



Alex Hood pictured last September with her father Robin trying out her new car.

Skin cancer: Father pays tribute to kind and happy 19-year-old

Teenager Alex was smiling to the end

By Sara Fenton The Courier 1st August 2008

“Kind” and “always smiling” are among the tributes paid to a Lillington teenager who has died.

Former Warwickshire College student Alex Hood died on July 17 after losing her battle with skin cancer.

The 19-year-old, who also suffered from epidermolysis bullosa – which causes skin to blister and fall off – learned doctors were unable to cure her in April after a number of operations.

Describing Alex, her father Robin said: “She got the best out of every day even though she was in pain. She should be an example for healthy adults to follow.

“She was kind and managed to smile and care for people right until the end. She was always smiling.

“We will miss her greatly but we know she has gone to a place with no pain.”

More than 300 people attended Alex’s funeral at Oakley Wood Crematorium in Bishops Tachbrook on July 25.

The ceremony was lead by Mr Hood and his son, who is also called Robin, with all guests wearing bright clothing, Mr Hood said: “Alex hated people being unhappy. She always tried to be happy and she was never depressed. Even at the end, when she knew she was dying, she managed to be happy.”

In September 2007, Alex appeared in the *Courier* with her specially-adapted car which was bought by Harrods owner Mohammed Fayed. But the teenager, who lived in Lillington with her mother Virginia, only managed to take six lessons in the vehicle before becoming too ill to drive.

Alex also gained a place at Leicester University and was due to start a course in development and interior design next month.

Mr Hood gave up his own business to work for charity Debra, which researches epidermolysis bullosa, in 1995. He is now head of the charity’s major events department and has helped raised millions of pounds for the cause.

He added: “I feel cheated that I am not going to get the cure I wanted for my daughter but there are lots of people younger than Alex who have the condition and I promised her I would not give up.

“We are so close now but without public support we will not be able to put this condition where it belongs – in the history books.”

• Warwick resident Amy Yates also suffered from epidermolysis bullosa. The ten-year-old died last August and had the condition from birth.



Moving: Cherie Blair backed Alex's cause



Giving: She gifts pup to Clinton envoy



So brave: Alex smiles with Robin despite blisters in 2001



Loving: Robin gives Alex a tender hug



Butterfly girl Alex dies aged 19

Please Daddy, after I am gone, carry on trying to save others

Exclusive by James Douglas News of the World 20th July 2008

Brave butterfly girl Alex Hood – whose courage amazed prime ministers and presidents – has lost her fight for life aged 19.

Just moments before her death in the early hours of Thursday, she **begged** her father to continue his campaign to find a cure for the horrific blistering condition which ultimately killed her.

Alex had been told on her birthday in February this year that her recessive dystrophic epidermolysis bullosa (EB) – which makes sufferers' skin as fragile as a butterfly's wing – had led to incurable cancer.

And last night distraught dad Robin – who has worked tirelessly to raise funds for charity in the hope she could recover – said: "Even at the end her thoughts were not of herself but of fellow sufferers.

EMOTIONAL

"Alex begged me, 'Please, Daddy, after I am gone carry on working. We are so close to finding a solution – please don't give up'.

"Her death has brought release from a life of pain but she inspired everyone who knew her. Days before she died, I met Sarah Brown, the Prime Minister's wife, who was visibly emotional when I told her about Alex."

Alex was diagnosed with EB – a rare

genetic condition which hits around 5,000 people in the UK – just weeks after her birth in Dumfries in 1989.

Robin and mum Virginia, 48, spent ten hours a day bandaging Alex as she blistered at the slightest touch – yet the plucky little girl managed to pass 11 GCSEs and study art at college. Last year she had an operation to separate fused fingers on her right hand – and was able to open Christmas presents for the first time in four years.

Alex's courage prompted world leaders to back the charity Dystrophic Epidermolysis Bullosa Research Association.

While in No10, Tony and Cherie Blair hosted a reception in 1999 that raised £100,000 and ex-US President Bill Clinton penned letters of support after Alex and labrador breeder Robin gave him a puppy.

Robin became a full-time fundraiser after Alex wrote to Santa one Christmas: "Please could I have new skin that will not fall off? Can you make it so it doesn't hurt when I pull a cracker?" After work broke up his marriage in 1995, Robin said: "Folk say I'm obsessed but I have a nightmare we'll lose Alex at the last fence."

Sadly, it came true and Alex died with her family around her. *Robin 51, vowed: "the funeral won't be doom and gloom but a celebration of having Alex."*



Rex House, 103 Bothwell Road, Hamilton ML3 0BW.
Tel: 01698 424210 • Fax: 01698 423654
email: debra.scotland@debra.org.uk • www.debra.org.uk

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