



ANNUAL 2023 REPORT

The Year in Review



Mission Statement



MISSION STATEMENT

Keratoconus Australia Inc is a not-for-profit association created to prevent and control the eye disease, keratoconus, and visual impairment caused by keratoconus. The Association was registered in April 2000 and is operated by volunteers. It is entirely self-funded from donations.

A committee of management administers the Association. All committee members have keratoconus or are parents or carers of children with keratoconus.

Full membership of the Association is open only to people with keratoconus or the parents and guardians of minors with keratoconus. Anybody can become a supporter of the Association or assist with its work.

Keratoconus Australia believes there are a number of ways to prevent and control the impact of keratoconus in the community. Our efforts are directed in particular at:

- (1) raising the awareness and understanding in the medical, optometric and general community of keratoconus, its signs, symptoms and effects;
- (2) promoting research into the causes, prevention and control of keratoconus; and
- (3) acting as a representative body on behalf of Australians with keratoconus and providing, where necessary, counselling, support and referrals to the people with keratoconus and their families.

We provide support for people with keratoconus and their families through regular group and public meetings, help lines, individual counselling and the dissemination of information.

We are also:

- Assisting people to find optometrists and ophthalmologists / corneal surgeons experienced in treating keratoconus
- Helping to develop a network of support groups throughout Australia
- Disseminating information on a wide range of issues affecting people with keratoconus via printed and electronic means, including newsletters and social media, and the annual KeraClub meeting
- Acting as a representative group for keratoconus patients to improve affordability and accessibility of treatments (contact lens and solutions, spectacles) and corneal surgery for all, with special focus on assisting socially and economically disadvantaged persons with keratoconus
- Leading efforts within the Australian vision community to assist persons suffering mental health issues due to vision impairment from keratoconus and other conditions.

Keratoconus Australia acknowledges and pays respect to the First Nations people throughout Australia as the Traditional Custodians of the land, sea and community in which we work, meet, live and play. We pay our respects to Elders past and present, and extend that respect to all Aboriginal and Torres Strait Islander peoples today in their ongoing fight for their rights, recognition, culture and vision for a brighter future.

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From the President



FROM THE PRESIDENT

Where to now?

As Keratoconus Australia approaches almost a quarter of century of delivering support to the keratoconus community, advocating on its behalf, promoting research and eye-carer training to improve outcomes for patients and their families, it's time to ask the question.

At a meeting last August of the Association's committee of management, I argued that the current model of a volunteer-based, self-funded association of people with keratoconus was simply not meeting the needs of our community any more. Too few people are doing too much on a budget that is too small and too unreliable.

That is not to say we are failing in our mission. Quite the contrary. I believe our achievements are many and praiseworthy. A review of our past annual reports illustrates that fact. However much has changed since that wintry night in 1999 when a group of keratoconus patients huddled in a Melbourne café to discuss their experiences with keratoconus and whether their lives could be improved by the creation of a peer support group. Back then, rigid gas permeable lenses ruled the roost, 15-20% of patients received corneal transplants due to contact lens failures and the Australian population of keratoconus patients was estimated officially at 15,000. Research into causes and cures for keratoconus was non-existent and there was a dwindling number of optometrists with competent skills in fitting the rigid gas permeable contact lenses required by anybody with more than mild keratoconus.

Twenty-four years later the keratoconus landscape is unrecognizable. Over the past 10 years, the widespread introduction of corneal collagen crosslinking (Medicare-funded since 2018) to stop disease progression and of speciality hybrid and corneal scleral contact lenses to fit advanced keratoconus have slashed corneal transplantation rates to less than 5% of the keratoconus population. Many of those are regrafts for older patients who never benefited from crosslinking. Two of Australia's leading eye research institutes, the Centre for Eye Research Australia and the Save Sight Institute have created keratoconus-specific registries to track keratoconus patient histories, quality of

life outcomes and investigate how bioengineering and artificial intelligence can be used to diagnose and treat vision loss from keratoconus.

Driving the new interest in keratoconus are studies that show prevalence of keratoconus could be many times higher than ever imagined and could be increasing in certain regions due to a range of genetic and environmental factors. Bigger markets attract bigger dollars.

As I described at our recent KeraClub webinar, we are now dealing with a larger pool of keratoconus patients who have less severe disease and a much wider range of treatment options. Thanks to our efforts, the eye health sector is finally acknowledging that low vision patients require specialised mental health care. The Australian Keratoconus Facebook support group operated by our members is another avenue for patients to discuss their issues directly online with Australian patients.

That could mean there is less need for the more traditional one-to-one support Keratoconus Australia has provided in the past. Should we focus more of our attention towards advocacy and promotional activities? Can that be achieved under the existing structure or should we transform into a foundation? In the absence of government funding, do we require corporate partnerships to strengthen our financial base and to enable us to shift away from the volunteer model towards a structure involving paid staff? Certainly, it has proved challenging over recent years to recruit self-motivated, committed volunteers. I thank everyone who has responded but unfortunately their input has not proved sufficient to advance many of the projects we had envisaged. Of course, COVID-19 and its enormous impact on our lives can be largely blamed and no volunteer based not-for-profit organisation has been immune from the COVID-19 effect.

Next year, the committee will conduct a full and frank discussion about the future of Keratoconus Australia. It is long overdue. The need was highlighted in our consultations with a public relations firm last May about our plans for a major eye rubbing prevention campaign. All options will be on the table – including my departure and the dissolution of the Association.

Everybody is welcome to join the conversation, bring their ideas and their energy to create a new future. It's time for change. Only you can make it happen.

Larry Kornhauser OAM
president@keratoconus.org.au
December 2023



Support



SUPPORT

INTRODUCTION

Keratoconus Australia's principal purpose is to provide peer support for people with keratoconus and their families and carers.

The Association is operated by people with keratoconus. We do not have medical qualifications or training nor do we provide medical advice or professional counselling. So please don't ask us for opinions on your eye conditions.

What we do have is long experience with living with keratoconus. We listen to patients and family members about their experiences with keratoconus. We recount our own experiences to help them understand how others are living with keratoconus.

We have access to a range of experienced optometrists and corneal surgeons working in the field of keratoconus and all medical questions are directed to these eye-carers for their expert opinion.



However, nobody can provide an opinion on a patient's individual issue without a full in-person examination of a patient's eye. Nor should they. Even a medical practitioner will provide clear and considered advice on keratoconus treatment and management options only after conducting such an examination. Which is why any guidance coming via Keratoconus Australia will always be non-patient specific and general in nature. The Association recommends that whenever possible, patients consult only clinicians experienced in keratoconus and who specialise in the disease to achieve optimal outcomes.

Never delay seeking medical advice if your vision is changing.

TRENDS IN SUPPORT

The latest year saw a sharp decline in requests for support from the keratoconus community as patients regained better access to their eye-carers after several years affected by COVID-19 lockdowns and appointment backlogs, etc. The number of support contacts logged by Keratoconus Australia totalled around 260 or almost half the previous year's total of 490 (-47%). All categories of support were down by close to the average with the major exception being support relating to mental health and ways of living successfully with keratoconus.

The impact of crosslinking on disease severity is translating into less need for specialised support as more keratoconus is being treated successfully in the early stages. This is a significant development and one that was always predicted as an outcome of the widespread safe and effective use of crosslinking. Corneal transplantation rates in particular have fallen dramatically over the past decade and researchers say transplants are now required by less than 5% of new keratoconus patients. (Given the limited life-span of grafts, existing graft recipients will probably continue to maintain demand for re-grafts at lower level).

However, the nature of support provided highlighted the fact that issues of access to eye-carers experienced in keratoconus remain a major problem for many patients while affordability of all treatments but notably contact lenses needs to be addressed urgently. The Association is constantly dealing with anxious patients who simply cannot afford speciality contact lenses (scleral and hybrid lenses) and some of the off-Medicare surgery being offered to them.

ACCESSIBILITY

Since its creation, the Association has devoted much of its support effort towards assisting patients and their families find eye-carers – especially contact lens fitters - experienced in keratoconus in their local areas. Direct requests for information about local eye-carers has always accounted for around 40-50% of total support contacts logged. In the 2022-2023 financial year these requests amounted to 40% of the total.

The Association also assists existing members who are relocating to other areas to find new eye-carers as well as international students, new migrants, returning expatriates and others arriving in Australia.

Optometrists have played a bigger role in assisting patients and the Association in improving access with the creation of Find An Optometrist/Practitioner search pages on the Optometry Australia and Corneal and Contact Lens Society of Australia websites which allow searches by location and speciality.

AFFORDABILITY

For many years now, we have reported that requests for assistance in finding an expert fitter of speciality contact lenses for keratoconus often arise from an affordability issue, with the patient seeking an eye-carer who will bulk bill or who works in a clinic offering discounted or subsidised contact lenses. More recently, some patients are asking to find a new optometrist who will offer a payment plan to enable them to defer the high up-front costs of speciality contact lenses over time.



Although we have logged only 6% of total support as directly related to affordability issues, a recent patient poll conducted at KeraClub 2023 meeting found over 80% of attendees were concerned about the rising cost of treatments, especially in contact lenses.

The Association's website includes a special section on the **Resources** page listing all the subsidised spectacle and contact lens schemes operated in each Australian State and Territory. It also collaborates with clinics in Victoria, NSW and Queensland offering discounted lenses to health and non-health card holders.

In addition to these direct requests for help in locating proficient keratoconus clinicians or more affordable treatment options, most other patient support

interactions, for whatever initial reason, usually conclude with the Association assisting the patient to find an expert keratoconus practitioner.

EYE RUBBING

One recurring theme in support relates to the widespread prevalence of eye rubbing amongst patients. The Association is constantly reminding members and posting to its socials about the dangers of eye rubbing which is the only patient-controllable factor in the progression of keratoconus. Some ophthalmologists even believe eye rubbing is the fundamental cause of keratoconus and that



stopping can have almost the same impact on progression as corneal collagen crosslinking. Researchers also believe that eye rubbing may be a significant factor in the increasing prevalence of keratoconus. The Association provides all new members with a flyer on the dangers of eye rubbing and how to stop doing it. We also inform all people contacting us for support that eye rubbing should be

avoided as much as possible. The issue was highlighted at KeraClub 2022 (see **Events**)

Data collated by Keratoconus Australia continues to show that **64% or almost two-thirds of our new members since 2015 admit they either rub their vigorously or have done so in the past.** This is a public health issue that needs to be addressed by eye health policy makers.

LIVING WITH KERATOCONUS AND MENTAL HEALTH

Living with keratoconus is not easy and the prospect of life-long vision impairment is certainly upsetting and can be a trigger for stress and anxiety. The arrival of COVID-19 in 2020 and the resulting restricted access to eye-carers all added to concerns of patients and their families. While fear of COVID-19 may have abated somewhat, other factors continue to create pressures for people with keratoconus.

- Young patients – especially teenagers – can experience difficulties with using contact lenses and may continue to progress even after crosslinking.
- Better early screening is required. Corneal surgeons say that too many patients are still being diagnosed too late for crosslinking to be performed on their thin corneas.

- The issues of access to and cost of treatments have a huge impact on the mental health of patients and their families
- Higher prevalence rates of keratoconus due to a range of possible factors, including eye rubbing, genetic factors and excess UV exposure are increasing the need for support at the diagnosis stage to ensure patients are reassured about their prognosis and receive the necessary treatments.

Everyone involved with Keratoconus Australia has keratoconus and so we understand that feeling when you receive the news of a keratoconus diagnosis. Keratoconus Australia was founded to help comfort patients, support them as they traverse the stages of keratoconus and direct them to the eye-carers who can restore and maintain their vision. Most people can then return to a fairly normal life.



Our peer group support is a critical element in that process as many have never spoken to another person with keratoconus in their lives. Sharing experiences is immensely therapeutic and provides patients with examples of positive outcomes and offers hope for the future.

However, we are not trained counsellors and if necessary, we will always direct patients to their own general practitioners, psychologists or mental health services.

PATIENT INFORMATION

Keratoconus Australia sends new members a range of information material about keratoconus and specific treatments and issues such as corneal collagen crosslinking and eye rubbing. We urge members to request this free information material from us in whatever format they prefer.

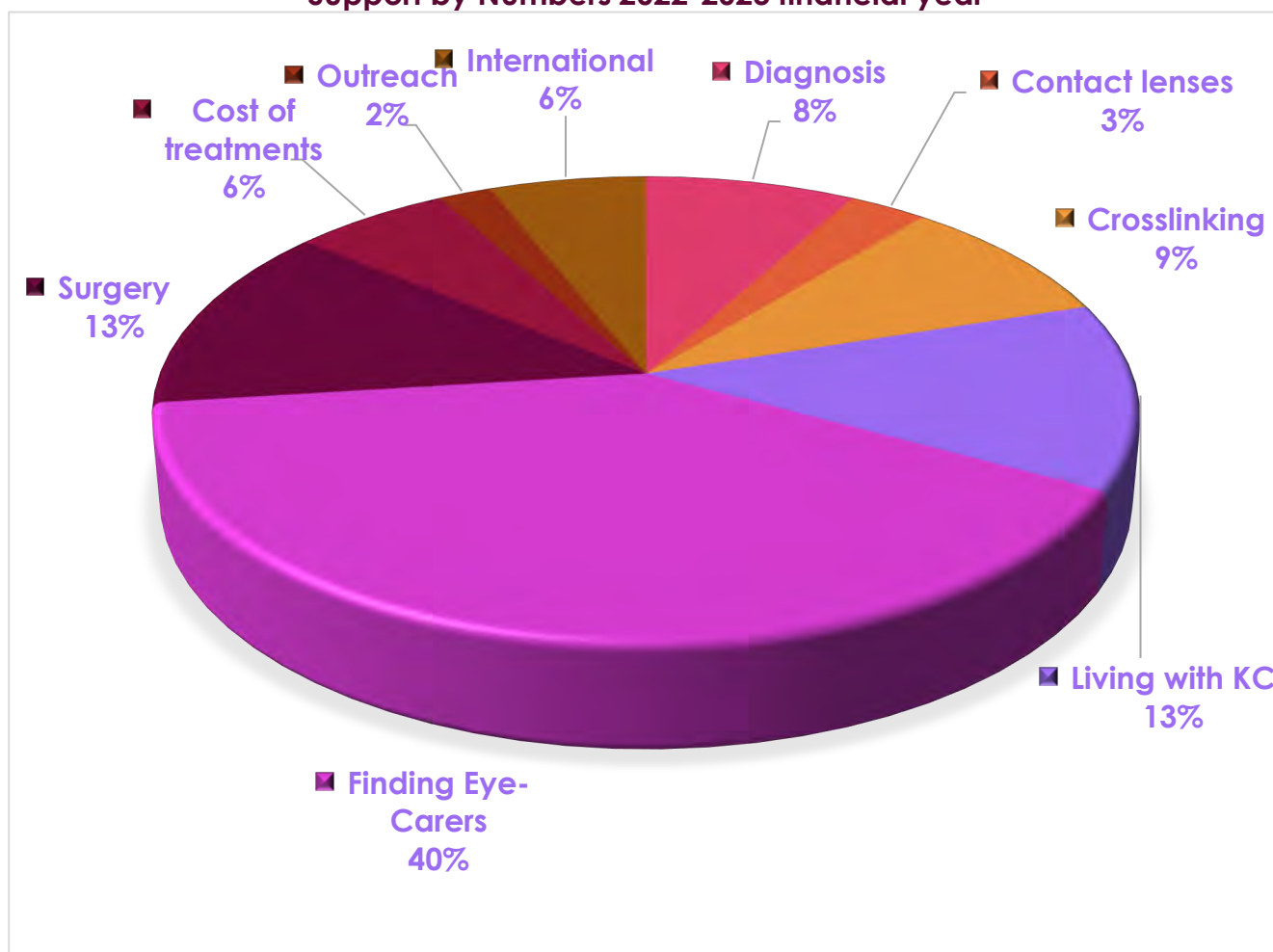
Many of the answers to patient questions can also be found on the **Treatments** and **FAQ** pages our website.

SUPPORT BY NUMBERS

Support contacts logged by the Association In the 2022-2023 financial year fell 47% to 260. Assistance in finding eye-carers accounted for 40% of the total followed support for people undergoing surgery (crosslinking and grafts – 22%), and people experiencing issues with the affordability of treatments and living with keratoconus. Support after diagnosis accounted for 8% of the total last year.

