



KERATOCONUS  
AUSTRALIA

# ANNUAL REPORT 2021









**The Association**



# WHO WE ARE

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 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 people 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 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

- Acting as a representative group for keratoconus patients to improve access to treatments (contact lens and solutions, spectacles) and corneal surgery for all but especially socially and economically disadvantaged persons with keratoconus

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**From the President**

## FROM THE PRESIDENT

Vision is precious. We all know that. Cancer is the only disease we fear more than losing our sight, according to research.

So, it is always a shock being diagnosed with any eye disease or condition that could lead to a rapid and significant loss in vision.

Keratoconus generally strikes just as a person is exiting their childhood and embracing the independence that accompanies adolescence and early adulthood. It is a time when our learning intensifies, as does our desire to break free of parental oversight and edicts, to explore the world around us and to heed the call of raging hormones.

It's no wonder then studies have shown that keratoconus has a more deleterious impact on a patient's quality of life than more common and serious eye diseases which develop later in life, like glaucoma or macular degeneration, the single greatest cause of blindness in Australia.

Unlike with most other eye diseases, vision loss stemming from keratoconus is usually correctible even if the disease itself isn't reversible. Most of our work involves talking people through their difficulties, offering them hope from our own experiences and finding them competent eye-carers in their areas who can improve their vision with contact lenses or in the extreme cases, surgery. In the past, this was enough to help patients weather their keratoconus storm.

But things have changed in the past five years.

A recent Centre of Eye Research Australia (CERA) study highlighted that keratoconus patients pay up to 30 times more for eye care today than the average Australian. Treatments are more expensive, government subsidies and rebates for complex contact lenses needed to restore vision are almost non-existent and clinicians able to fit these lenses correctly are dwindling in number and hard to find. Then, as if it's not enough to struggle through school, go to work, attend endless eye-carer appointments, manipulate tiny contact lenses, avoid dust and pollen, you find yourself in the middle of pandemic.

Thank you COVID-19!

Now there's a virus to avoid, job and income loss, fear of attending critical medical appointments, delays in surgery. Not matter how brave we try to be, it all becomes too much.

Over the past year, I have spoken to many people about their struggle to live with keratoconus. Sleep deprived mothers of new born babies struggling to convince their optometrist that the lenses may be technically correct, but they hurt and can't be worn for more than a few hours. Patients living in the country whose lenses are broken and can't be refitted by the local optometrist, others who have lost their jobs because of their poor vision, or who simply can't afford to pay thousands of dollars for the treatments which could restore their vision - and their lives.

I have spoken to teenagers who simply can't make their eye-carers or parents understand how little they can see. Crosslinking or not, contact lenses or not. Some "self-medicate," some lose themselves in video consoles with screens pressed to their faces, some just sleep walk through their lives, deprived of what they enjoy most: books, games, sport, hanging out with friends, whatever. And so they enter the vicious cycle of declining vision, anxiety, depression.

Some experts tell us the process of assisting people suffering vision loss is akin to grief counselling. A process not unlike helping those who have lost a limb or the capacity to perform daily tasks due to other health conditions, or to facing a battle with cancer etc. Perhaps.

We approached Vision 2020 Australia in mid-2020 to ask about what resources our members could access for their mental health issues. Nobody actually knew.

In early 2021 when Vision 2020 Australia wanted to canvass interest for a mental health initiative in the vision sector, the Association's Vice President Greg Harper took on the mantle of leading the discussion. Several meetings have already been held and there seems to be interest in creating a central pool of resources specific to loss of vision and mental health. A work program is now being drawn up. At our request, the Save Sight Keratoconus Registry is also upgrading its quality of life survey to monitor mental health markers.

Hopefully we can identify paths for assisting those suffering the mental anguish of fading sight. Please join us if you have any special knowledge or interest in this area.

A final note: keratoconus is a progressive disease and can move quickly. Stay COVID-19 safe, yes but don't delay that appointment with your eye-carer if your vision is deteriorating. Corneal collagen crosslinking surgery can be done only in the early stages of keratoconus.

Larry Kornhauser OAM  
president@keratoconus.org.au  
November 2021





**Support**



# SUPPORT

## INTRODUCTION

*Keratoconus Australia is dedicated to providing support for people with keratoconus and their families.*

*The Association is operated by people with keratoconus; we do not have medical qualifications or training nor do we provide medical advice. What we do is talk to patients and family members about our own experiences 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, a full examination of a patient's eye is required before even a medical practitioner will provide clear and considered advice on keratoconus treatment and management options. Which is why any counsel coming via Keratoconus Australia will always be non-patient specific and general in nature, with the caveat that the patient needs to be reviewed in person by a keratoconus specialist.*

*Never delay seeking medical advice if your vision is changing.*

## COVID-19 IMPACT

COVID-19 and the resulting lockdowns across Australia provided the biggest challenge to both the Association and the keratoconus community in 2020-21. Victoria faced an extended hard lockdown in the second half of 2020 that heavily impacted the ability and willingness of keratoconus patients to seek treatment. Patients in other states also faced shorter periods of restricted movement and access to eye-carers and treatments, especially elective surgery, during the reporting period. This was a trend noted across the entire health sector as people avoided what were perceived as high-risk places like medical and optometrist practices and hospitals.

Prolonged hard lockdowns from July to October 2021 in NSW and Victoria exacerbated the problem for many people with keratoconus-related issues. As a result, the Association reminded patients regularly that keratoconus is a progressive disease and that it is important they see their eye-carer if they notice any change in their vision to avoid irreversible loss of sight.

Treatments like corneal collagen crosslinking are only effective when performed before the cornea becomes too thin. Yet more than once, patients told us they would see their eye-carer “once the COVID-19 thing” had passed.

Our response has been and remains, if you are fully vaccinated and your eye-carer is too and adopts covid-safe practices, then you really should seriously consider having your eyes and contact lenses checked to avoid long term damage to your corneas and loss of vision.

### **NEW TRENDS**

Last year, a number of worrying trends emerged. Questions about non-crosslinking related surgery and in particular corneal transplantation more than doubled, with many patients being told by optometrists to consider a graft. In some cases, it appeared that the advice stemmed from poor contact lens fits or in others, without contact lenses even being suggested. This is of concern given the efforts being made by the Association – especially in Victoria – to improve optometrist training in keratoconus. Moreover, research is showing a sharp decline in corneal transplantation for keratoconus thanks to treatments such as corneal collagen crosslinking and larger corneal contact lenses.

We also receive many inquiries from patients who have done “research” on treatments via the internet and have pre-conceived ideas about what would resolve their issues – even without having had a proper review done by a keratoconus clinician.

In general, many patient queries can be answered by offering our information brochures on keratoconus and its treatments and/or person-to-person discussions. The Association usually then attempts find an expert fitter of speciality contact lenses for keratoconus of corneal surgeon near the patient so they can have a full examination of their keratoconus before deciding on treatment and management strategies.

Requests to help patients find keratoconus specialists in their local area accounted for 44% of the Association’s support work in the 2020-2021 financial year. This was similar to the previous year (45%) and higher than the long-term average of around 35%.



**A corneal transplant**

However, the actual number of support contacts that result in a recommendation to see an experienced keratoconus practitioner is probably closer to 85%. This is because vision loss from keratoconus can be complicated to rectify and local optometrists who diagnose a patient's keratoconus are not necessarily the best persons to manage it.

There is an urgent need for inexperienced practitioners, especially optometrists, to refer these patients to their more experienced colleagues to ensure keratoconus patients do not suffer further complications due to incorrect treatments or unnecessary and burdensome costs that may compromise their ability to seek help elsewhere.

### ***RISING TREATMENT COSTS***

In regard to this latter point, the economic impact of COVID-19 was felt throughout the year, especially in Victoria where repeat lockdowns led to severe income reduction and job losses for many patients, especially once Jobkeeper ended. This coupled with the ongoing rise in the cost of treatments, notably of larger scleral contact lenses, resulted in a steady stream of calls for help from distressed patients and their families unable to access or afford adequate vision correction.

Over the past six years, optometrist consultation costs have also continued to rise as more contact lens fitters switch from the smaller rigid gas permeable (RGP) lenses to the larger mini-scleral and hybrid lenses. These larger lenses offer benefits to many patients, especially with more advanced keratoconus, who are unable to wear the RGPs. But they can be hard to fit requiring more optometrist visits, they can be tricky to insert and remove, can have issues like fogging and more importantly can cost up to 5 times more than a standard RGP lens.

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*“A keratoconus patient spends 30 times more on eye care than the average Australian”*

*Centre for Eye Research Australia 2020*

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Last year, the Association continued to receive complaints from patients whose scleral lenses still did not work for a variety of reasons after their warranty had expired, but who could not afford a new pair after spending over \$3,000 on these unsuccessful lenses. We helped several patients negotiate a compromise with their contact lens fitter either over a partial refund of the cost of these

lenses or for the fit and supply of another heavily discounted pair of lenses. In one case, a “no success, no pay” deal on another refit was reached after the patient had paid for two unsuccessful fits.

While such ad hoc outcomes can resolve a difficult situation for a particular patient, a more robust system to deal with unsuccessful fits is needed for all patients. Optometrists would benefit too.

