

Before Robin Hood's teen daughter died of a rare skin disease, writes **Joy Orpen**, she urged him to carry on fund-raising to find a cure

**'D**ear Santa, please could I have some skin that will not fall off." These are the heartbreaking words of a beautiful little girl who was born with a most terrible disease. Robin Hood, her father — whose mother is Irish — says although his wife Virginia had had an amniocentesis, which is a diagnostic test, while pregnant, they had no idea what was in store when their daughter, Alex, was born in Scotland in 1989.

Just hours after the birth, Virginia and Alex landed up in isolation in intensive care. The skin on baby Alex's tiny right foot was suddenly flaming red and raw. It was just the start of a hard journey.

"The more nurses touched her, the worse she became," Robin recalls. "When she was fed, her tongue bled. There was a perfect thumb print from one of the nurses on Alex's body."

No one knew what was causing the problem. "It was one of the worst times of my life," says Robin.

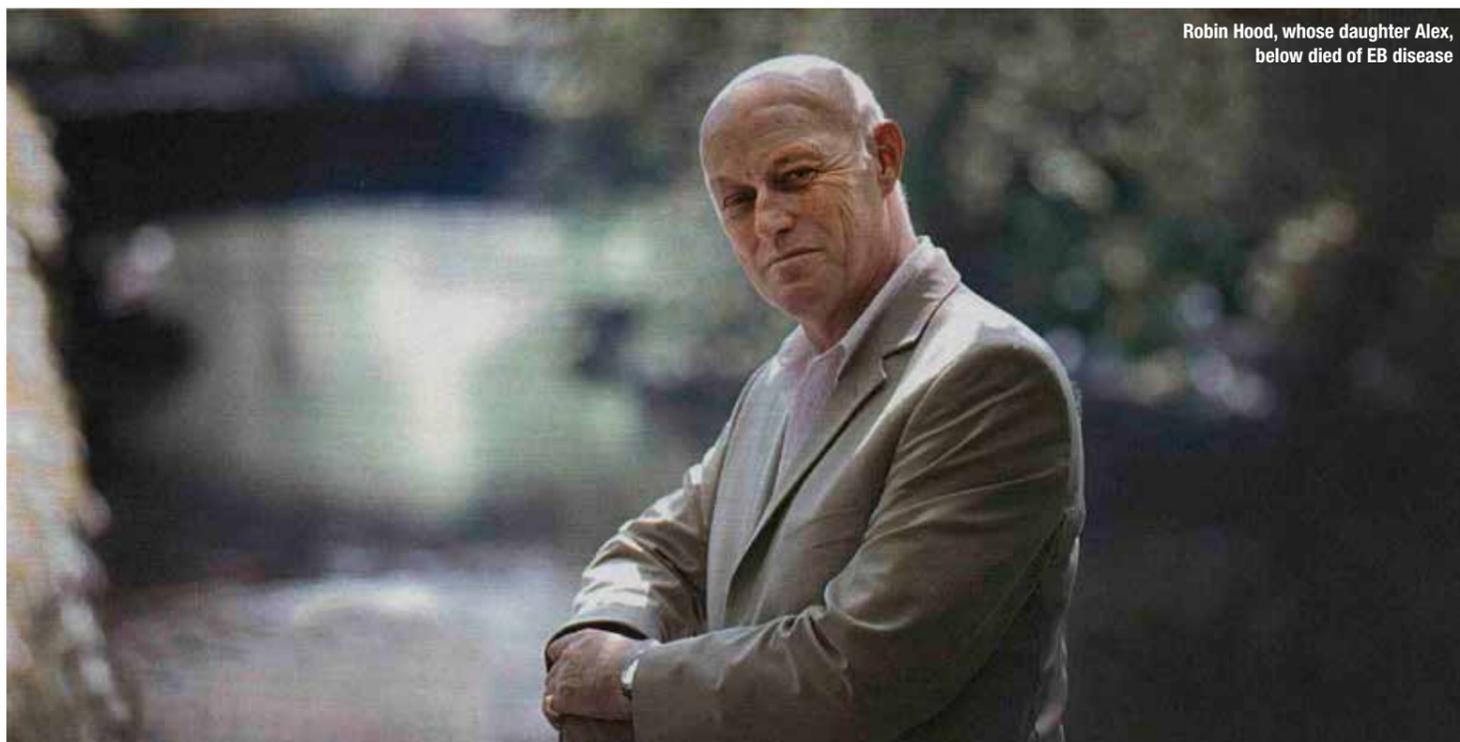
After six unbearable weeks, a dermatologist suggested the baby was suffering from a very severe form of epidermolysis bullosa (EB) and that she wouldn't see her first birthday.

