SIBLINGS SUFFER: Five-year-old Lachlan Woodward and his brother Hayden suffer from Epidermolysis Bullosa. PHOTO: BARRY LEDDICOAT

Brothers share affliction

By NICOLE FUGE

Fast facts

- Epidermolysis Bullosa (EB) is a rare skin disease which causes the skin to constantly blister.
- There are about 1000 people in Australia with some form of EB and more than 500,000 worldwide.
- If the parents have the gene, there is a one in four chance their children will inherit the disease.
- Details visit www.debra.org.au.

LACHLAN Woodward's skin is as fragile as a butterfly's wing. It blisters and tears, requiring frequent bandaging, like a patchwork doll.

The five-year-old from Little Mountain has a rare skin condition, Recessive Epidermolysis Bullosa Simplex, a debilitating disease likened to living with third degree burns.

Lachlan's brother Hayden, who is only nine months old, also has EB. Their parents Darren and Tagen constantly watch over their sons' skin, making sure all wounds are tended.

"Lachlan was born with EB, Hayden was not meant to be born with EB," Tagen said.

"I had all the tests done, they came back he's going to be fine. Three weeks after he was born I noticed blisters on his fingers.

"It was absolutely devastating, ... it's a new mutation for me, our odds of that happening, it's like winning the lotto."

Neither Darren or Tagen's family have a history of EB, which was why both diagnoses came as such a surprise. While they do everything they can to keep their sons healthy, Lachlan's frustration with his condition is escalating as he gets older.

"When I'm doing his dressings, he says, 'I hate this rare skin disease, I'm sick of this'," Tagen said.

"We want to explain to the boys it isn't our fault. As they get older, what are we going to be up for?"

Tagen said Lachlan's condition has progressively worsened because doctors don't know what they're dealing with. The family is now waiting on test results to determine the severity of Hayden's condition.

While they struggle to understand EB, they are thankful the boys do not have the most severe cases which cause blistering on their organs and oesophagus.

"Because their immune system has to fight so many things, it just gives up in the end. That's why it's important to keep them healthy and active, not wrapping them in cotton wool," Tagen said.

On Friday Lachlan participated in Milo cricket for the first time.

"Dad took his dressing case along. He took skin off his knee, but he patched him up and off he went," she said.

October 25-31 is International EB Awareness Week. Funds raised provide care, quality of life for families and fund research.