

I'll never give up my search for skin cure

Alex, 17, longing for day without any bandages



Smiling through... Alex is bandaged to stop her skin blistering.



Dad Robin in battle to help find a cure for Alex.

Exclusive by ANDREW TOLMIE

BUTTERFLY skin victim Alex Hood has vowed to step up her quest for a cure – after surviving a terrifying cancer scare.

The Scots teenager said the relief at being given the all-clear had inspired her even more to beat the agonising disease which has blighted her life. Brave Alex, 17, has become a role model for thousands of fellow sufferers around the world through her determination to overcome Epidermolysis Bullosa (EB) which makes her skin blister and tear at the slightest touch.

She has spent much of her life swathed in bandages and has lived constantly in the shadow of skin cancer, the disease which eventually kills most EB victims.

Two weeks ago her mother Virginia, 53, became alarmed by the worsening condition of Alex's skin. It was agreed Alex should be tested for cancer.

After an anxious wait for the test results, doctors at Great Ormond Street Hospital in London broke the news that Alex was all-clear.

Now she and her family are renewing their efforts to find a cure for EB. Alex said: "My test results were a massive relief and now I just want to get on with my life and help to raise awareness of EB."

Alex's father Robin, who is the director of EB charity DeBRA Scotland, said: "Waiting for the results of the test was hell. It was like waiting to be shot at dawn.

"Jonny Kennedy, who featured in the documentary 'The boy whose skin fell off', died of skin cancer. It is a death sentence for EB sufferers. Now I have to concentrate on staying positive and working day and night to find that cure and stop my daughter's pain before it is too late."

Despite having her hands constantly wrapped in bandages Alex is a talented artist, and amazes her proud family with works painted on her art and design course at college.

Mr Hood, from Kirkcudbright, wants his daughter to lead a normal life, and for that dream to come true gene therapy being pioneered by Scottish scientists will have to receive constant funding.

Professor Irwin McLean, of Ninewells Hospital in Dundee, is leading the research that could find a cure for EB. The programme, which has cured the disease in mice, has been pledged £1 million by DeBRA over the next three years. It works by correcting the faulty gene that causes EB so that healthy skin can be grown.

Professor McLean warns that a lot more time and money will have to be spent before the gene therapy is proven to work on humans. "I am confident that the gene therapy will work once we can test it," he said. "But there are a number of legal problems with testing gene therapies that slow the process down."

DeBRA, whose key supporters include Michael Portillo, president, model Nell McAndrew, vice-president, and golf legend Peter Alliss, believes clinical trials into effective treatments for EB are less than three years away. Around 200 children in Scotland suffer from the EB and many will die before they reach adulthood unless a cure can be found.

The constant blistering on their skin creates scar tissue which can cause fingers and toes to completely fuse together. The throat can also narrow, making eating almost impossible.

Most victims like Alex spend hours every day having their bandages replaced.

DeBRA
Working for a life free of pain

Scottish Office & National Shops Office

141b Quarry Street, Hamilton ML3 7DR

Tel: 01698 424210 • Fax: 01698 423654

email: info@debrascotland.fsnet.co.uk • www.debra.org.uk