MEDIA STATEMENT

Rapid vision loss from rare eye disorder leads to an experimental treatment and a new research focus for the Lions Eye Institute.

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One of the rarest and most baffling eye disorders is the subject of new research at the Lions Eye Institute (LEI).

A diagnosis of **Auto-immune Retinopathy** (AIR) is still controversial but it is believed that antibodies generated by the body to fight an unrelated infection or illness attack and damage the retina, resulting in rapid vision loss.

The research into AIR is being inspired and financially supported by Brad and Carolyn Miocevich. Mrs Miocevich was in her 30s when she began to lose her eyesight.

“She went from being able to read to the point where she couldn't drive, then walk without assistance. It was a dramatic change,” Mr Miocevich said.

“Carolyn had a previous diagnosis of retinitis pigmentosa (RP) but over a long period of time, we sought other medical opinions to make sure that diagnosis was correct.”

Eventually, Mrs Miocevich was seen by Associate Professor Fred Chen, head of the LEI’s Ocular Tissue Engineering Laboratory, who raised the possibility of AIR.

Associate Professor Chen arranged for blood samples to be sent to one of the few

clinics in the world – the Casey Eye Centre in Oregon, USA – that can test for the presence of antibodies reacting against the retina.

The tests returned positive, indicating an immune reaction to the retina had taken place. Together, Associate Professors Chen and Mei-Ling Tay-Kearney recommended exploring the option of using specialised medicine to modify the immune response to arrest the decline in her eyesight.

With help from Dr Dominic Mallon, an immunologist at Fremantle Hospital, an immune suppressant that is normally used to treat non-Hodgkin's lymphoma was released under special circumstance for treatment of Mrs Miocevich's AIR.

"The theory behind the treatment Carolyn is receiving is to get rid of those antibodies that react against the retina and slow or halt the rate of progression of the disease. This drug suppresses the body's production of antibodies," Associate Professor Chen said.

"Carolyn still has some limited vision and obviously she wants to retain that and not see it reduce further."

Her treatment, which is experimental but which has been described and used in the United States for this condition, began in December last year and according to Mr Miocevich, there are some positive signs.

"It's very early days but Carolyn has seen some improvement in the number of line of visual acuity of her left eye and it appears that the decline in her sight has been arrested," he said.

"The whole process led us to the conclusion that there was not a whole lot of understanding of this condition so we felt it would be a good thing to support further research in this area."

The result is the funding of a new research position – to be known as the Miocevich Retinal Fellow - who will work with Associate Professor Chen.

It is hoped the research will unlock some of the unknowns around AIR.

“Auto-immune Retinopathy is a very rare disease,” Associate Professor Chen said. “We are grateful to have this Fellowship to facilitate the establishment of a national database of this rare eye disease. Currently we have no idea how many people in Australia have auto-immune retinopathy – is it 10 or 100 or more?

“The second thing we’d like the Fellow to look at is the phenomenon of antibodies reacting against the retina in other common blinding retinal diseases such as retinitis pigmentosa and macular degeneration.

“There is still debate on whether these antibodies are produced in reaction to retinal damage or if they in fact contribute to progression of the disease.”

Mr Miocevich said eventually, his family would like to fund the position in perpetuity to ensure a breakthrough in the detection and treatment of AIR could be achieved.

“An important aim for us is also to raise awareness about this rare disorder and garner public support in finding a cure,” he said.

“For anyone who is going blind, it is a very different experience to someone who is born blind. Having something so important taken away from you is truly devastating although Carolyn is a very strong person and coming into contact with Associate Professor Chen who really listens and looks for alternatives gives hope to you.

“It is our wish that this new research will help others who may be affected by this disorder now and in the future.”

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