



**Join our
journey to
change lives
forever...**

Our work



DEBRA UK was the world's first EB patient support organisation, founded in 1978 by Phyllis Hilton whose daughter Debra was born with Dystrophic EB. When told by medical professionals that she should take her baby home as nothing could be done for her, she set out to find ways to treat Debra's skin herself using cotton dressings.

15 years later Debra sadly passed away. That year Phyllis met a parent seeking advice and realised that nothing had changed. She decided to act, organising the first ever meeting for parents of EB and so DEBRA was formed.

We have come a long way since then. We have achieved global recognition as a leading authority on EB and made significant progress in advancing diagnosis, treatment, and daily management of the symptoms of EB. DEBRA is international in scope with a network of DEBRA groups, including DEBRA UK, sharing information and best practice. We are committed to making sure that people with EB and their families and carers get the vital, wide-ranging care and support they need so that the devastating symptoms of EB can be reduced while we work towards finding effective drug treatments for every type of EB.





Our Vision

A world where no one suffers with EB.

Our Mission

Provide lifelong care, while seeking cures, for all those affected/impacted by living with EB.



Phyllis Hilton
Founder of DEBRA



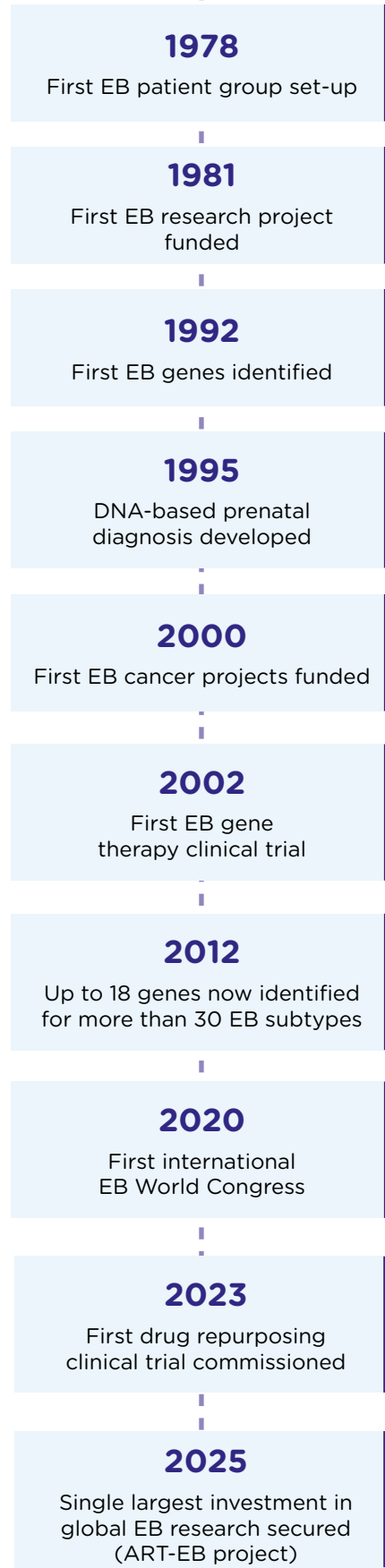
Our Journey



Finding effective treatments for every type of EB

DEBRA UK is the largest UK funder of EB research, and in the top 15 UK-based research funders across all diseases and conditions investing in global research. We have invested over £24m+ and been responsible, through funding pioneering research and working internationally, for establishing much of what is now known about EB.

We have an ambitious, patient-centred research strategy that drives us to fund science of the highest quality across the world, including prioritising investment in drug repurposing, to develop a treatment pipeline that will slow or stop the progression of EB.



- 45+** Years funding EB research
- 160** Research projects
- 122** Researchers
- 52** Research institutions
- 14** Countries



What is EB?



Skin as fragile as a butterfly's wings

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 wings, it 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 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.



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 which is rare.



Symptoms and complications

Symptoms vary and range in severity depending on the type of EB. 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, it 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 of EB 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.



No cures

There are an estimated 5,000 people 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.

Corporate Partnerships



Our corporate partners play a vital role in helping us #StopThePainofEB.

We pride ourselves on offering mutually beneficial partnerships that have a positive impact on your company and staff, as well as our work supporting the EB community, as we strive to find the treatments that will ensure no one suffers with EB.

A partnership with DEBRA UK is a great way to demonstrate and truly embed your business's corporate social responsibility strategy - this includes the causes you are committed to, the values you want to promote, and the overall impact your organisation has on the wider community. If executed correctly, a business's CSR strategy will positively impact its reputation, help attract the best talent, improve employee engagement, and even lead to increased profits.



Clifford Chance has a long-standing relationship supporting DEBRA UK. I became their relationship contact in 2009 and since then have really enjoyed arranging regular bake sales in our offices and in more recent times taking part in 100km challenge and their Fight Night.

What makes DEBRA UK stand out to me is the personal stories, hearing from the sufferers about what EB means for them and how much of a difference DEBRA UK can make to their lives.

Kelly Firmin

Practice Assistant, Clifford Chance

Help us change lives

Corporate giving primarily will make a demonstrable, tangible difference by providing key funds for four areas that are vital to people living with EB.



Research

Pioneering research to find effective treatments for every type of EB, including drug repurposing.



Community Support Team

Care and support to improve the quality of life for individuals and families living with EB.



Respite

Through member access to heavily subsidised DEBRA holiday homes across the UK.



Healthcare

DEBRA UK funds EB partnerships with the NHS.

Why now?

