

Your gifts provide **care** and **hope** to families struggling with EB

Maria and her mum are doing well – thanks to you

You might remember Maria from our Christmas raffle. This darling little girl was born with a severe form of EB. At the start, her mum Gunita was overwhelmed. There was so much she had to know simply to care for her baby daughter!

Because of EB, Maria's skin is so fragile, it can tear and blister at the slightest touch, leaving painful open wounds and sores all over her body, both internally and externally.

But you were there for

Gunita. Your support meant she had somewhere to turn. And encouragement, information, and advocacy when she needed it.

“ Maria is very much looking forward to starting primary school in September ”

Because of your kindness, DEBRA Ireland has supported Gunita throughout this journey. Eve, from our patient support team, checks in on her often and

is always a phone call away.

Maria will be 5 this August. She is a gorgeous little girl who is always smiling. She loves to draw and adores Peppa Pig and her big brother Mark. Maria is very much looking forward to starting primary school in September. Gunita mentioned to Eve this week that they were going to look at getting her school uniform organised.

Maria is just like any other 4-year-old. But there's no hiding from EB. Her care requires three



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bandage changes each week, to prevent her delicate skin from becoming infected. The process is excruciating for little Maria. And it breaks Gunita's heart to see her child suffer. Maria doesn't completely understand why, but the care is absolutely necessary.

Right now, there is no cure for EB. But, because of you, there is hope in research. (You can read

more about the groundbreaking research below). DEBRA Ireland receives no guaranteed state funding. So we must rely on caring people like you to ensure this vital research continues.

With your help, we can continue to search for new treatments and a cure. Your care means we can also keep giving our EB families all the support

possible.

Because of you, beautiful children like Maria can hope to someday experience a life without pain. Thank you so much for all you do!



We asked for your emergency help – and you answered with love

Recently, we came to you with an urgent request. The coronavirus crisis was making the already difficult lives of our EB families that much harder. You responded with so much love, to the hard road our smallest EB heroes must walk!

Because of you, we were able to provide direct help to our EB families. We have heard from so many of them, full of gratitude for you and your generosity.

We want to tell you how deeply moved we have been by your response. Your kindness – to us and to the families – has been overwhelming. Because of you, already burdened families had the support they desperately needed.



“Everyday is a challenge for our families. The virus and lockdown made the situation so much worse. But our wonderful supporters came through! The impact for our patients is beyond words. We are so grateful! 🌈”
Eve, Patient Support

Thank you so much!

Exciting research breakthrough that you made possible

New gene therapy holds promise as a treatment for EB

RDEB, or Recessive Dystrophic Epidermolysis Bullosa, is caused by a fault in the gene that makes collagen. Collagen is what binds our layers of skin together. For these patients, the slightest injury can cause painful blisters. Here in Ireland, about 300 people are affected with EB.

Patients with severe EB, like Maria Spirge, have lived with pain for their entire lives. But now, research holds the promise of a treatment – and possibly a cure – for this terrible condition.

Researchers at University College Dublin are working on a potential treatment using gene

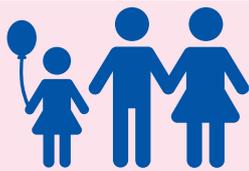
therapy. Pioneered by Professor Wenxin Wang at UCD, research like this is possible because of your support for DEBRA.

The potential impact of this treatment for EB patients would be simply huge. It would require no surgery; no painful skin-grafts. The gel could simply be

Our wish for EB families

Could you give one of these items to help families with EB?

€35



Can provide one hour of family support time for a family living with EB

€70



Could offer 2 hours with the EB Nurse for wound and health assessment

€100



Would provide specialised baby incubator mattress for newborn babies with EB

€150



You could provide one week of accommodation for a family if their child must be hospitalised

€360



Would cover one full bandage change for a child with EB

If you are able to help, your gift – of any size – will be used to help our families with EB. Please use the form we've enclosed... and thank you for your kindness!

Understanding EB

Did you know?

Epidermolysis bullosa (EB) is a family of rare genetic disorders that affect the skin. People with EB are born without the necessary protein that binds their skin layers together. Their skin is as fragile as the wings of a butterfly, and easily tears apart, blisters, and shears off. This can lead to severe pain, disfigurement, and wounds that may never heal.



EB can affect every part of the body, inside and out.



Because their skin is so delicate, skin cancer is a terrible risk.



Our eldest patient living with Dystrophic EB (Emma) turned 36 last month.



No matter what a parent does, EB is always in control. No painful bandage change will make it better.



Your generous support means more than you can know!

applied to the skin.

Dr. Jonathan O'Keeffe Ahern, one of the researchers, explains, "Rather like using a postcode, we can send in a genetic scissors to cut out the non-functioning part of a gene. And then the repaired cells know to fill that space and permanently repair the gene."

This exciting research, like so much research to understand and find cures for EB, is still in its

early stages. But we have great hope that someday, people born with EB will not have to live in pain.

Your generosity and caring are helping us make strides against EB, while caring for those who are suffering from the condition.

Thank you for your compassionate heart!



From left: Dr Irene Lara-Saez, Dr Sinead Hickey, and Dr Jonathan O'Keeffe Ahern

Our deepest thanks to our monthly supporters

You gift is a lifeline of caring support for EB families

When parents first learn that their child has EB, they're afraid. How can they grasp all they need to know to protect their new baby?

One thing they know for certain: they will do all they possibly can for their child. There is no hurdle too high, no challenge too big, to prevent them from doing all they can for their baby. They also know that they will need a great deal of help.

And there you are.

Your monthly gift is an island of certainty in a river of unknowns. Your constant kindness means emotional and medical support. And it helps to fund the critical research that will lead to the treatments their precious child needs.

For your monthly gift that gives our families hope and comfort from their daily struggles with EB, we cannot thank you enough!

Would you like to become a monthly supporter? You would be bringing steadfast support to people with EB and their families. You would also be helping us achieve the most immeasurably valuable gift for our patients – a cure.

To join today, just use the back of your reply form enclosed.

Thank you

Emma's 36 Challenge – 36k to celebrate her 36th birthday in June

My name is Emma, I am the patient ambassador for DEBRA Ireland, and I have EB. I have wounds over 80% of my body; I am in constant pain, and on more medication than I care to say.

I turned 36 on 25th June. To mark the occasion I took on an unprecedented challenge. With the help of the amazing Georgina, I "walked" 36kms in my wheelchair.

Although I can't walk, for me this was an endurance test of pain. Could I endure the ramps, the bumps, the potholes, a pebble on the road? Would I be able to get through the 36kms with all the pain I have?

With support from people like you, and our friends Colin Farrell, Johnny Sexton and Ray D'Arcy, I could, and I did! Colin and Johnny joined in – both cycling 36km to celebrate my success.

And it was all to support DEBRA Ireland. Without them we wouldn't be able to fight EB. We wouldn't be able to get nurses, research, funding, and resources. They deserve all the help we can give them!



Would you like to help Emma with her challenge? You can contribute here:

<https://www.justgiving.com/fundraising/emma-fogarty>

We will update you, of course, on Emma's challenge. And thank you, for making all the challenges of life with EB a little easier to bear for our families!