The Association is currently working with Optometry Australia to find a solution to the warranty and refund problems around keratoconus contact lenses. (see **Advocacy**)

Overall, the number of support contacts logged over the cost of treatments more than doubled in 2020-21 to 50, representing 11% of all support contacts.

Many requests for assistance in finding an expert fitter of speciality contact lenses for keratoconus were qualified by a need to find one who bulk billed or who worked in a clinic which offered discounted or subsidised 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.

We continue to advocate for special pricing arrangements for keratoconus patients and are hoping to launch new research in 2022 on the economic burden of keratoconus and in particular of contact lenses to assist in our advocacy efforts.

## **MENTAL HEALTH**

A diagnosis of keratoconus with its associated risk of a significant and possibly rapid loss of vision is obviously upsetting and a trigger for stress and anxiety. At Keratoconus Australia, we all have keratoconus and understand that feeling. But we also know that it usually can be treated and managed and that with early crosslinking, progression can be minimised. People with keratoconus can then live fairly normally, can drive, study, work and still have a rich family and social life. That’s why we created a support group in the first place: to reassure patients, support them as they traverse the stages of keratoconus and help them find the eye-carers who can restore and maintain their vision.

Our discussions with patients are a critical element of that process as many have never spoken to another person with keratoconus in their lives. Sharing

experiences is immensely therapeutic and providing them with examples of positive outcomes offers hope for the future.

However, we are not trained counsellors and must direct patients exhibiting signs of depression or other longer term issues to their own general practitioners, psychologists or mental health services.

In the past, we have found that most patients overcome their initial shock and distress of a keratoconus diagnosis or of a worsening in their condition once directed to an appropriate eye-carer. The advent of the COVID-19 pandemic heightened levels of anxiety and stress generally across the community but especially amongst people requiring health care from providers who were either unavailable due to government edicts or perceived as high risk.

The high cost of keratoconus treatments, coupled with the difficulty in affording and accessing them due to COVID-19 lockdowns therefore had a significant impact on the mental health of many people with keratoconus, and their families.

The Association fielded a number of calls from very distressed patients, unable to see or to access contact lenses to correct their vision and who were subsequently laid off their jobs making it impossible for them to afford treatment. One of these patients admitted to “self medicating” and blamed their optometrist for “ruining” their life.

In another case, we felt obliged to contact a mental health crisis centre, such was our concern for the patient’s welfare.

We have had in depth discussions with patient family members on a number of occasions about the mental health of their children who are suffering from the loss of vision due to keratoconus and its impact on their education, social, sporting and working lives.

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*Emotional well-being is strongly related to a patient’s vision in the worse eye*

*Save Sight Keratoconus Registry, Cornea 2019, 38(5):600-4*

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Fortunately, a number of these patients felt significantly better after being referred to other eye-carers who were able to work with them better and improve their vision at a reasonable cost.

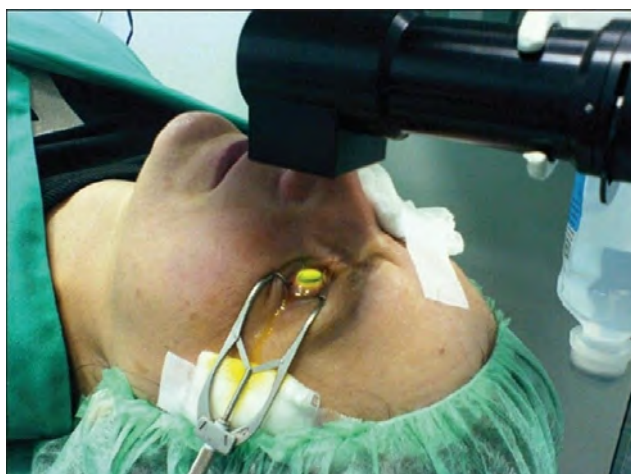
As discussed in the **Advocacy** section, the situation has become so serious that we approached Vision 2020 Australia last year for advice and suggested the creation of a working party to investigate the issue and the options for providing support for people suffering mental health issues specifically related to loss of vision.

At this stage, we don't collect data specifically concerning mental health issues and how they are impacting patients. But we are discussing ways of using tools like the Quality of Life survey included in the Save Sight Keratoconus Registry to measure this aspect of patient welfare.

One interesting finding already from the Save Sight Keratoconus Registry was that while vision in the better eye correlated with ability to perform daily tasks, vision in the worse eye was strongly related to emotional well-being (see **Research**).

### OTHER TRENDS

- Corneal collagen crosslinking is the only treatment that can slow or halt progression in keratoconus. The Association has written an information brochure on crosslinking in conjunction with the Save Sight Keratoconus Registry that is sent to all new members.



corneal collagen crosslinking

Nevertheless, there is still confusion around what it can and can't do and who can benefit from the operation. As a result, around 13% of all support contacts in 2020-21 related to this procedure. Many of the support requests pertaining to crosslinking last year involved questions as to whether sight would improve after crosslinking (usually not

by much if at all) and when to have it done.

The "when" issue is important because crosslinking can only be performed before the cornea becomes too thin. Keratoconus is most aggressive in adolescents and later tends to stabilise in most people as they reach around 35-40 years. So crosslinking is generally performed early for younger patients showing signs of progression, while older



patients may be monitored for longer if their keratoconus is not advancing much.

- We also received a number of calls from worried parents of young keratoconus-patients to seek reassurance about the safety and efficacy of crosslinking and the impact of keratoconus on their child's future. In many cases, we can put them in touch with other parents whose child had already been crosslinked or some of the young adults who have undergone the procedure.
- Support for patients just diagnosed with keratoconus rose slightly last year to 30 contacts (but declined as a proportion of total support given). Patients often requested more information about the disease and their prognosis than provided by their eye-carer or information about specialists in their area.
- Eye rubbing is a significant issue among people with keratoconus despite campaigns aimed at highlighting the dangers of this practice for eye health. Eye rubbing has repeatedly been shown in research to be a factor in both triggering underlying keratoconus and causing progression in the disease.



Eye rubbing can worsen keratoconus

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*“56% of new members rub their eyes”*

### *Keratoconus Australia data*

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Over recent years, the Association has been tracking eye rubbing amongst new members. Our data show that since July 1, 2020, nearly 56% of our new members with keratoconus admitted they rubbed their eyes vigorously or had done so in the past.

- There were less requests for support over contact lens-related issues. But problems with the costly scleral lenses were on the rise and the

Association intervened with several contact lens fitters to try to broker an acceptable solution to ongoing complications (notably lens fogging).

- As the older generation of contact lens fitters for keratoconus retire and others shift away from clinical practice, we received a growing number of calls from patients seeking help in finding a new contact lens fitter. This was particularly evident in Melbourne where personnel changes at two of the largest keratoconus practices resulted in many patients needing a new contact lens fitter.

We note that Keratoconus Australia has expanded the information material included in its new member kit about keratoconus and specific treatments and issues such as corneal collagen crosslinking and eye rubbing. Since COVID-19 closed our office in early 2020 and prevented us from sending hard copies of this material, we now provide members with electronic versions in pdf format. With the lifting of restrictions in Victoria, we will again have hard copy supplies of these booklets and brochures for those who prefer the information in that format. We urge members to request this free information material from us in whatever format they prefer.

