

Little Danielle takes next step back to life

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NINE days after she was born, little Danielle Sibbons was swathed in bandages under intensive care in a hospital burns unit.

Suffering a rare, life-threatening skin condition identified at birth, surgeons — using the surgical equivalent of a potato peeler — stripped away a black, hairy layer of skin covering 15 per cent of her body.

Now, 21-month-year-old Danielle is still covered in hundreds of smaller markings and carries the scars of surgery on her scalp.

She is the one in 500,000 people who suffer severe Congenital Melanocytic Nevus — giant, hairy moles covering large parts of the body.

Although sufferers are highly susceptible to deadly melanomas, mother Michelle Sibbons considers her daughter one of the lucky ones.

"Certainly, cosmetically it would have been a far greater challenge without the surgery," said Mrs Sibbons.

"The birth mark she had might have thickened, grown copious amounts of hair, she would not have a hair line at all and she was at a very high risk of developing a melanoma."

The rare and unsightly condition often leaves parents of newborns in shock during the two-week period after birth.

It is crucial that surgery take place in this period, according to Michelle Lodge, a plastic and reconstructive surgeon at Adelaide's Women's and Children's Hospital.

"To get rid of this pigment, you must scrap off these immature cells in the first couple of weeks of life otherwise you have missed the boat," Dr Lodge said.

Mrs Sibbons wants to make sure parents are armed with as much knowledge about the condition, so that they can attack it quickly.

"When Danielle was born, I remember sitting next to her in the



Lucky one: Danielle with Ms Sibbons, left, and Dr Lodge yesterday, and as a newborn with the rare condition

hospital room and feeling like she was the only one in the world with this condition. "I don't want any other mother to ever feel like that. I want them to know there is support and help at hand."

Mrs Sibbons is attempting to organise a national gathering in Adelaide of sufferers and their families early next year.

"One of the main problems is that people just don't know about the condition — parents don't know what to do or where to go," she said.



<http://communities.nine.msn.com.au/AussieNevusSupportGroup>