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'Butterfly kid' to spread her wings

Parents learn to cuddle with care

BRIGID O'CONNELL

HER skin may be as fragile as butterfly wings, but Blakely Morris refuses to be sidelined.

"She's very determined. She will watch you do something once and then wants to do it herself," her mum, Emma Minney, said.

"She's now walking, so she tries to put her own shoes on and tries to brush her own hair."

Ms Minney said her daughter was unexpectedly perfect at birth after a difficult pregnancy and fears about Blakely's small size and hearing.

Two days later, a blister appeared on her back. Probably just the nappy rubbing, they were told.

When the sore hadn't healed and she ran a fever, Ms Minney and fiance Jamie Morris returned their newborn to hospital.

As the doctor removed the bandage, it took with it all the skin on Blakely's back and she was rushed to intensive care.

It was the first step in her diagnosis of epidermolysis bullosa.

EB is a rare disease, affecting about 1000 Australians, who are missing the proteins that glue the layers of the skin

together.

Those with the condition are known as "butterfly kids" because their skin can blister and peel at the most gentle touch.

"Everything we read said you couldn't hug your kids or take them anywhere and they would be constantly bandaged," Ms Minney said.

"We thought, how are we going to bring a baby up like this?"

But, with the help of the Royal Children's Hospital and support organisation DEBRA Australia, the couple are raising a happy and healthy 14-month-old with a mild form of EB who gets on with life despite the pain and risk of infections.

The baby they once had to pick up in a unique scooping motion now nurses sores on her feet from walking and her new-found love of dancing.

The couple are running the 5km Melbourne Marathon this Sunday to raise money for DEBRA.

"I do worry what will happen when she goes to school and if people will want to be her friend," Ms Minney said.

"She's such a loving little girl but we worry people

won't be able to see that because of the skin condition.

"We want to bring her up thinking she's no different."
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Blakely with her
parents, Jamie
Morris and Emma
Minney. Picture:
JAY TOWN