

# Hopes rise of end to girl's constant pain as skin cell therapy trials start

ALEX Hood struggles daily against excruciating pain. She takes morphine every four hours, she has lost the skin from large parts of her body and the fingers of her right hand are fused together.

But the 18-year-old, who suffers from epidermolysis bullosa (EB), is determined to become a designer and is described as an inspiration by people who meet her.

Alex's father, Robin, has promised his daughter a cure for the devastating skin condition by the time she is 20.

This promise could become a reality with news that trials of a new treatment are planned in Dundee.

"Alex's body is in a dreadful state," said Mr Hood, of Castle Douglas.

"She has no skin on her shoulders, buttocks or legs. Her toes are fused together and her right hand is fused. But despite everything she has passed her exams, she is now in college studying design and her teachers say she is an inspiration."

Scientists at Dundee University now hope to start trials on genetically altered skin within the next 18 months in efforts to cure people like Alex with EB.

Professor Irene Leigh, who is leading the research, said they hoped to use a particular kind of tissue engineering called

"ex vivo gene therapy" to treat patients.

"EB sufferers are born with a gene mutation which affects their skin," she said.

"We want to take their skin cells, replace or correct the gene, and graft them back on. Evidence has shown this corrected skin can help treat the patients' blisters and wounds."

But more funding is needed for the £3 million study to equip specialist labs at Ninewells Hospital in Dundee.

The EB research charity DebRA Scotland is leading fund-raising efforts.

Mr Hood, who founded the Scottish branch of DebRA, said he hoped Alex would be among the first to take part in the tests in Dundee.

"I have promised Alex that she will have a cure by the time she is 20 which is just a couple of years away. These trials could help me meet that promise. I do not want this condition to kill my daughter."

In January, the family were given the devastating news that Alex had a cancerous tumour on her thigh.

Surgery to remove the tumour found an even more serious tumour underneath and she had to have a large amount of skin and tissue removed.

"The constant scarring on the skin can cause cancer. We are lucky that



Alex Hood, 18, left, with her friend Madeleine Brampton, has the condition epidermolysis bullosa, which causes skin loss

this has been treated, but every day is still a battle for Alex. Despite this, she copes with such dignity and is determined this will not stop her doing what she wants to do."

Alex, who is also learning Japanese, is going to Japan later in the year, and is also planning to

study art and design at university.

"She is very artful and delicate with the fingers. Even when they are bandaged she is able to text on her mobile phone. She is very dexterous. She is just an amazing girl," Mr Hood said.

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## MORE INFO

[www.debra.org.uk/inyourregion/Scotland.htm](http://www.debra.org.uk/inyourregion/Scotland.htm)  
[www.dundee.ac.uk](http://www.dundee.ac.uk)

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## A PAINFUL AND RARE GENETIC CONDITION

Epidermolysis bullosa (EB) is a very rare genetic condition which leaves sufferers in severe pain.

The illness causes the skin and internal body linings to blister at the slightest knock or rub, causing painful, open wounds.

Around 5,000 people in the UK are thought to suffer from EB, including 400 in Scotland.

People with severe forms of EB have a high risk of developing skin cancers, shortening their lives.

While much progress has been made in identifying the genes relating to EB, there is no cure.

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