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Macular*NEWS*

www.eye.usyd.edu.au/research/macular.html

Our aim is to develop new treatments that reduce blindness from macular disease, through multidisciplinary, patient oriented, world class research

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The Macular Research Group

Welcome to the 3rd edition of Macular News!

In the last newsletter we described the stem cell research activities of the lab research unit. In this issue we will tell you about the Fight Retinal Blindness! (FRB!) Project research.

The Macular Research Group of Sydney University's Save Sight Institute has separate Clinical and Laboratory research Units

The Fight Retinal Blindness Project

The macula is the central part of the retina, the tissue lining the inside of the back of the eye that picks up light. Macular disease is the leading cause of loss of vision and blindness in Australia. The Macular Research Group is devoted to reducing loss of vision and blindness from macular disease.

Highly effective treatments for macular disease are now for the first time being made available. The first condition that we are able to treat with these new drugs is age related macular degeneration. New and much more effective treatments for other common macular diseases, particularly diabetic retinopathy and retinal vein occlusion, are also being released. While these treatments can be very effective in preventing vision loss in some macular diseases, mainly where there is bleeding or leakage of blood vessels, it is not yet clear how they are best and most safely used. Many doctors use many different approaches.

The aim of the Fight Retinal Blindness! Project is to create a system to track the outcomes of the new treatments for retinal disease on a large scale, from many different retinal treatment centres across the country, in order to identify which treatment patterns maximise the benefits to patients and minimise the risks.

Registries such as this are becoming very effective ways to improve results, or "vision outcomes", for patients by tracking

on a large scale how eyes respond to the new treatments. Present treatment recommendations are based on data from 2 clinical trials completed over 5 years ago that went for only 2 years and had fewer than 1,000 patients treated with ranibizumab (Lucentis). Given the great expense of this treatment and its widespread use, it is essential to ensure that the results gained in the highly controlled atmosphere of a clinical trial are actually achieved for the general public.

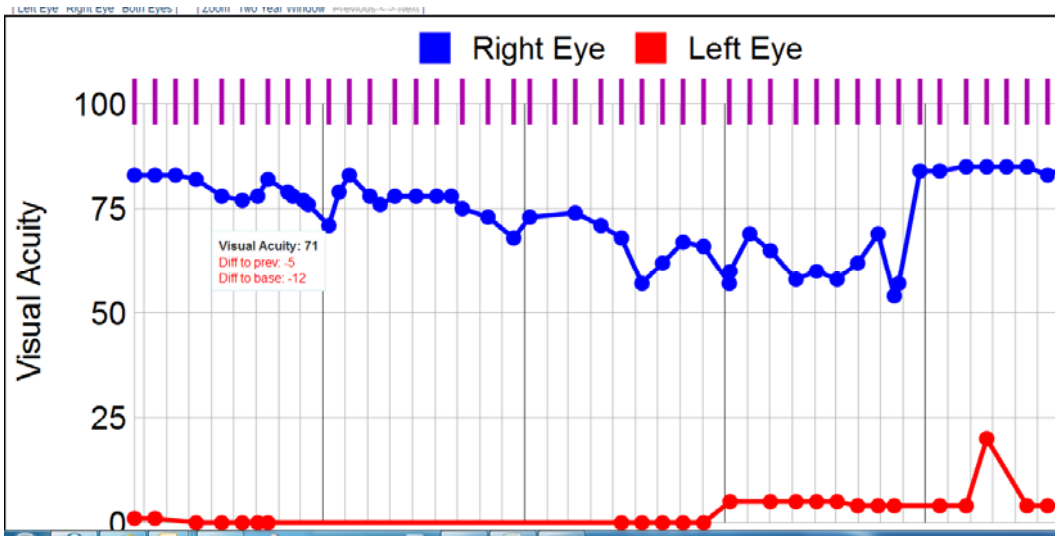
The FRB! team

From left: Daniel Barthelmes, Pari Herrera-Bond, Mila Kolmogorova, Mark Gillies

We have established an efficient, secure, internet-based system to track what type and how much macular disease is present in each eye, which treatment is given and how often. The results of treatment, including effect on vision and any side effects, are monitored. All patient data is de-identified in keeping with privacy regulations. The system also provides a graph of changes in vision during treatment. These graphs are a tool for the doctor and patient to use when monitoring and explaining the reasons for treatment. A sample graph appears below. The blue line shows the number of letters read at each visit in a patient with wet macular degeneration, while each purple bar indicates a treatment with Lucentis.

