Macular NEVS 7th Edition SPRING 20

SPRING 2013

http://sydney.edu.au/medicine/mac

To develop new treatments that reduce blindness from macular disease through multidisciplinary, patient oriented, world class research.

Our long-term goal is to prevent the development of the disease in people at risk, such as the children of patients with advanced AMD.

For further information on the FRB! Project visit our Youtube clip on:

http://youtu.be/ROyaDy **IGvpE**

FRB! Team 02 9382 7272



Fight Retinal Blindness! Project

The FRB! Project delivers a secure, internet-based software program designed to study the effectiveness of treatments for conditions, such as macular degeneration, as used in routine clinical practice. Currently most of the evidence for these treatments come from highly controlled clinical trials, with little confirmation that they work as well in the general population. FRB! is a scientific data collecting tool that currently allows doctors to track individual patient's responses to treatment of wet AMD. We hope to add modules for other conditions, such as Diabetic Retinopathy or Glaucoma, in the near future. Clinicians can monitor, track and audit patient outcomes, thus improving the treatment strategies to achieve best results for individual patients.

Currently the FRB! System is tracking outcomes of treatment from 2872 patients at 47 sites participating in the project. The information that these large numbers of patients is generating is extremely useful in establishing how the new treatments are used to deliver the best results.

^{*}Imagery by (L to R) 1. fred v, 2. guilhermeee, 3. GoRun26, 4., 6., 7. rosmary, 5. -, 8. Lori Greig @ Flickr

Macular degeneration

Macular Degeneration is the most common cause of blindness in Australians, and is estimated to cost \$A12B each year. Advanced Macular Degeneration alone results in up to 40,000 new cases of blindness in Australia each year. Two thirds of these cases can now be treated with new antivascular endothelial growth factor drugs (anti-VEGF). We aim to develop guidelines that will enable the new treatments to be implemented in the safest and most effective ways.

Recent Findings from the Project

We have recently reported two significant studies. The first was conducted to determine, using our non-identifiable data on eyes treated for wet AMD, what effect the "activity" (i.e. bleeding and leaking causing swelling of the macula) of the abnormal blood vessels that grow into degenerating maculas in wet AMD had on patient outcomes. The anti-VEGF drugs that we are inject into the eye stop the growth, leakage and bleeding of new blood vessels, making them "inactive" and reducing the risk of scarring and further loss of vision. We expected to find that eyes with abnormal blood vessels that remained active despite treatment would do worse than eyes that quickly responded to treatment (became inactive).

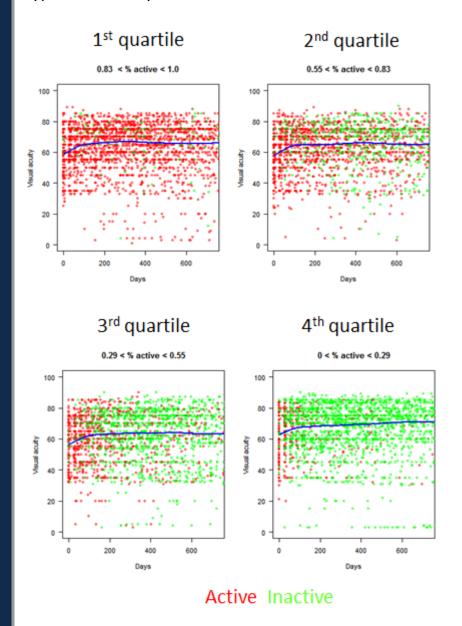
For each patient visit over a twelve month period, we were able to calculate, for each eye, the proportion of visits at which the lesion was graded active. Eyes were divided into four groups, Persistent, High, Moderate and Low activity. The visual acuity change from the patients' first anti-VEGF treatment to the end of the 12 month period was recorded as well as the number of injections the eye received.

The "scatter plots" below show the 4 activity groups. Each dot represents a measurement of visual acuity (vertical axis) during 12 months of treatment. A red dot indicates the eye was graded "active" while a green dot represents "inactive" status. The blue line fitted to the data shows the average group changes in vision (number of letters read on an eye chart) over time. Contrary to our expectations, we found that the most persistently active group gained almost as much vision as the group with the lowest lesion activity. Further studies are needed to confirm our findings, but this suggests that doctors may be able to accept some activity and still get good vision improvements in wet AMD, possibly resulting in a need for fewer injections. But this is

Support our research

The entire research group relies exclusively on external grants and fundraising. To make a donation to support the Macular 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: South Block Sydney Hospital, 8 Macquarie Street, Sydney NSW 2000. No amount is too small or too large, or you may consider remembering us when you make your will. Some people may not be in a position to give anything, and that's OK as well. We realise that many people with macular disease are pensioners. Funds from this mail-out will be used to support these and other exploratory projects of the Macular Research Group. We thank you for your support.

definitely something people should discuss with their doctor because every case is different and there are many different types of "activity".



The second study that we have recently published in *Ophthalmology*, the leading journal in our field, examined how the eye injections for wet AMD actually work in the general population compared with the original clinical trials that were conducted 10 years ago. The main clinical trial was the MARINA study, which reported that Lucentis was effective but it was conducted under ideal and standardised conditions on selected patients so it may not apply to the general population. The vision outcomes of patients treated with Lucentis over 12 months in the MARINA study and patients from our own "real

Where are we located?

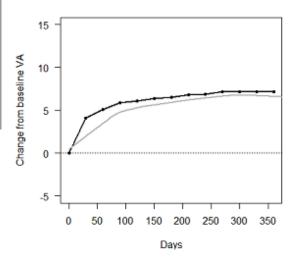
You will find us at the Save Sight Institute,

South Block Sydney Hospital, 8 Macquarie Street, Sydney NSW 2000

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world" patients who would also have been accepted into the MARINA study were compared.

The graph below shows the change in vision (letters read on a chart) for both groups. The black line is the change in visual acuity for patients treated in the MARINA clinical trial, while the grey line is our FRB! "observational study" data. The similarity of visual acuity improvement in the FRB! observational data with that of the phase III clinical trial suggests reassuringly that the results from the clinical trial can be achieved in real world clinical practice, at least for this treatment for wet AMD. Interestingly, the average number of injections from the FRB patients was 7 compared with 12 for MARINA in which injections were given every month. So it appears that many, perhaps most, patients, do not need monthly injections as was initially recommended.



FRB! Team



FRB! Team (R-L)

Chief Investigator: Prof. Mark Gillies

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Project Co-ordinator: Courtney Weston Project Manager: Amparo Herrera-Bond

Biostatistician: Richard Walton