debra
THE BUTTERFLY SKIN CHARITY
Help stop the pain of EB

Our focus for the next 3 years

(2027-2029)

Foreword from our Chair of Trustees and CEO

This strategy sets out our charity's focus for the next three years (2027-2029) and the steps we will be taking to achieve our goals on our journey to a world where no one suffers with epidermolysis bullosa (EB).

Since we issued our last strategic plan in 2021, we have had to navigate some very challenging market conditions. Our retail division has faced unprecedented cost increases which has led us to make some difficult but necessary decisions. And the ongoing cost-of-living crisis and the demands this creates only makes it more difficult to secure the funding we need to make a difference for people with EB.

Despite the challenges we have faced, we have achieved much in the last five years.

We now have a much deeper understanding of the needs of the EB community. This has come from the largest ever EB Insights Study which we conducted in 2023; the EB Priority Setting Partnership study in 2025, which identified the EB research priorities as determined by the global EB community; and the member services impact report in 2026, which evaluated our services for members and the difference they make. We will also have a better understanding of EB in England through the NHS England data project, due to complete in 2026. The support we offer our members has been enhanced. This has included renewing our portfolio of holiday homes with five new homes purchased and two refurbished, an increased number of financial grants given out to our members, and more opportunities for them to connect in person or online through DEBRA events. We have also increased the opportunities available for members to get involved with the charity through member involvement network initiatives.

Our drug repurposing journey has commenced with three clinical trials in progress, including the single largest investment yet, anywhere in the world, into EB drug repurposing research through the ART-EB project. By early 2027 we will have a total of five drugs being clinically tested and we plan to fund further EB clinical trials, all with the aim of improving the quality of life for people living with EB.

Awareness of EB is also increasing following our re-brand, our increased media presence, and thanks to the support of our many Ambassadors who have helped amplify our voice.

We couldn't have made this progress without you.

Every member of our team has played a key role in these achievements. Our colleagues and volunteers, our Royal Patron, President, Vice Presidents and Ambassadors, and our many supporters and partners, without whom we couldn't do the work we do. We must continue to work together as one, with our members always at

the centre of our thinking, if we are to turn our vision into reality. Every action we take, big or small, contributes to achieving our goals and ultimately making a difference for everyone affected by EB.

Your enthusiasm and commitment to improving outcomes for the EB community is the driving force behind achieving our mission. In today's world, our members need support more than ever before. Our goals are centred around making tangible improvements to their quality of life today whilst continuing to seek long-term treatments and cures for tomorrow.

Due to the decisions we have made and the strategies we have put in place over the last four years, we are on a solid financial foundation from which we can now push on and achieve our ambitious goals.

Together we can help stop the pain of EB. Thank you for everything you do for DEBRA and the EB community, let's continue this journey together.

Tony Byrne
DEBRA UK CEO

Carly Fields
DEBRA UK Chair of Trustees

Frequently Asked Questions

What is a strategic plan?

Our strategic plan is like a road map. It identifies the destination we are trying to reach – a world where no one suffers with EB. It also guides the work of our Senior Leadership Team (SLT), our colleagues, volunteers, and our Board. It gives direction on how we will arrive at this destination.

Why is having a strategic plan important?

The strategic plan reflects the needs of the EB community that we serve and the vision of what we want DEBRA to be. It also reminds us of what we want and need to achieve and clarifies what success will look like. The strategic plan helps us to coordinate the work of many different people across our organisation, which will make our combined efforts more effective. It also reminds us that as we work, we need to stay true to our values. Additionally, the strategic plan will help us to be more accountable and transparent to the EB community and our supporters, without whom we simply couldn't do the vital work we do.

How was the strategic plan developed?

The DEBRA strategic plan was created based around the key needs of the EB community as identified through a comprehensive insight programme. This included the EB Insights Study, EB Priority Setting Partnership Study, and the Member Services Impact Study, and the outputs from the inaugural Global EB Taskforce and NHS England EB data study. To address these key needs, each member of the Senior Leadership Team (SLT) developed their own plan with input from their teams. These individual plans were then summarised into directorate specific Plans on a Page (POP). The plans, and accompanying POPs, were then presented to the internal Board of Trustee committees that the directorates report into and were refined accordingly based on feedback received. The updated POPs were then presented to the DEBRA Board of Trustees in November 2025. Any final amends were then incorporated, and the final versions were approved by the committees in April 2026. These POPs form the basis of the strategic plan, and each directorate's POP is included as an appendix at the back of this document.

Our Vision, Mission and Values

The strategic plan reaffirms our mission and vision and the strategic ambitions to accomplish the vision.

It also reconfirms the values we must all live at DEBRA as we strive to achieve our mission and make our vision a reality.

Our vision

A world where no one suffers with EB.

Our mission

To provide life-long care whilst seeking cures for all those affected by EB.

Our values

Our values were refreshed in early 2026.

Following consultation with our members, colleagues, and the DEBRA Board of Trustees, we reduced them from six to three, to make them more memorable, and relaunched them to our colleagues, volunteers and members in April 2026.

Every day, we strive to improve the lives of people affected by all forms of EB. Our work is driven by purpose, passion, and the belief that together, we can create lasting change.

Care is at the heart of everything we do - whether for our members, colleagues, volunteers, supporters, or customers. We extend this care to the planet through our commitment to reuse, recycle, and reduce, ensuring a sustainable future for all.

We embrace diversity and respect every individual, regardless of race, age, gender, disability, medical condition, or background. We champion equal access and opportunities for our members and foster a workplace where everyone feels valued, heard and empowered.

Thank you
Merrow

Current state analysis

EB - The worst condition that most people have never heard of

When the skin is as fragile as a butterfly's wing

Epidermolysis bullosa (EB) is a group of incredibly painful genetic skin conditions that cause the skin to blister and tear at the slightest touch. With skin as fragile as a butterfly's wing, EB is often referred to as 'butterfly skin.'

EB can affect the hands and feet only or in the most severe cases any part of the body, including blistering on the eyes and internal organs.

Genetic condition

People living with EB have a faulty or mutated gene which means the skin cannot bind together and any friction can cause it to tear. Every person has two copies of each gene – one passed on from each parent. EB may be inherited as either dominant (only one copy of the gene is faulty) or recessive (both copies of the gene are faulty). Parents have a 50% chance of passing on a dominant form of EB to their child, whereas the chance of passing on a recessive form of EB drops to 25%. Both parents may carry the gene without knowing and displaying any symptoms. While EB is usually inherited from one or both parents, it can also be caused by a spontaneous genetic mutation. In these rare cases, the child develops EB even though neither parent carries the mutated gene, and there is no prior family history of the condition.