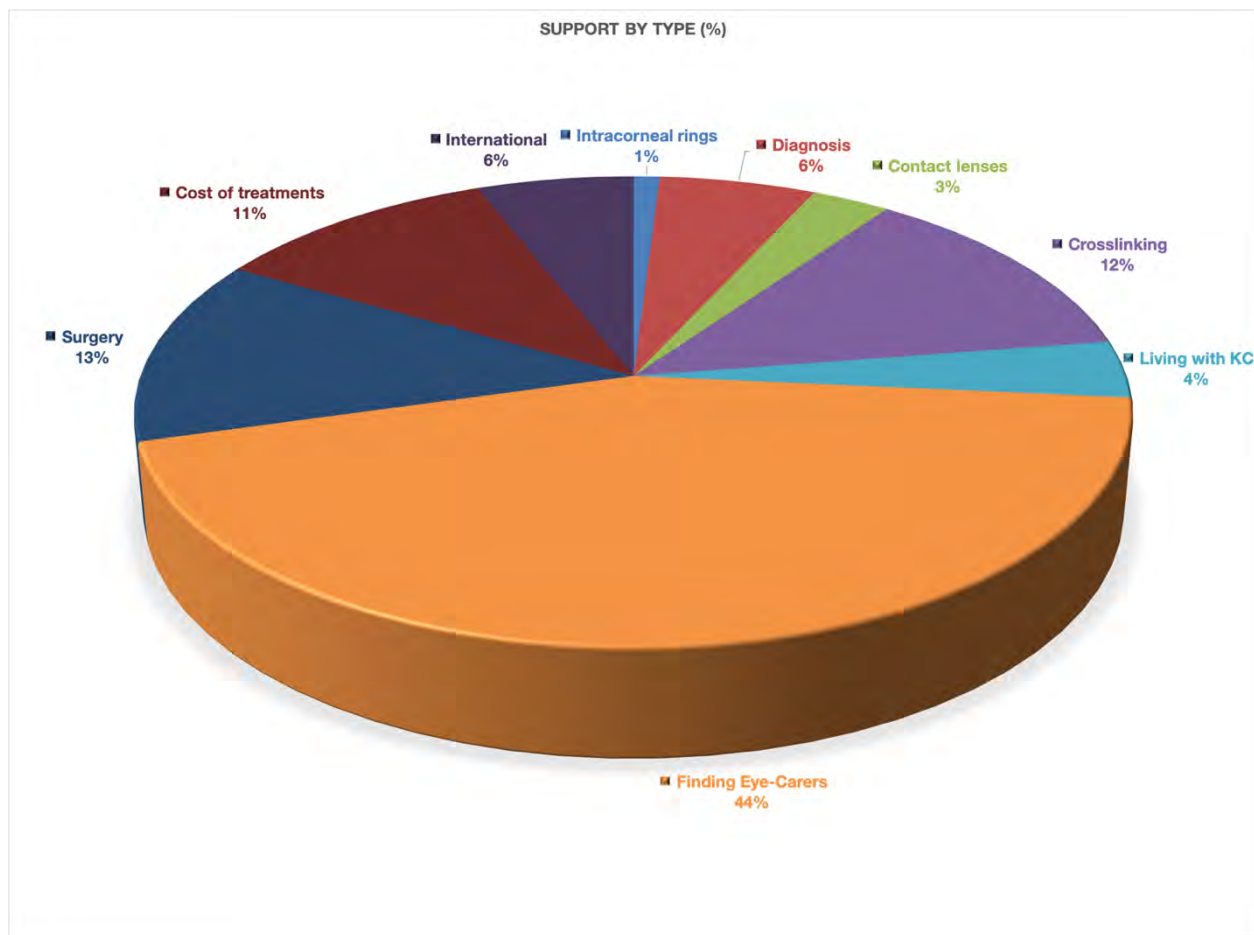
Many of the answers to patient questions can also be found on the **Treatments** and **FAQ** pages our website.

## **SUPPORT BY NUMBERS**

After the dramatic fall in support requests experienced at the start of COVID-19 crisis in early 2020, total support contacts logged by the Association jumped dramatically in 2020-21 to 466 - almost 80% higher than the previous period (260).

The method of recording support contacts reflects both the actual number of people assisted as well as the complexity of issues being discussed. Last year, the Association assisted over 100 individuals with many requiring multiple interactions to resolve the issues being confronted by the patient or family.

The pie chart below highlights the Association's support activities in 2020-21 by type of support given to patients.



## SUPPORT BY EXAMPLE

Keratoconus Australia offers members and anybody with keratoconus free support. We listen to what people are saying to us and then try to respond in a way that best meets their needs. Everyone with keratoconus is told to avoid eye rubbing if possible as this could potentially worsen their condition.

Below are some examples of support we provided in 2020-21.

- James lives in Mildura and had crosslinking and was looking for a local contact lens fitter to fit him with scleral lenses as his usual fitter had retired. Despite the Melbourne COVID-19 lockdown, he finally managed to get a lift into Melbourne to see one of the top fitters. He described the experience as “amazing” and had lenses fitted for both eyes. “I finally feel comfortable with the treatment I’m receiving,” he told us.
- John’s son has mild and stable keratoconus but was very concerned that he could lose his sight. Despite reassurances from his eye-carers that he was fine, he wanted crosslinking done on both eyes. We had long discussions with the family but eventually John’s son had the crosslinking performed on both eyes. In subsequent discussions, the

son was obviously feeling better but would sometimes still be anxious about the future.

In late 2020, John was kind enough to also discuss his son's crosslinking experience with Nadeem whose son was scheduled for crosslinking in the following week. Nadeem contacted us to say how reassured the family was to have the opportunity to talk through their fears with another parent who had recently gone through the same experience.

- Clara was diagnosed with keratoconus and felt she was being pressured into having both eyes crosslinked without sufficient monitoring for progression. She contacted us to ask if that was normal and if not, where she could go for a second opinion. We told her monitoring was the usual – especially as she was in her late 30s. She couldn't afford to see a corneal surgeon in private practice so we provided her with details of alternative public clinics for a second opinion.
- Natasha had bilateral crosslinking done in 2019 and was trying to get contact lenses fitted at a subsidised teaching clinic. Felt her concerns with the lenses were not being listened to. We contacted the head of the clinic who agreed to see her and refit the lenses himself. Things were going better with new lenses.
- Sonia, 60, asked if crosslinking could help restore her vision at her advanced age. We said crosslinking only stabilised vision and did not generally improve it. It is not usually done on older people as keratoconus is generally stable anyway. We referred her to our crosslinking brochure.
- Ryan was concerned about having crosslinking done and in particular with the newer, oxygen-enhanced epithelium-on protocol recommended by his corneal surgeon. After discussing with our consulting ophthalmologists, we said there was little research comparing this protocol with the epithelium-off methods. After much discussion, Ryan decided to continue monitoring his eyes for progression before opting for crosslinking.
- Ben was desperately unhappy after an unsuccessful crosslinking operation which apparently damaged his eye and made him unable to see with his contact lenses. He wrote a scathing letter about the quality of care he had received from his eye-carers. He said he had lost his job because of his vision and was "self-medicating" to survive. He didn't reply to our attempts to contact him. Finally, he told us he was seeing a

new contact lens fitter and things were going better. He was grateful for our concern and support. Over the ensuing months, we kept in touch and helped him as needed with advice.

Not all support contacts led to the desired outcome. In a number of cases, patients, were unable to afford treatments with private practitioners (especially contact lens fitters)- and had no access to subsidised clinics. COVID-19 restrictions also prevented patients from travelling for treatments.

- Natalie was unable to get properly fitted contact lenses from her local country town optometrist. She was very depressed and unable to work or drive. We tried to arrange an appointment for her with an expert fitter of speciality contact lenses for keratoconus. But she was unable to travel there because of COVID-19 lockdowns.
- Margaret had three crosslinking surgeries and was suffering after-effects, light sensitivity and allergic reactions to her contact lens solutions. She was not getting help from her corneal surgeon and then she moved interstate. We found some keratoconus eye-carers locally and in Sydney for her. But COVID-19 restrictions and the high cost of treatments deterred her from pursuing those solutions.

*"I did contact (the contact lens fitter) for a booking but the initial consultation fee was quite exuberant at almost \$500. Due to COVID19 and lack of financial security, unfortunately I will be putting that one on hold for quite a while until I have the funds available. Thank you for your assistance and phone call last week, I really appreciate it."*

- Finally, we have received many questions from around the world about a trial of IVMED-80 drops at Auckland University that would purportedly reshape a keratoconic cornea. We tell people we have no information about the trial and that they should contact the researchers directly. We understand that these trials are still underway.

## **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. Here is a sample of the kind words written to us in the past year.

- Warren was having trouble finding a keratoconus contact lens fitter. We sent him a list of fitters in his area.

*"Good onya. Thanks mate"*

- Betty sought help from us regarding her granddaughter's keratoconus and her need for crosslinking. We advised her to see a Melbourne-based specialist for a second opinion.

*"Thank you so much for leading me the way you did. The second opinion in Melbourne, certainly was very helpful."*

- From Clara (see above)

*"Thank you very much for your reply. I really appreciate the time you have taken to provide me with all this helpful information and I have some good options now."*

- From Tim

*"Thank you for all you do supporting KC. It's great to have regular support and advice through the changes in research and technology. Have a great Christmas"*

- From Carol

*"Thanks for all of your hard work over the past 20 years! You're one group in a million!"*

- From Di who we suggested see a contact lens fitter for keratoconus

*"Yesterday I went to Melbourne & saw the optometrist. What a lovely & knowledgeable person she is. I now have new contact lenses on the way, it will probably take a couple of visits to get them perfect but what a difference it is to see someone who knows about keratoconus."*

## **YOU HAVE TO LAUGH...**

A keratoconus patient told us that during a recent hospital stay for another condition, she was asked by staff to collect her things as she was being moved from the ward. When she asked why, the nurse told her the hospital had received complaints from other ward patients about her unacceptable behaviour.

Shocked, she asked what type of behaviour? Apparently, the other ward patients had watched her bending over her bed table several times a day with her nose



close to the surface while she was inserting and removing her contact lenses and thought she was snorting cocaine.

## **NATIONAL DISABILITY INSURANCE SCHEME**

We have received a number of 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.

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

Email: [enquiries@ndis.gov.au](mailto:enquiries@ndis.gov.au)

Website: [www.ndis.gov.au](http://www.ndis.gov.au)

Postal Address: GPO Box 700, Canberra ACT 2601



## **INTERNATIONAL SUPPORT**

Keratoconus Australia receives a small number of requests for support from people living with keratoconus in other countries. Last year we received support requests from Spain, the USA, Ethiopia and Pakistan. We try to offer these people general advice about keratoconus and refer them to the international **Keratoconus Group** on Facebook.

