

## These Three Kids Are Going Blind — But First They Want to See the World

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Kathryn, Sam and Matthew White are on a mission to see everything they can before they lose their sight to a rare genetic disorder.

Their mother Beth passed a faulty gene on to her children and together, the family is now in a race against time to complete a 'must-see' bucket list.

Beth started going blind when she was just five and by the time she married high school sweetheart David she was completely blind, but the disorder was so rare that scientists still haven't given it a name.

Two years ago a test revealed that all three kids suffered the same condition and would likely go blind in the coming years.

Kathryn, 13, Sam, 11 and Matthew, 8, are already losing their sight.

"To realize that you've got three beautiful children who are all going to need so much support ... it just didn't seem fair," said Beth.

But in a Sydney Hospital a team of scientists are also in a race against time to find a cure for the White children and recently were able to isolate the faulty gene.

The Eye Genetics Research Group at the Children's Medical Research Institute began searching for answers in 2013.

Associate Professor Robyn Jamieson who heads the research group, said her team used genome sequencing which allowed medical scientists to trawl through 23,000 genes in the human body to find the mutation.

"It's absolute needle in a haystack (work) because there's 23,000 genes but we have to look through 3 billion base pairs," said Associate Professor Jamieson.

"That's 3 gigabytes of data... each.

"That was a pretty exciting moment," Associate Professor Jamieson said, referring to the discovery of the gene responsible for the condition.

Dr Jamieson estimates they would need up to \$5 million in additional funding to fast track the development of treatment.

It is hoped experimental research will lead to a possible treatment for the White children and those suffering conventional Retinitis Pigmentosa – a more common condition Beth was originally diagnosed with.

But working on this cure will take time, between five and 10 years, and much more funding.

Catherine, Sam and Matthew are losing their sight at different rates and it is not known how long they have left to see.

"To have that level of hope – that's changed our lives," mum Beth said, "who knows what the outcome is going to be ... but having hope is everything, it really is."

"Unfortunately the condition is such that damage happens over time and it gradually gets worse, "

"We have to believe that this will work and even if this doesn't reverse the damage that has been done, maybe that it can stop the damage going any further.

On Channel 7's Sunday Night, the White family travelled to New Zealand to ride the world's fastest zip line at Gravity Canyon outside Wellington, an amazing experience to cross off their must-see list and one they won't soon forget.

Beth and David have put all their time and money into making the experiences for their kids, but say time and money is running out.

“That’s the scary part, how much time do we have?” said Beth.