THE FRB! TEAM

Prof. Mark Gillies
Chief Investigator
Head of Research, Leader of Macular Research Group

Amparo Herrera-Bond
Manager
Orthoptic, clinical trials and management background

Dymow Barbosa
Coordinator
Business and IT background and is currently completing an MBA.

Dr Vuong Nguyen
Biostatistician
Conducts data analysis for dissemination of findings through publications, presentations and posters.

Marco Garcia
Software Engineer
Constantly improving the efficiency of the system and developing new modules.

Roxy Medina
Research Officer

Winnie Zhang
Research Officer

With a background in orthoptics and clinical trials, they are facilitating the implementation of our system into Sydney Eye Hospital.

If you would like to make a tax-deductible donation or discuss leaving a bequest to support macular research please visit our website, call us on (02) 9382 7309 or post a cheque to Save Sight Institute, South Block, Sydney Eye Hospital, 8 Macquarie Street Sydney NSW 2000.

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

SAVE SIGHT INSTITUTE

THE UNIVERSITY OF SYDNEY

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MacularNEWS

The Macula Research Group has three teams: the Lab, Clinical Trials and Observational Studies. Every issue of MaculaNEWS is devoted to one of these teams, with this issue covering Observational Studies. We have performed two major studies recently, the first was a direct comparison of the results of two common drugs that are injected into the eye for "wet" age related macular degeneration (AMD), Lucentis and Eylea. The second was a study on the results of cataract surgery on eyes that are receiving injections for wet AMD.

Our data comes from our Fight Retinal Blindness! database which is tracking the outcomes of eyes being treated with injections of vascular endothelial growth factor (VEGF) inhibitors: Lucentis, Eylea or Avastin. We have been following "real world" patient outcomes since these VEGF inhibitors were first released 10 years ago.

The Fight Retinal Blindness! Project is now recognised as one of the world's leading "observational" databases which reports on what actually happens when drugs are used in routine clinical practice after they have been evaluated in clinical trials. Results of clinical trials, which are usually run by large drug companies, are not always applicable to the general population and they may not address important issues, such as whether cataract surgery is safe and effective in eyes with macular disease.

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

Our research relies exclusively on external grants and fundraising.

If you are in a position to support macular research, please know that we are extremely grateful and that your donation will be well used.

You may also like to consider remembering macular research in your will.

Thank you for your support.

Prof. Mark Gillies

Save Sight Registries
Fight Retinal Blindness

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 of treatments."

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.

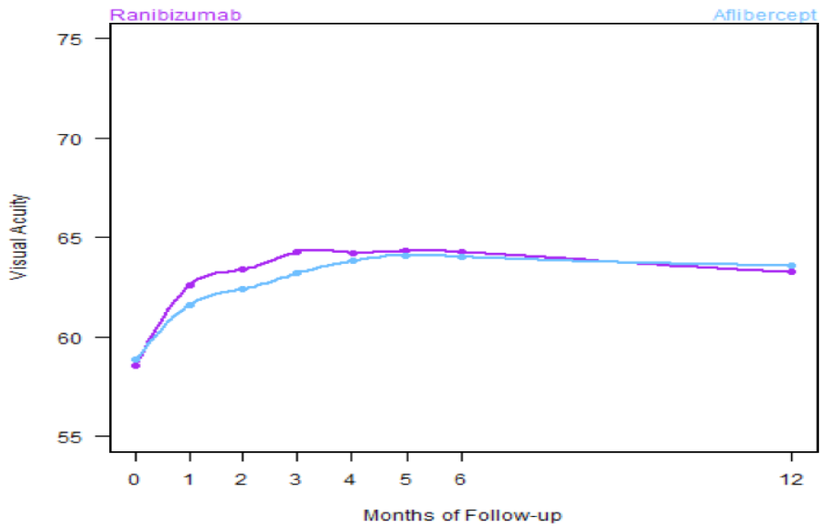
"Providing the best outcomes for patients."

To stay updated on all macular research and patient events please email macular.news@sydney.edu.au and ask to be placed on our e-mail notification list.

A "head to head" comparison of the results of Lucentis and Eylea injections for wet AMD

We studied eyes that started treatment with Eylea or Lucentis from 2013 when Eylea was first introduced in Australia. We identified around 400 eyes from our Fight Retinal Blindness database that were treated by around 60 ophthalmologists with either Lucentis or Eylea that were "matched" so that they had similar levels of vision when they started treatment. We found that the average improvement in vision12 months later was around 4 letters on a vision chart (5 letters = 1 line) for both groups (see Figure 1 for average change in vision for each group, "ranibizumab" = Lucentis, "aflibercept" = Eylea). We also found that each group received the same average number of injections (8 injections over 12 months).

1 *Figure 1:* Average change in vision for each group, "ranibizumab" = Lucentis, "aflibercept" = Eylea



This study indicates that the treatment outcomes of wet AMD are good for both Lucentis and Eylea and that there is little difference between the two drugs on average. We plan to perform further research to identify whether one drug might be better for an individual patient based on their genetic profile. We hope to start this study later this year and we will be approaching patients for permission to donate a sample that can be linked to their response to either of the 3 drugs we use.