The pie chart below highlights the Association's support activities in 2022-23 by type of support given to patients.

Support by Numbers 2022-2023 financial year



SUPPORT BY EXAMPLE

Keratoconus Australia offers members and anybody with keratoconus free support. People contact us with a range of issues and we do our best to assist them based on our experiences.

Below are some examples of support we provided in 2022-23.

- Russell had corneal collagen crosslinking done but had no improvement in vision. He said he couldn't afford a corneal transplant and can't work without his sight. Centrelink refused assistance as keratoconus is not a disability.
We explained that crosslinking does not usually improve vision, only stabilises it. We told him corneal transplants were available via Medicare in public hospitals. We asked if he had tried contact lenses. He hadn't been told about them so we directed him to speciality contact lens fitter in his area.
- Ali wanted information about corneal transplants. We directed him to our website page on the topic and sent him a free corneal transplant booklet.
- Andrew was looking for a corneal surgeon to perform either crosslinking or a corneal transplant under the public system. We explained they are completely different operations and done for different reasons. We explained where he could have the procedures done, how to obtain referrals and provided the names of some corneal surgeons in his area.
- Alan needed his driver's licence renewed and wanted an eye examination but his regular optometrist had moved to another practice. He was very concerned as he was his wife's full-time carer. We located the optometrist and sent him the details, thus relieving his anxiety.
- Linda's son had a poor contact lens fit from a chain eye store. She was looking for a more experienced contact lens fitter for keratoconus. We helped her find one in her area.
- Pino was suffering from glare and wanted better sunglasses. We suggested some types and brands of sunglasses more appropriate to his situation.
- Reece was concerned about his poor vision in his left eye and progression in his other eye. He was booked in for crosslinking but didn't understand why the bad eye was being done first. We explained that crosslinking had to be done before the cornea was too thin. We also advised him to minimise his habitual eye rubbing and provided him with information on

how to stop. We also sent him a list of contact lens fitters for keratoconus in his area.

- Greg wanted to know how other patients managed to travel overseas without wearing contact lenses on long flights. We discussed with him the back-up glasses option. He asked his optometrist about them but she was unable to assist him with a suitable script.
- Stacey broke her contact lens and needed an immediate replacement. As she was also undergoing cancer treatment, we asked around to find the closest practitioner to minimise the travel and inconvenience to her in her already difficult circumstances.
- Noel has deteriorating vision despite numerous attempts with contact lenses. We chatted to him about the need for a corneal transplant and have helped him over the past year to change surgeons and arrange a corneal transplant in the new year.
- Roxanne has 20 year old grafts and needs new ones. She has also started eye rubbing and was wondering if that was a sign of a failing graft. She asked if she should seek an earlier appointment with her ophthalmologist. We suggested she seek an immediate appointment with her optometrist if she couldn't book an appointment with her surgeon. We said her itchy eyes were probably due to an allergy and she should have that checked and treated quickly.
- Ahmed was poorly fitted with contact lenses and then referred for a corneal transplant. He could not afford a private surgeon and cancelled the operation. He was looking for alternatives.
We suggested he try another contact lens fitter and then get a referral to a public eye hospital if a corneal transplant was still deemed necessary. We provided him the names of some expert fitters of speciality contact lenses for keratoconus in his area.

Not all support works out for the patient or their family. In some cases, patients are unable to afford treatments and we try to find them options through the public health system. Where patients are unable to travel from regional or remote areas for treatment in metropolitan areas, we try to help arrange collaboration between their local eye-carer and colleagues more experienced in keratoconus.

The point is that failure is not an option for people suffering vision impairment. Some eye-carers give up with "difficult" patients and tell them not to return. That may resolve the problem for the eye-carer but it still leaves the patient without

useable vision. Our aim is always to help a patient find a solution to restore their functional vision to enable them to live and work in the community.

NOTES OF APPRECIATION

Volunteers at Keratoconus Australia offer their time freely to improve the lives of others with keratoconus. Many patients are very young and a sudden diminution of sight can be a very scary thing for all concerned. We don't seek praise for our work. But it's nice when a patient or family sends a note of appreciation or an update to let us know how our support work made a difference to their lives. Here is a sample of the kind words written to us in the past year.

- Tom moved to Melbourne and needed to find a contact lens fitter for keratoconus. We sent him a list of options.

Hi there. Really appreciate the list - thank you. I have registered with Keratoconus Australia.

- Adam was having trouble with his vision after cataract operations and wanted a second opinion from another ophthalmologist. We sent him a list of alternatives. He was very happy with the outcome.

I went and saw one of the doctors listed below. So good advice from him and a better explanation. So left eye cataracts put on hold. I have really good vision in that eye. He said the eye and brain had found the sweet spot

Cataract op in right eye had just missed to spot and a secondary's bulge of the cornea is involved. They are going to put a piggyback Toric lens. I had an amazing appointment with his practices optometrist; so different. A whole different power. Can't remember my other doctor doing a power test for the lens he put in. So thanks for the recommendations I have learnt a lot more.

- Ronit's son was having trouble at his school, which did not understand the particular keratoconus-related issues he was experiencing – both visual and relating to his mental health. Asked if we could provide information on keratoconus, we provided our free keratoconus booklet and also suggested her son see an expert fitter of speciality contact lenses for keratoconus to improve his vision. We also offered to speak to the school.

Below are extracts from Ronit's reply

Thank you so much for your time on the phone. You really helped a great deal. (My son) was diagnosed earlier in the year and until now did I only realise what kind of disease he has and how it can impact his life. The last couple of years, especially this year, I knew there was something I was missing because of the way he has behaving at school and preferring to be at home on his PlayStation. He has had school refusal too this year and now I'm understanding why this could be.

... In the meantime if you have any further advice, articles or references that may be beneficial, please send them to me.

... Thank you so much. You have really helped me feel better about of all this. And made me understand this is not a quick fix disease.

- Sonia was seeing a corneal surgeon about having a corneal transplant and wanted some information about the procedure. We sent her our booklet on grafts.

Thanks so much for the booklets they were very informative and helpful when I go and see the specialist. I shall be referring to it.

- Carsten's son was told he needed a bilateral corneal transplants. He was looking for options via the public health system. However, he had not seen an expert fitter of speciality contact lenses for keratoconus after having crosslinking done. We suggested he see one for a full review and then he could be referred for grafts if necessary. We sent the names of contact lens fitters in their area.

Many thanks for your phone call and also this extensive outline of options for (my son). I'm catching up with him on the weekend and will discuss this with him. It's great to have an organisation like yours to navigate patients of this disease through more effectively. I'll touch base with you next week again, after I've spoken to him. With many thanks and regards

- Liz's optometrist retired and was looking for a new one in her area. We sent her some options.

Thank you so much. One of the unexpected scenarios of getting older is seeing valued professionals retire!! I really appreciate this.

- Norm broke a contact lens and couldn't afford to pay \$1,000 for a new one from his pension. His health fund offered a \$35 rebate. He couldn't have a corneal transplant due to his high eye pressure – an operation

covered by Medicare – and asked why the government would not pay for a new lens instead. A perfectly logical question. We rang Norm and had a long chat about our efforts to advocate for change. We also urged him to lobby his optometrist who is on the boards of Optometry Australia and the Cornea and Contact Lens Society of Australia. Norm appreciated our concern:

Thank you for your email, your genuine concern and advice is greatly appreciated. Rarely one finds today a person who simply understands. Thank you I will take your advice.

NATIONAL DISABILITY INSURANCE SCHEME

We continue to receive queries from people with keratoconus asking about their eligibility for the National Disability Insurance Scheme (NDIS). Keratoconus of itself does not qualify you for access to the NDIS. This will depend on your personal circumstances and notably the impact of your keratoconus on your functional vision. There is definitely a “grey area” around the question of having one “good” eye as this could render a patient ineligible. You will need to contact the National Disability Insurance Agency for more information.



Eligibility guidelines seem to be fluid at the moment so please also discuss this with your treating clinician. The Association has information from some ophthalmologists that serious uncorrectable keratoconus is being accepted for NDIS support. (see **Advocacy**)

Phone: 1800 800 110 (8:00am – 8:00pm Monday – Friday)

Email: enquiries@ndis.gov.au

Website: www.ndis.gov.au

Postal Address: GPO Box 700, Canberra ACT 2601

INTERNATIONAL SUPPORT

Last year, we received a number of requests for assistance for people living overseas.

Sherman from the US broke his lenses and asked if we could help pay for new ones as his doctor would not honour a warranty on them. Although he “prayed” for us to supply new lenses, he did not understand we are a patient support group, not a contact lens supplier. We referred him to the National Keratoconus Foundation in Los Angeles.

Justine in the Philippines was looking for the names of Sydney corneal surgeons who could perform a corneal transplant for her. We sent a list of names.

Rabiya asked if glasses were okay to use with keratoconus before getting a “treatment”. We said they were if she could see with them.

Kana and Kul in New Guinea both thought we were ophthalmologists and asked if we could perform a corneal transplant. We could not.

Patrick from Kenya is coming to study in Melbourne and asked for the names of corneal surgeons who could manage his corneal transplants. We sent a list.

Finally, Richard from Zimbabwe asked if we could help finance a corneal transplant.

Affordability of eye-care is clearly a major issue in developing countries and an issue the World Health Organization has repeatedly highlighted in its reports on eye health.

SPEAK UP TO SUPPORT YOURSELF!

We are often contacted by patients and their families about problems with their contact lenses and surgical outcomes. There can be many reasons for these failures. Keratoconus can be a very tricky eye disease to treat and fitting contact lenses on a keratoconic eye is considered as much an art as a science in more advanced cases.

It is imperative that patient and eye-carer have a good relationship, much patience and that they communicate well. Patients need to speak up when they have a problematic contact lens. Often what looks good under the microscope can be unstable, may pop out, fog up, does not give acceptable vision or just feels uncomfortable after a short time.



Contact lens warranties are multifarious creatures that seem to vary according to the laboratory, type of lens and optometrist. But they do exist and patients need to ensure they enforce their rights if a contact lens is not working for them.

Refunds on unsuccessful fits are another vexed area. Some optometrists are offering 50% refunds on unsuccessful fits. Others don't offer anything and prefer to off-load the patient.

Telling patients to go elsewhere because they are too demanding may seem like a good business decision but it does not improve optometrists' reputations as health carers.

Warranties and refund policies should be disclosed by eye-carers to patients prior to ordering a lens, but often are not. Discuss contact lens warranties and refund policies with your optometrist before you agree to undergo a fitting process to avoid issues later.

Surgery can be troublesome too. But unlike contact lens fittings, patients are required to sign an informed consent form before agreeing to surgery. **Make sure you understand what you are consenting to before signing.**

Surgical outcomes in keratoconus can often be unpredictable in terms of a patient's post-surgery vision and **further correction with spectacles or glasses is often required**. You need understand that before you agree to a procedure to avoid being disappointed or angry if things don't go as you hoped.

Corneal collagen crosslinking can lead to hazing of the eye for weeks or months afterwards. Corneal transplants can reject at any time. Again, it is critical for the longevity of the cornea that patients contact their corneal surgeon **immediately** if they notice any pain or redness in their operated eye or change in their vision. **Most issues can be resolved if treated quickly.**

Eye-carers should be our best friends. Make sure you have one with whom you can discuss your issues freely and reasonably.

We also urge all people with keratoconus to ask their eye-carers - corneal surgeons and optometrists - to join the Save Sight Keratoconus Registry to ensure their keratoconus is being tracked anonymously and the quality of their treatments and quality of life are being monitored and benchmarked. This is critical to our long-term efforts to improve patient treatments and their quality of life living with keratoconus.



Research



RESEARCH

Keratoconus Australia promotes and supports research into the causes, prevention and control of keratoconus. The Association surveys its members for basic information about their keratoconus to help develop strategic objectives and to assist researchers identify particular areas of interest. It currently supports research projects in various ways including funding, collection of information and assistance in the recruitment of participants.

SAVE SIGHT KERATOCONUS REGISTRY UPDATE

Keratoconus Australia is a founding partner in the Save Sight Institute's **Keratoconus Registry** (SSKR) project which acts as a unique source of information on the outcomes of corneal collagen crosslinking and other keratoconus treatments done in Australia and overseas.

The SSKR is a growing multinational database tool that enables eye-carers to track the outcomes of patients with keratoconus, including patient reported outcomes. It is a world first, as it collects data from everyday practice to learn more about keratoconus and improve its treatment. (For full details of the project and its background, please see the 2018 Annual Report.)



Above: Save Sight Corneal Research Group. Professor Stephanie Watson OAM (centre).
Dr Himal Kandel (far right).

Dr Himal Kandel, Kornhauser Research Associate for the SSKR recently provided the following update on the registry:

The team has collectively published 14 scientific papers in 2022-23. This significant research contribution is summarised below:

The publications covered various aspects of keratoconus research and eye care, showcasing significant contributions to the field. Several studies (1, 4, 5 in Appendix 1) evaluated the outcomes of standard and accelerated corneal collagen cross-linking for keratoconus, with follow-ups ranging up to five years. The studies analysed efficacy, safety, and variations in cross-linking techniques, providing clinicians with real-world data that informed their practice.

A systematic review (study 3 in Appendix 1) explored the mental health impact of keratoconus. The study shed light on the emotional and psychological effects of the condition. The review received media coverage and was featured in a National Keratoconus Foundation newsletter.

Multiple studies (6, 7, 9, 12 in Appendix 1) delved into the quality of life and patient-reported outcomes of individuals with keratoconus. These studies highlighted the improvements in quality of life following cross-linking treatment and provided insights into patients' perspectives.

Further publications (10 and 14 in Appendix 1) focused on advancing diagnostic techniques for detecting keratoconus. These studies explored the use of corneal topography, pachymetry, and higher-order aberrations to identify subclinical keratoconus and predict disease progression.

The value of clinical registries was highlighted in several publications (2, 8, 12 in Appendix 1). These studies discussed the opportunities and challenges of using real-world data to advance eye care and provided insights into the treatment of keratoconus.

Publications (such as 10 and 13 in Appendix 1) emphasised international collaborations in research. These studies involved collaborations with optometrists, ophthalmologists, and researchers from multiple countries, showcasing the global effort in advancing keratoconus knowledge.

Overall, these publications contributed significantly to the understanding of keratoconus, its treatment, and its impact on patients' lives. They also highlighted

the importance of clinical registries, international collaborations, and innovative diagnostic methods in advancing keratoconus research.

Globally, clinicians, researchers and health policy makers have been informed by this significant body of work.

International collaborations

Currently, clinicians in Australia, New Zealand, Spain, Italy, France, Switzerland and Germany are contributing to the registry. The team are continually seeking opportunities to grow the registry internationally. Excitingly, ethics approval has been obtained and Memorandums of Understanding (MOUs) has been signed, which will facilitate the use of the registry in both Canada and Nepal.

Key Save Sight Keratoconus Registry Statistics

	August 2021	August 2022	August 2023	Change %
Eyes	6784	7,475	7,962	+6.5%
Finalised patient visits	17,426	19,309	20,660	+7%
Sites	77	80	109	+36%
Users	89	93	128	+38%

RECENT RESEARCH PUBLICATIONS

The Save Sight Keratoconus Registry published 14 new research papers in the 2022-2023 financial year and a number of papers are currently under review. (References of recent papers can be found in the Annex of this report).

SAVE SIGHT KERATOCONUS REGISTRY – THE FUTURE

In the upcoming 12 months, Dr Kandel's focus will be centred on several key initiatives and goals:

- Further expand the international reach of the registry by forging collaborations with partners in Canada and Nepal, leveraging the recently approved ethics and established Memorandums of Understanding.
- Engage with more clinicians and practices while increasing the pool of registered eyes and patient visits.

- Enhance the depth of research conducted using the registry's data, with a particular emphasis on generating valuable insights into the areas of real-world outcomes of keratoconus treatments.

(In this regard, Keratoconus Australia is keen to analyse the outcomes of the new speciality contact lenses and in particular corneal scleral lenses which have been associated with a range of negative outcomes from long term use.)

