Board is committed to achieving the highest standards of governance. Debra is 'Triple Locked' and complies with the Charities Governance Code, the Guidelines for Charitable Organisations on Fundraising from the Public, and the SORP (FRS 102) accounting standard for charities. Debra complies with General Data Protection Regulation (GDPR) and all other relevant legislation.

The Board is responsible for reviewing financial performance and ensuring there is effective internal control and risk management in place. The Board delegates day-to-day management of Debra to the senior management team, comprising the Chief Executive Officer and heads of function – Family Support Service; Research, Advocacy and Policy; Fundraising and Communications; and Finance and Operations.

Board Sub-Committees

To assist the Board in carrying out its duties and support its effectiveness, it has established three sub-committees – the Audit and Finance Committee, Research Committee, and Development Committee. Each committee operates under a Terms of Reference, comprises both director and non-director members and has an Chairperson.

Audit and Finance Committee

Members during the year: Mark Hyland (Chair), Colm Darling, Liam Keys and Michael O'Rourke.

Purpose: This committee's work covers all matters related to audit and financial reporting risk management, legal and regulatory compliance, and governance.

Research Committee

Members during the year: Leonora Bishop (Chair), Alan Irvine, Michael Griffith, Seamus Graham and Emma Creagh.

Purpose: This committee advises the Board on matters relating to research and supports the organisation in its work on behalf of people living with EB in all areas relating to EB research.

Development Committee

Members during the year: Fiona Duffy (Chair), Robert Healy, Joanne Byrne, Tom Butler, Rick Kelly, Jimmy Fearon and Anthony Galsworthy.

Purpose: This committee provides objective guidance and continued feedback and engagement on the development and implementation of the fundraising strategy.

Board recruitment and induction

Directors are recruited through a combination of canvassing Debra's membership, professional networking, and public advertising. Nominations of new directors are approved by the Board.

Appointments to the Board are prioritised according to Debra's requirements for expertise at a particular point in time.

All new board members are fully briefed on the activities of Debra, receive an induction pack, meet the chairperson and CEO, and have the option to meet any member of the Board or senior management team.

Matters reserved for decision-making by the Board include:

- sign-off of the strategic plan and annual operational budget and any projects outside the scope of the budget
- litigation
- appointment/removal of board or committee members, auditors or CEO
- approval for borrowing/finance facilities
- review of risk and internal control
- approval of the terms of engagement of the statutory auditor
- approval of new staff positions and remuneration policy for senior staff
- approval of contracts or projects as requirement under Debra's procurement policy
- setting reserve levels, deciding on assets acquisition and disposal, remuneration

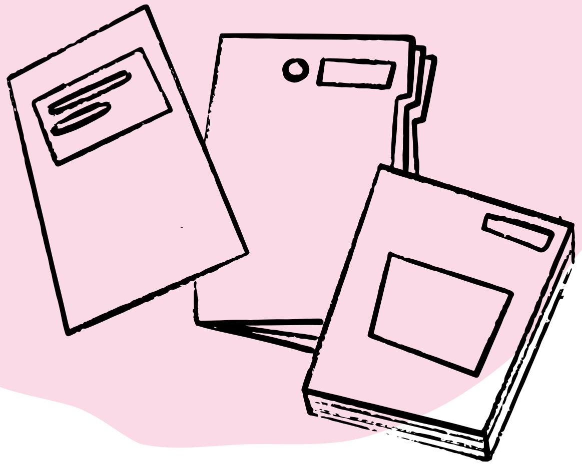
Risk management

The Board of Directors is committed to ensuring that managing risks is an integral part of Debra's activities. Effective risk management is critical in enabling and facilitating an organisation to meet its objectives. Debra has an effective risk assessment process in place. This process addresses how risks are identified and managed using a clear methodology and ranking.

Risks are captured in a risk register, along with the potential impact of those risks to the organisation, the perceived likelihood of occurrence, and responses taken to address and mitigate the risks. The senior management team monitors the risk register through the year, with regular reporting to the Audit and Finance Committee and thereafter to the Board.

The key risks facing the organisation in the last financial year were:

Risk	Mitigation
Financial risk that financial targets will not be met, and the organisation will have insufficient resources to maintain the desired level of services.	• Thorough annual budget process and bi-monthly financial reporting with rolling projections • Regular reporting and monitoring against the Reserves Policy • Fundraising strategy being implemented to ensure diverse and sustainable sources of income
People risk associated with recruitment, retention, and loss of key staff.	• Commitment to a flexible work environment • Ongoing training and development for all staff • Effective performance management
Data and cybersecurity risks leading to disruption to services or loss or compromise of data due to technology failure, a breach, or a cyberattack.	• Ongoing GDPR and cybersecurity training for all staff • Key systems are cloud-based with multi-factor authentication • Ongoing monitoring using various cyber security tools available
Governance and reputational risk arising from exposure to legal, regulatory, and reputational damage.	• Board and staff induction • Ongoing oversight of compliance and governance processes and procedures • Suite of internal policies and procedures that are reviewed and updated regularly • Crisis communication plan in place • Ongoing media monitoring



Financial review

Overview

The financial results for the year to 31 March 2024 are outlined in the Statement of Financial Activities, the Statement of Financial Position, and the Statement of Cash Flows.

The Board approved a budget for 2023/2024, aligned with the current strategic plan (2022-2025), where planned expenditure was expected to exceed current year fundraised income in the financial year. This planned use of existing strong reserves, which built up primarily during the COVID-19 pandemic when fundraising performed exceptionally and expenditure was curtailed due to the restrictions imposed by the pandemic, was built into the strategic plan process. As a result, Debra recorded a deficit of €238,650 in the financial year to 31 March 2024 (2023: €344,435 deficit).