## **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.

**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 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.)

**Professor Stephanie Watson**, Chief Investigator for the SSKR recently provided the Association with the following update on the registry:



**Professor Stephanie Watson**

*Despite the challenges involved with the COVID-19 pandemic, this year has been productive for Professor Stephanie Watson and the Registry Research Associate, Dr Himel Kandel. Several of the registry's papers were published in some of the highest-ranked ophthalmology journals, including British Journal of Ophthalmology, Cornea Ophthalmology. Similarly, in the past year, 15 of the studies from the registry have now been presented and accepted for presentations in national and international scientific conferences. (See Annex for a full list of recent*

*publications from the Save Sight Keratoconus Registry)*

*Professor Watson and Dr Kandel successfully applied and were able to organise and present the registry's research at an Association for Research in Vision and*

Ophthalmology (ARVO) webinar. ARVO is the largest and most prestigious vision research organisation in the world.

They also organised the Clinical Registry Information webinar for optometrists, which resulted in recruiting an additional 27 optometrists from Australia and New Zealand to the registry. Patients with keratoconus and their carers were informed via the KeraClub which has been held annually.

The impact of the COVID-19 pandemic has been extensive to research activities across the university. Professor Watson and Dr Kandel's team have been able to adapt to the change in work.

One of the main challenges has been that the data growth rate in the registry has been slower than in previous years. Nevertheless, new users and patients are being enrolled, even in difficult times.



**Dr Himel Kandel**

This is an encouraging sign because it signifies the usefulness of the registry platform in managing patients with keratoconus. We have also been able to find out what has happened to patients with keratoconus during the pandemic.

The overall data in the registry has increased by 12 to 18 percent.

	<b>August 2020</b>	<b>August 2021</b>	<b>Increase (%)</b>
<b>Eyes</b>	6012	6769	12.6
<b>Patients</b>	3257	3661	12.4
<b>KORQ</b>	780	922	18.2
<b>(final+ saved)</b>	29022	32647	12.5
<b>Final visits</b>	27425	31026	13.1
<b>CXL</b>	3012	3379	12.2
<b>Sites</b>	77	77	-
<b>Users</b>	87	89	2.3



*Dr Kandel has also been involved in research supervision. He co-supervised Dr Melvin Ling's research project at the registry which examines the outcomes of corneal crosslinking with isotonic versus hypotonic riboflavin.*

*This real-world observational study found that hypotonic riboflavin produced a greater change in visual acuity and corneal parameters in keratoconus one-year post-surgery.*

*Dr Kandel is also supervising three other research students and the Sydney Eye Hospital Foundation's corneal fellow's research project.*

***International** collaborations have played a crucial role in expanding the quantity and quality of the data collected by the registry as well as allowing the registry to capture advances in the field and emerging treatments.*

*For example, the European users have been instrumental in the recent addition of new fields that capture and track other treatments for keratoconus, including Intracorneal Ring Segments (ICRS), keratoplasty and photorefractive keratectomy (PRK). Eye research centres in Toronto, Tel Aviv, Norway and Salento have recently joined with the registry.*

## **RECENT RESEARCH PUBLICATIONS**

The Save Sight Keratoconus Registry published four new research papers in 2021 while a number of papers are currently under review. Details can be found in the Annex of this report.

Those papers published included:

- A comparative study of the efficacy and safety of standard versus accelerated crosslinking
- Predictors of progression in untreated keratoconus
- Microbial keratitis after corneal collagen cross-linking for corneal ectasia
- A study of how the Optometry module of the Save Sight Keratoconus Registry can use real world data to help advance eye care

## **SAVE SIGHT KERATOCONUS REGISTRY – THE FUTURE**

The Save Sight Keratoconus Registry is the world's largest keratoconus registry, collecting longitudinal patient reported outcomes (PROMS) data from everyday clinical practice. A recent review by the group's international steering committee highlighted the need to further strengthen the PROMs for keratoconus.

Some of the changes proposed include:

- SSKR has identified the need of a qualitative study to understand the comprehensive impact of keratoconus on quality of life and mental health.
- It has also highlighted the lack of evidence on the patient-reported benefits of keratoconus treatments. The outcomes research up until now has been based mainly on the standard clinical data such as visual acuity and keratometry. From anecdotal experience, it is understood that there can be a disparity in clinicians' and patients' perspectives on keratoconus outcomes. A formal investigation to identify and close the gap is required.
- The PROM data at the registry will also be used to answer key questions about quality-of- life in keratoconus patients and to improve our understanding of how effective the treatments are for enhancing this and what treatments/interventions are needed. Sub- group analysis will identify which keratoconus subgroups are more severely impacted and need visual rehabilitation.
- Assessment of the impact of keratoconus on quality of life compared to other eye diseases. Keratoconus treatments, such as contact lenses, and research both struggle to obtain equitable funding.

Compared to conditions such as macular degeneration, keratoconus has long life-time impacts and onsets at a crucial time in a person's development. Data is urgently needed to demonstrate the relative impacts of keratoconus on quality of life.

The Registry will also:

- Develop predictive models to allow better prediction of the outcomes and to help to minimize the adverse events of CXL and other therapies. Predictive models in the first instance could provide data for patient counselling on the risks and benefits of treatment. This work could be further enhanced by the collection of genetic material

These models could lead to recommendations of who should avoid treatments and ultimately may allow the development of targeted therapies.

- Study the role of cumulative ultra violet (UVR) light exposure in the development of keratoconus. It is hoped that new knowledge of the potential role of UVR in keratoconus can point to new directions for developing strategies to prevent and treat corneal diseases.

## CLINICAL REGISTRY WEBINAR FOR OPTOMETRIST



Save Sight Registries held a webinar for optometrists on March 22, 2021 as part of its campaign to recruit optometrists to join its Keratoconus and new Dry Eye Registries. The webinar attracted great interest: 221 registrations and 147 attendees. It also resulted in an uplift in optometrists joining the registry.

Keratoconus Australia president, Larry Kornhauser, was invited to speak about the role of Keratoconus Australia in supporting people with keratoconus and the importance of the registry projects to patients.

Mr Kornhauser outlined his personal journey with keratoconus, how the Association was formed and what it does. He ended his presentation by urging optometrists to join the registry project:

*“So why should you join? Apart from the benefits to your professional development and practice, remember this. When you join you give your patients a voice. You give them access to the KORQ quality of life survey, you give them an opportunity to express their views on how keratoconus affects their lives and how effective your treatments and management regimes are,”* he said.

*“Practice time constraints have always denied patients this opportunity in their interactions with you. Now you can get this feedback in a standardized format that will provide an evidence-based means for you to trace the impact of your work on your patient’s welfare. That seems like an incredible progress to me.*

*The other side of the coin is that if you don’t join up, you are denying your patients that voice. Most of us have been silenced for far too long to the detriment of everyone touched by keratoconus.*

*Finally, in joining the registry you will make it easier for patients to find optometrists working in keratoconus and who are committed to achieving best outcomes.*

*Unlike so many eye diseases, vision loss from keratoconus is fixable. That is incredible rewarding for a practitioner and life changing for a patient. So please join up and help us improve outcomes for everyone,”.*

## **CENTRE FOR EYE RESEARCH AUSTRALIA**

The Centre for Eye Research Australia (CERA) remains 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 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.

## **ECONOMIC BURDEN OF KERATOCONUS STUDY**

As reported last year, Keratoconus Australia and Dr Srujana Sahebjada have been working together since 2014 to determine the true economic cost of keratoconus to patients and the wider community. Our health cost survey of new members provided the initial basis for a research project which was then developed by Dr Sahebjada and her fellow researchers.

In 2020, the CERA team published a final paper entitled *Economic impact of keratoconus using a health expenditure questionnaire: A patient perspective*. This



Dr Srujana Sahebjada

paper estimated that KC patients are paying an average \$3365 over 12 months or 30-times what the general population spend on eye care.

## **COST OF CONTACT LENSES**

That startling but not completely unexpected outcome supported the Association's long held view that keratoconus patients have suffered huge increases in the cost of treatments – especially for contact lenses – in recent years which are excluding growing numbers of patients from receiving best practice treatments to restore their vision.

While optometrist fees are onerous, there is scope for bulk billing under Medicare in many cases to alleviate the burden for low income patients. Not so for contact lenses which have risen in cost with the widespread use of corneal scleral lenses (mini-sclerals) and hybrid lenses. Pension and health card holders can access these lenses at low cost in some state run optometry clinics but these lenses, which can cost well over \$2000 a pair, are out of reach for many others.

Dr Sahebjada has therefore agreed to work on a follow up study to survey patients and optometrists about their contact lenses costs and their satisfaction with their lenses. Dr Sahebjada started work on the study in 2021 but COVID-19 heavily impacted her progress. The Association hopes we can advance this study in the coming 12 months.

## **OTHER RESEARCH**

CERA is working on a suite of keratoconus research projects.

Last year, CERA researchers including Dr Sahebjada published papers on

- A novel model developed by CERA for detecting sub clinical keratoconus using artificial intelligence and advanced corneal tomography data.
- A review of literature on the link between eye rubbing and keratoconus. While an association has been shown in a limited number of small studies, the cause-effect temporal relationship cannot be determined. CERA called for more studies into the relationship between eye rubbing

and keratoconus. Dr Sahebjada is investigating the eye rubbing pattern and its influence on keratoconus.

