The Butterfly Effect

Summer 2026

Your kindness in action – how you're helping cool the pain of EB

Did you know?

Debra is the only charity in Ireland supporting people living with EB. Your support ensures that no one in Ireland has to face the challenges of EB alone.

Thanks to your support, a new self-cooling insole is bringing life-changing hope to families like Geraldine's.

"You are wearing your shoes, trying to get around, but no one can comprehend how painful every step is. When you say you have blisters, people dismiss them... they do not understand how painful the blisters are from EB simplex. But knowing that wonderful donors are backing this project gives us real hope."
Geraldine Wall

For Geraldine, living with EB simplex is a constant battle with an invisible disability. It was only when her daughter was diagnosed that Geradine discovered she also had EB.

She says "In general, I have a day-to-day routine that works for me to minimise the blisters. I keep steroid ointment, plasters, and needles to pop blisters available at all times. But life pauses when I have a severe outbreak. I don't feel well enough to leave the house, as it is emotionally and physically draining. Even getting upstairs to my bedroom would make me cry, thinking of the pain and discomfort. People often dismiss it to be like the odd blistered you'd get from new shoes. But it's so much more debilitating."

But today, your generosity is bringing real hope and relief directly into the lives of people, like Geraldine, living with EB. Anyone with EB knows that hot sweating feet increases blistering and makes the pain so much worse.

Therefore, keeping feet cool is absolutely vital to prevent blisters from forming in the first place.

Thanks to caring and compassionate people like you, Debra were able to fund a promising study led by Dr Linzi Ryan at Maynooth University. And now thanks to you Dr Linzi and her research team have successfully proved that a specially structured, flexible insole can pump and circulate cooling fluid under the normal pressure of walking.

Your continued support will help take these insoles from lab prototypes to inside the shoes of those like Geraldine, looking to ease the pain of their EB on a daily basis. When Geraldine looks at what the Maynooth University project can make possible, it fills her with hope.

Geraldine's wish:
"I would love someday to be able to walk part of the Camino. How achievable it is, I don't know, but if this insole project delivers what I am hoping it will, your kindness will have put me one step closer to considering it."

Every gift you send brings us a step closer to ending the pain of EB.

The EB Butterfly Review: How you are helping put it into action

Since the launch of the EB Butterfly Review last October, Debra has been working hard to ensure its recommendations are put into practice. These goals were determined by the lived experience of people in the EB community. They told us what needs to change, and thanks to your support, we are pushing for that change in both medical and political circles.

The review outlines five key areas where the community is demanding progress:

- **Better coordinated community care.**
- **Properly resourced teams** at specialist hospitals and for community outreach.
- **Financial relief**, including a national bandage scheme.
- **Greater education and awareness** of EB.
- **A smoother transition** from paediatric to adult services.

Three big projects are already underway thanks to you

Because of you, we have not waited to get started. Your support has already put three major projects into motion to address these calls for action:

1. **The e-learning programme:** We are developing specialised e-learning resources to educate healthcare professionals across the country. This ensures that when a person with EB walks into a hospital, they are met with expert care and true understanding.
2. **The cross-party group:** We have established a dedicated group in the Oireachtas. By bringing together politicians from all sides, we are keeping EB at the heart of the political conversation and ensuring our community's voices are heard where decisions are made.
3. **The national bandage scheme review:** We are currently undertaking a comprehensive review to build a strong and robust case for a national scheme. Families have told us in no uncertain terms about the staggering financial strain that the cost of bandages puts on them. It is only because of you that we can gather the evidence needed to fight for this essential financial relief.

You understand that the little things can make a big difference

Your kindness is providing daily comfort to those who need it most

Did you know?

Last year you made it possible for us to complete 84 home visits for people with EB.

When you live with EB even the smallest tasks or venturing beyond your front door can be a challenge. The constant pain, the hours required for bandaging, and the cycle of medical appointments are exhausting for both patients and their families.

But thanks to you, people living with EB and their primary carers can access Debra's Special Circumstances Grant.

Through this grant, you provide the practical items that take the pressure off and make the hardest days a little easier to bear. When something at home breaks unexpectedly, your support is there to relieve the sudden financial stress.

It can be as simple as:

- **A comfy chair** to sink into after a long day of struggling to get from A to B.
- **A fan** to help cool and soothe fragile skin during hot weather.
- **A footstool** to rest blistered feet and offer the relief that makes the next day feel possible.