Of the current year deficit, €193,150 (2023: €297,000) relates to expenditure on research activities from designated funds set aside at the end of the prior year. There is a deficit of €47,888 (2023: €20,579 surplus) on restricted funds as restricted income received in prior years was expended in the current year. A small surplus of €2,388 (2023: €68,014 deficit) arose from general operating activities.

Income

Most of our income comes from the generous support of the general public, corporates, trusts and foundations and fundraising events.

Gross income for the year was €1,814,224 (2023: €1,716,963) an increase of 6% compared to the prior year. While income from donations fell by almost €95,000 to €1,370,452 (2023: €1,465,104) this was solid performance year on year as the prior year included a boost of over €380,000 arising from an appeal on The Late Late Show in February 2023 which was not repeated in the current year.

Income from fundraising events performed very well this year with €230,046 (2023: €132,805) raised across three Debra-led events including the annual Kerry challenge which alone raised over €155,000 as it regained and exceeded its pre-pandemic participation levels.

Our community supporter-led fundraising activities also had an excellent year with more individual events than even being organized across the country. Total income from this source was €123,700 (2023: €40,715).

The value of donated services was €31,200 (2023: €26,652). Such donations are measured based on the value of the gift with a corresponding amount recognised in expenditure.

Government grants account for just 1% (2023: 2%) of total income. Grant income for the year included €23,150 (2023: €36,629) from the HSE National Lottery Grant (Respite) Programme and €349 (2023: €Nil) from Pobal, funded by the Department of Rural and Community Development, under the Community and Voluntary Sector Energy Support Scheme.

Expenditure

Debra is highly dependent on donors as just 1% of the year's income came from government grants (2022: 2%). It is necessary to incur expenditure in raising funds and we strive to do so as efficiently as possible in order to maximise the funds available for our core charitable activities. Our direct costs of fundraising activities fell by almost 15% this year to €242,770 (2023: €281,969).

Total expenditure on charitable activities increased slightly this year, by just over 2%, having grown significantly, by almost 40% in the prior year. Strategic initiatives spanning all areas of our service are driving expenditure with total investment this year of €1,810,104 (2023: €1,779,429).

The total value of grants made to patients and families exceeded €135,000 this year and we invested over €225,000 in research projects and grants.

Charitable Activities	2024	2023
Patient support	459,675	454,253
Research	466,121	519,824
Advocacy	185,460	131,548
Fundraising and marketing	668,074	616,963
Total programme costs	**1,779,330**	**1,722,588**
Unallocated general support costs	30,774	56,841
Total charitable expenditure	**1,810,104**	**1,779,429**

All the programme costs above include an allocation of support cost. Support costs consist of an element of the costs of personnel and overheads of the CEO, finance, human resources, communications and office administration and general costs related to premises/facilities and IT. The unallocated general support costs represent mainly the costs of governance (audit, compliance, governance etc.). Support functions play a crucial role providing core organisational support to ensure our services are delivered to the highest standards.

Financial position and reserves policy

Going concern

The financial statements have been prepared on a going concern basis. The Directors have reviewed the Statement of Financial Activities for the year ended 31 March 2024 and the Balance Sheet as of that date, along with financial projections for a period of at least 12 months from the date of approval of the financial statements. The Directors are satisfied that the Company has adequate resources to continue in operational existence for the next 12 months. There is no material uncertainty that affects this assumption that the Company is a going concern.

Reserves policy

Debra's policy is to retain sufficient reserves to safeguard the continuity of its operations. It has a clearly defined reserves policy which is reviewed annually by the Board. The policy is based on a careful assessment of the needs of the organisation in the event of unforeseen disruptions to income. As almost 100% of our annual income is fundraised, it is important that adequate reserves are held to ensure continuity of our services.

Debra's Reserves Policy is to hold sufficient free reserves to maintain essential services for an optimal period of up to twelve months with a minimum threshold of at least six months. Actual reserves are regularly reviewed by the Board. All budgeting and forecasting activities include an assessment of the likely impact on future reserve levels.

Debra's reserves comprise unrestricted general funds, restricted funds and designated funds.

Restricted funds are subject to specific conditions imposed by our donors and are within the overall objectives of the organisation. Restricted reserves at 31 March 2024 are €71,376 (2023: €119,264).

Designated funds are allocated by the Board to specific areas of future expenditure. As of 31 March 2024, the Board has set aside €528,850 (2023: €722,000) for a Research Fund to cover the current future commitments to ongoing projects and provide funding for new projects over the coming 24 months. A further €100,000 (2023: €100,000) has been designated as a Family Support Fund with a key focus on developing a psychosocial support hub for patients and their families and having sufficient funds to meet any unexpected and material applications under our Special Circumstances Grant programme which by its very nature is difficult to budget for with certainty.

Unrestricted general funds, which are not assigned to a specific purpose, as of 31 March 2024 are €1.665m (2023: €1.663m). These funds are used to further the Debra's charitable objectives, funding expenditure not covered by restricted or designated funds.

	31 Mar 2024	31 Mar 2023
Restricted Funds	€0.07m	€0.12m
Unrestricted Fund (General)	€1.66m	€1.66m
Unrestricted Fund (Designated)	€0.63m	€0.82m
Total Reserves	**€2.36m**	**€2.60m**

Post reporting date events

See Note 25 to the financial statements.

Directors and Secretary and their interests

The Company is limited by guarantee and does not have a share capital. Therefore, the directors and secretary who served during the year did not have a beneficial interest in the Company.

