



Albinos now say white is all right

Gene fault gets easier to live with

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HEALTH REPORTER

AS a young mother in the 1960s, Marian Morrison used to dye her white hair darker to try to stop the whispers behind her on the train.

Like her eldest brother, Ken Curtis, Mrs Morrison is an albino, lacking pigment in their hair, skin and eyes and making them stand out in a crowd.

"I wanted to take that real white look away," she recalls. "I could hear people talking about me. That's the thing that upsets you. They'd be in the train seat behind you and talking about you as if you've got no ears."

Mrs Morrison, now in her early 60s and living happily at Chermside, in Brisbane's north, said little was known about albinism when she and her brother were children growing up in Sydney.

"My parents were told to put my brother in a home," she said. "It's much, much better now."

Cameron Morgan, 9, is testament to how times have changed. When the Villanova

College student was born and diagnosed with albinism, the obstetrician who delivered him told his father, Graham: "I can show you a telephone book-sized list of all the genetic conditions that are worse than this. It's nothing."

Despite initially admitting to being shocked by the news, his mother, Carol, said she and her husband soon realised having a child with albinism was "not the worst thing in the world".

"It was just a case of coming to terms with the situation and realising there's so many worse things out there, ones that are potentially deadly and potentially disabling and he was none of those things. Off we went with life," Mrs Morgan said.

Albinos inherit a defect gene from both parents which affects the body's ability to make the pigment, melanin.

Albinism affects all races, including Aborigines, but there are no published statistics about its incidence in Australia.

Helene Johanson, of the University of Queensland's Institute for Molecular Bioscience, is researching albinism in Australia and the South Pacific for her PhD and hopes to shed light on the numbers.

In Ireland, one in 10,000 people is born with albinism and in the US, it affects one in 17,000. Ms Johanson has started a database of Australians with the condition.

Albinos have impaired vision because melanin is needed for the development of the eye's fovea, the small area of the retina important for viewing fine detail. A lack of pigment in the skin means they have to be particularly vigilant in the sun.

But except for an increased risk of developing skin cancer, people with the condition can expect to have a normal lifespan.

Rachel Perry, whose first child Zara, 2, has albinism, said taking the necessary precautions in the sun were no different to what other parents did with their

children.

"Zara's never been sunburnt; she wears sunscreen, wears long-sleeved clothes, hats and sunglasses," said Mrs Perry, vice-president of the Albinism Fellowship of Australia.

"You know what, there aren't many other kids out there who don't wear long-sleeves, hats and sunglasses either these days."

If she and her husband, Andrew, decide to add to their family, they have a one in four chance of producing another child with albinism for each pregnancy. But that's not an issue for the couple.

"Even if we knew which gene to test for, we wouldn't," Mrs Perry said.

Ms Johanson wants people with albinism to take part in her survey on the condition.

To access the survey, log on at <http://research.imb.uq.edu.au/albinism/>

The fellowship's website is: www.albinismaustralia.org



LIVING happily ... albino Marian Morrison at her Chermshire home. Picture: Lisa Clarke



FULL of zest ... Zara Perry, 2, of Sinnamon Park, with her mother Rachel, vice-president of the Albinism Fellowship of Australia. Picture: Liam Kidston