Types of EB

There are over 30 subtypes of EB, grouped into four main types: EB simplex (EBS), accounting for around 70% of patients, dystrophic EB (DEB) 25%, junctional EB (JEB) 5%, and Kindler EB (KEB) which is rare.

Symptoms and complications

Symptoms vary and range in severity depending on the type of EB and external factors, such as temperature and mobility. Blisters continuously form and must be drained and dressed daily, a painful process that can take several hours. Internal blisters such as inside the mouth can create difficulty swallowing. There can be narrowing of the oesophagus and airways. The build-up of scar tissue can cause fingers and toes to fuse together, EB can increase the risk of developing skin cancer, and in severe cases it can be fatal.

Treatments

There is currently only one approved EB drug treatment, Filsuvez®, a topical gel that can be used to treat partial thickness wounds associated with DEB and JEB. Other treatments that people living with EB may receive are primarily focused on alleviating the symptoms as much as possible, preventing further damage to the skin, and reducing the risk of complications such as infection.

The most common challenge amongst all types of EB is the pain and itching that occurs because of the blistering.

Cures

There are estimated to be at least 5,000 children and adults affected by EB in the UK and 500,000 worldwide. However, these numbers could be much higher as it often goes undiagnosed. Currently there are no cures for EB.

DEBRA - The EB patient support organisation

As the world's first EB patient support organisation, we have been improving quality of life for people directly affected by EB since we were established in 1978.

We are the only organisation that supports the EB community today while investing in research to create a better tomorrow.

Our charitable objects are:

- to promote research for the benefit of the public into the cause, nature, treatment and cure of epidermolysis bullosa and other related medical conditions and to publish the useful results of such research.
- to relieve physical and mental illness and distress among persons suffering from the said condition through the provision of practical advice, guidance and support, for both those with the condition and for persons responsible for their welfare and in such other ways as the Trustees shall determine.

The above charitable objects are legally binding. They define what we as a charity are set up to achieve. Our Board of Trustees are legally required to ensure that the funds we raise are used only for these purposes, and they must act for the public benefit. Any breaches could potentially result in legal action. We do not exist to fulfil any other objectives.

Every year we provide a range of support services that help improve quality of life for every person living with, or directly affected by, any form of inherited or acquired EB.

We are committed to making sure that people living with EB, their families, and carers get the vital and wide-ranging support they need, when they need it.

We are also one of the largest investors globally into EB research. From discovering the first EB genes to funding the first clinical trials in gene therapy and drug repurposing, we have played a pivotal role in EB research globally and have been responsible for making significant progress in advancing diagnosis, treatment, and daily management of EB.

We fund pioneering research that aims to secure effective treatments and ultimately cures for all forms of EB.

We are DEBRA

debra
THE BUTTERFLY SKIN CHARITY

Key challenges for the EB community

Research investment required vs. revenue

Drug repurposing has emerged as a key pathway to securing effective EB drug treatments. However, we estimate that it will cost up to £17.5m to test all the drugs that we need to if we are to secure effective treatments for all forms of EB.

We also need to invest in basic science that aids our understanding of pain and itch, and to recruit new researchers into EB. To raise the money required to achieve these goals, we must continue to navigate extremely challenging economic conditions every year. These include sustained cost increases which impact our retail profitability, and cost-of-living pressures which potentially can impact both the physical and monetary donations we receive.

Maintaining these key revenue streams is crucial if we are to deliver business as usual, i.e., the support services that our members need right now to improve their quality of life whilst having sufficient resources to invest in the research that is needed if we are to secure effective EB treatments.

Lack of awareness of the condition

As EB is a rare condition it thankfully touches a relatively small number of people. However, this does mean that awareness amongst the public is low, which makes it harder to secure the support we need. It also means the condition is less likely to touch people with a public profile compared to other more common conditions. This makes it more challenging to secure the support we need to raise awareness and drive donations.

Membership growth

Our current membership of over 4k includes circa 2k members living with EB. The 2k living with EB represents just 25% of the estimated total number of people in the UK living with EB. To maximise our impact, we must find effective ways to engage the wider EB community because we are the UK EB patient support organisation. We are here for the whole EB community, whichever subtype of EB, people living with EB, their families, carers, and professionals working in the field of EB.

Barriers to conducting EB research

The rarity and low awareness of EB create several barriers related to conducting EB clinical trials and securing investment into future EB treatments.

These include:

- difficulty in encouraging new researchers to choose a career in EB research
- difficulty in securing a critical mass of patient numbers required to complete clinical trials
- difficulty in creating the commercial business case for pharmaceutical companies to invest in potential treatments for a rare condition like EB.

Strategic plan - Executive summary

Between 2027 and 2029 we will accelerate our plan to stop the pain of EB while improving the daily lives of people living with the condition today. Our strategy recognises that meaningful progress requires the integration of research, member support, fundraising, communications, retail operations, and organisational capability.

At the heart of this strategy is a commitment to:

- empower people living with EB
- strengthen the EB community
- accelerate the discovery of effective treatments for all forms of EB, and
- ensuring we have all the resources (human, financial and other) we need to achieve the above.

We will continue to invest in world-leading EB research, while ensuring that the lived experience of people with EB directly informs both our research priorities and our support services.

During this period, we will also strengthen our organisational foundations. Investment in people, digital infrastructure, data capability and secure technology systems will ensure that decisions are evidence-based, operations are efficient, and services are delivered consistently across the organisation.

Retail and fundraising will expand and diversify their income streams, allowing us to increase sustainable funding for research, member services and our advocacy work.

By 2029 we aim to have:

- grown our membership so that more people living with all forms of EB can access the support they need
- delivered breakthrough research, including new drug repurposing programmes and expanded clinical trial capacity
- raised public and professional awareness of EB, supporting earlier diagnosis and stronger national recognition of the condition.

The combined effect of these efforts will be a stronger DEBRA — one capable of transforming the experience of living with EB today while accelerating the search for treatments and cures for tomorrow.

How research, member services and fundraising reinforce each other

The strength of DEBRA lies in the way our different activities reinforce each other to create a virtuous cycle of impact for people living with and directly affected by EB.

Through Member Services, we support individuals and families to navigate the complex realities of living with EB, providing information, practical support, community connection, advocacy and respite through our holiday homes. This work not only improves quality of life today but also generates vital insight into the lived experience of EB.

These insights inform our research strategy, ensuring that scientific work focuses on the issues that matter most to patients. By supporting global research collaborations, clinical trials and drug repurposing programmes, we can accelerate the development of treatments that can transform outcomes for people living with EB. Progress in research, in turn, strengthens our ability to inspire supporters and donors. When people see that real progress is being made—towards better treatments and ultimately cures—they are more likely to support the organisation financially and advocate for its work.

