

'Butterfly' girl in fabric trial

A young girl suffering a rare condition which leaves her skin as fragile as a butterfly wing has been given hope in her search for a pain-free life.



Melissa Hughes wakes up in pain every morning

Melissa Hughes, from Stockport, Greater Manchester, is one of 5,000 people in the UK with Epidermolysis Bullosa (EB).

The genetic condition causes blisters on the skin and internal body linings at the slightest knock or rub.

Now the 11-year-old is helping to trial a new silk-like fabric which does not cause friction against the skin.

Melissa lives in constant pain as a result of her condition and just turning over in bed can cause up to 30 blisters on her body.

Her condition means sufferers have become known as butterfly children.

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Melissa Hughes

Every morning, she spends about three hours with her mother removing bandages, lancing blisters and applying fresh dressings.

"It hurts every morning really but sometimes it just hurts more than others," she told the BBC.

"I do have a tendency to be a bit grumpy in the morning but now I'm not half as grumpy as I used to be [since the start of the trial]."

Melissa is one of the faces of DebRA, a charity which helps support families of sufferers and is funding research into trying to find a cure.

The anti-friction fabric - called Parafricta - has been made into a pillow and because of its silky texture does not rub so much against her skin.

She now hopes that it can be made into bed sheets and even clothes.

On Sunday, DebRA is launching a television appeal on the BBC to raise awareness of the condition.