

# Michelle seeks support for Danielle's condition

**T**HE warnings did not prepare Michelle Sibbons for the first time she saw her baby in the hospital nursery.

"I was hit with a combination of shock and grief for what might happen to Danielle but I also immediately felt protective towards her."

Danielle, who turns two in November, was born with congenital melanocytic naevus — a rare birth defect where large, dark, hairy birthmarks cover the body.

The birthmarks make sufferers highly susceptible to melanomas and can be fatal if they form on the brain or spinal cord.

"We were most afraid that what we saw would kill her."

Mrs Sibbons, of Seacombe Heights, said it took several frightening days after Danielle was born at the Women's and Children's Hospital to get a definite diagnosis on her condition.

"Most doctors have never seen it before."

About one in 500,000 babies are born with naevus in the giant form Danielle has.

Mrs Sibbons and husband Alan scoured the internet for information on the skin condition. "The more we found out, the worse it got."

At nine days old, Danielle had her first operation when surgeons peeled layers of her skin off.

She had another operation two days later, and has since had several more.

During her search of the internet for up-to-date information on the rare condition, Mrs Sibbons came across an



Michelle Sibbons with daughter Danielle, who was born with the rare congenital melanocytic naevus. Picture by Roger Wyman.

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Danielle Sibbons before surgery.

American-based support group for sufferers and their families.

"I was immensely relieved when we managed to get in

touch with other families going through the same thing.

Three Australian families who met through the American-based group have

since formed an Australian-based organisation.

Mrs Sibbons is trying to organise a national meeting of sufferers and their families in Adelaide in January next year.

She is seeking sponsorship or donations for the Big Bash, which she hopes to hold in the southwestern suburbs, to help the families who already face huge medical expenses.

*(To help, contact the Aussie Naevus Support Fund, C/- Department of Social Work, Adelaide Women's and Children's Hospital, 72 King William Rd, North Adelaide, 5006, or contact Mrs Sibbons on 8298 3080.)*

-RACHEL BROWN