Accounting records

The directors are responsible for ensuring that proper books and accounting records are kept by the Company as set out by the requirements of Sections 281 to 285 of the Companies Act 2014. The Directors believe that they have complied with these requirements by employing accounting personnel with appropriate expertise and by providing adequate resources to the finance function. The accounting records of the Company are maintained at the Company's registered office at Butterfly Cottage, 8 Clanwilliam Terrace, Grand Canal Quay, Dublin 2.

Audit information

The Directors believe that they have taken all steps necessary to make themselves aware of any relevant audit information and have established that the company's statutory auditors are aware of that information. Insofar as they are aware, there is no relevant audit information of which the company's statutory auditors are unaware.

Auditor

In accordance with the provisions of Section 383(2) of the Companies Act 2014, the auditor Grant Thornton, Chartered Accountants & Statutory Audit Firm, will continues in office.

This report was approved by the board on and signed on its behalf.

On behalf of the Board

Michael O'Rourke	**Mark Hyland**
Director	Director

Date: 9 July 2024

Financial statements for the year ended 31 March 2024

Directors' responsibilities statement

for the financial year ended 31 March 2024

The directors are responsible for preparing the Directors' report and the financial statements in accordance with applicable Irish law and regulations.

Irish company law requires the directors to prepare the financial statements for each financial year. Under the law, the directors have elected to prepare the financial statements in accordance with the Companies Act 2014 and Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland', and in compliance with the Statement of Recommended Practice "Accounting and Reporting for Charities", effective 1 January 2019.

Under company law, the directors must not approve the financial statements unless they are satisfied that they give a true and fair view of the assets, liabilities and financial position of the Company as at the financial year end date, of the profit or loss of the Company for that financial year and otherwise comply with the Companies Act 2014.

In preparing these financial statements, the directors are required to:

- select suitable accounting policies for the Company's financial statements and then apply them consistently;
- make judgments and accounting estimates that are reasonable and prudent;
- state whether the financial statements have been prepared in accordance with applicable accounting standards, identify those standards, and note the effect and the reasons for any material departure from those standards; and
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the Company will continue in business.

The directors are responsible for ensuring that the Company keeps or causes to be kept adequate accounting records which correctly explain and record the transactions of the Company, enable at any time the assets, liabilities, financial position and profit or loss of the Company to be determined with reasonable accuracy, enable them to ensure that the financial statements and Directors' report comply with the Companies Act 2014 and enable the financial statements to be audited. They are also responsible for safeguarding the assets of the Company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

The directors are responsible for the maintenance and integrity of the information on the charity's website. Legislation in Ireland governing the preparation and dissemination of financial statements may differ from legislation in other jurisdictions.

On behalf of the Board

Michael O'Rourke
Director

Mark Hyland
Director

Date: 9 July 2024

Independent auditor's report to the members of Debra

for the financial year ended 31 March 2024

Opinion

We have audited the financial statements of DEBRA Ireland (the 'Company'), which comprise the Statement of financial activities, the Statement of financial position, the Statement of cash flows for the financial year ended 31 March 2024, and the related notes to the financial statements, including a summary of significant accounting policies.

The financial reporting framework that has been applied in the preparation of the financial statements is Irish law and accounting standards issued by the Financial Reporting Council including FRS 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' (Generally Accepted Accounting Practice in Ireland).

In our opinion, DEBRA Ireland's financial statements:

- give a true and fair view in accordance with Generally Accepted Accounting Practice in Ireland of the assets, liabilities and financial position of the Company as at 31 March 2024 and of its financial activities and cash flows for the financial year then ended; and
- have been properly prepared in accordance with the requirements of the Companies Act 2014.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (Ireland) (ISAs (Ireland)) and applicable law. Our responsibilities under those standards are further described in the 'Responsibilities of the auditor for the audit of the financial statements' section of our report. We are independent of the company in accordance with the ethical requirements that are relevant to our audit of financial statements in Ireland, including the Ethical Standard for Auditors (Ireland) issued by the Irish Auditing and Accounting Supervisory Authority (IAASA), and the ethical pronouncements established by Chartered Accountants Ireland, applied as determined to be appropriate in the circumstances for the entity. We have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the director's use of going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the Company's ability to continue as a going concern for a period of at least twelve months from the date when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the directors with respect to going concern are described in the relevant sections of this report.

Other information

Other information comprises information included in the Directors' report, other than the financial statements and our auditor's report thereon. The directors are responsible for the other information. Our opinion on the financial statements does not cover the information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit, or otherwise appears to be materially misstated. If we identify such material inconsistencies in the financial statements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

Matters on which we are required to report by the Companies Act 2014

- We have obtained all the information and explanations which we consider necessary for the purposes of our audit.
- In our opinion the accounting records of the Company were sufficient to permit the financial statements to be readily and properly audited.
- The financial statements are in agreement with the accounting records.
- In our opinion the information given in the Directors' report is consistent with the financial statements. Based solely on the work undertaken in the course of our audit, in our opinion, the Directors' report has been prepared in accordance with the requirements of the Companies Act 2014.

Matters on which we are required to report by exception

Based on our knowledge and understanding of the Company and its environment obtained in the course of the audit, we have not identified material misstatements in the Directors' report.

Under the Companies Act 2014, we are required to report to you if, in our opinion, the disclosures of directors' remuneration and transactions specified by sections 305 to 312 of the Acts have not been made. We have no exceptions to report arising from this responsibility.

