



Welcome to the Kera-News. In this issue, I am pleased to share with you updates on our work including cutting-edge research and community events to support people with keratoconus.

Our work relies exclusively on external grants and fundraising. If you are in a position to support keratoconus research, please know that we are extremely grateful and that your donation will be well used.

Thank you for your support.

Professor Stephanie Watson  
Head, Corneal Research Group  
Save Sight Institute  
The University of Sydney

## Save Sight Registries (SSR): Fight Corneal Blindness! (FCB!) Project

The 'Save Sight Keratoconus Registry' (SSKR) is a world-first web-based simple yet powerful tool to collect data, including patient reported outcomes (PROMs), from a patient visit in under 60 seconds. The SSKR started in 2014 and now has over 35,000 patient visits; it is the world's largest keratoconus registry. It provides difficult to collect real world evidence on keratoconus and its treatment.

The SSKR and Save Sight Dry eye Registry (SSDR) are world-first cross-disciplinary registries actively collecting data from both ophthalmologists and optometrists. The Save Sight Registry's automatically generated reports allow clinicians to show patients their treatment journey and audit their practice (CPD accredited Royal Australian and New Zealand College of Ophthalmologists (RANZCO), Optometry Australia) and compare to benchmarks, driving improvements in care. They enable outcomes research, with the ultimate intent of enhancing care for people living with keratoconus and dry eye.



THE UNIVERSITY OF  
**SYDNEY**

Save Sight  
Institute



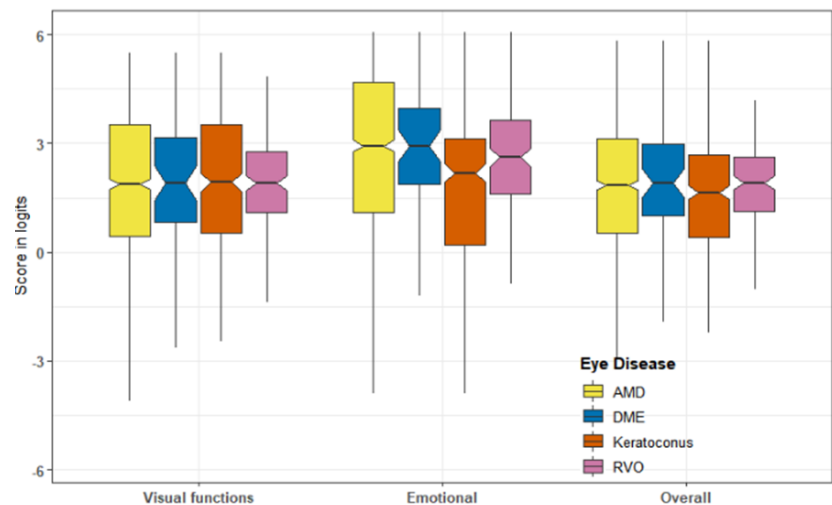
**Save Sight  
Registries**

Seeing Outcomes

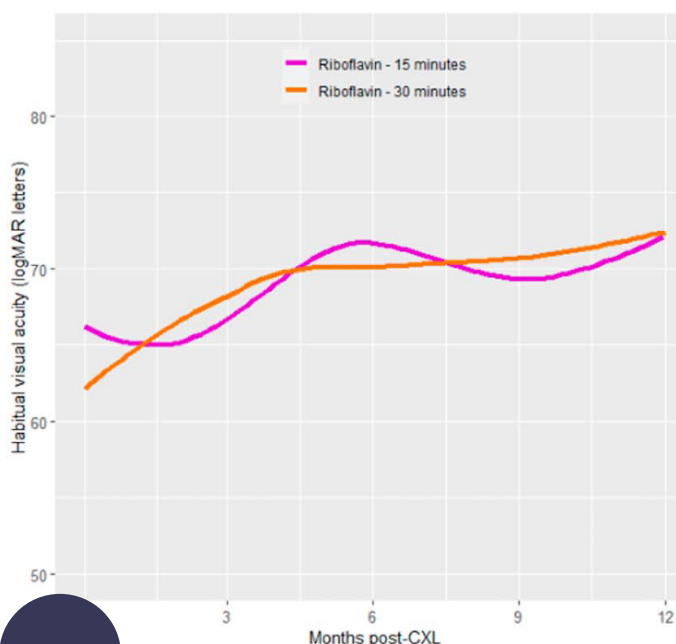
# WORLD-FIRST REGISTRY RESEARCH

## Quality of life impact of keratoconus

- In keratoconus, Quality of Life scores (QoL, Impact of Vision Impairment questionnaire scores) were worse than for retinal diseases, especially for emotional domain.
- Quality of life was lower if the visual acuity was poorer but this relationship was weak. We need more research to understand this finding and develop ways to improve QoL.