- Explore the psychosocial impact of keratoconus on patients' quality of life. Understanding how this condition affects individuals beyond visual functioning and symptoms can shed light on new interventions that can enhance their overall well-being and mental health.

Keratoconus Australia also recognises that crosslinking may have unforeseen very long term side effects and the Association sees the Save Sight Keratoconus Registry as the means to continue tracking all adverse effects into the future.

RESEARCH SUPERVISION

Dr Kandel and Professor Stephanie Watson OAM provide their expertise through the supervision of nine research projects. The focus of these encompass a range of topics related to keratoconus progression, quality of life impact, severity assessment, allergy and eye-rubbing connections, mental health implications, cross-linking techniques, and adverse events. Collectively, these research efforts underline a comprehensive approach to understanding keratoconus and its implications, showcasing a commitment to advancing knowledge in the field.

PARTICIPATING EYE-CARERS

The Save Sight Keratoconus Registry now publishes a list of ophthalmologists and optometrists contributing data anonymously to the registry. The list can be found on the SSKR website at <https://savesightregistries.org/clinicians/>

This list enables patients to find out whether their eye-carers are submitting data to the registry. Eye-carers who submit their data can provide patients with a history of their treatments and show an evolution of their disease before and after surgery. Eye-carer participation in the registry also provides patients with an opportunity to complete ongoing quality of life surveys that can enable both their clinicians and researchers to evaluate the impact of their treatments. Finally, the registry enables clinicians to evaluate the outcomes of their procedures and treatments in real time against best practice.

We urge all patients to check online if their eye-carer is participating in the Save Sight Keratoconus Registry and if not, to urge them to do so.

The list of practitioners can also be used by patients to find eye-carers who are committed to improving the management of keratoconus and also to providing patients with a voice to express how the treatments they receive are affecting their quality of life.

CENTRE FOR EYE RESEARCH AUSTRALIA

The Centre for Eye Research Australia (CERA) has long been a major player in Australian research into the causes of keratoconus, its treatments and its economic impact on patients.

Keratoconus Australia has collaborated with CERA since the early 2000s and in particular supported its world-first randomised trial of corneal collagen crosslinking in 2006.

The Association continues to liaise with the CERA corneal research team headed



Dr Srujana Sahebjada

by ophthalmic surgeon Professor Mark Daniell, and a team of dedicated researchers including Dr Srujana Sahebjada and Dr Elsie Chan - both of whom have previously presented their work at our Demystifying Keratoconus forums.

LATEST RESEARCH

CERA is currently engaged in a number of projects which look at different aspects of keratoconus, its causes and diagnosis via artificial intelligence. Dr Srujana Sahebjada, one of CERA's lead keratoconus researchers, provided the Association with a summary of CERA's current research projects.

Keratoconus Australia has been acknowledged as a supporter of CERA's work in seven papers

published over the past few years. These papers related to:

- The Keratoconus International Consortium and how it will advance keratoconus research
- Diagnosis and management of keratoconus from a clinician's perspective
- Keratoconus in pre-teen children. This study highlighted that keratoconus was present at an advanced stage in 25% of the pre-teens in the study group, and therefore, it is an important diagnostic entity when a refractive error is diagnosed, even in very young children
- Non-genetic risk factors for keratoconus. This study examined the important environmental risk factors and their association with keratoconus.
- The accuracy of Machine-Assisted Detection in keratoconus
- Eye rubbing and its role in keratoconus. This review of literature demonstrated that eye rubbing showed consistent association with keratoconus. However, it concluded the current evidence is limited to only a small number of case-control studies which present as heterogeneous and of sub-optimal methodological quality. Additionally, the cause-effect temporal relationship cannot be determined. Further studies are needed to address this intricate relationship of eye rubbing and its induction, ongoing progression, and severity of keratoconus.

(A full summary of CERA's recent keratoconus research papers can be found in the Annex of this report).

CURRENT AND FUTURE PROJECTS

Surveys

- Exploring Australian, New Zealand and international clinicians' perspectives on the diagnosis of keratoconus
- Optometrists' diagnostic trends and management of keratoconus patients
- Identifying Eye Rubbing Patterns in Keratoconus Subjects

Risk factor analysis

- Identifying Risk Factors in Keratoconus through Corneal RNA Sequencing

AI and Clinical

- AI-Driven Prediction of Keratoconus Progression and Clinical Parameters Using Pentacam Data

Risk Factor Analysis:

- Beyond the Cornea: Keratoconus and Comorbidity Connections
- Biomarkers Unveiled: Early Warning System for Keratoconus

Early Detection:

- AI Detectives: Predicting Keratoconus Before It Strikes
- Eyes on the Future: Keratoconus Screening and Prevention

Prevention of Progression:

- Halt the Progression: Strategies to Preserve Corneal Health
- Empowering Patients: Education for Keratoconus Prevention

New Management Strategies:

- Precision Care: Personalized Keratoconus Management
- Innovative Solutions: Advancing Keratoconus Management

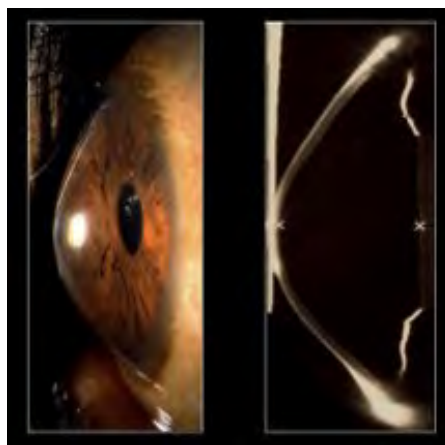
Translational Projects:

- Global Keratoconus Classification System (GloKCS): Defining the Global Standard for Keratoconus Care



FUNDRAISING FOR RESEARCH

Funding is required for all of these projects. Please contact the Association if you are interested in supporting this important research.





Eye-Carers



EYE-CARERS

Keratoconus Australia relies on its relationships with optometrists and ophthalmologists to keep informed of the latest developments in keratoconus treatments and management strategies. The Association also meets regularly with eye-carers to discuss issues raised by members such as access to low-cost treatment options and to seek advice on problems faced by patients and their families.

OPTOMETRISTS

Keratoconus Australia has been working for many years to ensure patients have access to optometrists skilled in the fitting of contact lenses for keratoconus. The arrival a decade ago of a new generation of speciality lenses for keratoconus such as hybrid and corneal scleral lenses has made lens fits easier than with the older smaller rigid gas permeable lenses. However, these new lenses have also tripled the cost of lenses to patients.

There are also concerns about the side effects of their long-term use. Keratoconus Australia has been working with researchers to better monitor the outcomes of these lenses. This requires cooperation from optometrists in entering their patient data anonymously into the registries created by the Save Sight Institute and the Centre for Eye Research Australia. So far, there is insufficient data on contact lens wear and outcomes for conclusive evidence to emerge from these registries.

In recent years, we have tried to collaborate with the principal optometry groups, in particular Optometry Australia (OA), the Cornea and Contact Lens Society of Australia (CCLSA) and the Department of Optometry and Vision Sciences (DOVS) at Melbourne University, to promote better training and understanding of keratoconus and the special issues facing people with the disease. Since COVID-19, it has been difficult to maintain momentum in discussions and to make significant progress.

One issue of particular concern to the Association and some of the ad hoc groups of optometrists interested in keratoconus has been the question of upskilling post graduate optometrists in fitting of speciality contact lenses for keratoconus. Too many patients come to us after spending significant amounts of money on unsuccessful fits of speciality lenses

Last year, we reported that as part of its moves to implement its Optometry 2040 report recommendations, OA had finally acknowledged a need for a special accreditation for optometrists fitting speciality contact lenses. That was expected in 2023. However, the latest update from OA president Margaret Lam seems to indicate that the accreditation could still be some years away. This is disappointing. It apparently reflects the belief that accreditation for other areas of optometry should be implemented before advanced contact lens fitting.

A system of accreditation would be welcomed by Keratoconus Australia as it offers the hope for patients that a registry of accredited contact lens fitters will finally be created to assist patients in finding an expert fitter of speciality contact lenses for keratoconus in their area.



In the meantime, patients can use the OA and CCLSA Find an Optometrist/Practitioner online search engines which have been upgraded following repeated requests from Keratoconus Australia. The CCLSA database probably works best now as the OA search facility still allows any optometrist to say they fit

contact lenses for keratoconus even if they don't have a corneal topographer or other modern equipment required to ensure a suitable fitting. We are hoping that the OA accreditation requirement will further assist patients in locating qualified contact lens fitters in the future.

Keratoconus Australia works with both OA and CCLSA optometrists who have been aiding the Association to find contact lens fitters for keratoconus in regional and country areas. This has been of immense benefit to patients outside of the metropolitan centres. This ad hoc working party has been extremely useful in finding optometrists able to assist patients in their local area.

AHPRA guidelines

An issue over unethical practices by optometry companies arose between Keratoconus Australia and OA/CCLSA after the Association drew attention to a FaceBook post by Optometry Australia about new Australian Health Practitioner Regulation Agency (AHPRA) guidelines to prevent optometrists making clinical decisions based on meeting business performance targets.

In a repost, Keratoconus Australia commented that one example of this in keratoconus practice could be the overuse of expensive scleral lenses rather

than cheaper rigid gas permeable lenses in certain instances. At the request of OA, we deleted the comment after optometrists complained that it could create mistrust among patients about the care they were receiving. However, OA and CCLSA officials escalated the matter to their board members. In response, the Association sent a strongly worded letter to both optometrist groups noting that the guidelines were published by AHPRA based on complaints about optometrists' unethical behaviour and reposted online by OA. We defended our right to notify members about regulatory guidelines designed to protect patients from illegal practices.

CORNEA AND CONTACT LENS SOCIETY OF AUSTRALIA (CCLSA)

Following discussions with OA and CCLSA officials around the AHPRA guidelines and the possible overuse of scleral lenses, Keratoconus Australia President Larry Kornhauser was invited to address a webinar of CCLSA members in May 2023 on the issue of Keratoconus: Management, Ethics & Economics.

Other speakers and panellists included optometrists Jessica Chi, David Foresto, and CCLSA CEO Alan Saks. The webinar covered topics including:

- Picking the best lens for the patient,
- Presenting options,
- Long-term management and options,
- Corneal cross-linking, grafts and intraocular lenses,
- Managing expectations,
- Ethics and economics,
- Corneal RGPs, sclerals, piggybacks, hybrids and soft lenses

Mr Kornhauser discussed his own journey with keratoconus, the Association's work in supporting people with keratoconus and the issues facing patients, largely because of the escalating cost of treatments. His full speech is provided in the **Annex** of this report.

MELBOURNE EYECARE CLINIC



Keratoconus Australia and Melbourne Eye Care (MEC) Clinic have been collaborating for over a decade to offer reduced price optometric services for Keratoconus Australia members (including contact lenses) and the opportunity for Melbourne University optometry students to have hands-on experience treating keratoconus patients. This win-win initiative ran into rough waters over recent years as the contact lens clinic raised prices to levels above those in available in private practices, thus rendering the discounts on offer almost meaningless.

Keratoconus Australia raised this situation with the incoming MEC director Dr Andrew Huhtanen in late 2022 who undertook a review of the keratoconus clinic and its pricing. Following this review, Dr Huhtanen agreed that the pricing of speciality contact lenses was not competitive. He adjusted pricing policies to rectify the issue and to add greater transparency of consultation fees. Keratoconus Australia members can again receive bulk billing on many services and up to 30% discounts on hard contact lens fits.

FUTURE GOALS

Last year, we set out a series of objectives for the Melbourne University optometrist course but were unable to advance them. We believe these are still worth pursuing in 2024 and look forward to members taking up these issues with the DOVS. Keratoconus Australia and the DOVS have identified that in the absence of further consolidation of their skills through additional training and exposure to keratoconus patients, post graduate and early career optometrists are losing their ability to treat and manage keratoconus patients effectively. There is therefore a need for two programs:

1. Student scholarship for post graduates to develop skills in fitting speciality lenses for keratoconus. This would include external placements with experienced clinicians, local and interstate and even with contact lens manufacturing laboratories.
2. A co-management program to create a network of regional and country clinicians and practices to work with experienced keratoconus clinicians to co-manage keratoconus patients. Experienced practitioners could also attend these keratoconus practices for intensive training. Co-management sessions could also be integrated into MEC clinic times to allow clinicians to work together via zoom to minimise patient travel.

In February 2023, Keratoconus Australia assisted a young optometrist interested in moving into keratoconus practice to find mentors locally in Queensland through our contacts at the CCLSA.

In March 2023, Dr Huhtanen notified us that a joint MEC-Australian College of Optometry Contact Lens Clinical Residency for a new graduate could be created in 2024.

Government and private health fund engagement should be sought for certification of these programs.

UNDERGRADUATE TRAINING

Keratoconus Australia and the University of Melbourne's Department of Optometry and Vision Sciences (DOVS) have been conducting keratoconus training clinics for undergraduate optometry students since 2006. These clinics provide optometry students with a unique opportunity to fit contact lenses onto keratoconus and post-corneal transplant patients prior to graduating. They are the only specific keratoconus training clinics in Australia and are training the next generation of specialist contact lens fitters for keratoconus.

After several years of disruption due to COVID-19, these clinics resumed in 2023. Keratoconus Australia assisted in recruitment of volunteers for the keratoconus clinic in March 2023 and the post-graft fitting clinics in May.

EYE-CARER SUPPORT

As part of its support work, Keratoconus Australia receives a range of questions from patients about their issues and the disease in general. As we are not medically trained, we submit these questions to a range of clinicians working in ophthalmology, optometry and keratoconus research. We thank all of the eye-carers who participate in this valuable support work.

DRY EYE

The Association was contacted by a representative of Seqirus in August 2022 to discuss the operation of patient support groups. Seqirus is a subsidiary of Commonwealth Serum Laboratories and makes a range of products for dry eye and funds the Save Sight Institute's Dry Eye registry. KA President, Mr Kornhauser, met with the Seqirus representative who inquired about our preparedness to join in promoting their products to keratoconus patients. At this stage, we have no plans to engage in this type of corporate partnership.



Advocacy



ADVOCACY

Keratoconus Australia acts as a support group for people with keratoconus and their families and the wider keratoconus community. That role includes advocating for issues relating to keratoconus. These may include government eye health policy, accessibility to and quality of treatments, patient welfare and rights and any other keratoconus-related matters deemed important by our members.

MENTAL HEALTH

The Association has been a leader in the eye sector in raising the issue of vision impairment and its impact on mental health.

Although access to eye-carers improved in 2023 after the COVID-19 lockdowns of previous years, rising treatment costs continue to make life hard for people with keratoconus and their families. As discussed in **Support**, the Association is dealing with more people suffering from stress and anxiety not only due to declining vision from keratoconus but the inability to afford treatments to improve their sight. This is totally unacceptable when a solution to vision loss is available.

Keratoconus Australia is tackling the mental health issue through two distinct strategies. First, establishing evidence of the mental health impacts of keratoconus on patients through the Save Sight Keratoconus Registry which has now added questions around mental health to its Quality of Life survey at our request. The registry expanded its mental health reporting in 2023 and began publishing research on the outcomes of its analysis. (see **Research**)

The second is to find pathways to assist patients through our work with the Vision 2020 Australia working party on mental health which was formed in 2021 - also at our request.

Keratoconus Australia Vice President, Dr Greg Harper, is currently chair of the Vision 2020 Australia working party and his report on the group's activities is below

"Keratoconus Australia is an Associate member organisation of Vision 2020 Australia and this gives a small charitable organisation like ours, access to the pooled resources of many larger organisations in the low vision and blindness community. Membership also gives us an opportunity to raise the special needs of Australians who have keratoconus.

We have been providing volunteers to the various policies committees of V2020A for many years, but our Vice President Dr Gregory Harper and President Mr Larry Kornhauser have been contributing to the Prevention and Early Intervention policy committee for the last three years.

In early 2022, KA stepped up its efforts in the area of mental wellbeing on behalf of its members, and Greg took on the chairmanship of the Mental Wellbeing and Vision Loss working group. At the first meeting in June 2022, the group set these priorities for its work.

- Investigating whether mental health screening, using existing tools and performed by ophthalmologists, optometrists and/or orthoptists, could be incorporated or amended to existing referral pathways.
- Investigating a course for psychologists in relation to vision loss, as CPD through the Australian Health Practitioner Regulation Agency.
- Asking researchers who have been exploring this issue previously to meet with the working group.