Fundraising and retail activities therefore provide the financial engine that enables us to invest in both research and member support. Through events, community fundraising, major donors, trusts and legacies, retail operations and digital engagement, we can mobilise a wide community of supporters united by the goal of stopping the pain of EB.

Marketing and communications amplify this cycle by raising awareness and understanding of EB with the public and healthcare professionals through education programmes. Awareness is also raised by sharing lived experiences of EB, and highlighting the progress made possible through research and community support.

Underpinning all of this is a strong organisational foundation. Investment in people, digital systems, data capability and secure technology infrastructure will ensure that we can operate efficiently, make informed decisions, and deliver services consistently across the organisation.

Together, these elements form a single integrated strategy with each part of DEBRA strengthening the other and creating a system capable of improving lives today while accelerating progress towards a future where EB can be effectively treated and ultimately cured.

Our Strategic Approach:

Inputs

Our strategic plan for 2027–2029 can be understood as a chain of connected activities that move from organisational capability through to real-world impact for people living with EB. To deliver our mission, we will draw on several key resources:

- **Our people: Colleagues, Volunteers, Trustees, Royal Patron, President, Vice Presidents, Ambassadors, and Independent Advisors.**
- **Member insight and lived experience of EB.**
- **Our supporters: donors, retail customers, and fundraising communities.**
- **Scientific expertise and research partnerships.**
- **Digital systems, data and technology infrastructure.**

These will allow us to mobilise knowledge, resources and relationships across the EB community.

Core activities

- **Member Services -**
  Empowering people living with EB, providing direct support, strengthening the EB community and championing our members' needs
- **Research -**
  Funding and coordinating scientific research, accelerating drug repurposing programmes, supporting clinical trials and strengthening the global EB research community
- **Fundraising and Retail -**
  Generating sustainable income through a balanced portfolio of activities including events, major donors, community fundraising, digital engagement and our retail operations
- **Marketing and Communications -**
  Raising awareness and understanding of EB including educating healthcare professionals, engaging supporters and members, and supporting income generation through targeted campaigns and compelling storytelling
- **People, IT and Data -**
  Building organisational capability through workforce development, strong culture, digital transformation, data-driven decision making and secure technology infrastructure

Outputs and outcomes

By undertaking the core activities detailed above we will deliver:

- **expanded membership and stronger engagement across the EB community -** leading to greater access to practical support and resources and stronger support networks for people living with EB
- **increased awareness of EB among the public and healthcare professionals -** leading to improved understanding of EB and earlier/more accurate diagnosis
- **increased investment for our member support services and EB research programmes**
- **improved member pathways and digital services.**

More engaged supporters and volunteers will create:

- **a stronger organisational culture and operational efficiencies.**

The ultimate aims of our 2027-2029 strategic plan are:

- **Improved quality of life for people directly affected by all forms of EB today.**
- **Accelerated discovery of effective treatments for all forms of EB.**
- **A stronger and more connected EB community.**
- **Increased public awareness and recognition of EB.**
- **All leading to further progress on our journey to a world where no one suffers with EB.**

Mission

To provide life-long care while seeking cures for everyone affected by EB

People living with EB

Their lived experience shapes our services, research and voice

Research

Accelerate treatments
Clinical trials
Drug repurposing
Research talent

Fundraising

Sustainable income
Donor growth
Events
Partnerships

Retail

Online growth
Community presence
Volunteers
Sustainability

People

Skilled workforce
Volunteers & Culture
Leadership & Development
DEBRA values in action

Marcoms

Awareness
Engagement
Advocacy
Storytelling
Campaigns

Member Services

Empower
Support
Champion
Community

IT/Data

Integrated systems
Digital transformation
Automation & AI readiness
Secure systems (zero trust)

Outcomes

Larger EB community
Greater awareness of EB
Stronger income streams
More research progress
Better member support

Impact

Better lives for people living with EB today
Accelerating treatments and progress towards a cure

Our focus for 2027-2029 by directorate

Member Services

Member Services sits at the centre of our mission to provide lifelong care for the EB community. The strategy for 2027–2029 focuses on enabling people living with all forms of EB, their families and/or carers to live with greater confidence, connection and quality of life.

The work of the team is structured around three guiding principles:

- **Empower.**
- **Support.**
- **Champion.**

Firstly, we will **empower people** living with all forms of EB by ensuring they have the necessary knowledge, information and clear pathways to navigate complex health and social systems. EB is a lifelong and often unpredictable condition, and many families face challenges in accessing the services they need. By providing clear information, proactive support and accessible digital resources, we will help our members make informed decisions about their care, education, employment, and daily living.

Secondly, through our EB Community Support Team we will **provide direct support** where and when it is needed. Many individuals and families affected by EB face financial pressures, social isolation, and emotional strain. Through grants, welfare support, discounted holidays, counselling and practical assistance, we will help reduce inequalities and improve their quality of life. Support will increasingly focus on early intervention and ensuring our members receive help before challenges escalate into crisis.

Finally, we will **champion opportunities** for EB community engagement by strengthening peer networks and amplifying the voices of people living with the condition. EB is a rare condition and is often poorly understood by wider society and some healthcare professionals. By building stronger community connections, facilitating peer support and gathering systematic member insights, we will continue to ensure that lived experience informs our research priorities, healthcare policy, and public awareness.

This work will be underpinned by improved data collection, partnership working with the NHS and social care providers, and expanded digital access to services. By 2029 we aim to have an expanded membership with increased engagement across the EB community and a member services offer that has the greatest impact on our members, addressing the key needs as identified in the Member Services Impact Report. The above will help ensure that more people living with EB feel informed, supported, and connected.

Research

Research remains central to our mission to provide life-long care whilst seeking cures for all those impacted by EB. We have played a pivotal role in advancing scientific understanding of EB and we will continue to invest strategically in research that delivers tangible benefits for patients.

Between 2027 and 2029 our research will focus on three strategic priorities:

- **Accelerating treatments for all forms of EB.**
- **Strengthening research capacity and knowledge.**
- **Improving knowledge of EB prevalence and impact.**

Firstly, we will **accelerate the development of effective treatments** through our continued focus on drug repurposing and EB clinical trials. Repurposed drugs offer one of the fastest, most cost-effective pathways to improving outcomes for people living with EB, and our aim is to see multiple repurposed therapies approved and available for the EB community through the NHS. We will also support the establishment of new EB clinical trials, including trials involving children, ensuring that patients have access to cutting-edge therapies that will address their symptoms.

