

# MacularNEWS



In this edition, I am pleased to share our research into treatment outcomes for patients with wet Age Related Macular Degeneration (AMD). This is part of the Fight Retinal Blindness! (FRB!) project.

Science is under increasing pressure to develop new treatments for macular disease, the leading cause of blindness in our older population.

A major issue is that we don't fully understand the extent to which current treatments work in the 'real world' as opposed to in clinical trial environments. We are one of just two groups worldwide working on this.

Major clinical trials of Lucentis and Aflibercept, two new drugs for wet AMD, involve treating eyes every month. This is not practical for many patients who are unable, or unlikely, to comply with such a treatment regime.

There has been a huge gap in understanding whether these treatment approaches continue to work in the long-term, and therefore what the best treatment regime is to save sight. We are working hard to answer these questions.

Prof. Mark Gillies  
Macular Research Group



## Save Sight Registries Fight Retinal Blindness

The Fight Retinal Blindness! (FRB!) team, led by Professor Mark Gillies, is pleased to announce the establishment of Save Sight Registries.

Save Sight Registries is a web-based data collection system that tracks the treatment outcomes of ophthalmic diseases, including Age Related Macular Degeneration, Diabetic Macular Edema and Keratoconus.

*FRB! is an initiative that tracks real-life outcomes*

Save Sight Registries provide evidence of real world effectiveness of existing and new treatments, highlighting treatment patterns that lead to the best outcomes for patients. Save Sight Registries is a scientific collaboration, nationally and internationally, which aims to develop benchmarks and drive improved patient outcomes.

*Providing the best outcomes for patients*

## Support Our Research

Our research relies exclusively on external grants and fundraising. To make a donation to support macular research you can send a cheque to the 'Macular Research Group' at South Block, Sydney Eye Hospital, 8 Macquarie Street, Sydney NSW 2000 or visit our website to donate online, selecting the Macular Research Group as your purpose. No amount is too small or too large - you may also consider remembering us in your will. Thank you for your support.

### Diary Date:

**Save Sight Registries Launch  
(lunch included)**

**Friday 20th November 2015  
11.00am - 1.30pm**

*Places are limited. To register please call our Events Team on  
(02) 9382 7316 or visit <https://ssiregistry.eventbrite.com.au>*

[www.savesightinstitute.org.au/macula-research-group/](http://www.savesightinstitute.org.au/macula-research-group/)  
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**To stay updated on all macular research and patient events  
please email [macular.news@sydney.edu.au](mailto:macular.news@sydney.edu.au) and ask to be  
placed on our e-mail notification list.**

We recently published two studies in the leading journal in our field, 'Ophthalmology'.

### **1. The Treat and Extend approach to treating wet AMD**

The first study investigated the two-year outcomes of treatment with vascular endothelial growth factor (VEGF) inhibitors, ie Lucentis or Eylea, for wet AMD using a 'Treat and Extend' (T&E) approach.

T&E involves extending the time between treatments, after the bleeding has stopped, with the aim of treating just before it starts again. This is contrast to regular monthly dosing, which was initially recommended but has proven difficult for most patients and clinicians to comply with.

The T&E approach aims to keep the disease inactive with the fewest possible treatments, therefore reducing the burden on both patients and physicians.

T&E has been used extensively in Australia, but until now there have been no studies to determine how effective the approach is.

We analysed the visual outcomes from around 1,200 eyes that were treated by doctors utilising the T&E methodology.

We found that these patients had a good improvement in their vision after two years of treatment.

Graph A shows the visual acuity changes over a 24 month period for an average patient utilising the T&E approach.

It can be seen that there was a rapid gain in vision within the first six months of treatment, which then stabilised over the following 18 months.

Importantly, patients only needed an average of 13 injections over 15 visits. This compares with 25 injections over 24 visits that would otherwise be required.

These results were much better

than a similar report from England where a pro re nata (PRN) regimen was used.

The PRN approach involves receiving treatment injections after bleeding and swelling is seen.

Our results are encouraging clinicians across the world to adopt a T&E approach to ensure best patient outcomes.