- The link between asthma and more severe cases of keratoconus. The study reported **asthma as the only risk factor found to be significantly associated with the severity of keratoconus.**
- CERA researchers were also involved in the first large scale multi-ethnic genome-wide association study of keratoconus including 4,669 cases and 116,547 controls. The study identified significant association with 36 genomic loci that, for the first time, implicate both dysregulation of corneal collagen matrix integrity and cell differentiation pathways as primary disease-causing mechanisms.

The results potential for the future development of a diagnostic test to detect susceptibility to disease, the authors concluded.

CERA kindly acknowledged Keratoconus Australia in these papers for its support.

- Dr Sahebjada is currently conducting the first global survey on the various approaches used by corneal specialists around the world to diagnose and manage keratoconus patients. This survey results will help us understand the clinicians' perspective of the condition and present the similarities/differences in global diagnostic and treatment ways of managing keratoconus subjects.
- CERA is also working with the Keratoconus International Consortium to enhance international collaboration and data-sharing to improve understanding of the disease.

We note that CERA researcher Dr Elsie Chan has made a big splash in the keratoconus world with the paper she and other researchers published in mid-2020 showing a much higher incidence of keratoconus than previously thought with a prevalence rate of 1 in 84 among the 20 year old West Australian participants.







**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.*

### UNIVERSITY OF MELBOURNE

### DEPARTMENT OF OPTOMETRY AND VISION SCIENCES (DOVS)

#### New ad hoc working group created

The retirement from clinical practice of several expert fitters of speciality contact lenses for keratoconus in the Melbourne area resulted in many patients contacting the Association in early 2021 for help in finding new contact lens fitters.

This raised the question of what was being done to upskill post graduate optometrists in fitting of speciality contact lenses for keratoconus.

Keratoconus Australia president, Larry Kornhauser, contacted Associate Professor Laurie Downie who heads clinical training at the DOVS and the corneal unit at The University's Melbourne Eyecare Clinic (MEC) to discuss the situation. An informal working party also including Associate Professor Richard Vojlay, DOVS Head Associate Professor Andrew Metha and the new head of the Melbourne Eye Clinic, Dr Andrew Huhtanen was convened.

Mr Kornhauser provided the group with an outline of the issues as seen by Keratoconus Australia and the desired outcomes. Briefly, these outcomes were:

- *MEC keratoconus clinic was founded to overcome many of the issues of providing contact lenses at a reasonable cost and has operated well for many patients since its inception. But discounts and rebates have apparently been applied inconsistently and need to be reviewed. MEC provides a model that should be extended to other states where possible and necessary*
- *Post graduate training and incentives for young optometrists to specialise in keratoconus should be considered to avoid a further shortage of specialist contact lens fitter for keratoconus*

- *Ideally, specialised contact lenses for more advanced keratoconus should attract a government subsidy as in New Zealand. We would like assistance in preparing a paper on the NZ and perhaps UK keratoconus subsidy schemes to use in submission to Vision 2020 Australia and governments.*
- *We are trying to work with CERA at present to develop a study on the costs of eye care and correction (notably contact lenses) for keratoconus to support these submissions*
- *Governments and health funds have shown a distinct lack of appetite to subsidise contact lenses for keratoconus unless they are fitted by specialists. This may require the creation of a post graduate diploma or certificate in fittings of complex rigid contact lenses for keratoconus (and/or other lenses)*

Mr Kornhauser concluded: *Hopefully as expert practitioners in this field, you could provide guidance and advice on how to deal with these seemingly intractable issues - especially access to experienced contact lens fitters and costs of lenses - which appear to be worsening in recent years.*

An initial meeting of the group was held on March 2, 2021 via zoom. A number of decisions were taken which can be summarised as follows:

### Melbourne Eyecare Clinic

- Development of a marketing plan to promote the clinic's ability to supply and fit contact lenses for keratoconus, to monitor for progression and refer for corneal collagen crosslinking if necessary and to offer discounted lenses for Keratoconus Australia members.
- Reassess patients numbers, means for assessing Keratoconus Australia member eligibility
- Review of MEC fees, including consultations, ancillary testing, contact lenses. Also to review warranties and refunds on unsuccessful contact lens fits

### Future goals

It was generally agreed that training for keratoconus under the current DOVS programs was of a high standard and did not require further improvement. The problem was that in the absence of further consolidation of their skills through additional training and exposure to keratoconus patients, post graduate and early career optometrists were losing their ability to treat and manage keratoconus patients effectively. The group identified 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.

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

### Finding skilled contact lens fitters

As discussed in **Support**, the biggest issue for a keratoconus patient is generally how to find an expert fitter of speciality contact lenses for keratoconus.

The group identified a variety of options to improve the current landscape.

- Greater collaboration between Keratoconus Australia and the eye-carers to identify experienced keratoconus clinicians around Australia. Also for the Association to check with laboratories and the Cornea and Contact Lens Society of Australia (CCLSA)
- Upgrade the CCLSA and Optometry Australia *Find an Optometrist* websites to filter for keratoconus practitioners.
- Gain access to the Save Sight Keratoconus Registry list of participating optometrists
- Access information from the Australian College of Optometry (ACO) regarding holders of their certificate of Advanced Contact Lenses

The group met again in April 2021 via zoom to review its progress and refine its goals in the light of repeat COVID-19 shutdowns and restrictions.

### Outcomes

A number of initiatives have since been taken.

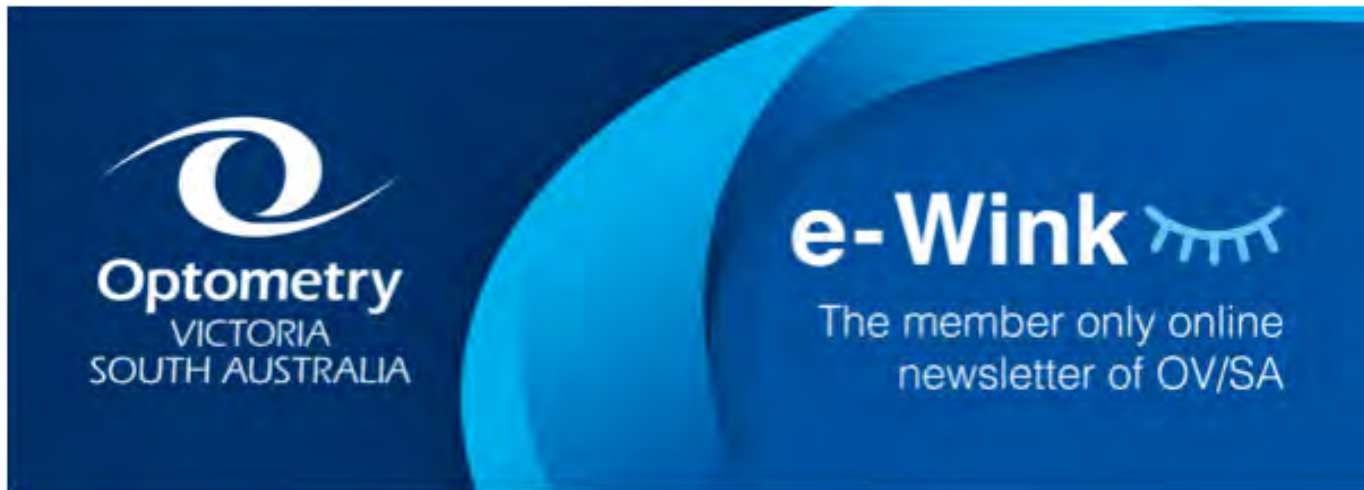
- A letter on University of Melbourne letterhead was drafted to distribute to all optometrists who completed the ACO Advanced Contact Lenses



course to survey their ongoing interest in keratoconus. ACO will send this letter to all the relevant optometrists.

- Based on this letter, an online survey was created to survey 1,800 optometrists in Victoria and South Australia.

This survey was publicised in the October 2021 newsletter e-Wink published by Optometry Victoria and South Australia (see below)



## Want to further your keratoconus care for patients?

Keratoconus Australia and The University of Melbourne are collaborating to improve the skills of optometrists who prescribe contact lenses to people with keratoconus. The project aims to develop ways of providing feedback and troubleshooting abilities so that optometrists can resolve real-world problems without having to refer patients to specialist contact lens practices. As a starting point, researchers would like to establish a registry of interested optometrists and depending on the responses, will look at various options for training.

[Complete the survey to join the partnership.](#)

- Identified a need to create brochures for patients and clinicians on contact lenses for keratoconus, when to fit them, what types- large or small – and advice on when to refer for corneal surgery, and when not to refer. The brochures would be distributed via Keratoconus Australia, professional bodies and conferences. Also target corneal surgeons, registrars in hospitals and ophthalmologists private practice.



It was agreed that the brochures should be prepared by experts from the Universities of Melbourne and Sydney to ensure credibility. This was delayed due to COVID-19 and hopefully will be started in 2022.