Secondly, we will **strengthen the global research ecosystem** for EB. This includes expanding international collaboration, supporting early-career researchers and building expertise in areas of unmet need, including more research into EB simplex. Through funding PhD students and supporting research partnerships, we will ensure a pipeline of future scientific leadership in EB.

Thirdly, we will **improve the understanding** of EB prevalence through initiatives such as the Global EB Atlas. Accurate data is essential for research planning, health system engagement, patient registries, and advocacy.

Through the above efforts we will position ourselves as a global leader in EB research, ensuring that scientific discovery translates more rapidly into treatments that improve the lives of people living with EB.

Fundraising

Fundraising provides the financial foundation that will enable us to deliver our mission. The strategy for 2027–2029 focuses on building a balanced, sustainable portfolio of income streams while strengthening the emotional connection between our supporters and the EB community.

Between 2027 and 2029 our fundraising strategy will focus on three strategic priorities:

- **Growing our supporter base – individual donors, major funders, corporate supporters and people attending our events.**
- **Increasing donations – the number and value of donations we receive.**
- **Developing our supporter journeys - building strong, longstanding relationships with our supporters through storytelling, stewardship, and clear, singular calls to action rather than solely relying on fundraising asks.**

We will seek to increase annual income significantly through a combination of major donor development, corporate partnerships, trusts and foundations, events and community fundraising, supporter stewardship, and improved use of data and technology.

A key priority will be the development of a strong supporter community, including Ambassadors, volunteers, patrons, engaged donors, and our members, all feeling personally connected to our mission. By strengthening donor stewardship and communication, the organisation will ensure supporters understand the impact of their contributions and remain engaged over the long term.

Events and community fundraising will remain an important entry point for new supporters, while digital platforms and better leveraging our CRM system will allow us to better understand supporter behaviour and tailor future engagement accordingly.

Equally important is the development of a strong internal fundraising culture, ensuring our colleagues and volunteers feel confident speaking authentically about the work we do with a willingness to communicate our case for support.

By 2029 our aim is to achieve substantial income growth that supports our drive for effective EB drugs treatments for adults and children and provides long-term investment for research and member services.

Retail

Our retail operations (physical stores and our online platforms) are a critical source of sustainable income. Our network of stores in England and Scotland also serve as an important point of engagement with local EB communities and help raise much-needed awareness of the condition.

The retail strategy for 2027–2029 focuses on strengthening the performance of our retail estate while ensuring stores remain compliant, sustainable, and well-integrated with the wider organisation.

The retail strategy will focus on three strategic priorities:

- **Increase net income.**
- **Delivering an ethical and sustainable retail division.**
- **Maintaining a safe and skilled retail operation.**

We will continue to invest in a hub-and-spoke retail model, with larger stores supporting smaller stores nearby with stock.

We will also improve our operational efficiency to drive stronger store performance. Our pricing strategies, product sourcing and online retail capabilities will be developed further to maximise income while maintaining ethical standards. Our online sales will play an increasingly important role and will be supported by enhanced digital infrastructure. Retail operations will also contribute to environmental sustainability through initiatives such as recycling programmes and “sustainable living” product ranges.

DEBRA stores will increasingly function as community hubs, supporting local engagement with our work and providing opportunities for volunteering and awareness building.

Through these measures we expect our retail income to grow steadily while strengthening the organisation’s presence in communities across the UK.

Marketing and Communications

Our marketing and communications function plays a central role in advancing our mission by raising much-needed awareness of EB, strengthening engagement with our members and supporters, and supporting our income generation.

Between 2027 and 2029, our marketing and communications strategy will focus on three strategic priorities:

- **Awareness and education.**
- **Engagement.**
- **Revenue generation.**

Firstly, we will work to increase awareness of EB among healthcare professionals and the wider public. Earlier diagnosis and improved understanding of EB are essential for better patient outcomes. Targeted campaigns and professional education programmes will ensure EB-related information is highly visible across the platforms used most by healthcare professionals.

Secondly, we will deliver engaging and relevant content across digital platforms to strengthen connections with both our members and our supporters. By using data insights and emerging technologies, including artificial intelligence where appropriate, communications will become increasingly personalised and responsive.

Thirdly, our marketing initiatives will support our fundraising and retail activities by effectively promoting campaigns, events and opportunities to support us. This will include leveraging our 50th anniversary in 2028 as a platform to highlight the progress we have made in EB research, to celebrate the EB community, and increase public awareness of the condition.

Through these activities we aim to expand our reach and deepen engagement with our supporters, members, and other stakeholders.

People

Our people—colleagues and volunteers, whether it is those supporting our retail functions, our head office functions including our events programme, or our Ambassadors—are essential to delivering our mission. Our People strategy focuses on building a supportive, inclusive, high-performing workplace where individuals feel empowered to contribute towards the impact we make as a charity.

Between 2027 and 2029 our people strategy will focus on three strategic priorities:

- **Organisational culture.**
- **People development.**
- **Employee experience.**

We will invest in learning and development through initiatives such as the DEBRA Academy and apprenticeship programmes. These initiatives will help colleagues build the skills and confidence needed to perform effectively and develop their careers within the organisation.

Colleague engagement and wellbeing will be central priorities, and we will aim to create a workplace culture where our people feel valued, supported and proud of the organisation's mission. Success will be measured through improved colleague engagement, measured through survey results, reduced turnover and lower absence rates.

We will also continue to grow and support our volunteer community, recognising the vital contribution volunteers make to our retail operations, fundraising, and member engagement.

By investing in people and strengthening our organisational culture, we will ensure we have the necessary skills, commitment and leadership capacity to deliver our strategic ambitions.

IT and Data

Our IT and Data strategy will create a strong digital foundation that enables us to operate efficiently, make informed decisions, and deliver the services that our members need most.

Between 2027 and 2029 our IT and data strategy will focus on three strategic priorities:

- **Automating data flows and manual tasks to increase efficiencies and generate cost savings.**
- **Achieving one 'source of the truth' – a single, reliable data source that enables data driven insight and decision making.**
- **Control and compliance - safe, accurate, reliable and accessible data.**

A central objective will be the creation of a modern data infrastructure, including a comprehensive data warehouse that brings together information from across the organisation. This will allow us to generate insights that inform strategic decision-making and improve operational efficiency.

Automation of manual processes will reduce administrative burden and increase data accuracy, while dashboards and analytic tools will enable our teams to monitor performance in real time.

Cybersecurity and compliance will remain critical priorities. We will adopt a "Zero Trust" security approach, ensuring that our systems are secure and that our colleagues, volunteers and partners can safely access the information they need, when they need it.

