

**Client:** DebRA  
**Source:** Hull Daily Mail (Female)  
**Date:** 30 March 2010  
**Page:** 6  
**Reach:** 47995  
**Size:** 1096cm2  
**Value:** 4822.4

# I'm running for baby Phoebe's future

## MY LIFE

For Claire Burcham, the London Marathon in April will be a challenge of a lifetime. **Laura Greendale** finds out more



**remember watching an emotional documentary on Channel 4 six years ago about a remarkable young man named Jonny Kennedy.**

The award-winning programme – entitled *The Boy Whose Skin Fell Off* – followed Jonny's personal journey and showed viewers how his life was affected by the genetic skin-blistering condition Epidermolysis Bullosa (EB).

When the film was first broadcast in March 2004, it attracted about five million viewers and helped to raise £500,000 for the EB charity DebRA.

Jonny passed away in his wheelchair in September 2003, while being filmed for the documentary, on a train returning from a meeting at 10 Downing Street with Cherie Blair.

It's clear I was not the only one who was touched by Jonny's story.

Claire Burcham of Beverley was also fascinated by Jonny's condition and has decided to take on the challenge of a lifetime to raise money for DebRA – to help those affected by the skin condition.

Claire, 35, will be taking part in the London Marathon next month with the hope of raising money and awareness of DebRA and its work.

"I'd set myself the goal of running the London Marathon

this year," said Claire, who owns Thrive Coaching, a personal and corporate coaching business.

"For years, I wanted to do it and last autumn I decided to give it a go.

"I'm not getting any younger and the race won't be getting easier, so I thought there was no better time than the present.

"I couldn't get a place through the ballot, so decided to run for a charity. I contacted DebRA and secured a place last October.

"I'd seen *The Boy Whose Skin Fell Off* when it was on television six years ago and, like a lot of people, his story stuck in my mind and I donated to DebRA after seeing the documentary.

"Since then, the charity has sent me regular newsletters about the work it is doing, so it seemed like a good choice."

In addition to Jonny's story, Claire was inspired to run the race by her old school friend, Nick Crowson.

Nick and his partner, Zoe Doyle, welcomed their new baby Phoebe into the world last October.

Only two hours after the birth, they realised something wasn't right with Phoebe's skin and a specialist EB nurse was sent to see her from Great Ormond Street Hospital, in London.

"After hearing about Jonny's condition, I didn't meet anyone who had EB until last October

when a friend of mine discovered

his daughter had it," said Claire.

"A lot of people can be a carrier of the gene and not realise. You don't have to have had the condition yourself and a lot of people have no idea.

"About 5,000 people in the UK suffer from EB, but the condition is relatively unknown."

When Claire contacted DebRA and was given a place for the marathon, she was put in touch with others who were running for the charity.

She knows of about 25 other people who are currently training, most of whom have friends or relatives with the condition.

"I knew next to nothing about the charity before I signed up to do the London Marathon," said Claire.

"A lot of people who are getting involved with the marathon are people who have a family member with EB.

"One of the reasons I wanted to support it was because, as a charity, it has quite a low profile and people don't know much about it.

"But it does some amazing work which should be recognised. It offers help and support to those with the condition and their families. They were great with Nick and Zoe when Phoebe arrived.

"Because it is a genetic condition, money raised for the charity can help with research

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and advances in medicine. This could help find a suitable treatment or perhaps even a cure one day."

Claire has embarked on a mammoth fundraising effort to collect £26,385 for the charity.

"A marathon is 26 miles 385 yards, so I decided to take up the challenge of raising £26,385 by finding 26,385 people to donate just £1 each," said Claire.

"Unfortunately, I don't have 26,385 friends, so am asking all of my business contacts, friends, relatives and family to spread the word among their contacts.

"It is going well so far and we have £2,000 already. I have given 70 sponsorship forms out to family and friends who are going to raise money on my behalf.

"My friends Nick and Zoe live in Lincolnshire and a group of mums who live near them are

doing a triathlon in the summer.

"They got in touch with me and told me the money they raise they will put in my pot, which was fantastic news."

Claire has run a few half marathons and has taken part on the Great North Run a couple of times but this will be her biggest challenge yet.

"I've been training for a while but the bad weather we had in January held me up a bit," she said.

"I've kicked on in the past couple of months and have done the East Hull 20-mile run so I'm getting there slowly."

## Charity's work aims to find a cure for rare, genetic skin condition

**EPIDERMOLYSIS Bullosa (EB)** is a rare genetic condition which causes the skin to blister and shear at the slightest touch, or even spontaneously.

EB has a number of distinct forms, at its mildest, blistering is confined to the hands and feet and, in more severe cases, the whole body is affected.

In its worst form, EB is fatal in infancy.

DebRA provides a team of nurses and social care staff to work directly with people affected by EB.

The charity also commissions world-leading research into the condition, with the aim of finding effective treatments and, ultimately, a cure.

A DebRA charity shop recently opened at Northpoint shopping centre, in Bransholme, Hull, to raise funds for people in the UK with the condition.

Claire wants to encourage everybody to get involved and donate £1 to help raise funds.

Claire is following in the footsteps of Hull man Graham Boanas who raised £119,000 for DebRA by walking across the River Humber and the River Mersey in 2006.

You can follow Claire's progress and get updates on her training and fundraising efforts by reading her regularly updated blog at:



**NO CURE:** Epidermolysis Bullosa is a rare genetic condition which causes the skin to blister and shear at the slightest touch.

[www.26385v1m.wordpress.com](http://www.26385v1m.wordpress.com)

If you can spare a £1, you can donate by visiting: [www.justgiving.com/claaires26385challenge](http://www.justgiving.com/claaires26385challenge)

For more information about DebRA, visit: [www.debra.org.uk](http://www.debra.org.uk)

“About 5,000 people in the UK suffer from the condition”

Claire Burcham



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**RUN FOR IT:** Claire Burcham of Beverley is prepared to suffer a few blisters during the London Marathon to help children whose lives are blighted by a skin condition which can leave their whole bodies blistered. **Picture:** Kate Woolhouse