The working group continued its work during 2023 and has leveraged the resources of other members of V2020A to achieve these outputs:

- The V2020A team completed a rapid review of the world scientific and medical literature on the causes of poor mental wellbeing for people with vision loss and identified opportunities for our sector to advocate for improvements. Key learnings from this review provided the foundations for the working group into 2023.
- The working group collated online and printed resources from all the low vision organisations within V2020A along with resources available from mental health support organisations in other health and community sectors. This resource collection has been named the Mental Wellbeing Resources Guide and is available for our members and their supporters at this link: <https://www.vision2020australia.org.au/mental-wellbeing-resources-guide/>.
- An awareness campaign was launched in September 2023 coinciding with the public release of the Resource Guide. Key social media posts were made on World Sight Day, World Keratoconus Day and during Mental Health Awareness Week.
- The working group recognised that eye health practitioners are a key point of intervention for better mental health outcomes, and so information

about the Resources Guide and its development were provided as a poster, authored by V2020A at two recent professional conferences:

- 4th World Optometry Congress/OMEGA Conference
- World Association of Eye Hospitals – in partnership with Catherine Mancuso (The Royal Victorian Eye and Ear Hospital)

The working group reasoned that there needed to be baseline data for the level of awareness of eye health practitioners in relation to the issues around poor mental wellbeing. Attendance of V2020A staff at the two professional conferences was taken as an opportunity to survey optometrists regarding their levels of experience, confidence and interest in mental wellbeing and vision loss. The survey was also distributed by V2020A members, including the Australian College of Optometry and Optometry Australia. Specsavers managers also uploaded the survey to their intranet for use by their corporate optometrists. The results of that survey are in summary:

Most of the 51 respondents had more than 10 years of clinical experience and worked in Australian metropolitan areas across varying practice types.

- Half of the respondents manage low vision patients on a weekly-monthly basis but only 12% of these optometrists refer patients regularly to services.
- There is strong agreement that this is an important area of education and professional development for optometrists, and the profession has a significant role in referring low vision patients at risk of poor mental wellbeing.
- There is strong agreement that resources that could help support screening at-risk patients and referrals would be useful.

The final meeting of 2023 was held on the 27th of November and the group discussed priority work for 2024 in order to capitalise on this incremental progress. Still a long way to go.”

VISION 2020 AUSTRALIA

Keratoconus Australia is an associate member of Vision 2020 Australia, the peak body for the Australian eye health sector. In addition to its work with the mental health group, Keratoconus Australia participates in the Prevention and Early Intervention Committee. The Association has been using this forum to highlight various issues affecting people with keratoconus including accessibility and affordability of treatments, especially for young, older and disadvantaged patients.

Carly Iles was appointed CEO of Vision 2020 Australia earlier this year, replacing Patricia Sparrow, and the Association sent our warm congratulations on her promotion. Carly has been a long term member of the Vision 2020 Australia team and we wish her all the best in her new role.

Vision 2020 Australia held a luncheon in April 2023 to allow Ms Iles and V2020A Chair Mr Christopher Pyne to meet the Victorian CEOs of the eye health sector. Keratoconus Australia President, Larry Kornhauser attended on behalf of the Association.

CONTACT LENS COSTS

Keratoconus Australia continues to agitate about the high and rising cost of contact lenses brought about largely by the shift towards corneal scleral and hybrid contact lenses over the past decade. These are charged at triple the cost of the older design rigid gas permeable lenses which were the standard type of contact lens for keratoconus for decades.

We have been seeking a support scheme for low income and disadvantaged keratoconus patients for almost 20 years now to almost no avail. Back then, most people paid around \$200-\$400 per lens. Today speciality lenses, which may account for almost 80% of new keratoconus lens fits, cost upwards of \$800-\$1,500 per lens. One patient recently reported paying \$2,500 for a single lens!

Keratoconus Australia has noted a disturbing trend of people who could once afford their lenses now finding themselves being priced out of treatment because of the high up-front cost of the larger lenses.

Concern is now spreading to the eye-carer community and the Association has been contacted by a number of optometrists and ophthalmologists worried about patients' inability to pay for treatments.

NDIS?

Association President Larry Kornhauser organised a meeting via zoom with a group of these senior eye-carers and leaders working in keratoconus during the International Cornea & Contact Lens Congress 2022 held in October 2022. CCLSA CEO Alan Saks provided background material on the contact lens support schemes for keratoconus patients in the United Kingdom and New Zealand, both of which could be a model for an Australian support scheme.

However, a consensus among the eye-carers emerged that low income and disadvantaged people with disabling vision loss due to keratoconus should be supported via the National Disability Insurance Scheme (NDIS). They observed

that some of their patients had gained entry into the scheme with support letters from their eye-carers (notably ophthalmologists). But it was noted that there are no clear guidelines for how keratoconus patients could or should be dealt with, which is leading to inconsistent outcomes for patient NDIS applications. It was agreed that Keratoconus Australia and the peak eye health bodies should pursue the NDIS avenue as a means of gaining financial support for patients unable to afford their contact lenses.

Mr Kornhauser had preliminary talks with officials at Vision 2020 Australia who indicated that the NDIS Review working party may be interested in providing funding to patients whose vision could be corrected with contact lenses to enable them to come off long-term disability support. The Association subsequently enrolled with the NDIS Review in November 2022 and made a submission to the Review in January 2023. OA kindly provided a letter of support for our submission. We have not received any acknowledgment or response to that submission calling for support for people unable to afford their contact lenses.

Since then, the NDIS Review group has published a series of updates – none of which indicate an appetite for or available funding to expand the scheme into areas like subsidised contact lenses for people with keratoconus.

The Association remains uncertain if NDIS could provide a pathway to subsidised contact lenses for any but those most severely disabled by vision loss due to keratoconus. The NDIS Review report released in December 2023 does offer some cause for optimism with its reference to the provision of “foundational support” for people with demonstrable disability.

The Association continues to meet with the leaders of Optometry Australia and the Corneal and Contact Lens Society of Australia and to advocate for the better treatment of low income and disadvantaged keratoconus patients amongst ophthalmologists and other eye health officials. Ultimately, we will need people able to lobby government to effect the changes required to the existing system.

WARRANTIES AND REFUNDS

The issue of warranties and refunds on unsuccessful contact lens fits remains problematic for many patients as no progress has been made with the optometric community on how such claims should be handled.

A number of optometrist refunds on unsuccessful keratoconus and the will become a minimum

However, some patients also being offered full do not return to the

This is may be a suitable

optometrists in question. But it does nothing to resolve the underlying vision impairment of the patient, many who don't know where else to find an expert fitter of speciality contact lenses for keratoconus.



practices already offer 50% contact lens fits for Association hopes that this industry standard.

are reporting that they are refunds on the basis that they practice for further fittings. business practice for the

The Association requires help from interested members in pursuing this issue with Optometry Australia.

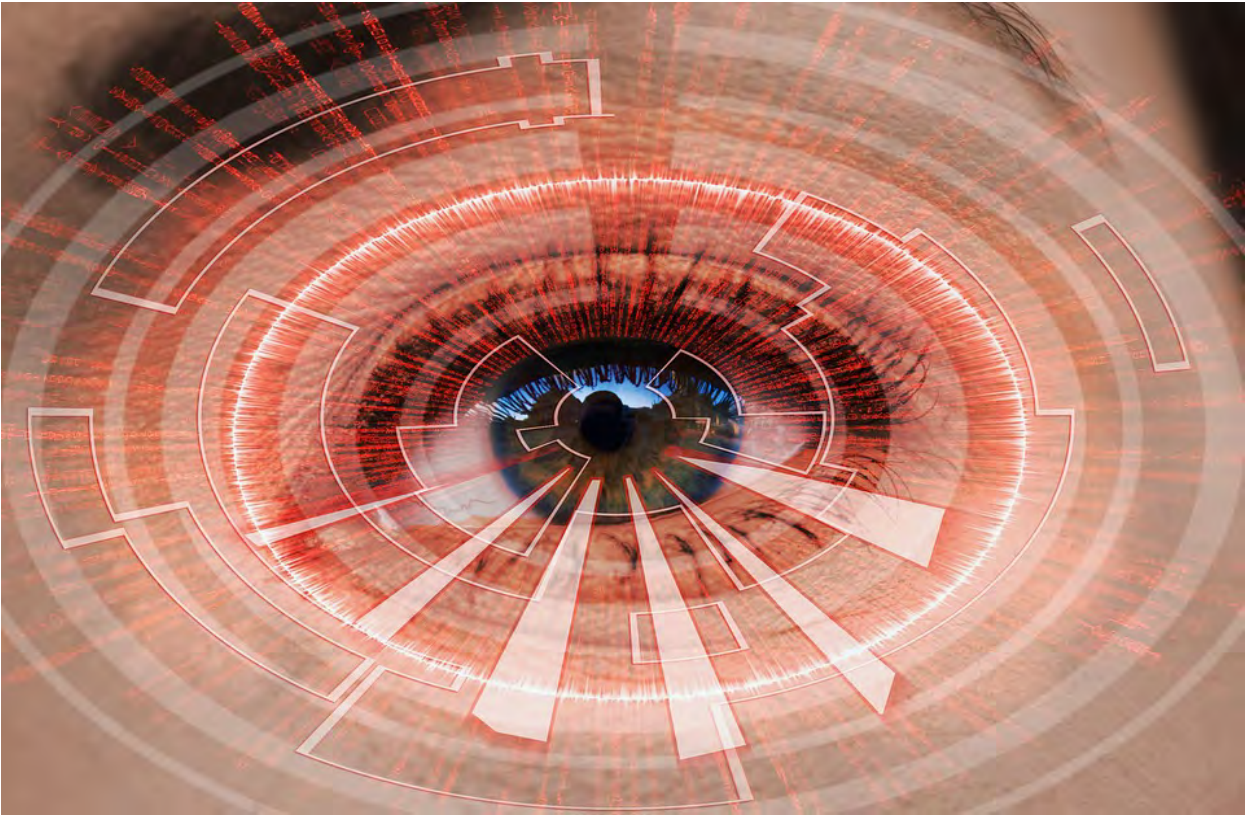
EYE RUBBING CAMPAIGN

The Association believes there is an urgent need for a public health campaign around the dangers of eye rubbing in the general community. Eye rubbing is the only known patient-controllable factor in keratoconus, and has been shown to trigger and worsen underlying keratoconus. Eye rubbing can also lead to other eye conditions including glaucoma.

After discussions around the issue with several optometrists and researchers, Keratoconus Australia approached a public relations firm Quay Communications, who produced a website for the Childhood Myopia Working group and seemed to understand eye health. With assistance from committee member Justine McLaughlin, the Association provided a reverse brief to Quay in February 2023 regarding our objectives for an eye rubbing campaign based on our limited budget.

In April 2023, Quay provided proposal for a campaign. Unfortunately, the proposal envisaged spending our entire budget for the eye rubbing campaign on a strategic review of the Association, its brand credentials, style, guidelines, website, stakeholder strategy etc. While there is a need for the Association to undertake a review of all of these aspects of its organization, the proposal failed to include any ideas or pathways for the eye rubbing campaign. The work with Quay remains in limbo for the time being.

The Quay proposal was provided pro bono. However, we still need to progress an eye rubbing campaign. Volunteers and donors welcome!





The Association



THE ASSOCIATION

MEMBERSHIP

Membership of Keratoconus Australia broke the 3000 mark in the 2022-2023 financial year for the first time. The Association had a total of 3,002 members at the end of the financial year. This was 2.3% more than in June 2022 (2,919).

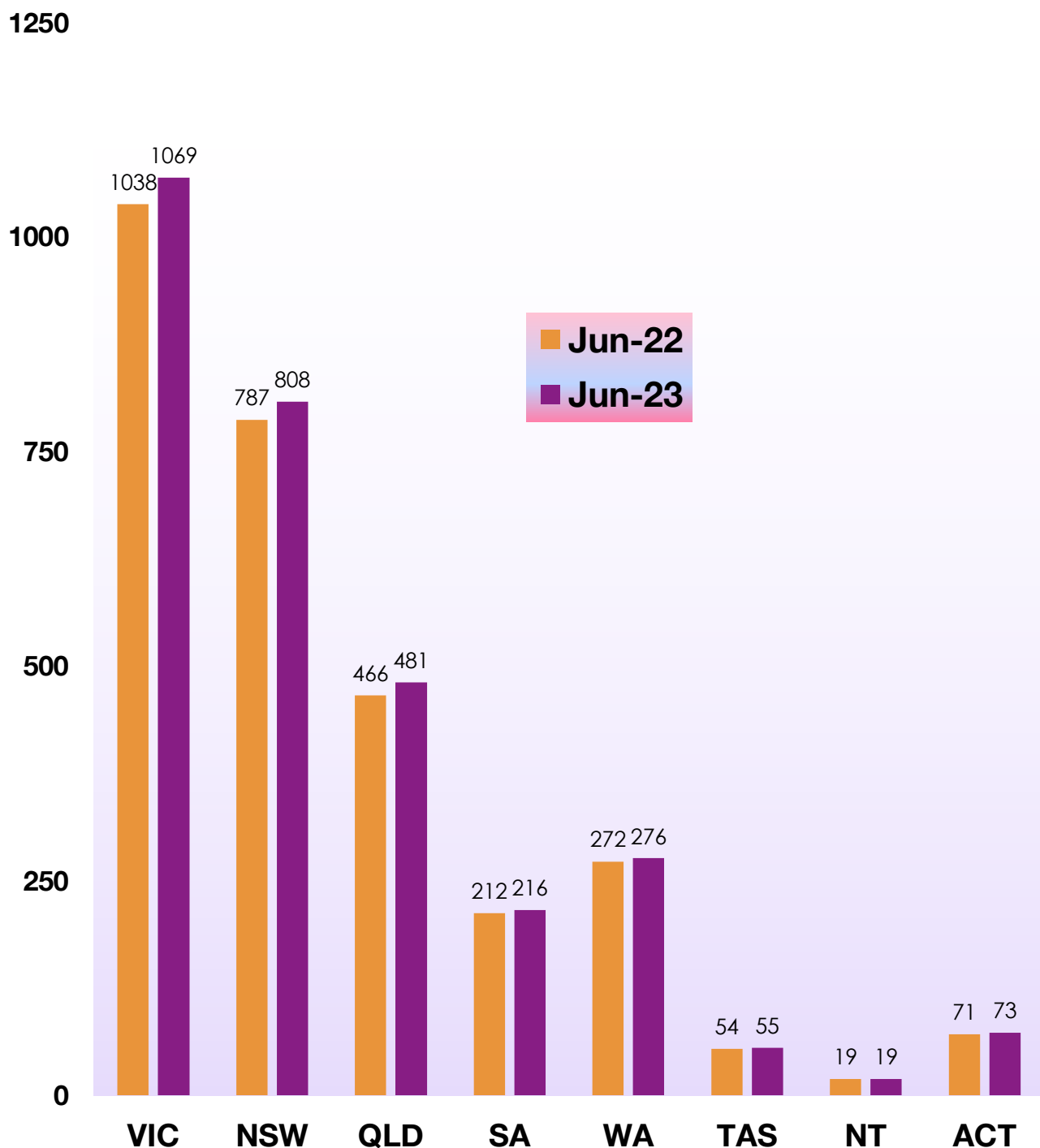
It represents a significant milestone for the Association and clearly establishes it as the voice of keratoconus in Australia. Until recently, the total population of those with keratoconus was thought to be only around 15,000. New research indicates the numbers to be far greater when those with sub-clinical disease are included – possibly as many as 300,000. However, it is unclear how many have more than mild vision impairment requiring correction with contact lenses or surgery.

3000+ MEMBERS

Victoria and Queensland provided the largest growth in new members (3% respectively) with NSW close behind (+2.7%). Membership growth generally mirrors shifts in support requests and this was true again last year. The Association's membership base remains centred in Victoria (1,069 members or 36% of the total), followed by NSW (808 or 27% of the total) and Queensland (481 or 16% of the total).

(Please note that constant updating of information in the KA database means that membership data is not directly comparable from one year to the next.)