Throughout this strategy period, we will continue developing our use of artificial intelligence to improve operational efficiency, supporter engagement, and service delivery. These enhancements will help us become a more data-driven organisation, able to respond quickly to opportunities and challenges while maintaining high standards of security and governance.

Finance

This three-year strategic plan (2027–2029) is being developed at a time of continued economic uncertainty, particularly with war in the Middle East and difficult trading conditions across the retail sector.

DEBRA's financial sustainability depends on a complex interplay of macroeconomic conditions, donor confidence, consumer behaviour, and operational cost pressures.

The period since 2023 has been characterised by successive external shocks to the UK economy and the charity sector, including high inflation, constrained household incomes, and volatility in energy and labour costs.

In contending with these factors, DEBRA has also had to address its Cash-Backed Free Reserves position. Against this backdrop, the purpose of this strategy is to position DEBRA to:

- **Deliver on planned research initiatives;**
- **Provide the best care for our members; and**
- **Ensure financial resilience by strengthening the reserves position.**

External Economic Context

1. **Inflation**
   The UK suffers from continued low growth and relatively high inflation. Independent forecasts suggest GDP growth of approximately 0.6% in 2026, and CPI inflation was 3.3% in the year to March 2026. Forecasts indicate inflation could peak above 3.5% during 2026 before gradually easing.

2. **Interest rates**
   Interest rates were expected to fall gradually in 2026, but events in the middle east may affect this. Households continue to struggle with the cost of living.

3. **Retail landscape**
   Real income growth remains modest, with declining footfall an issue across the sector. Wage growth is expected to soften to around 3% in 2026. The National Living Wage has risen to £12.71 in April 2026. Higher energy costs and broader inflationary pressures are expected to impact budgets.

   Charity shop numbers are declining, with several major charities announcing closures, and there is a shift towards larger, higher-performing store formats.

   Our focus is to grow income in our online operations and new 'bought in goods' (BIG), whilst maintaining focus on our in store performance.

4. **Fundraising and Voluntary Income**
   Cost-of-living pressures continue to impact donation frequency and value, and there is increased competition for donor attention, alongside global humanitarian demands. There is a trend towards digital and AI-enabled fundraising approaches. Innovation is required to achieve income growth.

Assumptions for DEBRA

Taking into account the economic context, the high-level financial plans for the next three years assume:

- **National minimum wage increases of 3% year on year**
- **General wage growth of 2.5%**
- **Income growth of 2.5%**
- **Other costs inflation of 2%.**

High-level 3 year plan

	2027	2028	2029
	£'000	£'000	£'000
Donations & giving	2,091	2,143	2,197
Events and challenges	1,336	1,370	1,404
Grants, trusts & legacies	516	529	542
Fundraising general	(0)	(0)	(0)
Fundraising contribution	**3,943**	**4,042**	**4,143**
Management & Admin	(512)	(523)	(533)
Net Fundraising Income	**3,431**	**3,519**	**3,610**
Retail income	12,742	13,061	13,387
Retail staff	(6,021)	(6,201)	(6,388)
Retail costs	(4,918)	(5,016)	(5,116)
Retail contribution	**1,804**	**1,843**	**1,883**
Management & Admin	(897)	(915)	(933)
NET Retail Income	**907**	**929**	**950**
Other income	50	50	50
NET INCOME	**4,387**	**4,497**	**4,610**
Research	(1,302)	(1,328)	(1,355)
Member Services	(1,639)	(1,672)	(1,706)
Marcoms	(1,280)	(1,306)	(1,332)
NET CHARITABLE SPEND	**(4,222)**	**(4,306)**	**(4,393)**
SURPLUS/(DEFICIT)	**165**	**191**	**217**

Appendices

DEBRA
Member services
Research
Fundraising
Retail
Marcoms
People
IT & Data
Finance

DEBRA

WHAT we'll do and WHY

EB Community

- Relieve physical and mental illness and distress through the provision of practical advice, guidance and support
- Enable choice and independence throughout the journey of life with EB
- Ensure specialist health and social care/support is available and known about
- Develop a sense of community and actively encourage involvement and engagement

EB Research:

- Promote research for the benefit of the public into the cause, nature, treatment and cure of all forms of EB
- Collaborate with national and international partners to fund research and other activities that lead to QoL improvements, effective treatments and cures for all forms of EB

Income generation:

- **Fundraising.** Grow the supporter base and increase the number of donations we receive – volume and value
- **Retail**. Maximise contribution from retail (stores, online, events) through income growth and cost control

HOW we'll do it and by WHEN

HOW we'll know if we've made a difference

Member Services:

- Increased no. of members living with EB – from 2k to 3k
- Individual members supported increased – 700 to 1.5k
- Involvement network participation increases – 200 active members to 300
- 100% increase in members accessing website pages empowering 'self help'

Research:

- Min of 2 EB approved repurposed drugs delivered into the NHS
- EB Atlas established with initial estimate of global prevalence
- Set up clinical trial involving children in the UK

Fundraising:

- Annual income increased from £3.2m to £4m
- Growth in active supporters (donated in last 2yrs) – 15k to 25k

Retail:

- Annual income post M&A costs up from £600k to £850k
- Gift Aid % increased – from 42% to 47%

Estates & Safety

- Annual RIDDORs maintained at current rate (1 PA) or <
- >95% H&S compliance achieved across the Estate

Marcoms:

- Social media growth – engagements up from 545k to 829k PA, overall audience up from 50k to 66k
- Increased unprompted awareness – EB - 8% to 12%, butterfly skin - 15% to 20%, DEBRA - 13% to 17%

People:

- Labour turnover better than CRA average
- Volunteer numbers up from 1300 to 1500

IT & Data

- DEBRA has a confident and data literate workforce
- Dashboards in place to support better/faster decision making

Finance:

- Year on year increases achieved for Cash Backed Free Reserves

Member Services

WHAT we'll do and WHY

Empower: enable choice and independence throughout the journey of life living with EB

- We strive to ensure that our members have access to holistic up to date information and advocacy relating to health and social care needs to enable choice and independence