- Liaise with the Corneal Graft Registry in Adelaide to collect data on the cost and frequency of corneal transplants for keratoconus
- Keratoconus Australia will pursue efforts to quantify the cost of contact lenses for keratoconus in collaboration with CERA (see **Research**)
- Dr Huhtanen will report on the Canadian fellowship program on keratoconus at Waterloo University

The Melbourne University working group will meet again in December 2021 for an update and we hope to have results from the early career optometrist survey available in 2022.

## 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.

Unfortunately, due to COVID-19 and the restrictions implemented in Victoria, the clinics were cancelled again in 2021.

## CORNEA AND CONTACT LENS SOCIETY OF AUSTRALIA



Keratoconus Australia held separate discussions with the CCLSA about improving its own *Find A Practitioner* database on its website which currently has no means of filtering for keratoconus or any other criteria

to allow patients to identify an expert keratoconus contact lens fitter. The Association was told CCLSA has been working on the issue for a long time and would continue to work towards making the site more useful in finding clinicians working in particular specialty areas.

Discussions were also held around the cost of contact lenses, the New Zealand contact lens subsidy scheme and other related issues.

## EARLY CAREER OPTOMETRIST WEBINAR

We also note that the Early Career Optometrist Victoria and South Australia group scheduled an in-person meeting on keratoconus in July 2021.

That meeting was cancelled due to COVID-19 restrictions and held as a webinar in September 2021.

The webinar attracted enormous interest and was attended by over 350 optometrists. The University of Melbourne early career optometrist survey on keratoconus was sent to all participants.



## PATIENT ASSISTANCE

As described in the Support section of this report, we often seek advice from our consulting ophthalmologists and optometrists to assist in providing support to patients. We thank those eye-carers for their professional advice on general issues affecting people with keratoconus and their families.

We have sometimes been asked to intervene directly with eye-carers on behalf of a patient having issues over treatment outcomes and costs.

In the past year, we have found it valuable for both patient and practitioner for us to discuss a patient's problems with the clinician prior to the patient's appointment. This has been useful in helping younger patients who feel intimidated by the contact lens fitting experience, who don't feel their concerns are being heard properly and other patients who simply cannot communicate effectively with their eye-carer about their problems.

Sadly, disputes over costs of unsuccessful treatments are becoming more frequent as patient expectations tend to inflate along with the cost of these treatments (see **Advocacy**).



**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

As if the stress of losing vision due to keratoconus wasn't enough, the arrival of COVID-19 in early 2020 and the economic and social dislocation it brought with it, made life very difficult for many patients and their families. Job and income losses, long periods of confinement, working and schooling online for unusually long periods at a time, always with the threat of serious sickness and death of loved ones was too much for many people with keratoconus and their families.

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*KERATOCONUS HAS A GREATER IMPACT ON QUALITY OF LIFE  
THAN MACULAR DEGENERATION  
(THE LEADING CAUSE OF BLINDNESS IN AUSTRALIA)*

*AMERICAN JOURNAL OF OPHTHALMOLOGY, 2004*

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The Association signalled the issue of vision loss and mental health in meetings with Vision 2020 Australia last year and noted our hope in our 2020 report that Vision 2020 Australia "can assist in creating a common resource specialising in psychological support for the vision sector."

Vision 2020 Australia convened two working party meetings in early 2021 to examine the issue. The most striking outcome was the lack of any sector wide dedicated resource to assist individuals or groups working with people suffering significant vision loss.

The Association's Vice President, Greg Harper, led the Vision 2020 Australia working party and filed the following report.

*"The challenges of the Covid-19 pandemic, and particularly the extended community lockdowns in Victoria and New South Wales, impressed on members*



*of the KA committee, how vision impairment exacerbates the deterioration of mental health that all citizens experienced. The committee decided to do something about this, as part of our forward agenda. Several of us did some background research as to the scale of the problem for people with keratoconus, the broader context of mental wellbeing for people with vision impairment, and what resources were currently available.*

*After we briefed two of the working groups of Vision 2020 Australia, it was clear that several other vision-related support groups were also interested in the problem and the solutions, and hence a new collaborative work area has now been established. Vice President Greg Harper will stay engaged with this activity on behalf of the KA committee.*

*No extra resources will be required at this time.”*

For its part, Vision 2020 Australia has since issued a report on the meetings and a work plan for continuing this initiative into 2022 (see below).

*“In meetings in early 2021, both our Prevention and Early Intervention Committee (PEIC) and Independence and Participation Committee (IPC) discussed and acknowledged that there was scope to improve mental health support for people living with vision loss.*

*Vision 2020 Australia (V2020A) convened a working group comprising interested members from both committees to explore this work further. A workshop was held in June 2021, with representatives from the following groups:*

- *Keratoconus Australia (Chair)*
- *NACCHO*
- *Royal Victorian Eye and Ear Hospital*
- *Macular Disease Foundation Australia*
- *Guide Dogs Victoria*
- *Apologies: VisAbility and The Royal Society for the Blind*

*The workshop identified that there was an opportunity to improve the availability of mental health resources for patients and providers, with potential for cross-sector collaboration and advocacy and resource development.”*

Vision 2020 Australia is proposing further meetings in 2022:

- To identify priorities, approach and potential resources
- To gather currently available resources grouped according to their relevance to particular groups of patients and practitioners, programs relating to awareness and training, resources for various types of vision loss, along with stories of lived experience of vision loss.
- To examine the possibility of engaging tertiary students to assist in gathering resources, mapping pathways and identifying opportunities for cross sector collaboration and advocacy.

We thank Greg for his work in this important area.

### **AGED CARE, DEMENTIA AND VISION**

Keratoconus Australia also made an important contribution to Vision 2020 Australia's submission to the National Consultation on the Roadmap and Implementation Plan for the MRFF Dementia, Ageing and Aged Care Mission in April 2021. Studies on the prevalence of eye disease in residential aged care facilities found 78% had eye diseases requiring ongoing management, 25% had low vision and 4% were legally blind.

The Association noted that that older people with keratoconus will need greater assistance with their hard contact lenses - inserting removing and cleaning etc - if they are to maintain their independence. This will require training for carers and nursing staff in hospitals and aged care clinics etc.

(We have had a number of people with keratoconus complain that hospital staff are unaware of what help is needed for these patients who become incapacitated if they don't have access to their contact lenses.)

As a result of our submission, Vision 2020 Australia modified its response as follows

*"Better identification, management and treatment of vision loss is critical to the quality of life of older Australians - keeping them healthy, engaged and independent for longer. **Training is also required to ensure that those living with low vision have the support necessary to manage their impairment (e.g. manipulating and inserting contact lenses).**"*

Keratoconus Australia expressed thanks to Ms Abbott who departed Vision 2020 Australia in mid-2021 and has welcomed her successor Patricia Sparrow with whom we have had preliminary discussions around our areas of interest.



## **OPTOMETRY AUSTRALIA**

As we noted last year, the Association held preliminary discussions in early 2020 with OA National Professional Services Manager Luke Arundel over the issue of warranties and refunds on unsuccessful contact lens fits.

A number of optometrist practices already offer 50% refunds on unsuccessful contact lens fits for keratoconus and the Association hopes that this will become an industry standard.

Efforts to further these discussions were delayed by repeat COVID-19 lockdowns in Victoria over the past 20 months. We raised the issue again recently with Mr Arundel and agreed to pursue the matter in 2022. The question of warranties i.e. the number of free refits offered by contact lens laboratories also needs review.

## **SUBSIDISED CONTACT LENSES**

We note that a number of public hospitals notably in Queensland have reduced or cancelled their subsidised contact lens programs. There is also limited if any access to publicly funded contact lenses in Western Australia.

The Association is currently engaged in discussions with optometrist groups in both states to find a solution to provide better access to contact lenses for low income patients.

We remind members that the Australian College of Optometry in Victoria has also expanded access to its contact lens clinic to non-health card holders who can now access discounted contact lenses there.