KA Membership by State



SUPPORTERS

Keratoconus Australia is fully funded from donations from members and supporters. We are grateful for the pro bono assistance we receive from a range of companies, institutions and individuals who make it possible for us to provide our services at minimal cost.

We thank all of these companies and institutions for their kind assistance again in 2022-23, notably Cameron Falt of Slomoi Partners for accounting services, Viewgrow Capital Pty Ltd (meeting venue and administrative support services) and Herbert Smith Freehills for legal services.

Special thanks go to Mary Prudden of the US National Keratoconus Foundation, which has been a long-time supporter of the Association and provider of its patient booklets on keratoconus and corneal transplants. These are available free of charge from Keratoconus Australia in hard and electronic (pdf) format. The keratoconus booklet is distributed free to all new members along with other materials.

We also thank Mary and the NKCF for establishing a **World Keratoconus Day** (WKD) on November 10 as a means of raising awareness about this disease.

Save Sight Institute at the Sydney Eye Hospital is a key partner of Keratoconus Australia and collaborates with us on a number of projects. These include the Save Sight Keratoconus Registry, the KeraClub and the Hands Off Eyes campaign to alert keratoconus patients of the dangers of eye rubbing. The Save Sight Keratoconus Registry and Keratoconus Australia also distribute a patient brochure on crosslinking. An updated crosslinking brochure and flyer will be available to patients and eye-carers in early 2024.

All new members joining the Association receive both the crosslinking brochure and the Hands Off Your Eyes poster as part of their welcome kit along with a NKCF booklet on keratoconus. These are available free to all members and keratoconus patients and their families by contacting the Association.

We again thank SSI's Professor Stephanie Watson and Dr Himel Kandel for their kind assistance in developing these research tools and patient resources with the aim of improving clinical outcomes for people with keratoconus. Professor Watson and Dr Kandel also participated in patient forums to keep our members updated on data from the Keratoconus Registry and to answer questions on different aspects of keratoconus.

We also acknowledge the University of Melbourne which continues to back the Association's efforts to improve access to well-fitted contact lenses for keratoconus patients through its Melbourne Eyecare Clinic, which runs regular keratoconus clinics.

David Pye at the contact lens clinic at University of NSW has also been supportive of efforts to supply contact lenses to low-income patients. Adrian Bruce at the Australian College of Optometry in Carlton, Victoria and David Foresto in Brisbane and Damon Ezekiel in Perth are also helping, by offering specialised keratoconus contact lens fits for low-income patients with and without Centrelink pension and health cards.

The Centre of Eye Research Australia (CERA) in Melbourne has also been a long-term partner of Keratoconus Australia in many projects over the years. CERA has recently initiated a number of new research projects into keratoconus. We thank in particular Associate Professor Mark Daniell, Dr Srujana Sahebjada, Dr Elsie Chan, Associate Professor Elaine Chong and Professor Paul Baird for their work into understanding the mysteries of keratoconus and how it impacts patients.

We also thank OA President, Margaret Lam and CCLSA CEO, Alan Saks for their assistance in our advocacy efforts and in supporting keratoconus patients.

FUNDRAISING

Anybody wishing to raise funds on behalf of Keratoconus Australia can do so by starting a fundraiser event on the GoFundraise platform at <https://www.gofundraise.com.au/> and also at MyCause <https://www.mycase.com.au/>.



DONATIONS



We thank all donors who made significant contributions during the 2022-23 financial year. Particular thanks again go to the Ray and Margaret Wilson Foundation for its long time and generous support of the Association.

Donations to the Association can be made by credit card online via the Give Now website at

<https://www.givenow.com.au/keratoconusaustalia>.

EVENTS

7TH KERA CLUB PATIENT FORUM

Prof Stephanie Watson OAM
Clinical impact of research

Dr. Himel Kandel
Quality-of-life research

Dr. Yogambha Ramaswamy
Bioengineering and Nanotechnology

Larry Kornhauser OAM
Keratoconus Australia's support activities

Narina Janian
Supporting Keratoconus Research

Mark Koszek
Contact lenses for keratoconus

Michelle Pritchard
Moderator

Justine McLaughlin
Living with keratoconus

KeraClub 2022

THE UNIVERSITY OF SYDNEY
Nano Institute

KERATOCONUS AUSTRALIA

THE UNIVERSITY OF SYDNEY
Save Sight Institute

KeraClub 2022 was again held as a webinar due to concerns over COVID-19 in the community. The event was chaired by **Michelle Pritchard** who has extensive experience with keratoconus and is a member of the Keratoconus Australia committee of management.

Over 160 people from across Australia attended the 7th annual KeraClub. The event was hosted by the Save Sight Institute and Sydney Nano, The University of Sydney and Keratoconus Australia on the 4th August 2022.

A video of the event can be found on the Association's YouTube channel at <https://youtu.be/Hko8aZBhxc> The video has already had more than 510 views.

Speakers at KeraClub 2022 included:

Professor Stephanie Watson OAM, a world-renowned corneal specialist known for her ground-breaking research in corneal therapies. She is head of the Corneal Unit at Sydney Eye Hospital, Head of Corneal Research Group at Save Sight Institute and Chair of Australian Vision Research (previously known as the Ophthalmic Research Institute of Australia). She is also the Deputy Director of Industry, Innovation and Commercialisation for Sydney Nano.

Professor Watson noted that ground-breaking research findings from the Save Sight Keratoconus Registry were informing clinical care today. The registries' global real-world data was informing clinicians on when to decide to perform corneal cross-linking, which patients are likely to progress, what types of cross-linking should be performed, and, if cross-linking safe. The SSKR is available free of cost to the clinicians and they can also get incentives such as CPD points for using the registry.

Dr Yogambha Ramaswami spoke on Bioengineering and Nanotechnology for Keratoconus as the new hopes for treatment. Dr. Ramaswamy is a senior lecturer in the School of Biomedical Engineering at The University of Sydney. She discussed how these advanced technologies may help repair damaged corneal tissue, and increase the quantity and quality of the cells in keratoconic corneas.

Optometrist Mark Koszek's talk on getting the most out of contact lenses for keratoconus patients provided practical information for patients with keratoconus. Mr Koszek is a founding partner and the Professional Education Officer of EyeQ Optometrists which has a network of 47 practices Australia-wide. Mark used case studies to discuss contact lens-related challenges and their solutions. He highlighted that using contact lenses such as rigid gas permeable (RGP) and scleral lenses may require the wearer to be patient but can improve a patient's quality of life. Importantly, Mark highlighted that patients with keratoconus who have difficulty with their contact lens wear should see their optometrist for a solution.

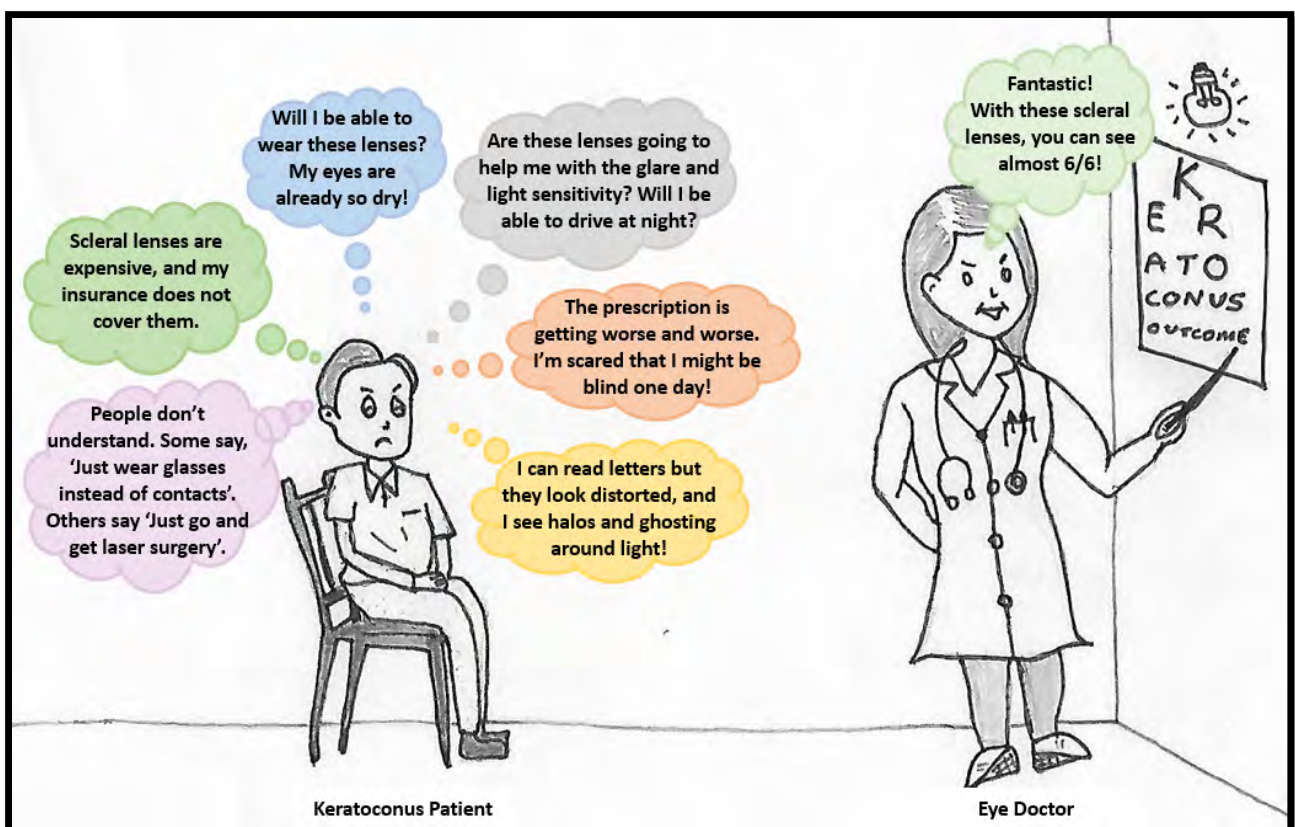
Keratoconus Australia president, **Mr Larry Kornhauser OAM**, provided a highly informative overview of the support group, Keratoconus Australia. His inspirational talk based on lived experience with keratoconus included the backstory to Keratoconus Australia creation in 2000 and the services being provided by the organisation since then, all free of cost. He opined that with a good contact lenses fitter and a corneal surgeon on the side, keratoconus patients can get through the difficult times.

Mr Kornhauser highlighted how patient and clinician perspectives may differ and how peer group support can be instrumental in keratoconus management.

Professor Watson thanked Mr Kornhauser for his dedication in supporting patients with keratoconus, many of whom have benefitted greatly from his work. Mr Kornhauser has worked tirelessly as President of Keratoconus of Australia and initiated KeraClub to help create a Sydney support group in conjunction with the Save Sight Keratoconus Registry. She announced a token of great appreciation for Larry for his contributions.

Ms Justin McLaughlin shared her patient perspectives and highlighted the importance of corneal tissue donation. Ms McLaughlin qualified as a solicitor and has spent the last decade in NSW Local Government as an elected Councillor and Deputy Mayor. She shared how she was diagnosed with keratoconus when she was in her early teens and felt that eye-rubbing made it worse, and discussed her experience of getting three corneal grafts. She encouraged everyone to get their friends and family to consider the donation of corneal tissue and emphasized that it can be an absolute game changer for those that need it.

Dr Himel Kandel, Kornhauser Research Associate, presented the patient-reported quality of life research at the Save Sight Keratoconus Registry. He highlighted why it is important to consider improving quality of life and visual functioning in keratoconus patients along with improving visual acuity and halting progression. This research focuses on understanding how patients with keratoconus live and what may limit their lives in order to find which treatments can overcome these limitations. He discussed a number of advantages of incorporating patient-reported outcomes in routine clinical practice including reducing the disparity in patient- and clinician- perspectives. The findings from the registry have been used globally by clinicians, researchers and policymakers to improve the quality of life of keratoconus patients.

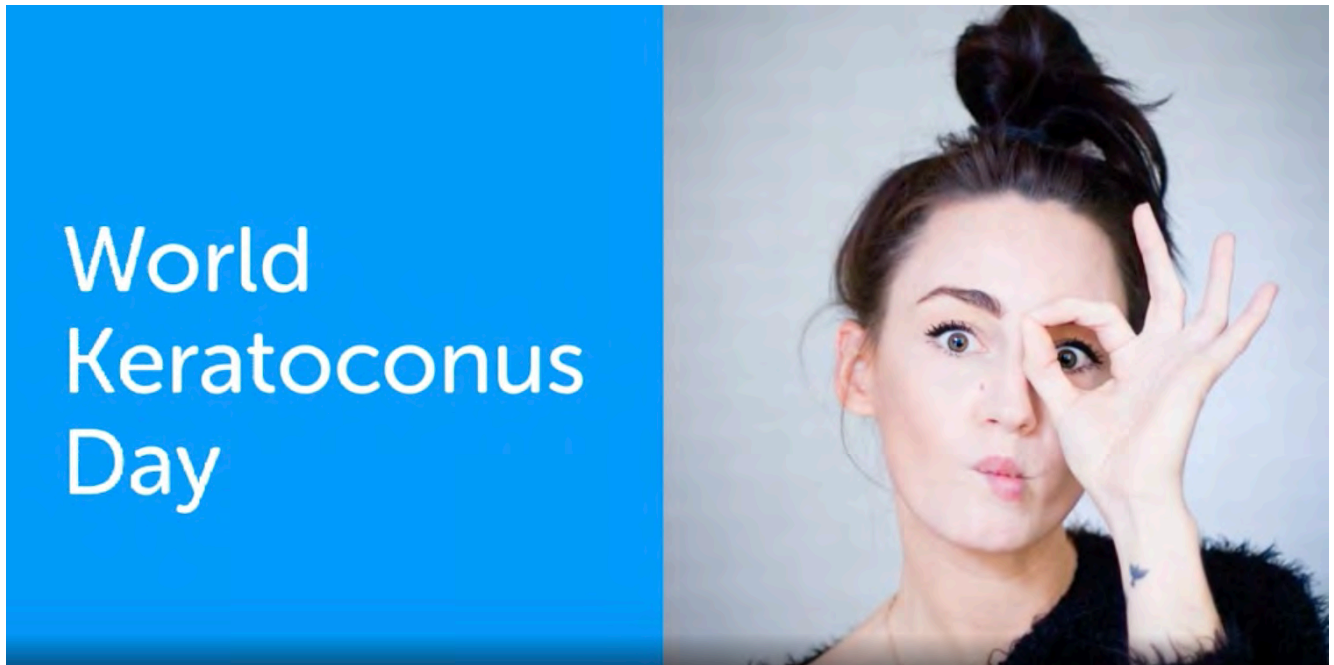


Disparity in clinician- and patient-perspectives

The talks were followed by a panel discussion moderated by Professor Watson.

WORLD KERATOCONUS DAY

World Keratoconus Day is held on November 10 as a way of raising awareness of keratoconus and the impact it has on people and their families.



Last year, the Association celebrated with a number of posts on Facebook relating to keratoconus and its management. Particular emphasis was given to preparing for spring and itchy eyes and how to avoid eye rubbing.



Diana Ward – Still Life

The US National Keratoconus Foundation, which launched World Keratoconus Day, again asked the Association to co-host a photographic competition “*Keratoconus through my Eyes*” in conjunction with the UK Keratoconus support group. Judges from NKCF, Keratoconus Australia, and UK-based Support Group found a mix of funny, serious and artistic photos that shared a slice of life for those with keratoconus.