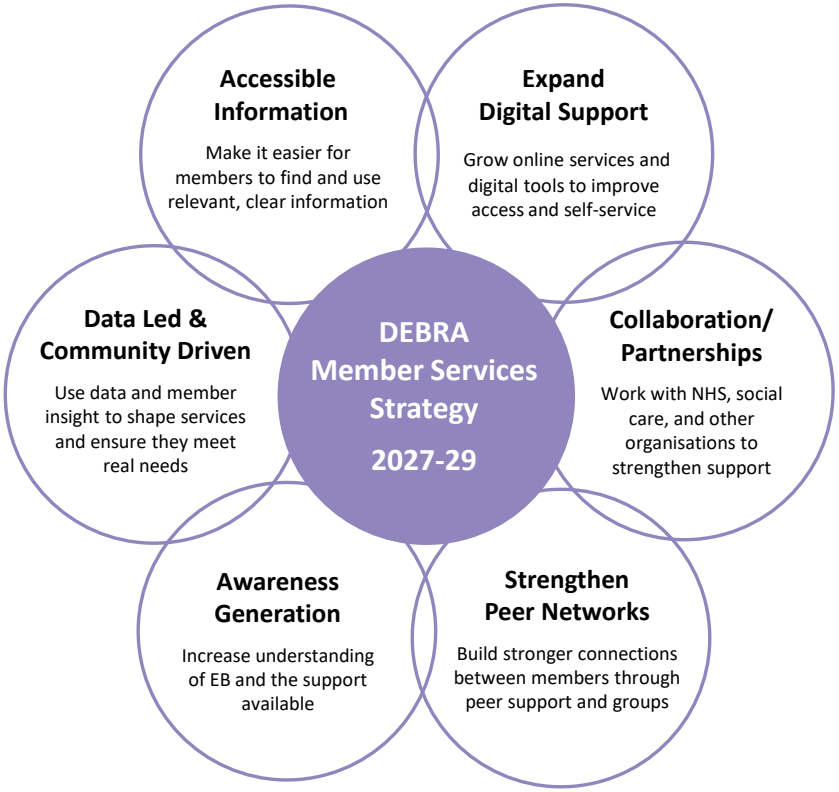
Provide: awareness and access to specialist health and social care/support

- EB is a rare condition requiring specialist care and support to ensure members' quality of life is maximised

Build: grow and engage the EB community

- Understanding the needs of members living and working with EB, while fostering connections that strengthen support, care, and community

HOW we'll do it and by WHEN



HOW we'll know if we've made a difference

Empower:

- DEBRA cited in national EB guidelines and industry reports
- 100% increase in members accessing website pathway pages empowering 'self serve'
- Members with all types of EB are empowered (representative % of members accessing support)

Support:

- Establish 6 regional EB care/support hubs to reduce geographic disparities
- Increase access to CST via welfare calls, help line, outreach clinics and member events (1.5k individuals)
- Develop formal partnership agreements inc. NHS trusts, social care and other agencies/companies (min.6)
- Holiday home occupancy increased to 80%
- Increase Support grant funding to £400k to enhance QoL / address cost of living needs
- Enhanced mental health provision inc. access to counselling and CBT for every member (Insights/satisfaction score >4)

Build community:

- Grow membership to 3k living with EB
- Implement/ track output and impact measures
- Positive member feedback on connection and support (Insights/Satisfaction score >4)
- Increase in peer support opportunities and 10 local member groups established

Research

WHAT we'll do and WHY

Attract: collaborative funding and partnerships

- Maintain DEBRA's leadership position as the trusted authority and partner for EB research globally
- Forge strategic collaborations with national and international partners to co-fund high-impactful projects that advance patient outcomes
- Maximise resources and expertise to deliver transformative results for the EB community

Lead: clear, ambitious research strategy

- Position DEBRA as a global leader in EB research, setting the agenda and shaping the future of innovation
- Inspire and mobilise the research community by demonstrating ambition, clarity, and commitment to impact
- Patient priorities, focusing on improving quality of life while striving for transformative therapies and ultimately cures

Build and sustain: EB research expertise

- Implement succession planning to ensure continuity and sustainability in EB research
- Create pathways for emerging researchers to establish themselves in the EB field through mentorship, funding opportunities, and collaborative projects
- Actively attract new expertise to bring fresh perspectives and accelerate EB research

HOW we'll do it and by WHEN

HOW we'll know if we've made a difference

Build Partnerships and Funding Streams:

- Secure co-funding agreements with multiple partners, including EB and non-EB organisations

Research:

- Establish a clear understanding of EB prevalence in the UK (est. range of 6k to 8k)
- Global EB Atlas – Established with initial estimate of global EB prevalence
- Minimum of 2 approved repurposed drugs in the NHS
- Clear pathway for drug approval in each developed nation, focusing on repurposed drugs
- Set up a Clinical trial involving children in the UK
- EB Research as part of a national Scar Hub
- Establish one additional Global Clinical Trial Hub for Adults

Grow and Sustain EB Research Expertise:

- Fund 10 additional PhD students and create pathways for early-career researchers
- Build expertise in EBS research to address unmet needs

Fundraising

WHAT we'll do and WHY

Grow:

- Grow the supporter base – individual donors; major funders (donors & trusts); corporate supporters; event attendees; Scottish footprint

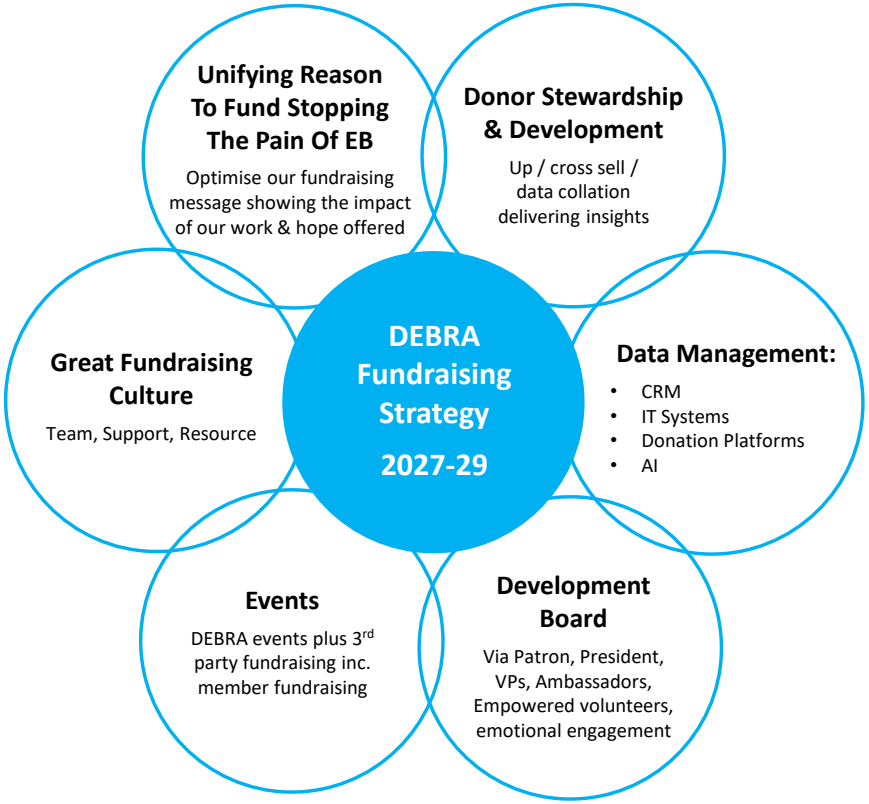
Increase:

