



# The View

News from the Ocular Repair Group at the Save Sight Institute



Welcome to *The View*, a newsletter for patients wishing to stay up-to-date on the latest research developments in ocular repair and regeneration.

The Ocular Repair Group has three major projects: Fight Corneal Blindness! (FCB!) Serious Ocular Infection, and Dry Eye. This issue will focus on FCB! and its Keratoconus Registry.

Our research relies exclusively on external grants and fundraising.

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

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

Leader, Ocular Repair  
Save Sight Institute

## Save Sight Registries and the development of the Fight Corneal Blindness! Project

The **Fight Corneal Blindness! (FCB!)** project is a web-based registry able to collect high quality outcomes data from patients with corneal disease in real-life clinical settings.

Clinicians engaged with the FCB! project form a network of experts working towards improving patient outcomes.

The FCB! project is a module in the Save Sight Registries (SSR), which was established in 2009, with the flagship Fight Retinal Blindness! (FRB!) project.

The **Save Sight Keratoconus Registry** is the first module of the FCB! project. Data collected on patients with keratoconus focusses on outcomes of treatment including corneal crosslinking (CXL), a new technique that utilises riboflavin and UVA to strengthen the cornea, to stop the progression of keratoconus. Patients with keratoconus are able to input the impact of their condition directly into the system.

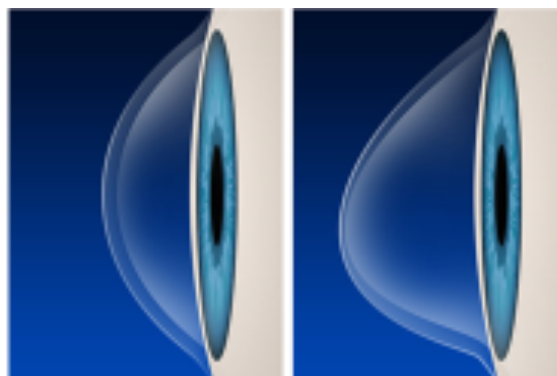
### The story so far...

Keratoconus, affecting 1 in 2000, progressively reduces vision. Onset occurs between childhood and young adulthood and brings with it the burden of life-long visual disability. Keratoconus bears significant cost to the individual and health system. Quality of life for keratoconics can be lower than that for macular disease, with mental health, driving, dependency and ocular comfort affected.

In keratoconus, vision may be corrected by spectacles or contact lenses. If this is not possible, patient corneal grafting may be needed and carries with it a life-long risk of graft rejection. In the case of weakening of the eye's stucture, corneal crosslinking may be needed.

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Figure 1: Normal cornea versus Keratoconic cornea



# Meet the FCB! Team



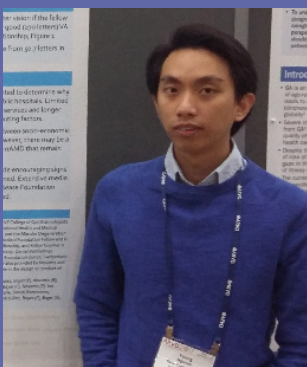
Professor Stephanie Watson  
Chief-Investigator



Amparo Herrera-Bond  
Project Manager



Dr Alex Ferdi  
PhD Student



Dr Vuong Nguyen  
Biostatistician

## What does the Save Sight Keratoconus Registry offer?

The **Save Sight Keratoconus Registry's** 'real life' data informs patients, clinicians and other stakeholders of the effectiveness of treatments for keratoconus. Through the user-friendly platform, treating clinicians can easily monitor the effectiveness of treatment administered to each individual patient (Figure 2).

The **Save Sight Keratoconus Registry** is supported by a National Steering Committee of experts and a Patient Advisory Committee, which ensures the project meets the needs of both clinicians and patients.

**2** Figure 2: The Treatment Journey of a Patient with Keratoconus



This graph summarises a patient's treatment journey for the right eye (blue) and left eye (red) and visual outcomes (y-axis) since 2011 (x-axis) whose keratoconus has been treated with corneal crosslinking.



Margaret Lam presenting at Kera Club 2016.

## Patient reported outcomes

At the Save Sight Institute, we recognise how much keratoconus can affect a person's life.

Information about how you cope with your keratoconus 'day to day' is really valuable as it gives us insight into how your quality of life is affected by your disease.

The Registry has implemented a patient survey, developed by Professor Konrad Pesudovs from Flinders University, South Australia\* to collect data on how your keratoconus is affecting you.

