



Emma and her mother

## What your kindness does when a warm night means agony

### Keeping cool is critical for people living with severe EB

**For someone with EB, even sleep can be a torment.**

**M**ost people with severe EB are covered in multiple layers of dressings.

Bandages are their protection and their only form of treatment, as an antibiotic is applied with the first layer. Their bandages serve as a barrier to infection that their own skin can't provide.

Sleeping means long periods in the same position, putting pressure on particular areas. Most of us shift in our sleep. But for people with EB, that sustained pressure is enough to result in intense wounding.

*Emma described it.*

*"If I need to turn during the night because of pain, I try to sit up. Then I use my arms to move my entire body and lift myself off the bed and into a new position.*

*All this to avoid causing any rubbing and worse wounds."*

Even in the mildest temperatures, sleep covered in bandages is hard. But for someone with severe EB, a hot sleepless night can result in more painful wounds.

So you can imagine how hard this summer's record-breaking heat wave was. Hot nights covered in layers of bandages

is miserable and painful. Our Family Support Team acted quickly, assessing our families' needs to ensure less pain, fewer extra bandage changes, and more sleep. For many, a specialist air-cooling unit made all the difference, keeping their extensive bandages cool so they could sleep without scratching and discomfort.

**Something that might seem small – like a cooling fan – is a tremendous help to our families. And your help makes it possible to take such good care of them. We're eternally grateful!**

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# New funding for important oral spray research!

Recently, DEBRA received a generous donation to support ongoing research into a healing oral spray for EB.

We're now able to push this project through. A treatment would have a significant impact on patients like Emma who suffer hugely with their mouths and throats.

For Emma, everyday activities such as eating and brushing teeth are painful. This spray could help people with EB eat again or increase the variety of foods they can consume.

Your support is so important to our research. Research will lead to dramatically reduced pain for Emma, Claudia, and thousands more who are suffering.

## Finding your balance when it's hard to find

### Claudia shares her mental health struggles to help others

Claudia Scanlon, the brave 17-year-old you might have seen on *The Late Late Show*, has been willing to share her struggles. "I hope my sharing may help people relate, not feel ashamed about struggling with their mental health, and ask for help. I want to spread awareness about mental health because it's so important."

It's hard being a teenager. But being a teenager with EB brings so much added challenge and distress. Claudia tries her best not to dwell on her situation. She says, "Live, love and laugh!"

"Mental health is severely affected when you have a disability. I struggle with depression and anxiety. It's a

constant up and down battle. I'm getting help, but it's hard. There are so many people who love you and want to help. But when mental health is low, we push people away. Then it feels as though nobody is there for you at all. It can be so isolating."

*"I want people to know they're not alone. If people are struggling, I hope they'll find a way reach out. They need to know they aren't alone, and people care. I care."*

While the physical pain of EB is often apparent, it takes its toll on the whole person. Your caring supports our families whatever their needs. **Thank you.**



# He cares for people with EB today

- and into the future

You can too!

Peter and his grandchildren



**P**eter has included DEBRA Ireland in his will. He feels strongly that this forever gift is a way he can leave something meaningful behind. He wants to continue to see others are looked after.

His daughter Michelle works at DEBRA. So in addition to monthly gifts, he often attends events and supports individual fundraisers.

*"I feel privileged to be able to support DEBRA's important work. I give what I can now, and I support DEBRA wherever I can. For me, leaving a gift in my will is my legacy – it means lasting support for patients and families living with EB – and that means so much."*

We're grateful for the extraordinary people who choose to leave a gift in their will to DEBRA Ireland. After you take care of your loved ones, even 1% of your estate will make a tremendous difference to people living with EB.



**If you're interested learning more about leaving a gift in your will, please ring Jayde Smith at 01 412 6924 or email [jayde@debraireland.org](mailto:jayde@debraireland.org). She would be happy to talk with you!**

## Recent research funding brings hope for the future



Researchers from the UCD Charles Institute of Dermatology, Dublin

**Research is the area EB patients most want us to invest in**, with wound-healing their highest priority.

With your help, our EB researchers are working on better ways to diagnose EB, understand how it affects the body, and develop therapies to treat and even cure it. Read on to learn about three recently funded projects.

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## Research, continued...

### You help us make the case for improved access to new treatments

A new research assistant will compare the cost and availability of EB treatments in Ireland and other European countries. This information will help persuade government to fund EB treatments.

### A new approach to inflammation and scarring

This project will look at whether combinations of 3 different drugs working together could be more effective in reducing inflammation and scarring in EB.

### You help ensure EB patients get the treatment they need

We're working to develop clinical practice guidelines for EB. These will provide the best information to help health professionals care for people with EB.

*Thank you! Your support for DEBRA will help reduce that suffering and improve the lives of EB patients not only in Ireland, but across the world.*

# Please welcome Kate to our Family Support Team

Kate



## Meet our newest Family Support Team member, Kate.

Our Family Support Team is at the heart of DEBRA's work. Deirdre and Eve have been with DEBRA for years and have developed deep relationships with our families. Now we welcome Kate.

*Kate says, "I think what's lovely about this team is that we literally do anything for our families."*

As part of Family Support, she's most looking forward to getting to know the families better. "They are just so lovely."

Already, she's seen the extraordinary way the team works with families. "People can pick up the phone at any time and they're completely listened to. They're treated with absolute care."

Our Family Support Team offers everything from help with housing to medical issues to supportive company and kindness.

**Your generous gifts are at work with our Family Support Team every day. Because of you, they are there to care for our families. Thank you!**