



**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."*



Working for a life free of pain

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