- Increase donations both in terms of numbers and values – moving to 6 and 7 figure values.
- Connect with more individuals who can facilitate donations / connections to grow DEBRA

Develop:

- Develop a supporter journey using emotional engagement; based on our strategic plan facilitated through our own events programme; relationship management and managed through our CRM
- Embed a PROUD fundraising culture in DEBRA

HOW we'll do it and by WHEN



HOW we'll know if we've made a difference

- Empower colleagues, Volunteers and Ambassadors to speak in an authentic manner about DEBRA's work and make a clear fundraising ask that they feel happy to articulate
- Income will increase from net £3.2m to £4m+ by 2029, with plans to realise £5m by 2031
- Database of active engaged supporters to increase from c.15k to 25k+ by 2029 to deliver greater charitable output
- Team retention, skill development, and efficiency gains – delivering stable income growth from a balanced portfolio of income streams
- Donors demonstrate / articulate a clear connection and passion to the cause

Retail

WHAT we'll do and WHY

Increase net income:

- To maximise income areas of DGS, Gift Aid, Online and Bought-in-Goods
- To operate an efficient and lean Retail Directorate
- To support our members, fund research, and raise awareness of EB

Ethical & sustainable retail division:

- To embed ESG principles into retail operations, champion ethical sourcing, and reduce environmental impact
- Promote community engagement that also supports our members

Safe & skilled retail operations:

- To protect our people, customers, and brand by maintaining a compliant, safe, and well-trained estate that supports consistent high-quality retail delivery

HOW we'll do it AND BY WHEN

HOW we'll know if we've made a difference

- Annual Net Income incl. M&A increased from £600k to £850k (subject to ongoing modelling).
- DGS Gift Aid % increase from 42% to 47%
- Online Gift Aid % increase from 43% 2026 to 45% 2029
- DGS Growth +2.5% YoY
- Online Sales 30% growth 2027 & +25% YoY to 2029
- Bought-in-Goods Sales 25% growth YoY
- Increased dilapidations provision of £1m
- Hub & Spoke model implemented
- Faster online customer service, higher conversion rates
- Defined parameters for ethical stock sourcing
- Sustainable Living Corners and recycling projects implemented
- Community hubs implemented in larger footprint stores with secured local funding where feasible; accessible for members
- Estate compliance 98%; audit actions closed out in 4 weeks; audit programme implemented
- Mandatory e-Learning compliance at 98%
- Consistency of training and induction across portfolio

Marcoms

WHAT we'll do and WHY

Increase EB diagnoses, DEBRA membership & uptake of the member offer:

- Invest in activity that raises EB awareness with healthcare professionals (HCPs)
- Invest in activity that engages the wider EB community and encourages them to join DEBRA
- Keep members informed of our progress and opportunities available to them

Expand our reach & drive revenue:

- Leverage digital and traditional marketing - organic and paid social media, DRTV, influencers, Ambassadors and PR activity to engage existing and new audiences and drive support/revenue

Secure political support:

- Encourage member involvement in campaigning and seek opportunities (select committees etc.) to raise awareness/support for our cause

Drive colleague engagement:

- Ensure colleagues are informed and fully engaged with our key charitable activities

HOW we'll do it and by WHEN

HOW we'll know if we've made a difference

Members:

- Growth in members with EB – from 2.4k ('26) to 3k ('29)
- Achieving a minimum 10% y on y increase in page views for member focused web content (EB information & resources)
- Email programme consistently achieving industry average opens and click throughs (40% & 3.2% respectively)

Supporters:

- Growth in engaged supporters – from 25k ('26) to 40k ('29)
- Social media engagement growth – from 545k PA ('26) to 829k PA ('29)
- Social media audience growth – from 50k ('26) to 66k ('29)
- Email programme consistently achieving industry average opens and click throughs (40% & 3.2% respectively)

Retail:

- Growth in volunteer leads generated - from 250 PA ('26) to 280 ('29)
- Growth in furniture collection requests generated - from 4.8k ('26) to 5.2k ('29)

Other metrics:

- **Growth in unprompted awareness:** EB (8% to 12%), Butterfly skin (15% to 20%), DEBRA (13% to 17%)
- **Growth in EB CPD completions (HCPs)**: from 650 ('26) to 890 ('29)
- **PR coverage:** consistently achieving a minimum of one new media 'event' every month
- **Government campaigning:** Min. 3 meetings secured PA with key influential politicians
- **Internal comms:** minimum 95% colleague understanding of mission and aims (benchmark 92% - April 25)

People

WHAT we'll do and WHY

Culture:

- Create a workplace culture where people feel a strong sense of inclusivity, connection and purpose
- To encourage open communication & celebrate diverse perspectives
- Invest in initiatives that strengthen trust and psychological safety to help make DEBRA a great place to work

Development:

- Empower our people through continuous development opportunities that build capability, confidence, and career growth
- Focus on creating accessible & relevant learning experiences that support both individual aspirations and the needs of the charity

Experience:

- Offer a compelling employment experience through competitive salary and benefits, support for work/life balance, and meaningful recognition of performance
- Ensure ongoing appreciation of our people to build an agile, innovative workforce that consistently delivers exemplary support for the EB community

HOW we'll do it and by WHEN

HOW we'll know if we've made a difference

- We make the most of our apprenticeship levy to support learning and development across the organisation (6 apprenticeships undertaken)
- We report fewer absence year on year, showing that our teams feel supported and more engaged (absence % better than CRA average)
- We hear from our colleagues that their experience at work is getting better, through positive feedback in our annual survey
- We reach a cultural score of 75 or more in our annual Empowered Engagement survey, showing we're building a workplace people feel proud to be part of
- We're keeping more of our people each year, with fewer leaving unexpectedly (LTO better than CRA average annually)
- We will grow our volunteer community to 1,500 by 2029, strengthening our collective impact. This growth will be achieved through a phased approach building from 1.3k volunteers in 2027, to 1.4k in 2028, and reaching 1.5k by 2029
- Our colleagues feel more confident and capable in their roles, due to the support they're getting through the DEBRA Academy and other learning opportunities (annual reporting via Colleague Survey)
- We consistently demonstrate DEBRA values in our decisions and interactions, reflected in 90% of colleagues agreeing that our values guide decisions (annual reporting via Colleague Survey)