By demonstrating the effectiveness

***“Our results are encouraging clinicians around the world to adopt a Treat and Extend therapy for better patient outcomes”***

of T&E (as opposed to PRN) we aim to prevent many thousands of people, throughout the world, from going blind due to less than optimal treatment.

### **2. Long-term wet AMD outcomes**

In the second study, we looked at the long-term benefit of treating wet AMD with VEGF inhibitors.

In this study, we tracked patients with wet AMD who received their first anti-VEGF injection at least five years previously.

Visual acuity, side effects and the number of injections were assessed up to seven years after initiating treatment.

There is only one other study in the world to do this, known as the “7-UP” study in the United States.

Our study included 1,212 eyes, with approximately half of patients persisting with treatment for over five years.

Our patients received an average of six injections in the first year, decreasing to five injections

annually thereafter for up to seven years. The rate of serious adverse events was found to be low.

In general, the average patient's vision improved after six months and was maintained for up to five years, followed by some loss by seven years.

After seven years, the average visual acuity was two letters lower than their initial vision upon commencing (see graph B).

These results were much better than those in the 7-UP study, which found that patients received an average of just two injections per year for the last three years.

40% of our patients still had reading and driving vision, whereas only 23% of 7-UP patients had this.

We again concluded that the better results achieved in Australia is because we are treating more efficiently.

We believe that these results will change treatment patterns around the world, benefitting many people with the condition.

We also looked at the relationship between vision at the first injection and vision gain over the time period.

We divided patients into three groups depending on their initial vision: good, intermediate and poor.

Graph C shows the outcomes of these three groups by five years.

It can be seen that those with poor vision to begin with, had much larger gains, but those with the best initial vision maintained the best vision, although it did not improve.

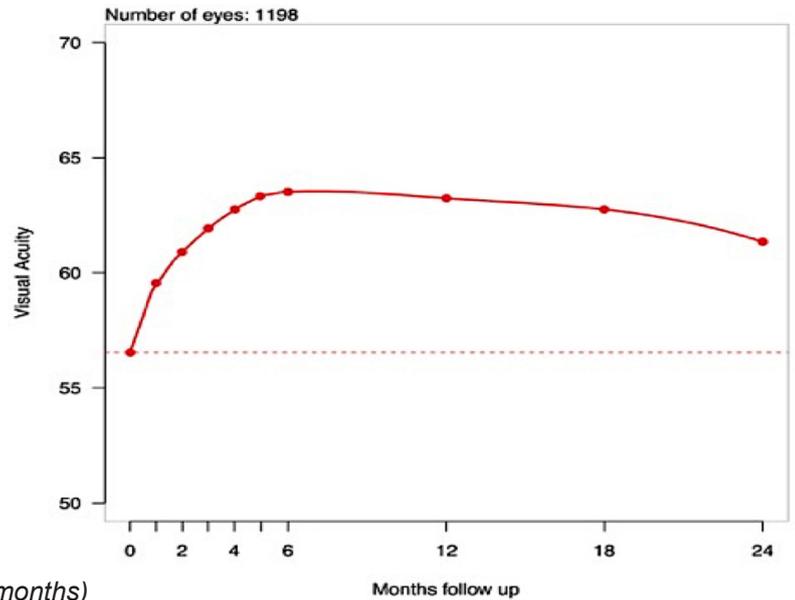
This study highlights the huge importance of early diagnosis and intervention for wet AMD.

We are working with the Macular Disease Foundation to find better ways of reaching people before the disease advances.

