

# Rest in peace Miss Butterfly

by Yvonne Bolouri Features Writer, The Sun, 16th August 2008

**A devastated dad plans to battle on for Scotland's butterfly children... even though his daughter died two week ago.**

Alex Hood lost her long and brave battle aged 19 against epidermolysis bullosa – a condition which makes sufferers' skin as fragile as a butterfly wing.

But it was skin cancer, triggered by damaged skin, which finally claimed Alex.

Devoted dad Robin, 52, said: "It was actually a relief when she passed away.

"She was fighting it, and even got out of bed at one point, despite her pain.

"She was scared and she didn't want to die on her own.

"But we were all with her and she was very peaceful at the end.

"Alex suffered so much. She wasn't expected to survive her childhood.

"But last year she managed to achieve 11 GCSEs and was accepted to study art at Leicester University and visited Japan."

But on her 19th birthday, in February this year, Alex received devastating news.

She was diagnosed with cancer for the **THIRD** time.

Robin said "I called to say happy birthday and she said, 'I don't want you to worry, but I've got bad news.' when she told me, I broke down, but Alex was very calm.

"She said, 'I don't want you to talk about it daddy – please just sing happy birthday to me'.

"I felt like such a failure.

"I had promised to find her a cure and felt that I had let her down.

"She said I hadn't and I needed to be strong for the thousands of other children who need help."

Four months ago, the cancer had spread to her spine and was working up to her neck.

Robin, from Dumfries, said: "It's an aggressive cancer which is linked to E.B.

"She had already had tumours cut from her thighs and buttocks.

"The skin on her left leg and left buttock had been sheared away.

"Now we were looking at Alex having around six months left to live.

"But she deteriorated so quickly in just two weeks, she didn't stand a chance.

"Alex was ready to go. She'd had enough.

"She was in hideous pain, until they gave her morphine.

"But Alex had lived all of her whole life in pain.

"She had to be wrapped in bandages every single day of her life.

"Just brushing lightly against her skin would peel it away.

"EB is just the most horrible condition.

"She couldn't eat or swallow like normal people, even going to the toilet was painful.

"Everything that we take for granted was torture for Alex."

Robin and his wife Virginia, 48, had

never heard of EB until Alex was born in Dumfries in 1989.

He said: "We were horrified. We discovered that we both carry the faulty gene which gives us a one-in-four chance of having a child with E.B.

## REFLECT

"For years we felt so guilty."

Four years later, Robin was involved in a car accident which was to change his life.

He said: "I was flat on my back for nine months, and had plenty of time to reflect on Alex's condition."

He began fundraising as a volunteer for charity DEBRA – which helps EB sufferers – using his accident compensation money to look after himself, Virginia, son Robin, then ten, and tot Alex. They even met Cherie Blair.

But his commitment knew no limits, and his workaholic approach sadly cost Robin his marriage.

He said: "Virginia went back to her home in Leamington Spa with Alex and young Robin, while I stayed here in Dumfries, fundraising.

"But I was always in close contact with them."

The weekend before Alex died, he had been invited to meet the Prime Minister's wife Sarah Brown at 10 Downing Street.

He said: "I'd just come out and was about to get the train back to Scotland when my son called and told me that Alex was in hospital in Leamington Spa, so I headed there.

"For the next three days I never left her side.

"My dog was about to have puppies and I'd promised Alex I would call one after her.

"Towards the end her breathing was very laboured and her heart was beating like a drum – so fast and so loudly.

"I could hear my son Robin soothing her and telling her to let go. I nodded off for a couple of hours and during that time her breathing eased and her heart slowed.

"When she passed over it was relief knowing that my darling daughter was at peace.

## MEMORY

"And at the same time as Alex passed away, the dog, gave birth to six puppies, one of which is now called Alex."

Robin plans to carry on his fundraising for DEBRA, in memory of Alex.

He has already increased the funding from £90,000 a year to more than £8million, with outstanding results. He said: "It would be unforgiveable if I didn't use all the knowledge and experience that I've acquired over the years."

Around 400 people in Scotland have E.B.

Researchers at Dundee University have already cured EB in mice and clinical trials are planned for humans.

Robin said: "They need on-going funding.