Overall winner was Diana Ward from Auckland, NZ who has lived with keratoconus for more than thirty years, and has undergone three corneal transplants. Her “still life” highlights the paraphernalia she uses daily to survive with her low vision. Other category winners can be found at <https://t.e2ma.net/click/ibkxmj/i7gg42/u0fw2kb>

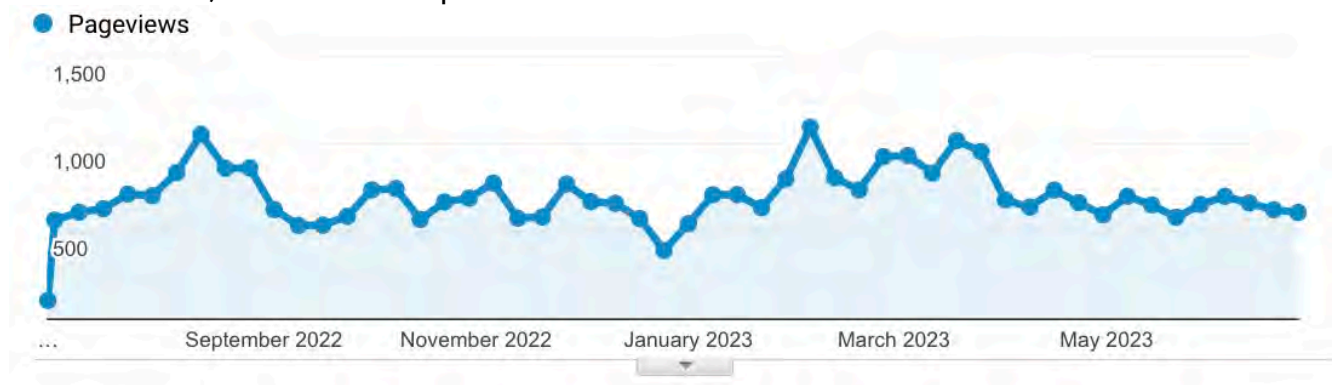
LOCAL AND STATE GROUPS

COVID-19 heavily impacted efforts to start new local groups and hopefully members will try to organise local meetings in 2024 as fears about COVID-19 seem to be receding.

We are always available to assist you start a local coffee catchup or wine and cheese event or information forum. In the meantime, we encourage you to use zoom for group catchups. We are hoping to organise regular zoom catchups in 2024 if volunteers can be found to host them.

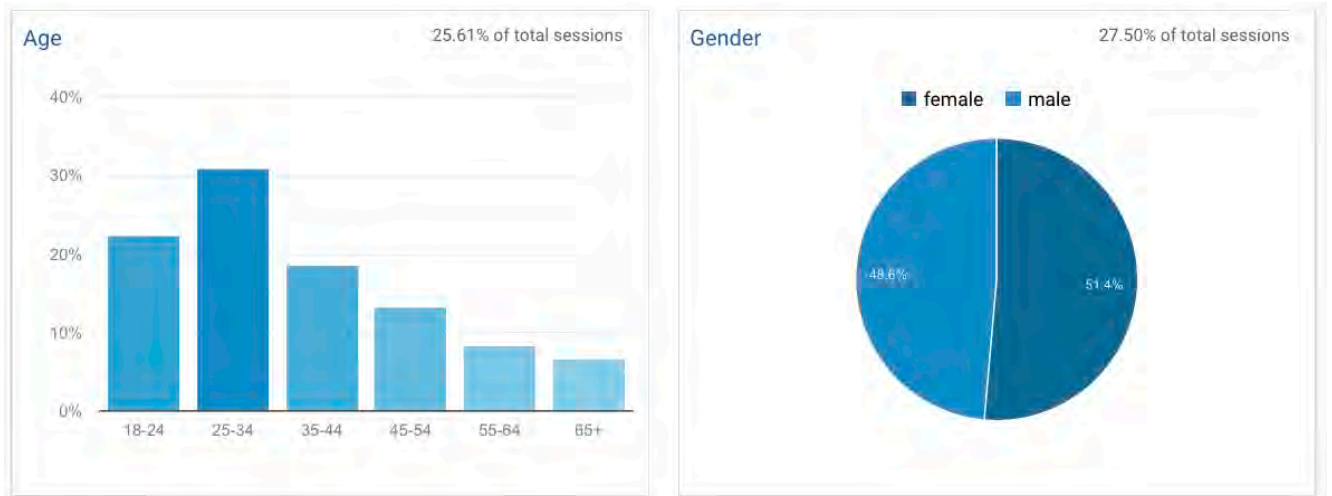
WEBSITE

The Association's website remains a popular source of information about keratoconus. Visits over recent years since the arrival of COVID-19 appeared to follow the rhythm of COVID-19 waves and the associated lockdowns, rising when people were confined to their homes and spending time online and then falling again as the pandemic eased. All key metrics for the site have been falling since the peaks reached in 2020 during the first extended lockdowns. 2022-2023 financial year continued that trend with another 5% decline in total web sessions recorded compared to the previous year: sessions fell to around 22,700, with page views falling 10% to 37,000. The number of users remained almost steady at around 18,500 over the period.



Most users were most interested in the Stages of Keratoconus page, which accounted for 25% of the total site visits with the Home page a close second with 20% of views on the site. Information on Corneal collagen crosslinking accounted for 14% of page views, followed by pages on the contact lenses (8%), Treatments home page (6%), and the Corneal transplant page. (56.5%).

Visitors came from Australia (58%) with most from NSW (36%) followed by Victoria (29%) Queensland (16%), Western Australia and South Australia. More than 16% of users came the United States and 6% from India followed by the UK (2.5%).



Keratoconus is a young person's disease and so not surprisingly, the bulk of visitors were in the 25-34 age group (29%), the ages most affected by keratoconus. Almost 71% of visitors were in the 18-44 age groups. The gender split of users was 50-50 last year.

FACEBOOK



We have continued to promote and post to our Facebook page and currently have 935 followers, up 12% from one year earlier (830). The Association uses Facebook to promote our events like KeraClub. We are also using Facebook to post articles on keratoconus, new research and information on eye-care in general. Last year, we posted 38 times with our most popular posts concerning World Keratoconus Day. A popular but controversial post was a repost from Optometry Australia about new AHPRA guidelines to prevent optometrists making clinical decisions based on meeting business performance targets.

We encourage you to follow us on Facebook to keep up with the Association's activities and latest developments and research in keratoconus.

People looking for keratoconus support via the Australian Facebook community should go to **Keratoconus Support, Australia Forum** - another Facebook group administered by Keratoconus Australia members.

COMMITTEE OF MANAGEMENT

The Committee holds regular meetings to discuss the Association's plans and projects and to review its finances and procedures. In 2022-23, the committee met twice and held informal discussions on other occasions.

The committee last year comprised:

Larry Kornhauser, President
Greg Harper, Vice President
Justine McLaughlin
Alejandro Molano
Michelle Pritchard
Cameron South

Mary Veal acts as the Association's Secretary in an unpaid capacity.



The Association acknowledges all committee members who give their time to ensure Keratoconus Australia continues to function and meets its statutory obligations while providing support to the keratoconus community.

Special thanks go to **Alejandro Molano** for his outstanding work in designing graphics for a variety of projects including the corneal collagen crosslinking brochure, newsletters, annual reports and our recent World Keratoconus Day posters and videos. Alejandro's works have received high praise from around the world.

Thanks also to Michelle Pritchard for her work as KeraClub coordinator which has enabled the Association to establish a strong presence in NSW and to liaise with Save Sight Institute in Sydney. We thank her particularly for continuing her involvement from the Netherlands where she was pursuing her music studies and Sydney since her return to Australia.

Greg Harper is our Vision 2020 Australia representative and his work with the peak vision health body on mental health has been ground breaking for that organisation.

We wish everyone a safe holiday season and good and healthy 2024.

The Keratoconus Australia Team





Financial Reports



FINANCIAL REPORTS 2022-23

Keratoconus Australia Inc. reported a net operating surplus of \$8,174 in the 2022-2023 financial year, up 53% on the surplus of \$5,341 recorded in the 2021-22 financial year. The increase was largely attributable to a significant rise in donations and interest income during the year. Donations rose by 30% to \$8,063 (\$6,222 previously). The repeat hikes in interest rates over the period from almost zero saw an almost 5-fold increase in interest revenue from term deposits. These surged from a paltry \$385 in 2021-22 to \$1,885 last year.

Higher income was partially offset by a sharp rise in total expenses, which were up by 40% to \$1,774 (\$1,266 previously). This was mainly due to higher postage costs (\$811) which jumped as the Association switched back to distributing hard copies of its information material after going fully digital during COVID-19 lockdowns. Vision 2020 Australia membership costs of \$260 also impacted the result. However domain name registrations fell significantly to only \$183 last year cf. \$454 in the 2021-22 financial year.

The balance sheet as at 30 June, 2023 was showing net assets of \$139,057 compared to \$130,883, one year earlier (+6%). The Association holds the bulk of these assets in term deposits (\$110,000) and recently rolled these to take advantage of higher interest rates.

As part of its foreshadowed strategic review, the Committee will examine options in 2024 to raise funds for research and for starting a fund to assist low income members in financing treatments..

We again thank Cameron Falt of Slomoi Immerman Partners for his assistance, in preparing quarterly GST returns and finalising and reviewing our annual accounts. Cameron prepares the Keratoconus Australia accounts on a pro bono basis.

Please direct any questions or comments about these accounts to Mary Veal.

Financial Information

Keratoconus Australia Inc
For the year ended 30 June 2023

Prepared by Slomoi Partners Pty Ltd

Contents

3	Public Officer's Declaration
4	Compilation Report
5	Income Statement
6	Statement of Financial Position
7	Notes to the Financial Statements

Public Officer's Declaration

Keratoconus Australia Inc

For the year ended 30 June 2023

The public officer declares that the incorporated association is not a reporting entity. The public officer has determined that this special purpose financial report should be prepared in accordance with the accounting policies outlined in Note 1 to the financial statements.

The public officer declares that:

1. the financial statements presents fairly the incorporated association's financial position as at 30 June 2023 and its performance for the year ended on that date in accordance with the accounting policies described in Note 1 to the financial statements;
2. in the public officer's opinion there are reasonable grounds to believe that the incorporated association will be able to pay its debts as and when they become due and payable.

Public Officer: _____

Larry Kornhauser

Date: _____

1/11/2023.

Compilation Report

Keratoconus Australia Inc For the year ended 30 June 2023

Compilation report to Keratoconus Australia Inc

We have assisted in the compilation of the accompanying special purpose financial statements of Keratoconus Australia Inc for the year ended 30 June 2023.

The Responsibility of the Public Officer

The public officer is solely responsible for the information contained in the special purpose financial statements, the reliability, accuracy and completeness of the information and for the determination that the financial reporting framework and basis of accounting used is appropriate to meet their needs and for the purpose that the financial statements were prepared.

Our Responsibility

On the basis of information provided by the public officer, we have assisted in the compilation of the accompanying special purpose financial statements in accordance with the financial reporting framework and basis of accounting as described in Note 1 to the financial statements and APES 315 Compilation of Financial Information. The Statement of Financial Position and Income Statement information has been extracted from the Xero accounting records which have been solely maintained by the public officer and management of the incorporated association.

We have applied our expertise in accounting and financial reporting to compile these financial statements in accordance with the financial reporting framework and basis of accounting as described in Note 1 to the financial statements. We have complied with the relevant ethical requirements of APES 110 Code of Ethics for Professional Accountants.

Assurance Disclaimer

Since a compilation engagement is not an assurance engagement, we are not required to verify the reliability, accuracy or completeness of the information provided to us by management to compile these financial statements. In addition, these procedures do not include an assessment of the integrity of the Xero files provided to us. Accordingly, we do not express an audit opinion or a review conclusion on these financial statements.

The special purpose financial statements were compiled exclusively for the benefit of the public officer of Keratoconus Australia Inc. We do not accept responsibility for the contents of the special purpose financial statements.



Slomoi Partners Pty Ltd

Cameron Falt

Director

Dated: 3 November 2023

Income Statement

Keratoconus Australia Inc
For the year ended 30 June 2023

Income Statement

	2023	2022
Income		
Donations Received	8,063	6,222
Interest Received	1,885	385
Total Income	9,948	6,607
Total Income	9,948	6,607
Expenses		
Bank Charges	10	6
Domain Name Registration	183	454
Office Expenses	38	52
PO Box Rental	139	-
Postage	811	238
Printing & Stationery	26	-
Subscriptions	-	282
Telephone & Internet	109	103
Vision 2020 Membership	290	-
Website Hosting	167	131
Total Expenses	1,774	1,266
Profit/(Loss) for the year	8,174	5,341
Undistributed Income	8,174	5,341

The Financial Information should be read in conjunction with the attached Compilation Report.

Statement of Financial Position

Keratoconus Australia Inc

As at 30 June 2023

Statement of Financial Position

	30 JUN 2023	30 JUN 2022
Assets		
Current Assets		
Bank Accounts	28,729	20,657
Term Deposits	110,000	110,000
Goods and Services Tax	49	47
GiveNow Receivables	279	178
Total Current Assets	139,057	130,883
Non-Current Assets		
Intangible Assets		
Website Development - at Cost	6,975	6,975
Less: Accumulated Depreciation	(6,975)	(6,975)
Total Intangible Assets	-	-
Total Non-Current Assets	-	-
Total Assets	139,057	130,883
Net Assets	139,057	130,883
Equity		
Current Year Earnings	8,174	5,341
Retained Earnings	130,883	125,542
Total Equity	139,057	130,883

The Financial Information should be read in conjunction with the attached Compilation Report.

Notes to the Financial Statements

Keratoconus Australia Inc

For the year ended 30 June 2023

1. Summary of Significant Accounting Policies

The public officer of the incorporated association has prepared the financial statements of the incorporated association on the basis that the incorporated association is a non-reporting entity because there are no users dependent on general purpose financial statements. The financial statements are therefore special purpose financial statements that have been prepared in order to meet the requirements of the constitution and the information needs of the members.

The financial statements have been prepared in accordance with the significant accounting policies disclosed below, which the public officer has determined are appropriate to meet the purposes of preparation. Such accounting policies are consistent with the previous period unless stated otherwise.

(a) Revenue and Other Income

Revenue from direct donations is recognised on a cash receipts basis.

Revenue from GiveNow is recognised on a receivables basis and paid by GiveNow to the incorporated association in the month following receipt.

(b) Cash and Cash Equivalents

Cash and cash equivalents include cash on hand, deposits held at call with banks, other short term highly liquid investments with original maturities of three months or less, and bank overdrafts. Bank overdrafts are shown within short term borrowings in the current liabilities on the Statement of Financial Position.

These notes should be read in conjunction with the attached Compilation Report.

ANNEXES

2022-23 RESEARCH PUBLICATIONS

THE SAVE SIGHT KERATOCONUS REGISTRY

Appendix 1

1. Kandel H, Abbondanza M, Gupta A, Mills R, Watson AS, Petsoglou C, Kerdraon Y, Watson SL. Comparison of standard versus accelerated corneal collagen cross-linking for keratoconus: 5-year outcomes from the Save Sight Keratoconus Registry. *Eye* 2023 DOI: [10.1038/s41433-023-02641-6](https://doi.org/10.1038/s41433-023-02641-6).
2. Kandel H, Gillies MC, Watson SL. Opportunities and challenges for clinical registries. *Clinical & Experimental Ophthalmology*. 2023. DOI: 10.1111/ceo.14260.
3. Durakovic E, Kandel H, Watson SL. The Mental Health Impact of Keratoconus – A Systematic Review. *Cornea*. 2023 42(9):p 1187-97 Covered by media: <https://www.optometryadvisor.com/general-optometry/keratoconus-affects-mental-health-and-emotional-qol/> [Featured in National Keratoconus Foundation newsletter 2023]
4. Benito-Pascual B*, Kandel H*, Abbondanza M, Mills R, Sullivan L, Watson SL. Efficacy and safety of standard corneal cross-linking procedures performed with short vs standard riboflavin induction: a Save Sight Keratoconus Registry study. *Cornea*. 2023;42(3),326-31.

*Joint first authors

5. Ferdi A, Kandel H*, Nguyen V, Tan J, Arnalich-Montiel F, Abbondanza M, Watson SL. Five-year corneal cross-linking outcomes: A Save Sight Keratoconus Registry study. *Clinical Experimental Ophthalmology*. 2023;51(1):9-18.

*Corresponding author [selected for CPD by the Royal Australian and New Zealand College of Ophthalmologists (RANZCO); Editor's choice and feature article of the issue; featured in an upcoming issue of the American Academy of Ophthalmology's "Academy Express - Asia Pacific Edition"].