The patient survey complements our readings of your eyes so we can tell if your keratoconus is getting worse. Not only is this helpful for us but we can help you understand how your eyes and needs are changing.

In the future, we aim to use this tool to look at how surgeries, like cross-linking and corneal transplants, affect the quality of life for different people and hopefully find out who really benefits from surgery and who doesn't.

## But wait, there's more!

The annual **Kera Club** has become an important event on the **FCB!**'s calendar. Co-founded with Keratoconus Australia and hosted by Michelle Urqhart, the evening provides a unique opportunity for patients and their family and friends to meet and hear updates on research breakthroughs and treatment options. It provides an opportunity to network and share their individual stories of success and difficulties in a safe and supportive environment.

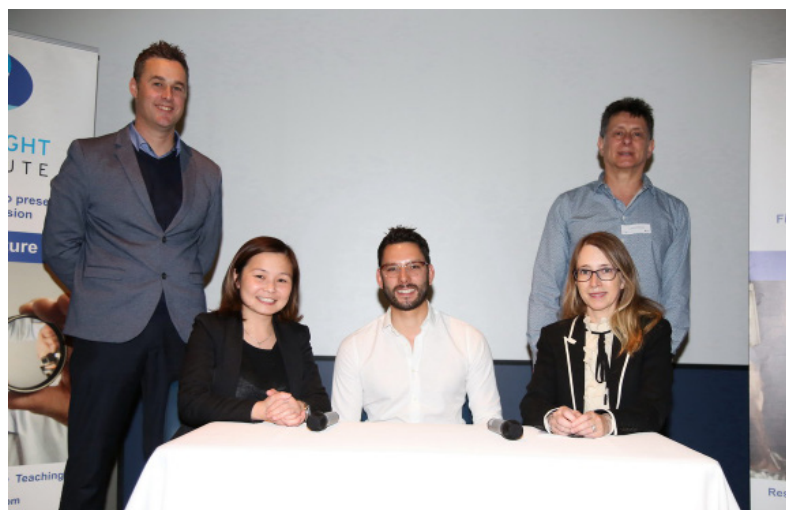
**Please join us at our next event:**  
**Kera Club** event will be held on  
**Thursday 2nd November from 6pm.**  
Registrations are online at:  
<https://kera-club-2017.eventbrite.com.au>

\*Based on research conducted by Pesudovs, Konrad and Khadka, Jyoti and their The Keratoconus Outcomes Research Questionnaire (KORQ)

## What's the future?

The future of the **FCB!** is promising. The number of consultants entering data into the system is growing rapidly, with annual growth over 60 percent and data from 10,000 patient visits. The dataset will allow us to determine the correct timing and choice of treatment for patients with keratoconus.

**FCB!** is gaining international recognition, with a growing number of centres world-wide. We are expanding collaborative efforts across the eye health care sector will allow the **FCB!** to meet the needs of clinicians, patients and stakeholders.



*L to R: Mark Koszek, Margaret Lam, Dr Alex Ferdi, Prof Stephanie Watson and Larry Kornhauser (Keratoconus Australia) at a recent Clinician Education event for optometrists and general practitioners.*



*L to R: Larry Kornhauser (Keratoconus Australia), Margaret Lam and Prof Stephanie Watson answering questions during Kera Club 2016*

# How you can help



## Spread the word



Know someone with keratoconus? Do you have keratoconus yourself?  
Would you just like to know more about your eye health?

Sign up to receive our newsletter



Join our Facebook page @savesightinstitute



and receive updates on upcoming events and research breakthroughs.

# Support Eye Research

Like all research projects at the Save Sight Institute, the FCB! project relies 100 percent on grants and donations. A donation to the FCB! project means they can continue to grow the registry, hold important community engagement events and continue to ensure that patient perspectives and outcomes are monitored, enabling the best treatments to be recognised and become standard practice.

You can also call (02) 9382 7306 to make a credit card donation. **Donations over \$2.00 are tax deductible.** Save Sight Institute is a centre of The University of Sydney.

### Our FCB! project team:

Professor Stephanie Watson (leader), Dr Alex Ferdi, Amparo Herrera-Bond, Dr Vuong Nguyen, Professor Mark Gillies, Dymow Barbosa, Marco Garcia and Sharon Irvine.

### Our Supporters:

Keratoconus Australia, Mr Larry Kornhauser, The Claffy Foundation, Ophthalmic Research Institute of Australia, NHMRC, Cornea & Contact Lens Society of Australia, NSW Health.

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