EB covers a number of genetic disorders that occur when the skin is missing 'sticky' proteins that bind the layers together. The result is that the skin is immensely fragile — like a butterfly's wings — and can blister and tear very easily. "The pain is relentless, care is endless," says Robin.

The Hoods were put in touch with the Dystrophic Epidermolysis Bullosa Research Association (Debra) in the UK.

Shortly after, a specialist nurse was sent up to Scotland to examine Alex. "She explained that this was genetic and not contagious." A biopsy established that baby Alex was actually suffering from dystrophic EB, a less severe form of the disease. Her life expectancy was in the 30s. "I was hoping a cure would be found," says Robin.

The nurse showed Virginia how to care for her little girl. It was hugely time-consuming business. Every single morning, Virginia would have to lance at least 30 blisters — otherwise they caused further damage to the child's fragile skin.



Robin Hood, whose daughter Alex, below died of EB disease

## IT'S ALL FOR ALEX

She would spend up to three hours swaddling Alex in bandages. "She couldn't crawl because that would take the skin off her knees," Robin says. "And she couldn't eat normally — for her it was like eating broken glass — she'd get blisters on the tongue. I once saw her sneeze so hard the skin inside her nose came off."

So Alex was tube-fed directly into her stomach. And that worked well — she reached a normal weight for her height. But that brought its problems too. When she sat down, the weight caused the skin on her buttocks to become damaged and she had to wear pads infused with morphine paste. It was a living nightmare for the little girl. And yet she retained a great sense of humour and a wonderful smile.

What was she like? "If she were here now she would not want to talk about EB," says her dad. "She loved girlie things — she'd ask about your brightly coloured cardigan or where you got your earrings. She just wanted to be normal. And in spite of her problems, she got 11 GCSEs and three distinctions at art college. She also won a scholarship to university."



He recounts how an education officer offered her more time to write her examination papers when he saw her fused fingers, but Alex refused. She didn't want to be treated differently.

Then, in 1994, desperate to find a cure for this horrendous disease, Robin decided to work full-time on a voluntary basis for Debra UK, the national charity that supports individuals and families affected by EB. He began furiously fund-raising, leaving no stone unturned — no one was too important to be approached. It brought attention and much-needed funds to the cause. He has letters from Tony Blair, Bill Clinton, Queen Elizabeth, Prince Charles and boxing promoter Frank Warren, among many other notables. Currently, Sophie, the Countess of Wessex, Prince Edward's wife, is Debra UK's patron.

In 2009, Debra UK raised a staggering £9m for the charity, with a big chunk of that going into crucial research.

So far, 13 genes have been identified as responsible for EB. Robin says there are some very promising leads in relation to making skin stronger, using gene therapy and in preventing skin cancer, which is prevalent among EB sufferers.

"That is what killed my daughter," he says, still deeply troubled. "On Alex's 19th birthday we got a call from the hospital to **'When they told us her cancer had spread, I cried. Alex immediately said, 'Daddy, I'm going to die — not you!'**"

say her cancer, which had begun the previous year, had come back. She had had five operations to remove

all the skin on the upper part of her left leg.

"But then they discovered the cancer had spread to her vertebrae. When they told us, I started to cry. Alex immediately said, 'Daddy, I'm going to die — not you! Smile every day for the rest of your life and do not give up fund-raising for Debra.'" She left this world in July 2008.

But before her sad passing, she did a wonderful painting, expressly to raise funds for Debra. "Daddy, get as much money for this as you can," she urged Robin. "I don't want other people to suffer as much as I have."

Recently, the painting was sold at a Debra function for €3,400. The purchaser plans to keep it for a year; then put it up for sale again. When it has finally fetched €100,000 for Debra, it will be handed back to the family.

In 2010, Robin moved to Dublin to head up marketing for Debra Ireland. The 300 or so families in this country affected by EB can but benefit from his enthusiasm.

Brave Alex planned her own last, goodbye. There was a song by Puff Daddy and You Are My Sunshine was played at her request. No black was worn and Robin was warned to eject tearful mourners. Still, he could not hold back the tears when it came time to scattering his dear Alex's ashes into the loch near where she grew up, a Scottish piper by his side.

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**Robin Hood**  
Lochside of Ken Cottage  
Mosssdale • Castle Douglas DG7 2NQ  
Telephone: 01644 420619  
Robin Hood: 07503 963825  
robinjohnngerardhood@gmail.com