6. Kandel H, Chen JY, Sahebjada S, Chong EW, Wiffen S, Watson SL. Cross-linking improves the quality of life of people with keratoconus: A cross-sectional and longitudinal study from the Save Sight Keratoconus Registry. *Cornea*. 2022 DOI: 10.1097/ICO.0000000000003185 [Featured in National Keratoconus Foundation newsletter 2023].
7. Kandel H, Pesudovs K, Nguyen V, Chen JY, Poon A, Mills RL, Watson SL. Patient-reported outcomes in keratoconus: a Save Sight Keratoconus Registry study. *Cornea*. 2022 DOI: <http://dx.doi.org/10.1097/ICO.0000000000003119>.
8. Borchert GA, Watson SL*, Kandel H*. Oxygen in Corneal Collagen Crosslinking to treat Keratoconus: A Systematic Review and Meta-analysis. *Asia-Pacific Journal of Ophthalmology*. 2022; 11(5):453-459

*Equal senior authors [Paper selected for AAO highlights].

9. Kandel H, Nguyen V, Piermarocchi S, Ceklic L, Teo K, Arnalich-Montiel F, Miotto S, Daien V, Gillies MC, Watson SL. Quality of life impact of eye diseases: a Save Sight Registries study. *Clinical Experimental Ophthalmology*. 2022;50(4):386-97.

Note: Altmetrics 15 (top 10%); GS cited 10; large-scale study involving data from multiple modules of the Save Sight Registries. It was a major international collaboration (10 authors from 6 countries; data from 44 sites). This study is useful to all eye researchers, clinicians, and policymakers.

10. Kandel S, Chaudhary M, Mishra SK, Joshi ND, Subedi M, Puri PR, Gyawali P, Bist J, Kandel H. Evaluation of corneal topography, pachymetry and higher-order aberrations for detecting subclinical keratoconus. *Ophthalmic and Physiological Optics*. 2022;42(3):594-608.

Note: This publication was Dr Kandel's mentoring achievement; he led this international collaboration project with Nepalese optometrists and ophthalmologists and published it as the final author in the leading optometry journal. This paper helped attract funding from IBM Australia for a study to look at developing an artificial intelligence model for keratoconus detection.

11. Kandel H. Quality-of-life outcomes of long-term contact lens wear: A systematic review *Contact Lens and Anterior Eye*. 2022;45:101521.
12. Kandel H, Downie LE*, Watson SL*. The Save Sight Keratoconus Registry – Optometry Module: An opportunity to use real-world data to advance eye care. *Clinical Experimental Ophthalmology*. 2022;105(1):96-99

**Joint senior authors*

13. Gokul KC, Kandel H, Valiño L, Kaiti R, Roy P, Sohail M, Gurung DB. Computational study for Temperature Distribution in ArF Excimer Laser Corneal Refractive Surgeries Using Different Beam Delivery Techniques. *Lasers in Medical Science*. 2022;37(3):1709-1716.
14. Ferdi AC, Nguyen V, Kandel H, Tan J, Arnalich-Montiel F, Abbondanza M, Watson SL. Predictors of progression in untreated keratoconus: A Save Sight Keratoconus Registry study. *British Journal of Ophthalmology*. 2022;106(9):1206-12.

Appendix 2

2022-23 Conference Presentations

1. Borchert GA, Kandel H, Gupta A, Chen JY, Kerdraon Y, Mills RA, Watson SL. Corneal Collagen Crosslinking in the Save Sight Keratoconus Registry: Epithelium on or off? Association for Research in Vision and Ophthalmology (ARVO) 2023, USA.
2. Watson SL, Abbondanza M, Samarawickrama C, Gupta A, Arnalich F, Kerdraon Y, Yeung S, Apel A, Ang A, Kandel H. Ten-year outcomes of corneal cross-linking: A Save Sight Keratoconus Registry study. Association for Research in Vision and Ophthalmology (ARVO) 2023, USA.
3. Arnalich F, Kandel H., Watson SL. Interocular predictors of progression in untreated keratoconus: a Save Sight Keratoconus Registry Study EUCornea 2023.
4. Leona Ngo, Sharon Thai, Kandel H, Watson SL. Implementing FCB! SSDR. Bachelor of Vision Science / Master of Clinical Optometry, School of Optometry and Vision Science Presentation, University of New South Wales (UNSW) 2022.
5. Benito-Pascual B, Kandel H, Abbondanza M, Mills R, Sullivan L, Watson SL. Efficacy and Safety of Standard Corneal Cross-Linking Procedures Performed With Short Versus Standard Riboflavin Induction: A Save Sight Keratoconus Registry Study. European Society of Cataract and Refractive Surgeons (ESCRS) Milan, Italy, 2022.
6. Watson SW. Walter Wright Symposium, Canada 2022/12/2-3.

7. Watson SL, Downie L, Stapleton F, Mingo Bolton D, Arnalich F, Rauz S, Recchioni A, Daien V, Babeau F, Craig JP, Geerling G, Kandel H. Do dry eye signs and symptoms correlate in the real world? RANZCO 2022 meeting, Brisbane [Rapid-fire presentation at the RANZCO 2022 meeting, Brisbane].
8. Kandel H., Watson SL. One-year outcomes of corneal cross-linking in thin corneas with keratoconus: a Save Sight Keratoconus Registry study [Rapid-fire presentation at the RANZCO 2022 meeting, Brisbane].
9. Borchert G, Kandel H, Watson SL. Corneal Collagen Crosslinking in Keratoconus: Epithelium on or off? A Systematic review and Meta-analysis [RANZCO 2022 meeting, Brisbane; Best poster award.
10. Taher A, Kandel H., Watson SL. Diagnostic utility of corneal parameters measured with Pentacam in the diagnosis of early Keratoconus [RANZCO 2022 meeting, Brisbane; Best poster award].
11. Kandel H, Watson SL. The Utility of Save Sight Keratoconus Registry to Understand Contact Lens Wear in Keratoconus International Cornea & Contact Lens Congress (ICCLC), Sydney, 2022.
12. Benito-Pascual B, Kandel H, Abbondanza M, Mills R, Sullivan L, Watson SL. Efficacy and Safety of Standard Corneal Cross-Linking Procedures Performed With Short Versus Standard Riboflavin Induction: A Save Sight Keratoconus Registry Study. European Society of Cataract and Refractive Surgeons (ESCRS) Milan, Italy, 2022.
13. Kandel H, Watson SL. Factors affecting quality of life in keratoconus. European Society of Cataract and Refractive Surgeons (ESCRS) Milan, Italy, 2022.
14. Kandel H, Watson SL. Comparison of standard versus accelerated corneal collagen crosslinking for keratoconus: 5-year outcomes from the Save Sight Keratoconus Registry Association for Research in Vision and Ophthalmology (ARVO) 2022, Denver, USA.
15. SL Watson, Gupta A, Abbondanza M, Sullivan L, Apel A, Kandel H. Comparison of standard versus accelerated corneal collagen cross-linking for keratoconus: 2-year outcomes from the Save Sight Keratoconus Registry Royal Australian and New Zealand College of Ophthalmologists (RANZCO) 2022.

Appendix 3

2022-2023 Conference Proceedings

1. Borchert GA, Kandel H, Gupta A, Chen JY, Kerdraon Y, Mills RA, Watson SL. Corneal Collagen Crosslinking in the Save Sight Keratoconus Registry: **Epithelium on or off?** *Investigative Ophthalmology & Visual Science*. 2023 Jun 1;64(8):1677-.
2. Watson SL, Abbondanza M, Samarawickrama C, Gupta A, Arnalich F, Kerdraon Y, Yeung S, Apel A, Ang A, Kandel H. **Ten-year outcomes** of corneal cross-linking: A Save Sight Keratoconus Registry study. *Investigative Ophthalmology & Visual Science*. 2023 Jun 1;64(8):4788-.
3. Borchert G, Kandel H, Watson SL. Corneal Collagen Crosslinking in Keratoconus: Epithelium on or off? A Systematic review and Meta-analysis. *Clinical and Experimental Ophthalmology* 2022;50(8):907.
4. Taher A, Kandel H, Watson SL. **Diagnostic utility of corneal parameters** measured with Pentacam in the diagnosis of early Keratoconus *Clinical and Experimental Ophthalmology* 2022;50(8):907-8.
5. Kandel H, Watson SL. **Comparison of standard versus accelerated** corneal collagen crosslinking for keratoconus: 5-year outcomes from the Save Sight Keratoconus Registry. *Investigative Ophthalmology & Visual Science*. 2022;63:2381 – A0184.
6. Kandel H, Howes F, Abbondanza M, Watson SL. The outcomes of **transepithelial corneal cross-linking**: Real-world one-year outcomes from the save sight keratoconus registry. *Clinical and Experimental Ophthalmology*. 2022;49(8):863-4.
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THE CENTRE FOR EYE RESEARCH AUSTRALIA

Non-genetic risk factors for keratoconus

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Abstract

Keratoconus is a complex and multifactorial disease and its exact aetiology remains unknown. This current study examined the important environmental risk factors and their association with keratoconus. This study was registered in the PROSPERO International Prospective Register of systematic reviews under registration number CRD42021256792 in 2021. Scopus, Web of Science, PubMed, and Cochrane CENTRAL databases were searched for all relevant articles published from 1 January 1900 to 31 July 2021. National Institutes of Health Quality Assessment Tool was used to assess the methodological quality of the studies. The assessment for statistical heterogeneity was assessed using the Z-statistics on RevMan v5.4. P-value of <0.05 was considered as statistically significant and $I^2 < 25\%$ as homogenous. Thirty studies were included in this meta-analysis. Pooled odds ratio was calculated with 95% CI. The pooled odds ratio (OR) of eye rubbing, atopy, asthma, and eczema was 3.64 (95% CI, 2.02, 6.57), 1.90 (95% CI, 1.22, 2.94), 1.36 (95% CI, 1.15, 1.61) and 1.90 (95% CI, 1.22, 2.94), respectively. The OR for diabetes was 0.86 (95% CI 0.73, 1.02), and use of sunglasses, contact lens, allergic conjunctivitis, side sleep position and prone sleep position was 0.40 (95% CI, 0.16, 0.99), 1.68 (0.70, 4.00), 2.24 (95% CI, 0.68, 7.36), 3.81 (95% CI, 0.31, 46.23), 12.76 (95% CI, 0.27, 598.58), respectively. Twenty studies were considered to be of high quality, nine to be moderate and one to be low. Environmental risk factors have been identified to play a role in the susceptibility of keratoconus. However, further large-scale longitudinal studies are needed to understand the mechanisms between environmental risk factors and keratoconus.

Review Graefes Arch Clin Exp Ophthalmol . 2021 Aug;259(8):2057-2067.

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Eye rubbing in the aetiology of keratoconus: a systematic review and meta-analysis

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Abstract

Purpose: Keratoconus is a potentially blinding condition that slowly deforms the cornea in young people. Despite the increasing prevalence of keratoconus, the exact aetiology of the condition is unknown. This first systematic review examines the evidence of eye rubbing and its association with keratoconus and presents the findings of the meta-analysis.

Methods: Two independent reviewers searched the electronic databases for all potential articles published from 1st of January 1900 to 31st of July 2020 on eye rubbing and keratoconus. The researchers assessed the methodological quality of the studies using the Newcastle-Ottawa scale for observational studies. The assessment for statistical heterogeneity was estimated using chi-square and I-square (I^2) tests. A p value of < 0.05 was considered as statistically significant and $I^2 < 30\%$ as homogenous. Begg funnel plot was used to interpret the asymmetry or small study effects.

Results: Eight case-control studies were included in this systematic review. Two studies assessed eye rubbing without odds ratios and thus were excluded. The pooled odds ratios for the six remaining studies included in the meta-analysis was 6.46 (95% CI 4.12-10.1). The study results were heterogenous ($I^2 = 71.69$ [95% CI 35.14-87.88]). All the studies scored moderate quality methodology on the Newcastle-Ottawa scale. Begg funnel plot showed asymmetry supporting heterogeneity.

Conclusion: Eye rubbing showed consistent association with keratoconus. However, the current evidence is limited to only a small number of case-control studies which present as heterogeneous and of sub-optimal methodological quality. Additionally, the cause-effect temporal relationship cannot be determined. Further studies are needed to address this intricate relationship of eye rubbing and its induction, ongoing progression, and severity of keratoconus.

Indian J Ophthalmol. 2022 Oct;70(10):3508-3513. doi: 10.4103/ijo.IJO_2579_21.

Keratoconus in pre-teen children: Demographics and clinical profile

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Affiliations expand PMID: 36190036 DOI: [10.4103/ijo.IJO_2579_21](#)

Abstract

Purpose: To study the demographics and clinical profile of keratoconus (KC) presenting in pre-teen children in India.

Methods: This was a retrospective case series conducted as a single-institutional study at a tertiary eye center in India. A total of 586 eyes from 294 KC patients

(aged 12 years or less) without any active comorbid conditions of the eye were included in the study. Slit-lamp biomicroscopy was used to document the clinical signs of KC. Information on age; gender; reason for consultation; family history; history of allergy, atopy, and eye rubbing; manifest refraction; uncorrected and best-corrected distance visual acuity (UCVA and BCVA, respectively); clinical presentation; and contact lens usage were also analyzed, along with data on types of medical and surgical treatments for KC and their outcomes.

Results: The mean age of this pediatric KC patient cohort was 9.3 ± 1.8 years, and there was a male (70%) preponderance. Baseline mean UCVA, BCVA, steep keratometry, and flat keratometry were 0.86 ± 0.58 logMAR, 0.44 ± 0.38 logMAR, 54.82 ± 8.4 D, and 48.21 ± 9.5 D, respectively. Progression, necessitating collagen crosslinking (CXL), was noted in 12.7% eyes. Post-CXL, visual and topographic parameters remained stable without any complications till 6 months posttreatment. However, in eyes that did not undergo CXL, significant progression over time ($P < 0.001$) was observed. A keratoplasty was required in 2.3% eyes.

Conclusion: KC was present at an advanced stage in 25% of the pre-teens in our series, and therefore, it is an important diagnostic entity when a refractive error is diagnosed, even in very young children.

Comput Biol Med . 2021 Nov;138:104884. doi:

10.1016/j.compbimed.2021.104884. Epub 2021 Sep 28.

Review J Clin Med 2022 Jan 18;11(3):478. doi: 10.3390/jcm11030478.

Accuracy of Machine Learning Assisted Detection of Keratoconus: A Systematic Review and Meta-Analysis

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Free PMC article

Abstract

(1) Background: The objective of this review was to synthesize available data on the use of machine learning to evaluate its accuracy (as determined by pooled sensitivity and specificity) in detecting keratoconus (KC), and measure reporting completeness of machine learning models in KC based on TRIPOD (the transparent reporting of multivariable prediction models for individual prognosis

or diagnosis) statement. (2) Methods: Two independent reviewers searched the electronic databases for all potential articles on machine learning and KC published prior to 2021. The TRIPOD 29-item checklist was used to evaluate the adherence to reporting guidelines of the studies, and the adherence rate to each item was computed. We conducted a meta-analysis to determine the pooled sensitivity and specificity of machine learning models for detecting KC. (3) Results: Thirty-five studies were included in this review. Thirty studies evaluated machine learning models for detecting KC eyes from controls and 14 studies evaluated machine learning models for detecting early KC eyes from controls. The pooled sensitivity for detecting KC was 0.970 (95% CI 0.949-0.982), with a pooled specificity of 0.985 (95% CI 0.971-0.993), whereas the pooled sensitivity of detecting early KC was 0.882 (95% CI 0.822-0.923), with a pooled specificity of 0.947 (95% CI 0.914-0.967). Between 3% and 48% of TRIPOD items were adhered to in studies, and the average (median) adherence rate for a single TRIPOD item was 23% across all studies. (4) Conclusions: Application of machine learning model has the potential to make the diagnosis and monitoring of KC more efficient, resulting in reduced vision loss to the patients. This review provides current information on the machine learning models that have been developed for detecting KC and early KC. Presently, the machine learning models performed poorly in identifying early KC from control eyes and many of these research studies did not follow established reporting standards, thus resulting in the failure of these clinical translation of these machine learning models. We present possible approaches for future studies for improvement in studies related to both KC and early KC models to more efficiently and widely utilize machine learning models for diagnostic process.

Machine learning with a reduced dimensionality representation of comprehensive Pentacam tomography parameters to identify subclinical keratoconus

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Free article

Abstract

Purpose: To investigate the performance of a machine learning model based on a reduced dimensionality parameter space derived from complete Pentacam parameters to identify subclinical keratoconus (KC).