Cataract surgery on eyes that are being treated with injections for wet Age-Related macular degeneration.

Cataract surgeons remove cataracts with the aim of improving vision; however retinal specialists are more cautious as cataract surgery may negatively impact on macular diseases. There is no doubt that cataract surgery causes inflammation in the eye, which can sometimes cause swelling of the macula even in eyes without macular disease. Research over the last 20 years has shown that there is much more inflammation in the common macular diseases, including age related macular degeneration, diabetic retinopathy and retinal vein occlusion, than was previously thought. We now believe that cataract surgery may exacerbate this inflammation and cause progression of macular disease if the macular disease is not adequately treated.

There are many things to think about when cataract surgery is considered in people with macular disease. If people already have advanced loss of vision from macular disease then they are less likely to benefit from removal of a cataract since most of their loss of vision is caused by the macular disease rather than the cataract. Doctors also pay attention to whether the macular disease is active or not. It is best if the macular disease is brought under control before cataracts are surgically removed. One common situation is whether cataracts can safely be removed from eyes being treated for "wet" AMD. This refers to eyes with macular degeneration that develop bleeding of the macula which may quickly lead to blindness unless it is treated. We have analysed one of the largest series of patients with wet AMD that had cataract surgery since we have been following "real world" patient outcomes since these VEGF inhibitors were first released 10 years ago.

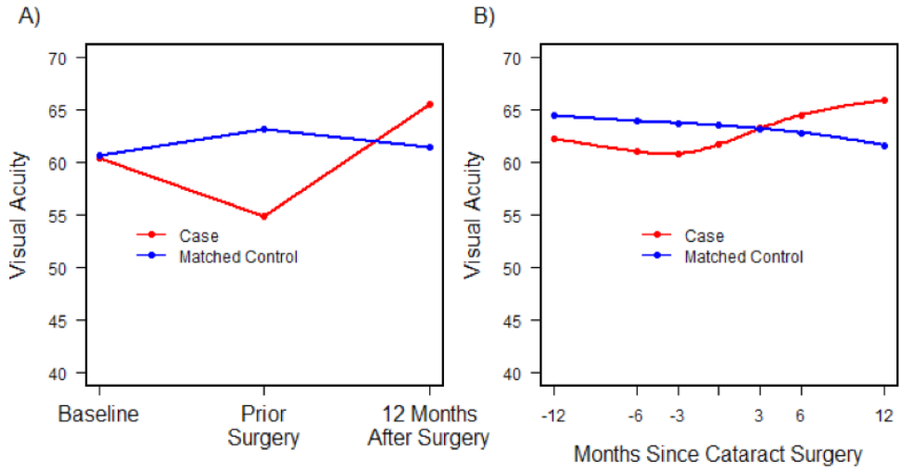
We studied long-term vision results and the frequency of injections of VEGF inhibitors around the time of cataract

surgery in 139 eyes being treated for wet AMD and compared this with a group of around 400 eyes that were also being treated but did not have surgery. Eyes that underwent cataract surgery had gained on average around 10 letters, or 2 lines on a vision chart, 12 months following surgery (see Figure 2); 28% had gained 3 or more lines while only 2% had lost 3 or more lines of vision.

The macular disease was more likely to be graded as active in the 12 months following cataract surgery in eyes undergoing cataract surgery than the "control" unoperated eyes, and eyes that had surgery received more injections after the operation. This study indicates that it is usually safe to remove cataracts from eyes that are receiving injections for wet AMD and that vision usually improves, but patients may need to be followed more carefully by their doctor in the months after surgery.

The Fight Retinal Blindness software that tracks the outcomes of treatment of macular disease is now being introduced in several European countries. We aim to monitor outcomes from all over the world in order to identify how the emerging treatments for macular disease can be used to get the best outcomes for patients in "real world" clinical practice.

2 *Figure 2:* Visual Acuity pre and post cataract surgery



Generous Bequest to the Save Sight Institute continues legacy of Di Mackintosh

Diana Mackintosh was described by her friends and family as a humble person, generously giving herself to all that she was passionate about, with a zest for life and a unique sense of humour. A teacher by trade and a traveller by nature, Di combined her passions travelling the world and teaching children, instilling them with her own love of life, independence, humour and compassion for others. Her travels took her to Guam, Japan, China, Korea, Hong Kong, the Philippines, New Guinea, the United Kingdom, across much of Europe and United States and a seven-year teaching post in Canada.

"People think I have led a quiet life, but in truth, I was a very active person and was blessed with a profession that allowed me to travel and one which gave me great satisfaction. I have loved every minute of my life."

Sadly, Di passed away in 2016 but in her passing, she has ensured her legacy of compassion and empathy for others with her generous bequest to the Macular Research Group at the Save Sight Institute. The Macular Research Group aims to develop new treatments to reduce the prevalence of blindness from macular disease through multidisciplinary, patient orientated, world class research.

Di's sister Margaret presented Professor Mark Gillies with her bequest knowing that such a donation would help many people in the future.