Responsibilities of management and those charged with governance for the financial statements

As explained more fully in the Directors' responsibilities statement, management is responsible for the preparation of the financial statements which give a true and fair view in accordance with Generally Accepted Accounting Practice in Ireland, including FRS 102, and for such internal control as they determine necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, management is responsible for assessing the Company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless management either intends to liquidate the Company or to cease operations, or has no realistic alternative but to do so.

Those charged with governance are responsible for overseeing the Company's financial reporting process.

Responsibilities of the auditor for the audit of the financial statements

TThe auditor's objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes their opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (Ireland) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

As part of an audit in accordance with ISAs (Ireland), the auditor will exercise professional judgment and maintain professional scepticism throughout the audit. They will also:

- Identify and assess the risks of material misstatement of the financial statements, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for their opinion. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control.
- Obtain an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the Company's internal control.
- Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by management.
- Conclude on the appropriateness of management's use of the going concern basis of accounting and, based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that may cast significant doubt on the Company's ability to continue as a going concern. If they conclude that a material uncertainty exists, they are required to draw attention in the auditor's report to the related disclosures in the financial statements or, if such disclosures are inadequate, to modify their opinion. Their conclusions are based on the audit evidence obtained up to the date of the auditor's report. However, future events or conditions may cause the Company to cease to continue as a going concern.
- Evaluate the overall presentation, structure and content of the financial statements, including the disclosures, and whether the financial statements represent the underlying transactions and events in a manner that achieves a true and fair view.

The auditor shall communicate with those charged with governance regarding, among other matters, the planned scope and timing of the audit and significant audit findings, including any significant deficiencies in internal control that may be identified during the audit.

The purpose of our audit work and to whom we owe our responsibilities

This report is made solely to the members, as a body, in accordance with section 391 of the Companies Act 2014. Our audit work has been undertaken so that we might state to the members those matters we are required to state to them in an auditor's report and for no other purpose.

To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the members of the DEBRA Ireland as a body, for our audit work, for this report, or for the opinions we have formed.

Mr Damian Gleeson FCCA
for and on behalf of
Grant Thornton Chartered Accountants
and Statutory Audit Firm Limerick

Date: 9 July 2024

Financial statements

for the year ended 31 March 2024

Statement of financial activities

for the financial year ended 31 March 2024

	Notes	Unrestricted Designated Funds 2024 €	Unrestricted General Funds 2024 €	Restricted Funds 2024 €	Total 2024 €	Total 2023 €
Income from:						
Fundraising	5		1,420,377	358,520	1,778,897	1,701,905
Investments	6	-	28,844	-	28,844	-
Other income	7	-	6,483	-	6,483	15,058
Total income		-	1,455,704	358,520	1,814,224	1,716,963
Expenditure on:						
Raising funds	8	–	242,770	-	242,770	281,969
Charitable activities	9	193,150	1,210,546	406,408	1,810,104	1,779,429
Total expenditure		193,150	1,453,316	406,408	2,052,874	2,061,398
Surplus/(deficit) for the financial year before transfers	13	(193,150)	2,388	(47,888)	(238,650)	(344,435)
Transfers between funds during the year		–	–	–	–	–
Movement in funds for the year		(193,150)	2,388	(47,888)	(238,650)	(344,435)
Fund balances at beginning of financial year	21	822,000	1,663,093	119,264	2,604,357	2,948,792
Fund balances at end of financial year	21	628,850	1,665,481	71,376	2,365,707	2,604,357

All amounts relate to continuing operations.

The notes on pages 46–59 form part of these financial statements.

Statement of financial position

as of 31 March 2024

	Notes	31 March 2024 €	31 March 2024 €	31 March 2023 €	31 March 2023 €
Fixed assets					
Tangible assets	15		**16,944**		13,723
Current assets					
Stocks	16	**12,619**		9,454	
Debtors: amounts falling due within one year	17	**70,135**		24,500	
Cash at bank and in hand	18	**2,889,966**		3,134,383	
		2,972,720		3,168,337	
Current liabilities					
Creditors: amounts falling due within one year	19	**(623,957)**		(577,703)	
Net current assets			**2,348,763**		2,590,634
Net assets			**2,365,707**		2,604,357
Reserves					
Restricted funds	21		**71,376**		119,264
Unrestricted funds					
Designated funds	21		**628,850**		822,000
General funds	21		**1,665,481**		1,663,093
Total funds			**2,365,707**		2,604,357

The notes on pages 46–59 form part of these financial statements.

On behalf of the Board

Michael O'Rourke
Director

Mark Hyland
Director

Date: 9 July 2024

Statement of cash flows

for the financial year ended 31 March 2024

	31 March 2024 €	31 March 2023 €
Cash flows from operating activities		
(Deficit) for the financial year	**(238,650)**	(344,435)
Adjustments for:		
Interest received	**(28,844)**	-
Depreciation of tangible fixed assets	**5,595**	5,208
Donated fixed assets	**-**	(5,600)
Increase in stocks	**(3,165)**	(5,779)
Decrease/(increase) in debtors	**(45,635)**	36,831
Increase in creditors	**46,254**	182,602
Net cash generated from operating activities	**(264,445)**	(131,173)
Cash flows from investing activities		
Purchase of tangible fixed assets	**(8,816)**	(4,200)
Interest received	**28,844**	-
Net cash used in investing activities	**20,028**	(4,200)
Net (decrease) in cash and cash equivalents	**(244,417)**	(135,373)
Cash and cash equivalents at beginning of financial year	**3,134,383**	3,269,756
Cash and cash equivalents at end of financial year	**2,889,966**	3,134,383
Cash and cash equivalents at the end of financial year comprise:		
Cash at bank and in hand	**2,889,966**	3,134,383

The notes on pages 46–59 form part of these financial statements.