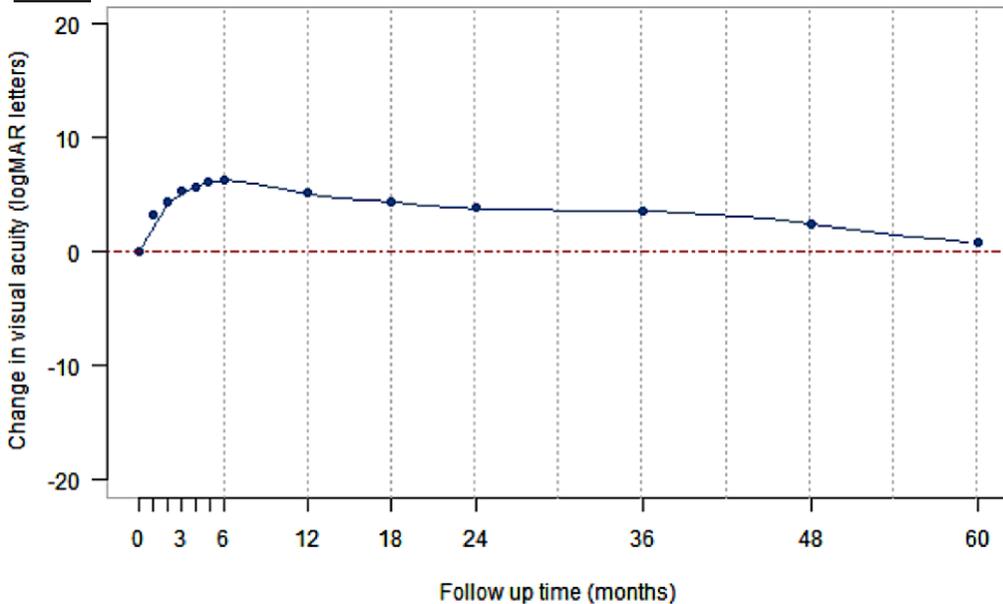
Ultimately, we want to save sight by ensuring a more timely diagnosis and effective treatment regime for wet AMD sufferers everywhere.

This important research could not be undertaken without the support of our generous donors.

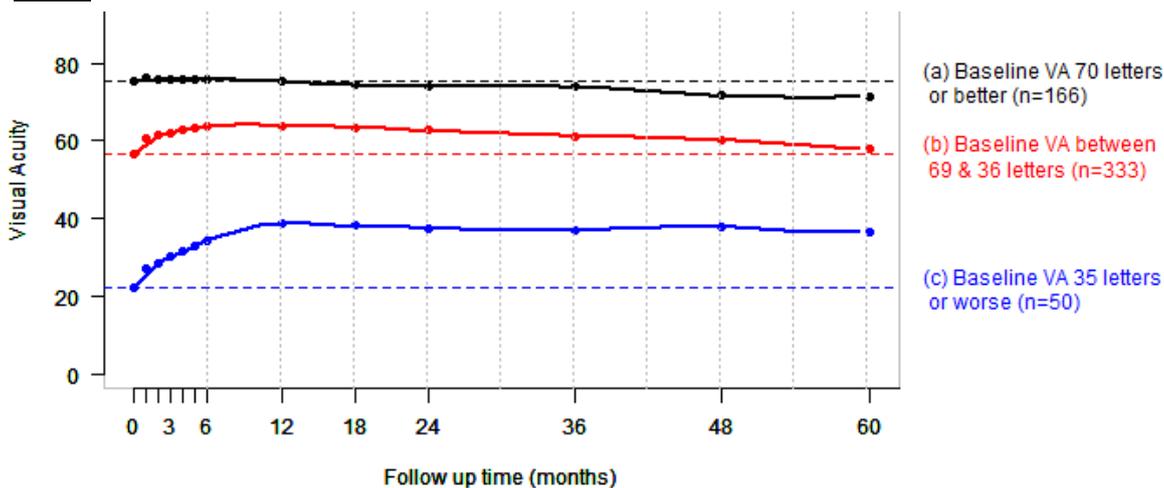
**A** Figure A: the change in vision for eyes that follow the treat and extend (T&E) approach with 24 month follow-up.



**B** Figure B: Change in vision over time (in months)



**C** Figure C: Change in vision over five years. Divided into three groups: very good starting vision (black line), intermediate starting vision (red line) and poor starting vision (blue line).



## The FRB! Team



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**We thank and  
acknowledge our  
loyal supporters,  
without whom this  
important research  
could not take place.**

**Save Sight Institute is a centre of The University of Sydney.**



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If you would like to make a tax-deductible donation or discuss leaving a bequest to support macular research please visit our website or contact us:

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