



Sunday, 5 May 2019

Family connections - are you next in line for AMD?

More than 60 per cent of Australians are unaware of the strong familial risks associated with Australia's leading cause of blindness, putting their direct family members at risk of vision loss, says Macular Disease Foundation Australia (MDFA) Patron Ita Buttrose AO OBE.

"People with siblings or parents with age-related macular degeneration (AMD) are in a high-risk category and have a 50 per cent chance of getting the disease," Ms Buttrose said. "The best defence against vision loss from AMD are awareness and early detection."

To coincide with Macula Month, which runs throughout May, Macular Disease Foundation Australia (MDFA) commissioned two YouGov Galaxy surveys targeting both the general population and Australians with AMD. They showed that:

- 63 per cent of the general population don't know there's a familial risk associated with AMD
- Among Australians diagnosed with AMD, only half (50.1 per cent) are aware of the hereditary connection – of those, many dramatically *underestimate* the risk
- Of the people who *do* understand the familial connection, almost one third (29 per cent) have not told all relevant family members they may be at risk themselves
- Only one in three (33.2 per cent) of those with AMD recalled being informed about the potential familial risk by their eye health professional.

AMD – a painless, progressive eye disease that destroys central vision – is the most common macular disease, accounting for 50 per cent of all cases of blindness and severe vision loss in Australia.* One in seven Australians over the age of 50 – almost 1.3 million people – already have some evidence of AMD.

There is no cure for AMD but there is effective sight-saving treatment (anti-VEGF injections) for one form of the disease (wet or neovascular AMD) if detected early. As well, a macular-friendly diet and lifestyle changes, such as regular exercise and quitting smoking, are proven to delay onset and progression of AMD.

"From my experience as MDFA Patron, I know that people living with macular disease are extraordinarily stoic. They know their sight loss places a burden on their loved ones. I suspect many people with AMD don't talk about the risk because they don't want the people they love to worry.

"But we *must* start talking about how this disease can run in families," Ms Buttrose said. "My father had AMD. Two of his siblings were diagnosed with it. I'm at risk which is why I am proactive about my eye health."

MDFA CEO Dee Hopkins said the statistics were alarming – both for the community generally, but also for eye health professionals.

“Familial risk is crucial information and we’ll be working closely with eye health professionals on ways to better communicate this to their patients. Early detection is vital to help slow progression of the disease.

“The conversation needs to start with our families. Know your risk: a family history is a risk; age is a risk; smoking is a risk, but early action can save your sight,” Ms Hopkins said.

ABOUT MACULAR DISEASE FOUNDATION AUSTRALIA (MDFA)

MDFA is the peak national body representing the voice of the macular disease community.

MDFA provides a range of information and support services via its National Helpline 1800 111 709.

** Eyes on the future – a clear outlook on age-related macular degeneration* Report by Deloitte Access Economics & Macular Degeneration Foundation, 2011. (2018 prevalence estimates are derived from a straight line extrapolation between 2015 and 2020 estimates in this report.); Taylor H et al. ‘Vision Loss in Australia’ *MJA* 2005;182:565-568.

ABOUT THE SURVEY

Two studies were conducted by YouGov Galaxy: a national survey of 1,000 Australians, and a second national survey of 653 Australians who have AMD.

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