Notes to the financial statements

for the financial year ended 31 March 2024

1. General information

DEBRA Ireland is a company limited by guarantee and not having a share capital, incorporated in the Republic of Ireland registered under the number 141279. The registered office is at Butterfly Cottage, 8 Clanwilliam Terrace, Grand Canal Quay, Dublin 2, which is also the principal place of business of the Company. The nature of the Company's operations and its principal activities are set out in the Directors' report.

2. Statement of compliance

The financial statements have been prepared in accordance with FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland" (FRS 102). The financial statements have also been prepared in accordance with Statement of Recommended Practice (SORP), effective 1 January 2019 "Accounting and Reporting by Charities".

3. Critical accounting estimates and judgements

Management is of the opinion that there are no critical judgements and accounting estimates that have a significant effect on the amounts recognised in the financial statements.

4. Summary of significant accounting policies

The significant accounting policies applied in the preparation of these financial statements are set out below. These policies have been consistently applied to all years presented unless otherwise stated.

a) Basis of preparation

The financial statements have been prepared in accordance with Financial Reporting Standard 102 "The Financial Reporting Standard Applicable in the UK and Republic of Ireland" ("FRS 102") and the Companies Act 2014. The financial statements have also been prepared in accordance with Statement of Recommended Practice (SORP) – Accounting and Reporting by Charities" as published by the Charity Commission for England and Wales effective 1 January 2019, who are recognised by the UK Financial Reporting Council (FRC) as the appropriate body to issue SORP's for the charity sector in the UK. Financial reporting in line with SORP and is considered best practice for charities in Ireland. The directors consider that the adoption of the SORP requirements is the most appropriate accounting to properly reflect and disclose the activities of the organisation. The financial statements have been prepared on a going concern basis under the historical cost convention, modified to include certain items at fair value.

Going Concern

The directors have prepared budgets and cash flows for a period of at least twelve months from the date of approval of the financial statements, which demonstrate that there is no material uncertainty regarding the Company's ability to meet its liabilities as they fall due, and to continue as a going concern. On this basis, the directors consider it appropriate to prepare the financial statements on a going concern basis. Accordingly, these financial statements do not include any adjustments to the carrying amounts and classification of assets and liabilities that may arise if the Company was unable to continue as a going concern.

b) Income

All income is recognised in the Statement of Financial Activities ("SOFA") when the Company is entitled to the income, any performance related conditions have been met, receipt is probable and the amount can be quantified with reasonable accuracy. Income comprises grants for charitable activities, donations and legacies, and other trading activities.

Income is analysed as Restricted or Unrestricted. Restricted funds represent income recognised in the financial statements, which is subject to specific conditions imposed by the donors or grant making institutions. Unrestricted funds represent amounts, which are expendable at the discretion of the Company, in furtherance of the objectives of the charity. Such funds may be held in order to finance working capital or capital investment.

Monies received in respect of expenditure that must take place in a future accounting period is accounted for as deferred income and recognised as a liability up until the accounting period allowed by the condition to expend the resource.

Donated goods are recognised as income when sold. The value is derived from the resale value after deducting the cost to sell the goods. Donated services are measured and included in the financial statements on the basis of the value of the gift to the charity, a corresponding amount is then recognised in expenditure in the period of receipt.

For legacies, entitlement is taken as the earlier of the date on which either: the Company is aware that probate has been granted, the estate has been finalised and notification has been made by the executor(s) to the Trust that a distribution will be made, or when a distribution is received from the estate. Receipt of a legacy, in whole or in part, is only considered probable when the amount can be measured reliably, and the Company has been notified of the executor's intention to make a distribution. Where legacies have been notified to the Company or the Company is aware of the granting a probate, and the criteria for income recognition have not been met, then the legacy is treated as contingent asset and disclosed if material.

Grants are included in the Statement of Financial Activities on a receivable basis. The balance of income received for specific purposes but not expended during the period is shown in the relevant funds on the Balance Sheet. Where income is received in advance of entitlement of receipt, its recognition is deferred and included in creditors as deferred income. Where entitlement occurs before income is received, the income is accrued.

Interest on funds held on deposit is included when receivable and the amount can be measured reliably by the company.

c) Expenditure

All expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all costs related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of the resources. The Company is not registered for VAT and accordingly expenditure is shown gross of irrecoverable VAT.

Expenditure is recognised once there is a legal or constructive obligation to transfer economic benefit to a third party, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is classified by activity. The costs of each activity are made up of the total of direct costs and shared costs, including support costs involved in undertaking each activity. Direct costs attributable to a single activity are allocated directly to that activity. Shared costs which contribute to more than one activity and support costs which are not attributable to a single activity are apportioned between those activities on a basis consistent with the use of resources. Central staff costs are allocated on the basis of time spent, and depreciation charges allocated on the portion of the asset's use.

Expenditure on raising funds includes all expenditure incurred by the charity to raise funds for its charitable purposes and includes costs of all fundraising activities events and non-charitable trading.

Expenditure on charitable activities is incurred on directly undertaking the activities which further the charity's objectives, as well as any associated support costs.

Grants payable are charged in the year when the offer is made except in those cases where the offer is conditional, such grants being recognised as expenditure when the conditions attaching are fulfilled. Grants offered subject to conditions which have not been met at the year-end are noted as a commitment, but not accrued as expenditure.

All expenditure is inclusive of irrecoverable VAT.

d) Operating leases: the Company as lessee

Rentals paid under operating leases are charged to the Statement of financial activities on a straight line basis over the lease term.

e) Reserves

DEBRA Ireland's policy is to retain sufficient reserves to safeguard the continuity of its operations. It has a clearly defined reserves policy which is reviewed annually by the Board, and the level of reserves held is reviewed periodically throughout the year.