## **The Association**

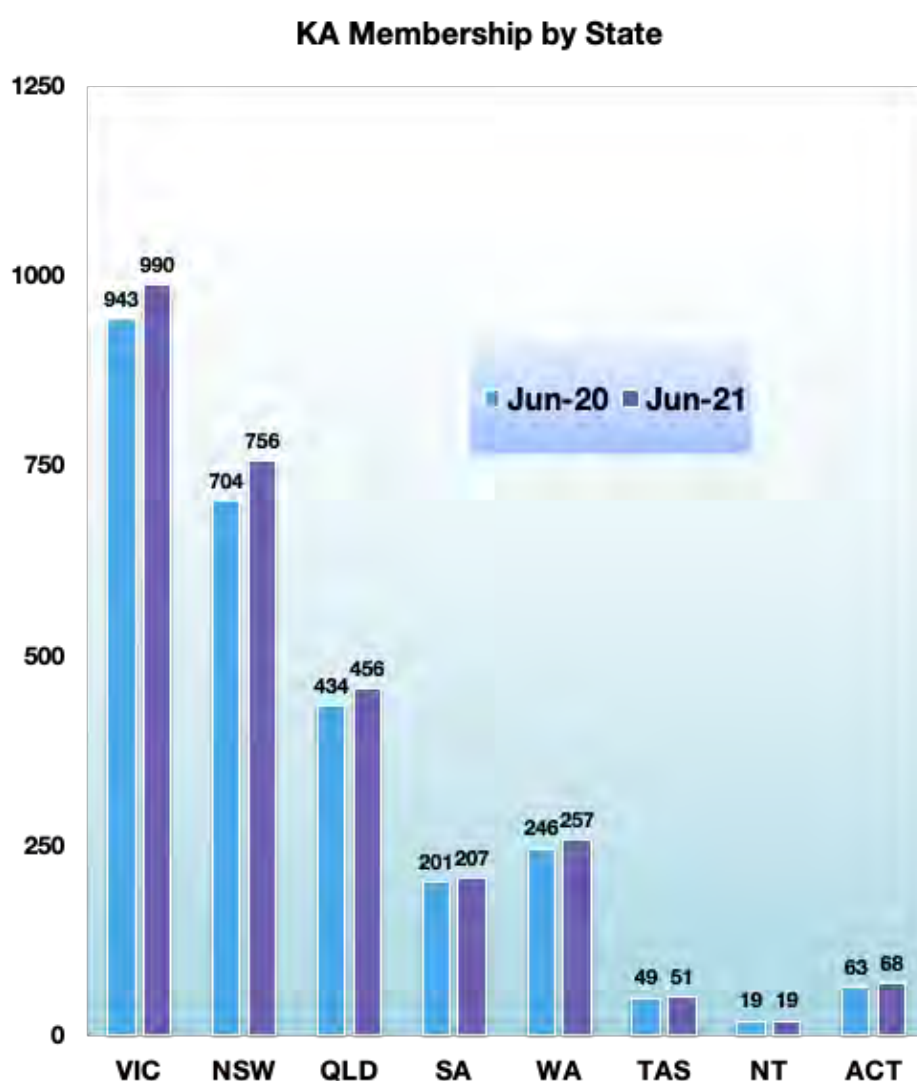
# THE ASSOCIATION

## MEMBERSHIP

Growth in Keratoconus Australia membership was again strong in 2020-21, with total numbers rising by 5.5% to 2,803. This followed an increase of 6.3% in 2019-20. The impact of COVID-19 was difficult to discern as the reporting period again covered multiple extended lockdowns in Victoria and NSW along with shorter ones in other states. While patients seemed reluctant to visit eye-carers unless absolutely necessary, patient support requests to the Association bounced back strongly from the lows of early 2020 (see **Support**). Membership growth generally mirrors shifts in support requests.

The rise in membership was spread across the larger states with New South Wales membership up by 7.4% compared to last year to a total of 756 members on June 30, 2020.

Victoria (990 members), and Queensland (456) were up by about 5% while Western Australia (257) grew by 4.5%. (see graph).



Keratoconus Australia members remain concentrated in its home state of Victoria which over the past decade has accounted for around 36% of the total. NSW has maintained its share of around 27%, followed by Queensland (16%), WA (9%) and SA (7.4%).

(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.)

## SUPPORTERS

Keratoconus Australia is fully funded from donations from members and supporters. We are grateful for the 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 2020-21, 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. In 2020, the NKCF went digital with these publications and these are now available free of charge from Keratoconus Australia in hard and electronic (pdf) format. The keratoconus booklet is distributed free to all new members.

We also thank Mary and the NKCF for establishing a **World Keratoconus Day** on November 10 as a means of raising awareness about this disease that affects so many people. Keratoconus Australia celebrated WKD last year with videos made by committee member **Alejandro Molano** which were posted on our website and Facebook page.

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. We have also produced a patient brochure to explain crosslinking (see our 2018-19 Annual Report).

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 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 cheap, well-fitted contact lenses for keratoconus patients through its Melbourne Eyecare Clinic, which runs regular



keratoconus clinics. These clinics are staffed by specialist contact lens fitters for keratoconus including Richard Vojlay, Luke Arundal, Jessica Chi and Laurie Downie who oversee contact lens fits by student optometrists, and offer discounts of 25% to Keratoconus Australia members.

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 Sahebzada, 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.

## **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 2020-21 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/keratoconusaustralia>.



## EVENTS

### 5TH KERA CLUB PATIENT FORUM



KeraClub was launched in October 2016 as a joint initiative with the Save Sight Institute to provide a meeting place for Sydney-based Keratoconus Australia members and others interested in keratoconus.

Last year, COVID-19 ended any chance of in-person meetings so KeraClub went fully online as a webinar for the first time.

Co-hosted by Save Sight Institute and Keratoconus Australia, KeraClub 2020 attracted over 230 participants, including patients with keratoconus and their carers from inter-state as well as participants from New Zealand, the Netherlands, Nepal, India, Pakistan, Brazil and Mexico. There were 147 Australian participants, the majority from New South Wales and Victoria.

Last year's event included presentations on The Save Sight Keratoconus Registry and its research by Professor Stephanie Watson and Dr Himal Kandel from the Save Sight Institute and the University of Sydney. Optometrists Allan Ared and Jessica Chi discussed the impact of eye rubbing on keratoconus and COVID-19 and contact lenses respectively. Musician Michelle (Urquhart) Pritchard, who has a lived experience of keratoconus, chaired the webinar and took the opportunity to highlight activities carried out by Keratoconus Australia to support keratoconus patients (see a full report on KeraClub 2020 in **Annexes.**)

## WORLD KERATOCONUS DAY

World Keratoconus Day was created by the US-based National Keratoconus Foundation 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 two video posts on Facebook created by Alejandro Molano which attracted enormous attention.

The event is now gathering steam as an international celebration of those living with keratoconus and their eye-carers. NKCF chair, Mary Prudden, contacted us mid-year about holding a photographic competition "*Keratoconus through my Eyes*" for the 2021 event, in conjunction with the UK Keratoconus support group.

The competition was launched in October 2021 and finalists were recently posted to our Facebook page. The winners will be announced soon.

Please let us know if you have ideas for how the Association can mark World Keratoconus Day 2022.

## LOCAL AND STATE GROUPS

### GOLD COAST

Long-time Keratoconus Australia member Renee Shaw was in Elanora on Saturday 13 February, 2021 spreading the good word on keratoconus. Renee spent the morning at the Pines Shopping Centre distributing information on keratoconus and chatting to locals about her (vast) experience in managing the disease and dealing with eye-carers.

Renee would like to meet up with other people with keratoconus in the Tweed-Gold Coast area. Message if you're interested in catching up for a coffee sometime.

COVID-19 heavily impacted efforts to start new local groups and hopefully members will try to organise local meetings once restrictions are lifted in 2021-22.

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.



Renee Shaw in Elanora

## WEBSITE

The Association's website remained a popular source of information about keratoconus throughout the 2020-21 financial year. After falling in the first half of 2020 as COVID-19 lockdowns took hold, total page views climbed steadily from April 2020 and remained fairly stable for the rest of reporting period. Visits dropped briefly over the 2020 summer holiday period but then recovered to average levels by March 2021.



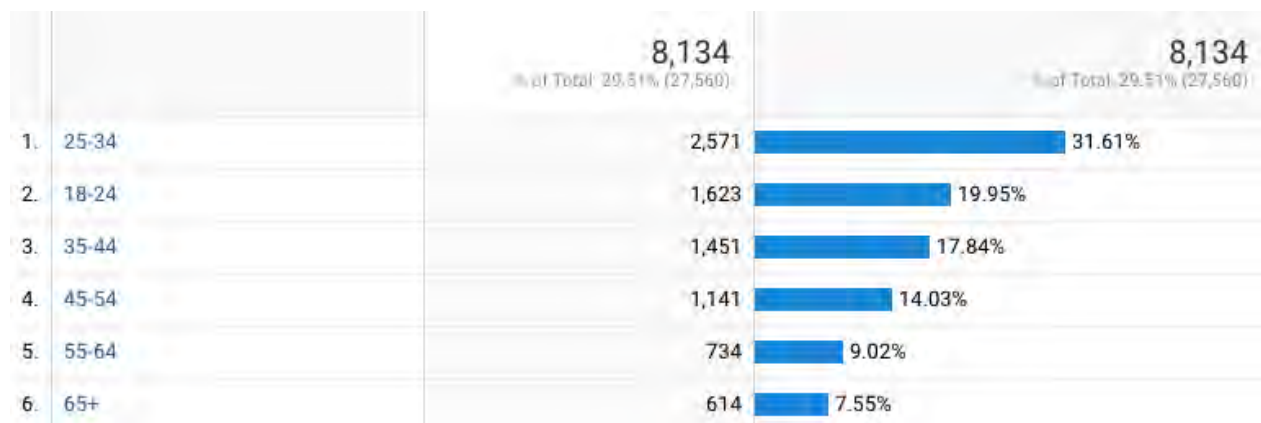
<b>Sessions</b> <b>26.67%</b> 27,560 vs 21,757	<b>Users</b> <b>31.36%</b> 21,800 vs 16,595	<b>Pageviews</b> <b>18.56%</b> 48,508 vs 40,916	<b>Pages / Session</b> <b>-6.41%</b> 1.76 vs 1.88
<b>Avg. Session Duration</b> <b>-10.81%</b> 00:01:39 vs 00:01:51	<b>Bounce Rate</b> <b>3.69%</b> 71.55% vs 69.01%	<b>% New Sessions</b> <b>4.00%</b> 78.73% vs 75.70%	

### Key website statistics 2020-21

Overall, almost all key metrics were higher in 2020-21 with page views up 18.6% to 48,500, while users were 31% higher to 21,800.

