

# The mutant gene that will rob three Sydney siblings of their sight

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## Sunday Night: The White Family



### **WHAT if you discovered you were going blind?**

How would you react? How would you cope?

But what if you were a parent and you realised you had passed on the gene that caused the blindness to all your children.

You knew they would all eventually lose their sight.

Tonight on Seven's Sunday Night, one family reveals they are going through just that — gradual and certain blindness.

Beth White and her three children carry the gene which has triggered a rare type of Retinitis Pigmentosa — a hereditary disease affecting the retina.

But what they have is slightly more mysterious. Their disease is so rare it doesn't yet have a name.

Beth is a 39-year-old mother from North Rocks in Western Sydney. She's been blind for much of her life.

Almost 20 years ago she married David and together they had three children — Kathryn 12, Samuel 10 and Matthew 8.

You might be tempted to judge, but if doctors gave you a 50-50 chance of a faulty gene being passed down with it skipping the kids altogether — what would you do?

Beth and David rolled the dice.

Every year, the children were tested. Every year, they were cleared.

Then Sam began to show the tell-tale signs of the genetic disorder.

To test him properly, the doctors also examined Kathryn and Matthew.



The three White children — Matthew 8, Samuel 10 and Kathryn 12 — will all lose their sight over the course of the adult lives. Picture: Courtesy of Channel 7

Last year, the unthinkable was confirmed.

All three children were all found to have inherited mum's mutant gene.

"I wanted to have three beautiful children but now they're stuck with the rest of their lives to live," Beth told me.

"The guilt was that I'd created all this. That was my biggest problem.

"For David I felt guilty that I had done this to all his children."

Time is now their best friend and their worst enemy.

One by one, the White children will eventually lose their sight — just like mum.

That's not exactly easy news to accept when you're still at school writing in HB pencil and playing with transformers and Rubik's cubes.

It's also not what you want to hear when your dream is to be an actress, a pilot or an astronomer.

That's the new reality for the White children.

But you wouldn't know it.

I've had the privilege of spending the past two months with this family and they've taught me much about life — mostly, that it doesn't end with a disability.

Beth cooks, works as a massage therapist, and is a triathlete and an adrenaline junkie.

She skis, wakeboards, sky dives and loves zip lining.



Sunday Night reporter PJ Madam with the White family. Parents David and Beth and their children Matthew, Samuel and Kathryn. Picture: Courtesy of Channel 7

Just because Beth can't see, doesn't mean she can't feel.

"I just don't feel I don't have a disability, in my mind," Beth said.

"I just feel we've got to learn how to do something different".

Beth's attitude and self-respect would put most people with sight to shame.

Her kids have a similar outlook.



The White family. Picture: Courtesy of Channel 7

They know time is running out. But instead of wallowing in the diagnosis, they've put together a type of 'must see' list — all the things they want to see before the shutters go down.

Surfing, touching snow, seeing the Eiffel Tower, Grand Canyon, Pyramids of Giza, the Great Wall of China — the list is endless.

It's their perception that life is short and they're literally living every minute of it, that's so infectious and inspiring.

That's even in the face of good news with scientists at the Children's Medical Research Institute, isolating the mutant gene that's caused their blindness.

It's needle-in-a-haystack work and it's a world first. It's the first sign of hope there might be a cure.

But time and money is against them.

Not for a second do I believe that life is less worthy without the gift of sight.

Her children may have inherited her mutant gene — but they've also inherited Beth's resilience.

That makes them stronger than what any pair of eyes can see.

The White's story will air on Channel Seven's Sunday Night tonight at 9pm.