Methods: All 1692 available parameters were obtained from the Pentacam imaging machine on 145 subclinical KC and 122 control eyes. We applied a principal component analysis (PCA) to the complete Pentacam dataset to reduce its parameter dimensionality. Subsequently, we investigated machine learning performance of the random forest algorithm with increasing numbers of components to identify their optimal number for detecting subclinical KC from control eyes.

Results: The dimensionality of the complete set of 1692 Pentacam parameters was reduced to 267 principal components using PCA. Subsequent selection of 15 of these principal components explained over 85% of the variance of the original Pentacam-derived parameters and input to train a random forest machine learning model to achieve the best accuracy of 98% in detecting subclinical KC eyes. The model established also reached a high sensitivity of 97% in identification of subclinical KC and a specificity of 98% in recognizing control eyes.

Conclusions: A random forest-based model trained using a modest number of components derived from a reduced dimensionality representation of complete Pentacam system parameters allowed for high accuracy of subclinical KC identification.

Other papers

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Keratoconus International Consortium (KIC)- advancing keratoconus research. **Sahebjada S, Chan E, Sutton G, Pang CPC; Srujana Sahebjada for KIC Members; Kerdraon Y, Natarajan S, Meteoukki W, Ang A, Daniell M, Baird PN.** BMC Ophthalmol. 2023 Jul 27;23(1):337.

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Speech to Cornea and Contact Lens Society Australia May 2023

Larry Kornhauser, President Keratoconus Australia

Thank you, Alan, for inviting me to speak tonight and to everyone for joining the webinar and showing interest in keratoconus and its management.

Alan's invitation arose out of discussions between Keratoconus Australia and the Contact Lens Society members about the soaring cost of treatments and especially contact lenses for keratoconus over recent years as new speciality designs have been introduced, and the impact these higher costs are having on patient access to lenses, their welfare and outcomes. In particular, there was discussion as to whether these lenses were being over-prescribed due to practitioner inexperience with RGP fittings. David has already addressed some of these issues.

Before I explore these issues from a patient perspective, first a little about my background.

I was diagnosed with keratoconus at 12 and managed with glasses until I started university. Then I suddenly lost all useable vision in my left eye and was hustled off for a corneal transplant. Back then, a graft was considered major surgery and I spent 10 days in the intensive care ward after the operation, watching many of my ward companions leaving under a sheet.

The first we ever heard about contact lenses for either eye was when the grafted cornea was healing. Lenses for keratoconus were far from brilliant in the 70s and there was pretty much only one fitter in town. Despite having red eyes and lenses that regularly popped from my eyes like popcorn, I survived on youthful exuberance and blissful ignorance of how much worse things could have been.

Over the years, contact lens fitters and lenses improved and I managed to graduate as an economist, work as a financial journalist, travel and live overseas. My graft started to reject after about 13 years when I was living in Europe, and I received ongoing treatment in hospitals and clinics in London and later Paris in the mid-1980s.

Things continued to deteriorate but at least I could console myself with a good eye rub at the end of the day after taking out my irritating lenses. Not surprisingly, by 1993, I was told my keratoconus was still progressing and I could no longer wear lenses – I needed bilateral transplants.

Older and wiser, I said no thanks and started the search for the world's greatest contact lens fitter. I found him lurking in the leafy suburbs of Melbourne. A young enthusiastic optometrist named Richard Vojlaj. It was a life changing encounter in several ways.

First not only did he fit me with workable lenses but he also broke the great taboo of keratoconus optometry by doing something I'd been requesting for 23 years – he prescribed me backup glasses for when I couldn't wear my lenses. It was a big step for both of us. He put aside his preconceptions about people with keratoconus and listened to his patient and I finally got the spectacles I needed. Thank you David for emphasizing this point. (I should note 30 years on, I'm still in RGPs, glasses and my graft recently turned 51.)

Richard also suggested I meet with some of his patients to consider forming a support group for people with keratoconus.

What I heard at our first meeting as each person told their own story deeply shocked and moved me. A litany of debilitating and life changing hardship due to vision loss, the difficulties of finding competent eye-carers, of poorly fitted contact lenses, endless expense and always the lack of information. The common theme was about not being listened to by family, friends and worse even by those people paid to treat our vision loss- our eye-health professionals.

I heard that some optometrists thought many of us had a *keratoconus personality* that made us angry and anxious and difficult to manage. In short, we were patients to avoid if you wanted a peaceful, profitable practice.

Yet it seemed these people had good reason to be angry and anxious.

And so in 2000, Keratoconus Australia was formed.

Keratoconus Australia (KA) is a self-funded, volunteer operated patient support group born from the realisation that people with keratoconus were suffering significant disadvantage and that only patients and their families could/would instigate change. Today, the group has 3,000 members and despite its minuscule budget has punched well above its weight in changing the Australian keratoconus landscape.

Keratoconus Australia's principal function is to provide peer support for people with keratoconus and their families. All of us have keratoconus so we all have lived experience. It is only one of two peer-operated support groups for keratoconus identified in the world.

KA has assisted thousands of people traverse the various stages of keratoconus. It targets patients' health literacy by providing them with information booklets, brochures, pamphlets and a website covering a range of topics ranging from keratoconus, its treatments and management strategies, crosslinking, corneal transplantation the dangers of eye rubbing, to the need for eye tissue donation. It runs public information seminars to enable eye-carers and patients to meet in a neutral, open forum as equals to learn from each other and also to inform family and friends.

It advocates on behalf of patients to government, and through peak eye-care bodies and engages in student optometrist training courses to help develop the contact lens fitters of the future. We also initiated and now chair a new Vision 2020 Australia task force created to address the impact of vision loss on mental health.

The group funds keratoconus research (notably the Save Sight Keratoconus Registry) to monitor outcomes of treatments and their impact on patient QoL. Keratoconus Australia uses its member database to recruit patient volunteers for research projects. KA feedback enables researchers to ensure their studies are tailored to reflect a patient perspective and needs.

Using information from a range of sources including CCLSA, KA compiles lists of eye-carers around Australia that it offers patients to help them get timely access to clinicians and optometrists with the appropriate expertise. This also relieves a major source of stress for patients and their families.

Great progress has occurred in keratoconus research and treatment options over the past two decades. Corneal crosslinking which can stabilise keratoconus has radically changed the prognosis for keratoconus patients if done early enough. The new contact lens designs can be used on more advanced keratoconus than RGPs. Both are leading to a welcome decline in corneal transplantation rates.

However, we believe there is an urgent need for more action to improve outcomes, especially for people from low income and other disadvantaged groups.

Public policy regarding keratoconus has long been hindered by a failure to acknowledge the extent and seriousness of the disease for patient vision and quality of life. New Australian research highlights these failures.

Keratoconus is now recognised as being far more prevalent than ever thought and possibly growing. Until recently, the most commonly cited global prevalence

figure was 1 per 2000, arising from a 1986 American population study. (Kennedy et al., 1986) ⁱ

Today, advanced scanning technology show much higher levels of keratoconus in various populations. A 2017 study in the Netherlands found a prevalence of 1 per 375 (Godefrooij et al., 2017) ⁱⁱ while in 2019, a 20-year longitudinal study in Western Australia published by the Centre of Eye Research Australia (CERA) identified a 1 in 84 rate in the study cohort (Chan et al., 2019). ⁱⁱⁱ Mideast studies show even higher rates.

So whereas the local keratoconus population had been pegged at some 13,000 people, the Dutch results imply a more plausible figure of 70,000 Australians with some form of disease while the WA study points to a figure of over 300,000!

Other research confirms the significant impact of keratoconus on quality of life. A 2022 Save Sight Keratoconus Registry cross-sectional study showed that today, people with keratoconus record worse QoL scores than patients with retinal disease. The study found that QoL outcomes of keratoconus are far more dependent on quality of vision (contrast sensitivity, glare, halos and measures of visual function) than just visual acuity. The young age of patients and their inability to adjust well to rapid vision loss is also an important factor.

The authors concluded that the relative impact of keratoconus on QoL compared to other eye diseases should now inform public health planning and resource allocation.

Another Save Sight study published this month in *Cornea* refined those results to show that female gender, contact lens wear, reduced visual acuity, and higher disease severity were all associated with worse QoL outcomes.

Yet policy makers still seem reluctant to act to ensure patients have access to safe and affordable care from a well-trained eye health workforce – the fundamental requirements of the World Health Organisation’s recommended Integrated People-Centred Eye Care (IPEC) policy - leaving it essentially to private health providers to manage the issue in Australia. This contrasts to the situation in many other countries, e.g. New Zealand, France, Germany, Italy and the United Kingdom, where keratoconus is recognised at government level as a serious eye condition meriting special attention, funding and research. NZ and the UK provide contact lens subsidies for patients unable to use spectacles.

Affordability is a key barrier to better eye health globally. Keratoconus is no exception and especially in Australia.

At around \$3-400 each, rigid gas permeable lenses (RGPs), which need replacing every 12-24 months, were already considered expensive by those with progressive disease. The widespread use of customized hybrid and semi-sclerals has more than tripled the upfront cost to patients to over \$1000+ per lens. Hybrids need replacing every 6-12 months, although thicker semi-sclerals can last 3-4 years or more with careful handling and cleaning regimes. Those with progressive disease may need several refits annually. As David has just explained, post crosslinking flattening can also lead to regular contact lens changes – especially for patients in RGPs.

A 2019 patient reported study of the economic burden of keratoconus conducted by the Centre of Eye Research Australia (CERA) concluded that regardless of their insurance status (full private and ancillary or not), keratoconus patients still faced out-of-pocket expenses for almost the full cost of contact lenses. Out-of-pocket private surgery costs could range as high as 6-45 times more than in public hospitals. Overall, kc patients reported an average annual outlay of around \$3,500 or 30 times the average Australian spend on eye care. (Chan et al.; 2019) ^{iv}

Apart from their high up-front cost, there are questions around the long term performance of the larger speciality lenses. There has been a massive shift from RGPs to these newer designs since 2012. New Zealand optometrist Grant Watters reported in this forum on an analysis of his patient data which showed a halving in RGPs from 80%+ of total fits to 40%, between 2012-18. (Watters, 2020) ^v

Semi-sclerals are supposedly easier to fit, more comfortable and stable, keep out dust and allergens and provide better oxygen transference. Yet the Watters study showed almost the opposite was true. His data showed they resulted in more patient complications over time than a correctly-fitted but cheaper RGP, and are harder for the patient to manage. Semi-sclerals had a 50-60% rate of complications, notably discomfort, lens fogging and corneal neovascularization, and 16% or more of these were sight threatening. Certainly, patient forums are replete with all sorts of grumbles about them too.

For the optometrist, they may seem easier to fit initially (less chair time) than RGPs, and bring in far more income. Yet Watters concluded that semi-sclerals and hybrids and other speciality lenses may require greater practitioner expertise, not less, to achieve optimal patient satisfaction.

Watters argued that more research was required to evaluate the long-term performance of semi-sclerals which are seriously adding to the economic burden

of keratoconus. So far, that research has not been done. David is obviously a huge fan of sclerals.

Limited warranties and inconsistent optometrist refund policies mean that patients are often incurring huge bills for unsuccessful fits and are then unable to afford to seek assistance elsewhere.

Medicare has been of little benefit and doesn't even recognise keratoconus as a disease. I'm sure you all understand the inadequacies of the current rebates. Since the mid-teens when optometrist fees were uncapped by the Australian government, the situation has worsened leading to more hardship and mental stress for many patients.

Many of these are people who could previously afford their RGPs but no longer can. Some are persisting with old lenses, which may be damaging their corneas - especially if their keratoconus is still progressing. Many are flirting with surgical options (even corneal grafts) in the often-mistaken belief that in the long term, they will be financially and visually better off than with contact lens-based solutions. Some are trying to manage with spectacles while others have given up and have exited the eye care system altogether. These are the ones we worry most about.

We get a constant stream of these financially-bereft, visually impaired patients who can no longer cope with their poor vision and are seeking a way of re-entering the system to access proper eye care. It is not easy for most, especially for those living in regional and remote areas. Many have other health issues or sources of disadvantage.

So the real questions for tonight's discussion from our viewpoint are firstly, how can more research be done into the long term safety of the high cost semi-sclerals being used widely today and secondly, what can be done to ensure all people with keratoconus continue to have access to affordable contact lenses and expert fitters of speciality contact lenses. Finally, given that crosslinking should be reducing the severity of keratoconus generally and logically the difficulty of fits over time, are expensive speciality lenses being overprescribed by practitioners who simply have lost the art of RGP fittings?

Regarding research, funding is being cut from CERA's Keratoconus International Consortium (KIC) project while the Save Sight Keratoconus Registry is surviving only on funding from our patient support group. Both are engaged in the type of global research needed into the impact of keratoconus treatments including contact lenses on patient welfare. But both will be seriously handicapped or closed down without government or philanthropic support.

As with all eye health measures, the economic benefits to patients and society of reducing vision impairment from keratoconus would far outweigh the costs. For example, using Lancet Global Health disability weightings and applying them to the Australian Government,^{vi} statistical life year values, one can calculate a rough estimate of the “value” to the individual (or government) of correcting vision loss. That approach yields a “benefit” amount of \$6,700 to an individual or almost double the average annual outlays by keratoconus patients identified by the CERA economic burden study. So it makes economic sense to fix vision loss.

Keratoconus is a young person’s disease. It strikes from puberty, and advances through an individual’s “core education, prime earning and child rearing years.” Which is why it has such a great impact on patient quality of life (Chan, et al 2019)^{vii}

The consequences of uncorrected vision impairment for young individuals are severe as described by the WHO:

- school age children experience lower levels of education and self-esteem than normally-sighted peers
- they suffer higher rates of bullying, sexual violence, and difficulty in managing other health issues
- as adults, they have lower rates of workforce participation, productivity, poverty
- later, they experience higher risks of falls, accidents, fractures (notably hip), motor accidents, early entry into nursing care, limited mobility and cognitive decline
- the cumulative effect is higher rates of anxiety and depression than the general population at every age, with all the additional associated impacts of poor mental health

There are also impacts for care givers who are required to engage in extra support for these people, often at the expense of their own physical and mental health.

Not surprisingly then, a 2009 Access Economics study showed that these indirect consequences account for 80% of the true economic cost to society of vision impairment. That study concluded that treating vision impairment (including keratoconus) would therefore yield a 500% return on investment or more.

Solutions to the issues facing Australians with keratoconus require a major shift in public and private eye health carers attitudes. Optometrists in private practice will need to consider the potential conflict of interest between their role as eye health providers and small business owners, and how they manage that conflict when dealing with disadvantaged patients not holding government health cards. They will require more training, specialisation and certification to improve patient access to quality care including well-fitted, lower cost contact lens options like RGPs .

Some here argue that low income and disadvantaged people with keratoconus should receive access to NDIS funding. We agree that could provide one avenue for some patients. Given the numbers involved, we believe the dollars needed would be very small – perhaps no more than several million annually or less. But all the signs indicate that accessing NDIS funding will get harder in the future, not easier. In that case, more needs to be done in state-funded public eye clinics to bolster funding and contact lens fitter expertise. State based spectacle schemes might also be expanded to include contact lenses for keratoconus. Ultimately contact lenses for keratoconus need to be classified as a medical device by both government and private health insurers and treated as prostheses like hearing aids.

Preventative measures like better screening for 11-15 year olds, early diagnosis, crosslinking, and keratoconus information and anti-eye rubbing campaigns should be implemented too. These will all lead to a reduction in the seriousness of keratoconus, improved vision correction and therefore better QoL outcomes. Stem cell and gene therapies may one day even correct vision loss and halt the changes in the cornea caused by keratoconus. But more action is needed now.

Finally, the needs of older patients who remain dependent on contact lenses must also be considered. They should not be left to manage with their low vision simply because they can no longer insert and remove their contact lenses.

Optometrists are the health carers who provide us with the miraculous lenses that restore our vision and potentially give us back our lives. We thank you for your immeasurable contribution to our welfare and look forward to working with your profession to improve outcomes for *all* people with keratoconus – not just those who can afford best-practice treatments. (just one small thing, please don't call us keratoconics)

Thank you

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