In this issue we introduce you to the Fight Retinal Blindness! Project

This patients' vision declined gradually over a couple of years despite the regular injections, but it improved greatly after her cataract was removed and is now stable. Seventy letters are what is required to get a driver's licence. This patient's other eye, which developed advanced macular degeneration before Lucentis became available, can only read 5 letters.



The first three major centres involved in this research were from Sydney University, Melbourne University and the Lions Eye Institute in Western Australia. The private practices of another 10 retinal specialists from Perth, Adelaide, Canberra and Sydney have also joined the project, bringing us closer to our goal of tracking what happens to most people being treated for macular disease in Australia.

Some clinical trials may only have a couple of hundred patients on treatment, whereas the Fight Retinal Blindness! Project will collect data on tens of thousands eventually. So far we have data on 2,000 patients, some of which go back 4 years. Even small benefits or uncommon side effects are more likely to be picked up in larger studies such as this. The information that these large numbers of patients is generating will be extremely useful in establishing how the new treatments are used to deliver the best results. In particular, we will establish what is the minimum dose that is most effective while reducing unwanted side effects.

"The information that these large numbers of patients is generating will be extremely useful in establishing how the new treatments are used to deliver the best results."

Support for the project is being sought from all "stakeholders" in the treatment of macular disease. We are particularly looking for support to engage a **biostatistician** who can commence the detailed analysis of the data that is currently accumulating.

This individual will also work to "mine" databases by linking data from sources such as the Pharmaceutical Benefits Scheme (e.g. to identify people who are receiving Lucentis treatment)

and hospital separations (the summary of what a patient went to hospital for, such as a stroke or a heart attack, which is recorded every time a patient leaves a hospital in Australia). In this way we will be able to identify whether the new treatments for macular disease might increase the risk of these diseases and issue recommendations on how to reduce this risk.

In 2012, the FRB! Project will have rolled out the latest version of the software for collection of data on patients being treated for macular degeneration and the detailed analysis of these data will commence. This will result in guidelines for treating eye doctors on how to best manage this condition which will be presented at the Australian College of Ophthalmologists meeting in November. Two new modules to collect data from other macular diseases, diabetic retinopathy and macular hole, will be added to the system.

The Fight Retinal Blindness! Project has tracked data going back 4 years from people receiving treatment with Lucentis for wet macular degeneration. Next year we will use this to test immediately whether switching to VEGF-TRAP, the new wet AMD treatment, really is as big an improvement on the current treatment that some authorities are saying it is. VEGF TRAP is planned to be released towards the end of 2012. As far as we are aware, research such as has not been done anywhere else for macular disease on this scale.

Support our research

The entire research group relies exclusively on external grants and fundraising.

To make a donation to support the Fight Retinal Blindness research team at the Save Sight Institute and the Sydney Eye Hospital, you may send a cheque to Professor Gillies made out to the “Macular Research Group” at the address below. No amount is too small or too large. Any excess funds will be used to establish a scholarship for future PhD students, of which we start around one every year.

Alternatively you may complete the enclosed donation form.

You have received this newsletter because you have, or you have shown interest in, macular disease. If you do not want to receive this newsletter, just let us know on 02 9382 7309.

www.eye.usyd.edu.au/research/macular.html

Where are we located?	**You will find us at the Save Sight Institute, located at:** **South Block, Sydney Hospital,** **8 Macquarie Street, Sydney NSW 2000**