DEBRA Ireland's current reserve policy is to hold sufficient unrestricted reserves to maintain essential services for a minimum period of 6 months and with an optimal timeframe of up to 12 months. The Board may also set aside, where it deems it appropriate, designated reserves which are unrestricted funds that have been allocated by the Board for specific purposes.

f) Employee benefits

The Company provides a range of benefits to employees, including paid holiday arrangements and defined contribution pension plans.

Short term benefits

Short term benefits, including holiday pay and other similar non-monetary benefits, are recognised as an expense in the period in which the service is received. A provision is made for the estimated liability for annual leave as a result of services rendered by employees up to the end of the financial year.

Pension

The pension costs charged in the financial statements represent the contributions payable by the Company.

g) Functional currency and presentation currency

Monetary assets and liabilities denominated in foreign currencies are translated into Euro using the spot rates of exchange prevailing at the year end date. Transactions in foreign currencies are recorded at the date of the transactions. Any gains or losses are taken to the statement of financial activities.

h) Fixed assets

Fixed assets are stated at cost less accumulated depreciation.

Depreciation is calculated with reference to original cost less their residual values over their expected useful lives at the following annual rates:

Computer Equipment:	33% Straight Line
Fixtures and Fittings:	15% Straight Line
Motor Vehicles:	20% Straight Line

i) Stocks

Stocks are valued at the lower of cost and net realisable value.

j) Debtors

Trade and other debtors are recognised at the settlement amount after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due.

k) Creditors

Trade and other creditors are recognised initially at the transaction price and subsequently measured at amortised cost using the effective interest method.

l) Cash and cash equivalents

Cash consists of cash on hand and demand deposits. Cash equivalents consist of short term highly liquid investments that are readily convertible to known amounts of cash that are subject to an insignificant risk of change in value.

m) Financial instruments

The Company has elected to apply the provisions of Section 11 "Basic Financial Instruments" of FRS 102 to all of its financial instruments.

Financial instruments are recognised in the Company's Balance sheet when the Company becomes party to the contractual provisions of the instrument.

Financial assets and liabilities are offset, with the net amounts presented in the financial statements, when there is a legally enforceable right to set off the recognised amounts and there is an intention to settle on a net basis or to realise the asset and settle the liability simultaneously.

Basic financial assets

Basic financial assets, which include trade and other receivables, cash and bank balances, are initially measured at their transaction price including transaction costs and are subsequently carried at their amortised cost using the effective interest method, less any provision for impairment, unless the arrangement constitutes a financing transaction, where the transaction is measured at the present value of the future receipts discounted at a market rate of interest.

Discounting is omitted where the effect of discounting is immaterial. The Company's cash and cash equivalents, trade and most other receivables due with the operating cycle fall into this category of financial instruments.

Other financial assets

Other financial assets, which includes investments in equity instruments which are not classified as subsidiaries, associates or joint ventures, are initially measured at fair value, which is normally the recognised transaction price. Such assets are subsequently measured at fair value with the changes in fair value being recognised in the profit or loss. Where other financial assets are not publicly traded, hence their fair value cannot be measured reliably, they are measured at cost less impairment.

Impairment for financial assets

Financial assets are assessed for indicators of impairment at each reporting date.

Financial assets are impaired when events, subsequent to their initial recognition, indicate the estimated future cash flows derived from the financial asset(s) have been adversely impacted. The impairment loss will be the difference between the current carrying amount and the present value of the future cash flows at the asset(s) original effective interest rate.

If there is a favourable change in relation to the events surrounding the impairment loss then the impairment can be reviewed for possible reversal. The reversal will not cause the current carrying amount to exceed the original carrying amount had the impairment not been recognised. The impairment reversal is recognised in the profit or loss.

Financial liabilities

Financial liabilities and equity instruments are classified according to the substance of the contractual arrangements entered into. An equity instrument is any contract that evidences a residual interest in the assets of the Company after the deduction of all its liabilities.

Basic financial liabilities, which include trade and other payables, bank loans and other loans are initially measured at their transaction price after transaction costs. When this constitutes a financing transaction, whereby the debt instrument is measured at the present value of the future receipts discounted at a market rate of interest. Discounting is omitted where the effect of discounting is immaterial.

Debt instruments are subsequently carried at their amortised cost using the effective interest rate method.

Trade payables are obligations to pay for goods and services that have been acquired in the ordinary course of business from suppliers. Trade payables are classified as current liabilities if the payment is due within one year. If not, they represent non-current liabilities. Trade payables are initially recognised at their transaction price and subsequently are measured at amortised cost using the effective interest method. Discounting is omitted where the effect of discounting is immaterial.