## Corneal cross-linking with standard vs short riboflavin induction



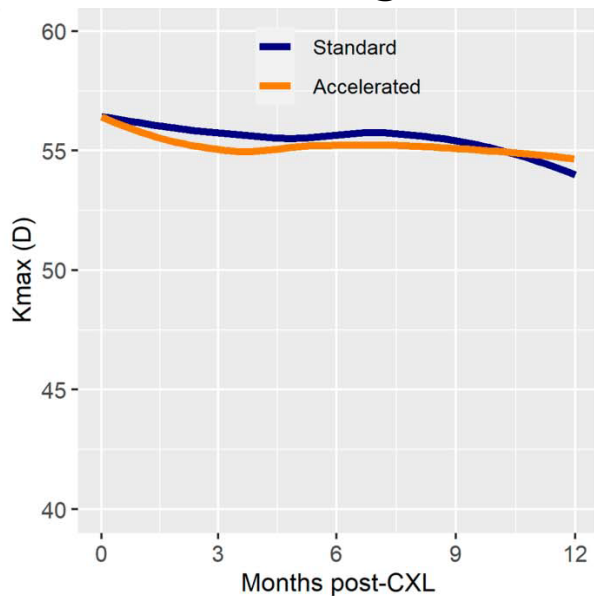
- For corneal cross-linking, the patients who had riboflavin induction for 30 minutes or 15 minutes, at one year of follow-up, had similar results in terms of K2 and visual acuity (VA). The 15 minutes group though had better outcomes in Kmax and minimum corneal thickness (MCT) but with higher rates of haze - without impact on the final VA. Shorter riboflavin induction times can be considered for cross-linking.
- Our study was the first to compare different riboflavin times. It provides new data to guide practice and inform patients.
- Longer term follow up data is now needed.

# Natural history of keratoconus



- Steeper Kmax and younger age were the most clinically useful baseline predictors of keratoconus progression; they were associated with worsening of two clinical parameters:
  - Every 1D steeper Kmax was associated with a 7% and 3% greater risk of worsening VA and thinning MCT, respectively.
  - Each 1 year younger was associated with a 4% and 2% greater risk of steepening Kmax and thinning MCT, respectively.

## Corneal cross-linking with long vs short time UV exposure



- Corneal cross-linking with both long (30 min) and short (10 min) UV light exposure were found to be similarly safe and effective in stabilizing keratoconus at 1-year post-surgery in the real-world setting.
- These findings supported the adoption of short corneal cross-linking for time and convenience.

## Weak association of dry eye signs with symptoms



- In a Save Sight Dry Eye Registry study, we found that evaporative dry eye was more common and less symptomatic than aqueous deficient dry eye in the real-world setting.
- The Ocular Surface Disease Index score was not correlated with ocular surface staining, Schirmer's test, and tear-film break up time.
- The results highlighted that signs and symptoms of dry eye have weak association and complement each other.
- Appropriately evaluating patient-reported outcomes, particularly symptoms, in clinical practice is essential.



# KeraClub 2022



This year, the 7th annual KeraClub, an event for people with keratoconus, will be held as a hybrid event: face-to-face and a webinar on 04 August. The KeraClub is a joint initiative of Save Sight Institute, The University of Sydney, and Keratoconus Australia.

This year's talks include topics on 'What's next for the patients with keratoconus?' and the 'Save Sight Keratoconus Registry updates'. Scan the QR code to find out more and register for the KeraClub 2022.



To get alerts on our community events & the latest research findings:



Follow us

@CornealResearch

@profswatson

@kandelhimal



Sign up at

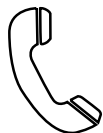
<https://eepurl.com/dvSQtz>

or scan the QR code



Contact us at:

[ssi.ssr@sydney.edu.au](mailto:ssi.ssr@sydney.edu.au)



+61 2 9382 7304

+61 2 9552 2539

(Gift hotline number)



Listen to the

Sydney Eye Podcast

## Support our Research

We can't do what we do without the support of our patients and community. Our research is funded 100% by grants, donations and bequests.

To help us find new and improved ways to save sight, please consider making a donation to the Corneal Research Group via our donation form online at: <https://www.sydney.edu.au/save-sight-institute/support-us/donate.html> [or scan the QR code ]

& select '**DONATE NOW**' & then '**CORNEAL RESEARCH GROUP**'



Donations over \$2 are tax deductible.

If you are interested in discussing making a substantial contribution to The Corneal Research Group, please contact Narina Janian ([narina.janian@sydney.edu.au](mailto:narina.janian@sydney.edu.au) or 0437 533 725)



THE UNIVERSITY OF  
**SYDNEY**

Save Sight  
Institute



**Save Sight  
Registries**

*Seeing Outcomes*