Because of you, we can respond quickly to real and immediate needs. While these supports might seem simple from the outside, they make a world of difference to someone's daily comfort and health.

Thank you for providing the small things that mean everything to someone living with EB.

You're pushing for progress

Because of you, we are not just providing comfort for today. We are calling for a better tomorrow. You are giving us the tools to push for a healthcare system that truly recognises and supports the needs of everyone living with EB.

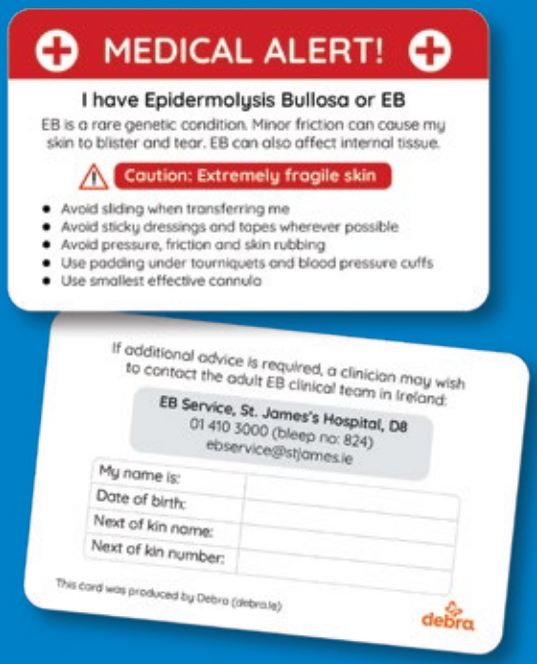
Thank you for standing with us and for being the force behind the push for change.

Did you know?

Because of you, Debra Family Support is a lifeline for families across Ireland. Your kindness provides everything from a listening ear to help with starting school. From emotional support to financial grants, you're helping families all over Ireland.

Did you know?

So far you've helped 79 people living with EB receive a vital Medical Alert Card. These cards inform medical staff about the fragility of EB skin and provide emergency contacts, giving patients and their families peace of mind when it is needed most.



You're helping fast-track solutions for people with EB

Thanks to you, researchers are discovering how an eczema drug may ease itching, blistering and pain for people with EB

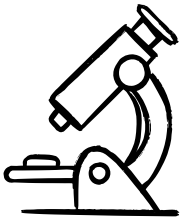
Further from home, you are also funding the groundbreaking research of Professor Amy Paller at Northwestern University, USA. Her team is pioneering drug repurposing by testing whether existing, safe medicines can be used to treat EB.

Because repurposing skips the years of development required for new drugs, your support could bring relief to families much faster. Professor Paller is currently testing if a common eczema medication can significantly reduce the intense itching, blistering, and pain that define life with EB.

You are the reason this progress is possible

It is only thanks to you that Debra has been able to fund these groundbreaking projects. These are just two examples of the vital research and progress you're making possible.

You're bringing us closer to the day when everyone in the EB community can live a life free from relentless pain. Let's keep pushing for that future.



Thank you for helping raise the voices of people with EB in Ireland on the global stage

Your support is making sure Debra is at the heart of the global fight for an EB cure

In February this year some of the Debra team joined over 520 delegates, from 35 countries, at the EB Congress 2026, in Brazil. Jimmy, Debra's CEO along with Ale (Head of Communications) and Deirdre (Head of Family Support) packed their bags and headed off to São Paulo. This gathering provided an invaluable chance to share and exchange ideas with organisations from all over the world.

These conferences serve as a powerful reminder that the EB community is truly global. Across different languages and healthcare systems, we are united by a single mission to find effective treatments and ensure they are accessible to everyone.

Hearing the voices of families and experts together reinforces how every Debra organisation is working in unison to share knowledge and stand stronger than any of us could alone.

By coming together, we strengthen our pursuit of shared goals, including driving progress, developing new treatments, and reaching the ultimate goal of finding a cure.

You're ensuring that the Irish EB experience contributes to a worldwide movement toward better care.

Did you know?

Debra's Inside Out campaign is going global. Debras in Canada, Colombia, Czechia, France and Italy, amongst others, are all making plans to run their own version of the event.

Ale, Head of Communications

Insights from our team in São Paulo

Our impact reaches far beyond our borders

"It was so powerful to see just how big and strong the EB community is around the globe. Our experiences are both unique and shared, reminding us of how much we've achieved and how much more there is still to do. Even more inspiring was seeing the ideas and approaches coming from the EB community in Ireland shaping care and support in other countries. It's a reminder that together, our impact reaches far beyond our own borders."