5. Income from fundraising

	2024 Unrestricted €	2024 Restricted €	2024 Total €	2023 Unrestricted €	2023 Restricted €	2023 Total €
Fundraising events	**230,046**	**-**	**230,046**	132,805	-	132,805
Donated funds	**1,035,431**	**335,021**	**1,370,452**	1,161,417	303,687	1,465,104
Donated services and goods	**31,200**	**–**	**31,200**	26,652	–	26,652
Events by supporters	**123,700**	**-**	**123,700**	40,715	-	40,715
Grants – restricted	**-**	**23,499**	**23,499**	-	36,629	36,629
	1,420,377	**358,520**	**1,778,897**	1,361,589	340,316	1,701,905

Grant monies include the following:

	Grant	Purpose	Term	Total Awarded €	Total 2024 €	Total 2023 €
Health Service Executive (CHO1)	**National Lottery**	**Respite**	**1 year**	**–**	**–**	4,000
Health Service Executive (CHO2)	**National Lottery**	**Respite**	**1 year**	**4,000**	**4,000**	4,000
Health Service Executive (CHO4)	**National Lottery**	**Respite**	**1 year**	**6,000**	**6,000**	4,500
Health Service Executive (CHO5)	**National Lottery**	**Respite**	**1 year**	**3,000**	**3,000**	3,129
Health Service Executive (CHO6)	**National Lottery**	**Respite**	**1 year**	**5,000**	**5,000**	5,000
Health Service Executive (CHO7)	**National Lottery**	**Respite**	**1 year**	**650**	**650**	10,000
Health Service Executive (CHO8)	**National Lottery**	**Respite**	**1 year**	**4,500**	**4,500**	6,000
The Department of Rural and Community Development	**Community and Voluntary Energy Support Scheme**	**Energy costs**	**1 year**	**349**	**349**	–
					23,499	36,629

6. Income from investments

	2024 €	2023 €
Interest receivable	**28,844**	–

7. Income from other activities

	2024 €	2023 €
Royalty income	-	10,626
VAT compensation scheme	6,483	4,432
	6,483	15,058

8. Expenditure on raising funds

	2024 Unrestricted €	2024 Restricted €	2024 Total €	2023 Unrestricted €	2023 Restricted €	2023 Total €
Fundraising events	67,108	–	67,108	51,944	–	51,944
Donated funds	161,271	–	161,271	216,624	–	216,624
Events by supporters	2,071	–	2,071	2,125	–	2,125
Other fundraising expenses	12,320	–	12,320	11,276	–	11,276
	242,770	-	242,770	281,969	–	281,969

9. Expenditure on charitable activities

	2024 Unrestricted Designated €	2024 Unrestricted General €	2024 Restricted €	2024 Total €	2023 Unrestricted Designated €	2023 Unrestricted General €	2023 Restricted €	2023 Total €
Patient support	-	244,179	215,496	459,675	-	255,207	199,046	454,253
Research	193,150	156,524	116,447	466,121	297,000	102,133	120,691	519,824
Advocacy	-	115,403	74,116	189,519	-	131,548	-	131,548
Fundraising	-	664,384	-	664,384	-	616,963	-	616,963
General support costs	-	30,056	349	30,405	-	56,841	-	56,841
	193,150	1,210,546	406,408	1,810,104	297,000	1,162,692	319,737	1,779,429

10. Staff numbers and costs

	2024 €	2023 €
Salaries	860,821	815,263
Social welfare costs	95,128	88,057
Other – retirement benefit costs	36,888	33,040
	992,837	936,360

The average monthly number of persons who received emoluments during the financial year, analysed by category, was as follows:

	2024 number	2023 number
Patient support, research and advocacy	6	6
Fundraising, marketing and communications	8	7
Management, governance and general support	3	3
	17	16

The number of employees whose emoluments for the financial year fall within the following bands are as follows:

	2024 number	2023 number
€70,000 – €79,999	–	1
€80,000 – €89,999	–	–
€90,000 – €99,999	–	–
€100,000 – €109,999	1	1
€110,000 – €119,999	–	–

Emoluments include salaries and all employee benefits.

Key management personnel

The cost to the Company (including employer PRSI) of remunerating the 6 members of the Senior Management Team (2023: 7 members) for planning, directing and controlling the charity is €482,127 (2023: €464,900).

11. Pension costs

The Company operates a contribution group PRSA pension scheme in respect of its employees, which is independently administered. This scheme is operated on the basis of defined contributions by reference to current salaries which are charged to the statement of financial activities in the year in which they become payable. The charge for the year amounted to €36,888 (2023: €33,040) and the amount payable at 31 March 2024 was €8,321 (2023: €24,820).

12. Directors’ emoluments

The Directors serve on the Board in a voluntary capacity and receive no fees or remuneration for time spent in carrying out these duties. Relevant expenses, such as travel and subsistence costs, are reimbursable. There were no reimbursements in the current financial year (2023: Nil).

13. Surplus/deficit for the financial year

Surplus/(deficit) is stated after charging:

	2024 €	2023 €
Depreciation of tangible assets	**5,595**	5,208
Auditor’s remuneration (audit services only)	**13,530**	9,102
Operating leases – land and building	**44,500**	44,500

14. Taxation

The charity has been granted charitable exemption by the Revenue Commissioners and is a registered charity with the Charities Regulatory Authority with charity registration number 20021726.

15. Tangible assets

	Computer equipment €	Furniture & fittings €	Motor vehicles €	Total €
Cost				
At 1 April 2023	21,710	7,423	6,500	35,633
Additions	7,847	969	-	8,816
At 31 March 2024	**29,557**	**8,392**	**6,500**	**44,449**
Depreciation				
At 1 April 2023	17,345	1,963	2,602	21,910
Charge for the financial year	3,334	961	1,300	5,595
At 31 March 2024	**20,679**	**2,924**	**3,902**	**27,505**
Net Book Values				
At 31 March 2024	**8,878**	**5,468**	**2,598**	**16,944**
At 31 March 2023	4,365	5,460	3,898	13,723

16. Stocks

	2024 €	2023 €
Merchandise stock	**12,619**	9,454

In the opinion of the directors, the replacement cost of the stock did not differ significantly from the figure shown.