IT & Data

WHAT we'll do and WHY

Discover:

- We will increase efficiency and create cost savings by automating data flows and manual tasks
- Run Change Advisory Boards and workshops to enable faster deployment of IT solutions

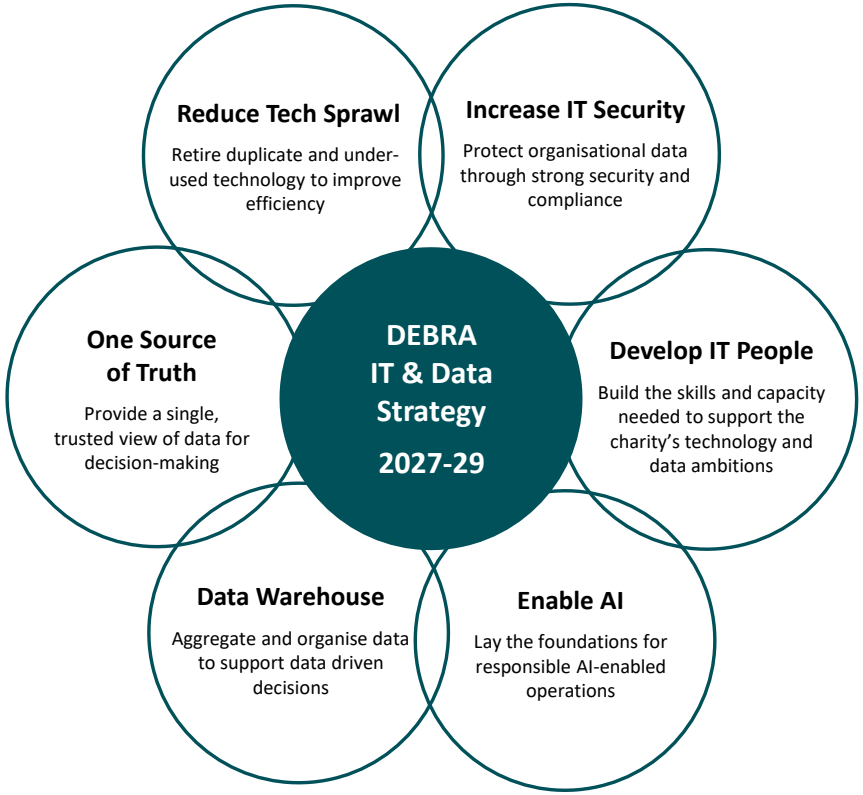
Develop:

- We will develop 'one source of truth' to enable reliable data driven insights
- We will increase efficiency and cost savings by automating data flows
- We will enable, as appropriate, AI technologies to increase efficient working practices

Control & comply:

- Ensure all data is accurate, reliable and accessible
- Ensure that all IT systems follow a 'Zero Trust' approach to be secure, safe and compliant

HOW we'll do it and by WHEN



HOW we'll know if we've made a difference

- 100% of business data will be held and accessible in a data warehouse
- DEBRA has a confident and data literate workforce
- Digital processes will automate business process and provide more accurate data
- Dashboards that support better and faster business decisioning
- AI technologies are available and producing accurate and trusted output
- DEBRA IT tech stack will be efficient, well designed and will integrate data flows
- DEBRA will have adopted a 'Zero Trust' security stance exceeding Cyber Essentials plus
- All DEBRA colleagues, trustees, volunteers and committee members, and third parties will have safe, secure access to DEBRA systems
- MS security scores remain above 60% and keep click prone rates below 6%
- No fines or penalties from legal or regulatory bodies
- 100% IT Projects are delivered on time

Finance

WHAT we'll do and WHY

Develop and integrate:

- Continue to develop Access Financials
- Investigate the potential of AI
- Introduce PowerBI reporting where appropriate
- Work closely with budget holders as a critical friend – advising on financial performance and strategy
- Work with IT on greater integration with CRM and EPOS
- Increase shop and events attendance

Strong balance sheet and financial performance:

- Robust budget process and monitoring
- Increase supplier SLA monitoring, working with directorates
- Keep balance sheet strong, manage cash flows carefully and assess options for managed funds investments

Compliance and control:

- Review performance on Internal audit service and identify where they can most benefit
- Assess alternative formats for Annual Review, Financial statements
- Comply with all Tax, VAT and corporate filings
- Increase retail gift aid filings

HOW we'll do it and by WHEN

HOW we'll know if we've made a difference

- Completion of Access improvement plan and assessment of alternative finance and expense systems
- Use of some AI tools
- Full assessment of Power BI for retail and implementation of any recommendations
- Regular monthly meetings with budget holders throughout the strategy period
- API integration where possible
- Head of Finance / Finance Director attendance at shops quarterly and 2 events per year
- Year-on-year increases to CBFR, monthly risk & opportunities monitoring to SLT, quarterly to FRA
- Management accounts issued by working day 7
- Monthly supplier reviews after creating a review/assessment template
- Sufficient working capital and use of cash deposits
- Internal audit service mapped to risk register with plan for covering key risks
- Agreement of any new Annual Review format for reporting.
- Compliance with all requirements throughout the strategy period
- 4 Gift Aid filings PA

aprilia

Abbreviations

AI	Artificial Intelligence
ART-EB	Advancing Repurposed Therapeutics for Epidermolysis Bullosa
BiG	Bought in Goods
CBFR	Cash Backed Free Reserves
CBT	Cognitive Behavioural Therapy
CPI	Consumer Price Index
CRA	Charity Retail Association
CRM	Customer Relationship Management
CST	(DEBRA) Community Support Team
DEB	Dystrophic EB
DGS	Donated Goods Sales
DRTV	Direct Response TV
EB	Epidermolysis Bullosa
EBS	EB Simplex
ESG	Environmental, Social, Governance
FRA	Finance, Risk & Audit Committee
GDP	Gross Domestic Product
GP	General Practitioner
HCP	Healthcare Professionals
JEB	Junctional EB
KEB	Kindler EB
LTO	Labour Turnover
M&A	Management & Administration
PA	Per Annum
POP	Plan on a Page
PR	Public Relations
QoL	Quality of Life
SLT	Senior Leadership Team

debra
THE BUTTERFLY SKIN CHARITY
Help stop the pain of EB

DEBRA is the patient support organisation for anyone directly affected by any form of EB.

We are also one of the largest investors globally into EB research. We aim to improve quality of life today and secure effective EB treatments for tomorrow.

Together we can #StopThePain of EB.

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DEBRA President - Graeme Souness CBE

amrc
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