

Raising funds and awareness for EB – the deadly skin condition affecting children

Four marathons in three days

Shane Willmoth, Engineering Contracts Manager, UK & Ireland at The Rezidor Hotel Group is pushing himself to the limit to raise funds for a little known skin condition called Epidermolysis Bullosa (EB). This is a group of genetic skin conditions that cause the skin to blister and tear at the slightest touch.



Will you help him to raise £10,000 for DEBRA, the charity committed to finding a cure?

Shane has signed not only for a 52km marathon hike on the Isle of Wight at the beginning of May but also will take on the fearsome Iceland Challenge in July.

In Iceland, Shane will be climbing the equivalent of Ben Nevis at a minimum speed of 4km per hour on the first day and the equivalent of Scafell Pike on the second day.

Shane says: "I wanted to do something to help children who suffer so much from EB, which is sometimes referred to as the worst condition you've never heard of. This small charity needs all the help it can get and the money I raise will help to underpin urgent research for a cure, hopefully in the next few years, if sufficient funds are found."

Shane learned about EB through a colleague at work, whose

four-year-old daughter suffers from one of the most severe types of the condition.

Those born with EB have skin so fragile they are called 'butterfly children' – their skin is quite simply as fragile as the wing of a butterfly.

Painful open wounds and sores form where this exceptionally fragile skin is damaged – in many cases, internal linings and organs are also affected. Complications as a result of secondary infection and extensive scarring are factors that people living with EB often have to face.

Tragically, certain types of EB can be fatal in infancy and others are severely life-limiting. We estimate that there are more than 5,000 people living with EB in the UK, and 500,000 worldwide.

There is currently no known cure for EB. At DEBRA, their work includes funding research to change this, while also supporting people living with EB to enhance their quality of life through improved healthcare, access to information and respite care.

Shane will be pushing himself through the pain barrier on the four marathons. He still suffers from the effects of a cliff fall 30 years ago that left him with a broken back, which means he has to wear a brace when needed. He also has to contend with knee problems that have already required six operations.

But he thinks the pain will be more than worth it, if he reaches the £10,000 target. In 2014 he completed a sponsored 100km walk through some very tough terrain in Vietnam, raising funds for Help4Heroes as well as completing the Isle of Wight coastal way challenge in the same year for the same charity.

SaveMoneyCutCarbon is supporting Shane and it would be great if you could do the same!

Shane's fundraising page is:

<https://give.everydayhero.com/uk/shane-willmoth>



DEBRA is the national charity that supports individuals and families affected by Epidermolysis Bullosa (EB) – a painful genetic skin blistering condition which, in the worst cases, can be fatal.