Desperate to cure his daughter

Alex Hood's rare condition is a killer, but her father is fighting to save her, writes **Lynn Cochrane**

Life of agony: her illness prevents Alex, now 12, leading a normal life

Running for his daughter's life: Robin Hood, above, has raised £250,000 to fund research into finding a cure for butterfly syndrome

ROBIN HOOD promises his daughter Alex that one day they will walk barefoot along a beach. The feeling of sand between the toes is one of life's simpler pleasures, yet it is one denied 12-year old Alex because she suffers from a rare genetic condition that causes even the gentlest of touches to blister her skin.

She is in a wheelchair, must be fed through a tube into her stomach and requires morphine to endure three-and-a-half hours of painful bursting and dressing of blisters each morning and evening. Ultimately the condition, known as butterfly syndrome or, more technically, Dystrophic Epidermolysis Bullosa, can lead to premature death.

Her father, however, is determined Alex will not die prematurely. Having given up his job organising angling and shooting holidays near his home on the shores of Loch Ken, Galloway, he works full-time raising funds to find a cure. "Friends tell me I'm obsessive," he says. "But I just don't want to go to my daughter's funeral."

Hood, who runs the Scottish arm of the charity Debra (Dystrophic Epidermolysis Bullosa Research Association) hopes research being carried out at Dundee University could find a cure within five years. However, because butterfly syndrome is rare, affecting only one in 17,000 in Scotland, the scientists may not be able to find a pharmaceutical firm willing to fund the research.

"It would cost less than £10m – the same as building a couple of miles of motorway. It doesn't seem much, does it?" he says, with a sad shrug.

Hood, 45, sits in his whitewashed cottage overlooking the loch. Shelves are crammed with photographs of Alex, a pale, pretty girl with blonde hair, and his son Robin 21.

His children no longer live in the house. The amount of time he has spent fundraising for the charity wrecked his marriage and Alex now lives with her mother Virginia. However, Robin remains on good terms with his former wife and he sees Alex at weekends and holidays.

Robin is with the King's Own Scottish Borderers. "I think all this really affected him," says Hood. "I used to shout 'watch your sister' if he went anywhere near her. Poor Robin was banished to his room."

Hood had never heard of EB before Alex was born on February 5, 1989. After her delivery in Cresswell Hospital, Dumfries, he held her in his arms before rushing home to tell the rest of his family the good news. When he returned to the hospital four hours later, Alex's tiny foot was a mass of raw blisters.

"She had been rubbing it against her cradle," he says.

The condition was so rare that it took the medical team a fortnight to establish what was wrong with Alex. In the meantime, she was taken to a special baby care unit. Hood and his wife wore gowns and masks when visiting her. "You could see people looking at us. They thought it was contagious," he says.

Eventually, a doctor broke the news that Alex had EB.

"You feel as though you are the only person in the world. My life fell apart," Hood recalls. The hospital put he and his wife in touch with Debra.

Hood, shocked by the news, telephoned John Dart, the charity's director, who suggested that, rather than accepting the doctor's diagnosis, they organise a skin biopsy to be taken from their daughter.

He explained that there are three types of EB. Alex, the Hoods discovered, has dystrophic, a particularly crippling form of the condition, but not immediately fatal.

"When we heard, it was like a death sentence being lifted. Suddenly instead of a few months we had a reprieve of maybe 30 or 40 years."

Life became a daily routine of tending and dressing Alex's skin as she screamed in agony. Even rolling over in bed can cause up to 60 new blisters each night. Watching her learn to walk was nerve-racking. One fall could take the skin off her legs.

Once, when Alex was a little girl, she stumbled while out with her mother. Virginia's reaction was to catch her. She grabbed her daughter's hand and took a sheet of skin off. "Alex said 'never mind, it will get better'," says Hood.

His daughter is a courageous girl, he says. She has a panic button by her bed if she is in pain during the night. However, knowing that her mother is often exhausted caring for her, she tries not to press it.

Alex loves animals and she is good at drawing and painting, despite scarring on her hands that limits her movements. Scarring also affects her throat – swallowing food can tear the skin – which is why she is given nourishment via a tube in her stomach.

Alex is admitted to hospital at least 10 times a year because of the numerous complications that arise from EB. The latest side effect she has had to cope with is osteoporosis.

Her peers can be cruel. Hood recalls one incident when Alex was at primary school. Three classmates wrote her a letter saying that she smelled (her skin is so raw that it does sometimes have a different odour), she could not run around in the playground and took too long to have lunch. They did not want to be her friend any more.

"I do get terribly protective of her. I'm one of those 'don't mess with my daughter' kind of fathers."

As awareness of the condition grows, more cases of EB are coming to light.

"But numbers are not growing in real terms," says Dr Irwin McLean of Dundee University. He is one of the Scottish scientists whose research into gene therapy could lead the world in eradicating the condition. Last month a team led by him succeeded in deactivating the gene responsible for the simplex form of EB. Can a cure be found for it in Scotland?

"Absolutely," says McLean. "As well as our work, there's another team at the medical school in Dundee under Professor Birgit Lane looking at EB from a different angle, and a third team with Professor Seth Schor in Dundee working in wound healing – one of the main problems for sufferers. We've made a lot of progress, but the process is incredibly expensive.

"We are reliant on people like Robin and Alex," he adds. A gene therapy cure would involve the manufacture of artificial genes in the laboratory. They would then be placed in the skin cells of sufferers.

But McLean explains that because EB affects only a handful of people, none of the pharmaceutical companies may come forward to fund a cure.

Hood raises £250,000 a year to fund research. He targets heads of government and big companies for backing. For the past three years Scottish Power has sponsored a golf tournament for the charity. This year at Turnberry it raised £30,000. To publicise Debra, Hood gave former President Bill Clinton a chocolate-brown labrador and numerous letters to Downing Street resulted in an invitation to meet Tony and Cherie Blair in April 1999.

"I remember after we met them Alex turning to me and saying: 'Dad, that was okay but could we be a normal daddy and daughter?' I felt awful. She doesn't want attention drawn to her. She just wants to be like everyone else."

Meanwhile Alex is recovering at home after treatment in Great Ormond Street hospital for children in London.

"I sat on the side of her bed and asked her how she felt about having EB. She said to me: 'Once I get better. I am going to relive my childhood.'"