Ale, Head of Communications, Debra

Stronger together for the community at home

"Traveling to conferences allows us to connect and share with our international partners in a way that only these gatherings make possible. We get to sit and listen to EB communities and professionals from around the world, learning from them while also sharing what we are doing in Ireland. From my 19 years of experience in this field, just three days with this incredibly talented group energise me to keep striving to do better for the EB community here at home. We are stronger together."

Deirdre, Head of Family Support, Debra

You're helping make space for people with EB

How your support is helping us fight for fair disability parking access

Whenever barriers exist that hold back people affected by EB, we take action. Your support is helping us challenge unfair rules and ensure the community's voice reaches the heart of government.

Demanding fair parking access

This year, we are using our platform to tackle a major challenge identified by the EB Butterfly Review: disability parking. Currently, the rules for getting a Blue Badge in Ireland are far too strict. Many people living with the constant pain of EB simply do not qualify. **We are determined to change this with the help of all those who signed our Blue Badge petition. Our aim together is to ensure that people with EB are seen and get the supports they need to help them live their lives with a little more ease.**

Why your support matters!

Disability parking is not a "nice to have". When you live with EB, even a short walk can cause blisters and serious pain. The current rules fail to recognise this reality. A person might be able to walk 150 metres, but if doing so leaves them wounded and in need of bandages, then they should qualify for a badge.

Your support has given us the ability to put this issue directly onto the Minister for Transport's desk.

Did you know?

Thanks to your support last year we provided 20 people living with EB with the driving lessons they needed to increase their independence.

"For me, walking is not something I can take for granted. Even a short distance can cause blisters and pain that lasts for days. Disability parking is an essential support that allows me to access healthcare and work with less risk."

Amanda Nugent, living with EB simplex

Your action helps us to take action

Advocacy plays a vital role in Debra. Part of our strategy is to advocate for the government to put measures in place so that people living with EB are heard and seen, and ultimately supported. With that these supports are then within the government infrastructure and should remain there for all those who may need them down the line.

Thank you for standing beside all those living with EB and for being the force behind the push for better.

Would you like to trek amongst the butterflies in Italy? Then read on...

Debra is very excited to be undertaking its first **Alpine Butterfly Trek** in **June 2027**. Taking place in the Italian Alps in the Valle d'Aosta region for one unforgettable week.

Places will be very limited, so we recommend you get in touch once we launch the trek in a couple of weeks. Keep an eye on our website for details soon. In the meantime if you'd like to register interest or get information please contact susan.woodcock@debra.ie

Community fundraising

Climbing mountains and jumping off buildings – there is no shortage of dedication when it comes to our wonderful donors doing wonderful things for all those living with EB in Ireland. Here is just a snippet of what's been done over the last few months, and what's coming down the line. Thank you to everyone from the bottom of our hearts.

This year, Inside Out is going global!

Our Inside Out campaign asks people to wear clothing inside out for a day. This is to show how even a seam on a piece of clothing can cause painful blistering to those living with EB.

Thanks to you, last year's campaign was a huge success. You helped to raise awareness throughout your communities about EB. And as a result Canada, Colombia, Croatia, Czechia, France and Italy (to name but a few!) will be going Inside Out this year too! Keep an eye out for the launch coming very soon.

Polo puts the fun into fundraising!

Join us for an elegant afternoon at the historic All-Ireland Polo Club.

Set against the timeless backdrop of the Phoenix Park, this event offers a unique opportunity to enjoy the skill and speed of world-class polo in exceptional company, all while raising vital funds for those living with EB in Ireland.

Tickets are limited and priced at €150, contact louise.delahunty@debra.ie for more information.

Steps were taken on the Kerry Challenge – approximately 54,000 of them!

Massive thanks to everyone who took part in our Kerry Challenge, covering around 40km over two sunny days in May. An absolutely staggering €150,000 was raised by everyone who attended.

Registration for 2027 will open in the Autumn. In the meantime please feel free to contact susan.woodcock@debra.ie to register your interest.

The Nugent Family feel seen – thanks to you!

Massive thanks to you and everyone who responded so graciously to our recent appeal featuring Amanda Nugent and her son Ruaidhrí. Their story touched many hearts, and we are so grateful to them for sharing it with us.

Kerry Challenge participants, 2026.

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