

## Two ways you can help people with EB like Jonny and Melissa

Send for this FREE Guide to making a will  
 Please tick this box if you would like a free copy of The Law Society's Guide to making a will.

Remembering us in your will.

Legacies are so important to DeBRA as they help us to plan ahead. We'd like to be able to thank you in person so please inform us if you have, or intend to, remember us in your will.

I have already remembered DeBRA in my will.

I intend to remember DeBRA in my will.

It is a:  pecuniary gift (set amount)  
 residuary gift (the rest of my estate after other gifts)

This information will be treated in strictest confidence and not disclosed to a third party.

Title \_\_\_\_\_

First name \_\_\_\_\_

Last name \_\_\_\_\_

Address \_\_\_\_\_

Postcode \_\_\_\_\_

Email address \_\_\_\_\_

(Optional) Telephone No \_\_\_\_\_

Please tick this box if you do NOT want to receive regular information about DeBRA

**THANK YOU!**

Please post to: DeBRA, FREEPOST, Crowthorne, Berks RG45 6ZZ

(no stamp needed but thanks for saving costs if you attach one.)

Or phone us on 01344 771961 – alternatively email [legacy@debra.org.uk](mailto:legacy@debra.org.uk)

Registered charity No. 1084958

## Findlay's story – a baby with EB

Parents Ian and Gillian Piggott had their first child, Findlay, in April 2003. He had EB and lived for just three months, covered in angry blisters and sores.

However, Gillian says:

*"Every day we remember the children's EB Nursing Service and DeBRA. Without their specialised medical care, Findlay would have had no quality of life. Knowing that people with EB have access to the same care and support as Findlay received keeps us buoyant in a world that for us will never be the same."*



Thank you for helping us to help people with EB and their families

Registered Charity Number 1084958

[www.debra.org.uk](http://www.debra.org.uk)



## Remember Jonny Kennedy?



Five thousand children and adults live with EB in the UK  
**Here's how to help them – and their families**

## Why make a will?

**Making a will is one of those things many people mean to do – but keep putting off! Or they've made one but don't get round to updating it. They think it's hassle – but in fact, making your will can be quite quick and easy – and puts everything under your control.**

Most people are surprised how enjoyable making their will can be – it's one of the few opportunities you have to give fairly large amounts to family, friends and favourite charities without actually taking out your cheque book. Apart from that, making a will is really important, because if you die without leaving a will the state directs who inherits, not you. So your friends, favourite charities and relatives may receive nothing.

It's also vital if you have children or dependents who may not be able to care for themselves, you have overseas property, you own a business or are not married to your partner. It's also essential to review it every five years or so. Details are in the FREE leaflet by The Law Society available from DeBRA on **01344 771961**

## Why DeBRA?

DeBRA is the only charity in the UK that provides care for people with EB and their families. Around five thousand people are affected by EB and without government funding, DeBRA relies on the support of individuals to fund its services and international research programmes.

The research programmes include genetic research into effective treatments and wound healing; over the last ten years DeBRA's research has resulted in big leaps forward in our understanding of EB and improvements in both the quality of life and life expectancy for people with this distressing condition.

Our services to people with EB and their families include:

- ▶ funding **ten travelling nurses** who visit newborn babies with EB in hospital, providing support and care to both babies and parents and visit children and adults with EB at their homes.
- ▶ a **welfare team** who ensure people with EB receive the specialist equipment, education, housing and benefits and also provide the all-important emotional support and respite holiday homes for people with EB.

EB – Epidermolysis Bullosa is a currently incurable genetic condition that causes blistering or shearing of the skin and the body's internal linings. There are three types of EB; at its most severe, babies with EB do not survive the condition. One severe type of EB is likely to cause fatal skin cancer.

EB is very painful and causes many complications for people living with the condition, often having to have blisters lanced and drained daily, taking up to three hours.

## How you can help

Jonny Kennedy, who was featured in the documentary *The Boy Whose Skin Fell Off*, had Recessive Dystrophic EB. DeBRA has embarked on a five year research programme at Barts and Royal London Hospitals to discover why people with Jonny's type of EB have a 70% likelihood of getting skin cancer.

Jonny's EB was severe; he was very disabled and lived in constant pain. However, Jonny worked tirelessly for DeBRA, increasing its profile and raising funds, in the desire that children born with EB today would not have to experience the pain and distress that he did.

Please help DeBRA make Jonny's dream come true by remembering us in your will.

It would help us a lot if you could return the form on the right to let us know about your gift so we can plan ahead. **Thank you!**

*Nine year old Melissa has EB. It takes Melissa's mother three hours to remove her bandages, lance her blisters, cut and shape bandages and help her get dressed. And they go through this painful procedure every morning.*



## Message from Anthea Turner



*I have supported DeBRA for a number of years, after meeting a little boy who lives with severe EB. This really is the most distressing condition I have seen and I believe it is vital that we do everything possible to ensure tomorrow's children do not have to suffer the agony of EB. Leaving money in your will to DeBRA will ensure that the charity can continue to give people with EB the best possible quality of life and fund research which will hopefully find a cure for this horrific condition. Please support DeBRA*

Leaving money to charities in your will can make sense because charitable gifts are exempt from Inheritance Tax – so it can actually reduce the tax to be paid from your estate. Why not discuss this with your solicitor or financial adviser?

Remembering DeBRA in your will can help us continue our crucial work. This is an example of what your gift could pay for:

|         |                                                                               |
|---------|-------------------------------------------------------------------------------|
| £1000   | could Provide a laptop computer to help a child with EB with their schoolwork |
| £3,000  | could maintain a DeBRA mobile home for respite breaks for a year              |
| £5000   | could fund information materials for affected families for six months         |
| £10,000 | could fund a specialist nurse for three months                                |
| £20,000 | could fund a research project for six months                                  |