"We live in an era of enormous scientific and medical innovation, which has created real opportunity for breakthroughs in EB research into future treatments, but these treatments are needed now; patients living with EB can't wait, they need effective control of symptoms and a better quality of life. With your help we can accelerate the pace and breadth of our research into treatments and together we can achieve this ambitious and essential journey to change lives and end suffering."

Tony Byrne
CEO, DEBRA UK





EB Community



I do
sometimes
think “why me”.

I get up, I go to the toilet and even that is a struggle, I can't dress myself. I am at my worst when I am having my bandages changed, the pain is unbearable, it makes me scream and I must take strong painkillers every day.

I get blisters on the inside, on my oesophagus where a balloon is inserted down my throat and blown up whilst I am under general anaesthetic to get my throat back to its normal width. I still have fingers, but the skin has formed over them. I do wonder what I would be doing if I didn't have EB but there is no point wondering when this is what life has dealt me. **I do sometimes think “why me” though.**

Isla, 17 from the Scottish Highlands
Living with Recessive Dystrophic EB (RDEB)



How you can get involved



Charity of choice

Create a truly transformational partnership with us by implementing a bespoke programme that works for you.



Employee fundraising

We have a variety of runs and challenges for you to take part in.



Match funding

Encourage your employees to support DEBRA UK by boosting their fundraising efforts through match funding.



Payroll giving

Donating to DEBRA UK through your pay is the most tax-efficient way to make a difference to the lives of people with EB.



Cause related marketing

Align your business, service or product with DEBRA UK and mutually increase awareness, drive sales and show social responsibility.



Volunteering opportunities and pro bono work

Encourage your employees to give their time to DEBRA UK.



Attend our events

Our fundraising events help raise awareness and provide our supporters with an exciting opportunity to network.



Sponsorship

Build your brand awareness and visibility by sponsoring our events.



Retail challenge

Ignite the fire of teamwork within your talented workforce! Take over two or more DEBRA UK stores for the day and 'battle' to win a trophy.



Store donations

Your donations can make a huge difference to people with EB.



DEBRA UK Charity Partner, Tektronix, take on the Retail Challenge!

Tektronix, a long-term supporter and charity partner of DEBRA UK, took on the retail challenge at our Crowthorne and Martins Heron charity shops. Two teams took over the stores and battled to win a trophy, one for those with the largest increase in sales, and one for the highest amount of fundraising.

"We had an amazing experience and thoroughly enjoyed our time supporting DEBRA UK. I'd highly recommend any company to take part in a retail challenge, as a way of both supporting DEBRA UK and bringing the team together".

[Find out more on how to get involved](#)



How DEBRA UK can support you



Help meet your CSR or ESG targets



Improve staff morale



Positive PR



Teambuilding activities



Networking opportunities



Tailored fundraising advice

Support for today

The DEBRA UK community support team provide lifelong support for EB families and carers. Their aim is to empower and advocate, ensuring that our members can access the full range of vital support services available and the care they need.

They offer a personal, individualised support service and information and guidance from benefits and finance to bereavement support, social opportunities, respite, and advocacy. They engage with organisations from schools to new employers, to ease major life transitions. They connect the EB community, creating virtual and in-person opportunities to share experiences and gain peer-to-peer support, access specialist expertise and information and contribute to the development of services for EB.

They also work alongside clinicians and healthcare professionals to provide complementary social care and emotional support for people living with all types of EB.



Effective drug treatments for tomorrow

“Patients with EB are suffering from devastating symptoms - pain, itch, cancer, wounds that require hours of dressings, and blisters that can lead to infection. The EB community is at the heart of all we do. Their voices drive our commitment to do more to increase our programme of world-class research into life changing treatments, and to make what was once impossible, possible.

We want a future with treatments that end the everyday challenges, the pain and suffering that people with EB face. We are calling on the wider scientific community, corporate supporters, and our industry partners to come and join us on our journey to accelerate life changing treatments in EB and to save lives.”

Dr Sagair Hussain, DEBRA UK Director of Research





Case Study



Peninsula Group, DEBRA UK Charity Partner

Peninsula Group, a leading Manchester-based global employment law and HR consultancy agreed a 3-year charity partnership with DEBRA UK in 2024.

Recommendations for new charity partners were encouraged from colleagues across the Peninsula group of companies and DEBRA UK was chosen as one of three charity partners from the 500+ charities nominated.

In this exciting new charity partnership, Peninsula Group have committed to raise a minimum of £1 million over the next 3 years to support DEBRA UK and help make a difference for people living with all types of EB.

Colleagues from across the Peninsula Group will be taking part in multiple fundraising activities throughout the partnership, starting with the London Marathon in April 2024, as well other challenge events. Other ways that the team at Peninsula have committed to support DEBRA UK include payroll giving, where all colleague deductions will be matched pound for pound by Peninsula corporate donations. They will also hold fundraising activities in the office, such as bake sales, raffles, and quizzes!



“

Following our successful partnership with Royal Manchester Children’s Hospital, I wanted to find out what causes our employees hold close to their hearts. After reading through hundreds of nominations, there were three causes that clearly stood out, so we’re delighted to make this commitment to them today.

I was absolutely blown away when we met with DEBRA UK CEO Tony Byrne and Vice President Graeme Souness CBE **at the scale of the need for support and the real difference that our partnership can make in the lives of people suffering from EB** - let me tell you, they really do suffer.”

Peter Done,
CEO and Founder at Peninsula Group



Corporate Partnerships

Please get in touch with Ann, Emma or Ruth to find out how our company could benefit by working with DEBRA UK and the difference your support could make to people living with EB.



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DEBRA UK Royal Patron - HRH The Duchess of Edinburgh, GCVO
DEBRA UK President - Simon Weston CBE

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