"They have to correct the faulty gene that causes EB so that healthy skin can



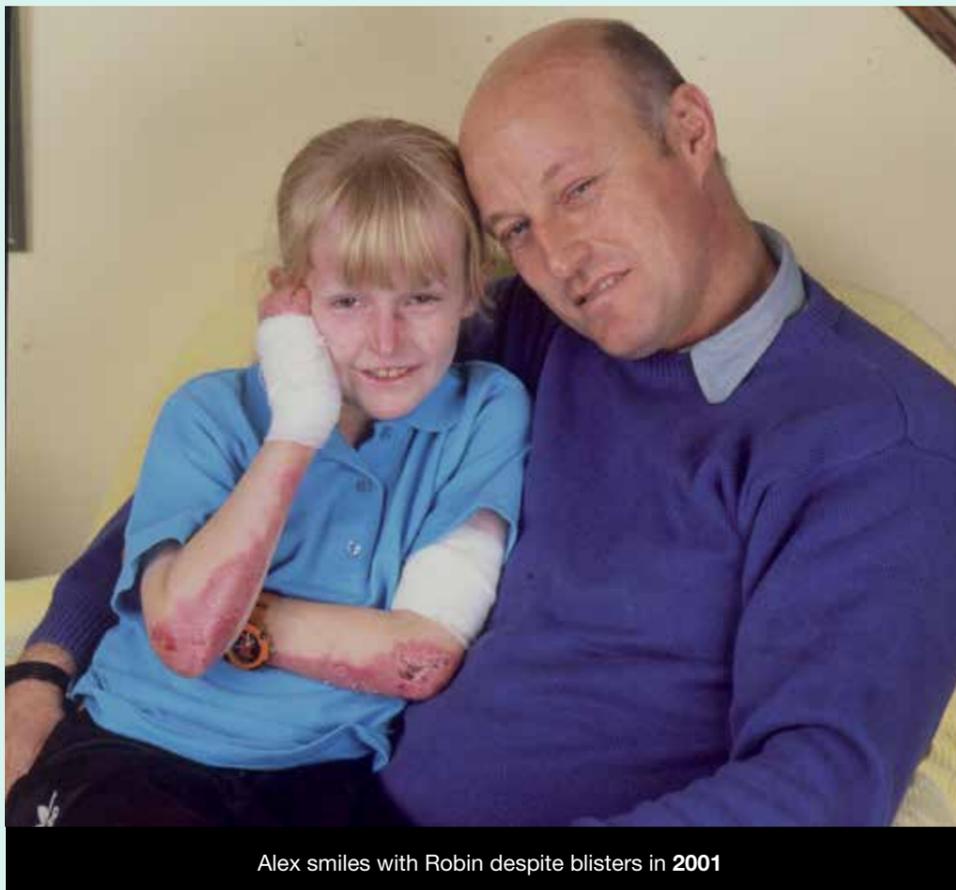
1993: Little Alex, aged four, was already in pain as she battled cruel skin disease



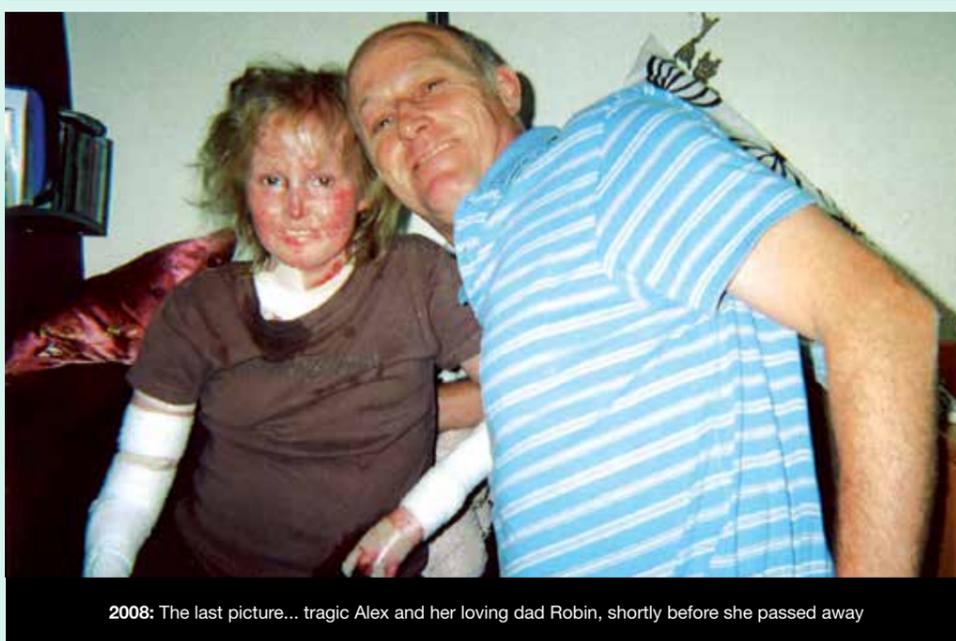
1999: Alex and Robin meet then PM's wife Cherie



2000: Brave girl plays though her arms are bandaged



Alex smiles with Robin despite blisters in 2001



2008: The last picture... tragic Alex and her loving dad Robin, shortly before she passed away

grow.

"And I'm optimistic that we're only a few years away from finding a cure." Two years ago, Alex appeared on the BBC1 documentary 'Lives Less Ordinary.'

Robin said: "It made a wonderful impact on raising awareness about this horrible disease, and raised £350,000 in

donations from viewers.

"Now I'm writing to the BBC to see if they will show it again. If enough people ask to see it, they will.

"I'll keep on raising funds and banging on doors until scientists find a cure.

"And I'm positive that it's just around the corner."