17. Debtors

	2024 €	2023 €
Trade debtors	**44,107**	11,314
Prepayments	**17,374**	11,814
Income receivable	**8,654**	-
Other debtors	**-**	1,372
	70,135	24,500

18. Cash and cash equivalents

	2024 €	2023 €
Cash at bank and in hand	**2,889,966**	3,134,383

19. Creditors

Amounts falling due within one year

	2024 €	2023 €
Trade creditors	**73,833**	43,186
Accruals	**486,290**	454,532
Deferred income (Note 20)	**42,647**	57,778
PAYE/PRSI/USC	**21,187**	22,207
	623,957	577,703

Trade creditors are payable at various dates in the next 3 months in accordance with the suppliers’ usual and customary terms.

PAYE/PRSI/USC is repayable monthly in line with tax and authority guidelines.

20. Deferred income

	Balance at 31 March 2023 €	Received 2024 €	Statement of Financial Activity 2024 €	Balance at 31 March 2024 €
HSE EB Outreach nursing grant	16,963	–	–	**16,963**
Future fundraising events	20,475	15,684	(20,475)	**15,684**
EB training & education funding	14,000	10,000	(14,000)	**10,000**
Research funding	6,340	–	(6,340)	**-**
Total	57,778	25,684	(40,815)	**42,647**

In respect of prior year:

	Balance at 31 March 2022 €	Received 2023 €	Statement of Financial Activity 2023 €	Balance at 31 March 2023 €
Trusts and Foundations	5,000	-	(5,000)	-
HSE EB Outreach nursing grant	16,963	-	-	16,963
Future fundraising events	4,700	20,475	(4,700)	20,475
EB training & education funding	-	14,000	-	14,000
Research funding	17,387	37,640	(48,687)	6,340
Total	44,050	72,115	(58,387)	57,778

21. Statement of funds and analysis of net assets between funds

	Balance 31 March 2023 €	Income €	Expenditure €	Transfer €	Balance 31 March 2024 €
Patient and family care	112,384	242,764	(289,612)	-	65,536
Research funding	6,880	115,407	(116,447)	-	5,840
Trusts and Foundations	-	-	-	-	-
Government CVESS	-	349	(349)	-	-
Restricted funds	119,264	358,520	(406,408)	-	71,376
Research	722,000	-	(193,150)	-	528,850
Patient & family care	100,000	-	-	-	100,000
Unrestricted Designated Funds	822,000	-	(193,150)	-	628,850
Unrestricted General funds	1,663,093	1,455,704	(1,453,316)	-	1,665,481
Total Funds	2,604,357	1,814,224	(2,052,874)	-	2,365,707

	Unrestricted Designated €	Unrestricted General €	Restricted €	Total €
Balance 31 March 2024	628,850	1,665,481	71,376	2,365,707
Represented By:				
Tangible assets	-	16,944	-	16,944
Current assets	628,850	2,077,910	265,960	2,972,720
Current liabilities	-	(429,373)	(194,584)	(623,957)
	628,850	1,665,481	71,376	2,365,707

In respect of the prior year:

	Balance 31 March 2022 €	Income €	Expenditure €	Transfer €	Balance 31 March 2023 €
Patient and family care	48,315	261,629	(197,560)	-	112,384
Research funding	2,882	78,687	(74,689)	-	6,880
Trusts and Foundations	47,488	-	(47,488)	-	-
Restricted funds	98,685	340,316	(319,737)	-	119,264
Research	694,000	-	(297,000)	325,000	722,000
Patient & family care	100,000	-	-	-	100,000
Unrestricted Designated Funds	794,000	-	(297,000)	325,000	822,000
Unrestricted General funds	2,056,107	1,376,647	(1,444,661)	(325,000)	1,663,093
Total Funds	2,948,792	1,716,963	(2,061,398)	-	2,604,357

	Unrestricted Designated €	Unrestricted General €	Restricted €	Total €
Balance 31 March 2023	822,000	1,663,093	119,264	2,604,357
Represented By:				
Tangible assets	-	13,723	-	13,723
Current assets	822,000	2,054,627	291,710	3,168,337
Current liabilities	-	(405,257)	(172,446)	(577,703)
	822,000	1,663,093	119,264	2,604,357

22. Financial commitments

The minimum lease payments under non-cancellable operating leases are as follows:

	2024 €	2023 €
Land and building		
Due within one year	**44,500**	44,500
Between one and five years	**90,950**	135,450
After 5 years	**-**	-
	135,450	179,950

Debra Ireland had no capital commitments or contingencies for the year ended 31 March 2024 (2023: €Nil). The charity is committed to funding research projects in the coming years. Costs and projections for committed projects vary depending on project details and timings. As of 31 March 2024, the total value of future committed funding for these research projects is €217,500 (2023: €326,892). This planned future expenditure is a component of unrestricted designated reserves as of the year end reporting date.

23. Related party transactions

The Company's governing documents require a majority of the board of directors to be patient representatives, as such certain directors or families of directors, are eligible to apply for EB Community Care grants.

Total EB Community Care grants advanced to directors or families of directors, during the financial year amounted to €23,202 (2023: €14,513). A payment of €2,211 (2023: €NIL) was made to the child of a director for work completed during an internship with DEBRA Ireland.

24. Comparative information

Comparative information has been reclassified where necessary to conform to current year presentation.

25. Post reporting date events

There has been no significant events affecting the Company since the financial year end.

26. Company status

This is a Company limited by guarantee and accordingly has no share capital. In the event of the Company being wound up, each member is liable to an amount not exceeding €1.27.

27. Approval of financial statements

The board of directors approved these financial statements for issue on 9 July 2024.

We are Debra, the butterfly skin charity. Uniting for change for everyone with skin as fragile as a butterfly wing.

debra.ie

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