Most users arrived on the site via the Home page, which accounted for 18% of the total site visits. Information on corneal collagen crosslinking accounted for 14% of total page views followed by contact lenses (9%), corneal transplantation (7.4%) and the Treatments home page (9%). Visitors also headed to information about the general information pages about keratoconus (6%) and answers to frequently asked questions (4%).

Most visitors came from Australia (74%) with almost an even split between those from Melbourne and Sydney (21%) followed by Brisbane (11%), Perth and Adelaide.



**Website visitors by age and gender**

Keratoconus is a young person's disease and so not surprisingly, the bulk of visitors were in the 25-34 age group, the ages most affected by keratoconus. Almost 70% of visitors were in the 18-44 age groups. The gender split was 52-48 in favour of males.

## FACEBOOK

We have continued to promote and post to our Facebook page and currently have almost 690 followers. This represents a huge increase from one year earlier (309). Facebook has proved a useful tool in promoting our events. We are also using Facebook to post articles on keratoconus, new research and information on eye-care in general. Our most popular posts have been the videos created by Alejandro Molano for World Keratoconus Day on November 10. The photo of Renee Shaw distributing information on the Gold Coast in February 2021 also attracted much attention.



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 2020-21, the committee met twice and held informal discussions on other occasions.

The committee last year comprised:

Larry Kornhauser, President

Greg Harper Vice President

Alice Delaney

Neil McFarlane

Rod Swift

Alejandro Molano

Michelle Pritchard

Susan Scarr



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 is pursuing her music studies.

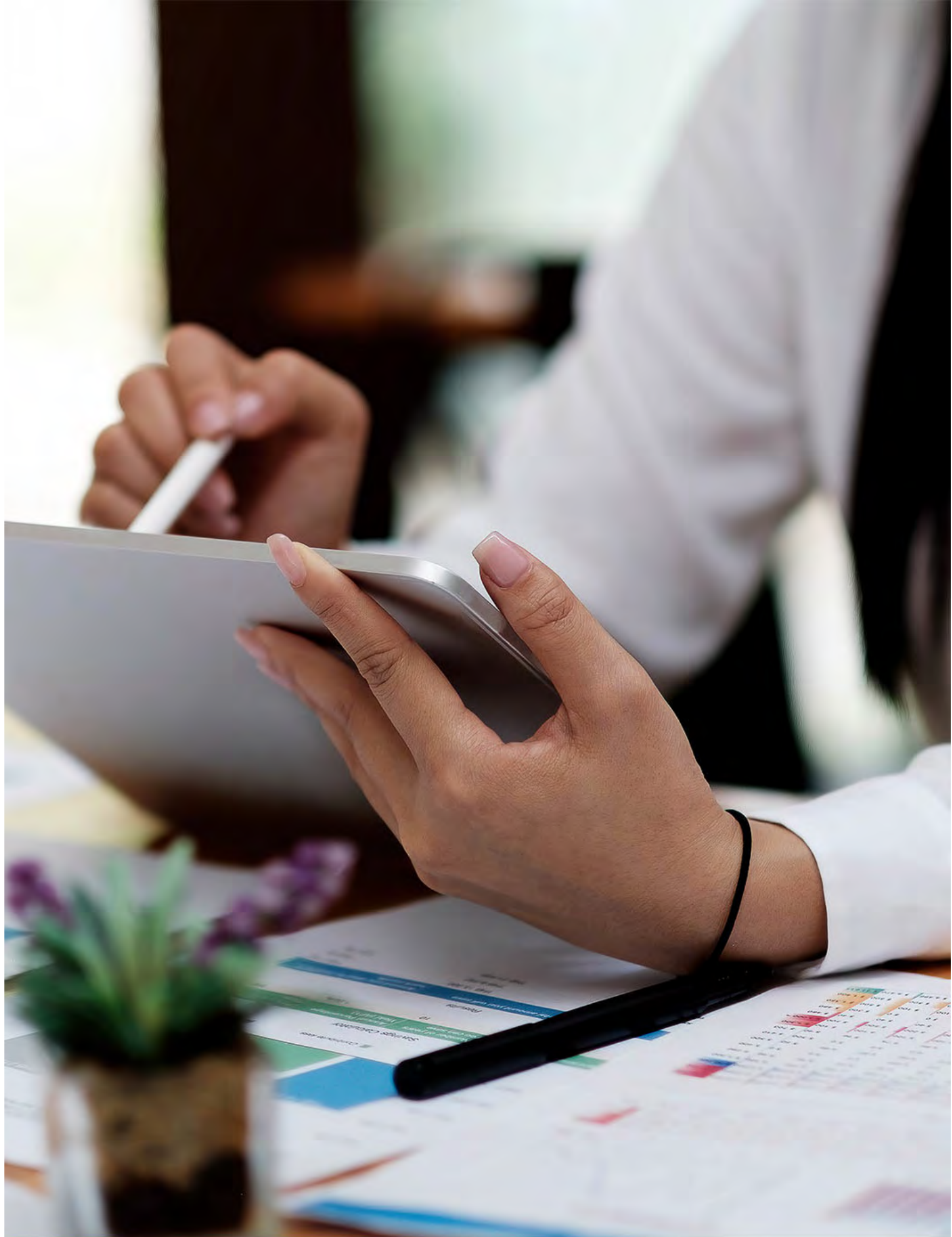
Greg Harper is our Vision 2020 Australia representative and his work with the peak vision health body on mental health has been ground breaking for that organisation.

We wish everyone a good and healthy 2022

The Keratoconus Australia Team







## Financial Reports

# FINANCIAL REPORTS 2020-21

Keratoconus Australia Inc. reported a net operating surplus of \$3,611 or less than half the surplus of \$7,865 recorded in the 2019-20 financial year. The 54% drop was attributable essentially to a significant fall in donations during the year. These were down by 45% to \$4,075 (\$7,430 previously). The fall in interest rates to almost zero also impacted interest revenue from term deposits which was only \$1,239 last year, or 40% down on the previous year (\$2,000).

The situation was exacerbated by a rise in total expenses, which rose by 12% to \$1,879 mainly due to a sharp increase in office expenses (\$526) and domain registration costs (\$312). Last year, the National Keratoconus Foundation ceased to supply us with its booklets on keratoconus in printed form at a subsidised rate. The Association decided to have the booklets printed locally to ensure access to hard copies for distribution to both patients and eye-carers. This resulted in a 10-fold increase in printing costs to \$547 – some of which should be recovered from sales to eye-carers.

Postage costs were down significantly to only \$265 (\$750 in 2019-20) as more material was sent to members via email and social media. COVID-19 restrictions in Melbourne closed our offices for much of the reporting period and made it difficult for the Association to conduct mail outs to members not on email or who have failed to inform us of their new email addresses.

The balance sheet as at 30 June, 2021 was showing net assets of \$125,542 compared to \$121,931, one year earlier. The Association holds the bulk of these assets in term deposits and seeks to maximize returns in the current low interest rate environment.

The Committee will look at options in 2022 to raise funds for research and at 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.

# Income Statement

Keratoconus Australia Inc

For the year ended 30 June 2021

## Income Statement

	2021	2020
<b>Income</b>		
Donations Received	4,075	7,430
Interest Received - Cash Accounts	13	36
Interest Received - Term Deposits	1,239	2,000
Other Revenue	163	-
<b>Total Income</b>	<b>5,490</b>	<b>9,466</b>
<b>Total Income</b>	<b>5,490</b>	<b>9,466</b>
<b>Expenses</b>		
Bank Charges	5	(286)
Domain Name Registration	312	49
Entertainment	-	19
Office Expenses	526	296
Postage	265	750
Printing & Stationery	547	51
Telephone & Internet	119	78
Vision 2000	-	546
Website Hosting	105	98
<b>Total Expenses</b>	<b>1,879</b>	<b>1,601</b>
<b>Profit/(Loss) for the year</b>	<b>3,611</b>	<b>7,865</b>
<b>Undistributed Income</b>	<b>3,611</b>	<b>7,865</b>

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

# Statement of Financial Position

Keratoconus Australia Inc

As at 30 June 2021

## Statement of Financial Position

	30 JUN 2021	30 JUN 2020
<b>Assets</b>		
<b>Current Assets</b>		
Bank Accounts	32,326	39,024
Term Deposits	93,011	82,000
Goods and Services Tax	75	27
GiveNow Receivables	130	880
<b>Total Current Assets</b>	<b>125,542</b>	<b>121,931</b>
<b>Non-Current Assets</b>		
<b>Intangible Assets</b>		
Website Development - at Cost	6,975	6,975
Less: Accumulated Depreciation	(6,975)	(6,975)
<b>Total Intangible Assets</b>	<b>-</b>	<b>-</b>
<b>Total Non-Current Assets</b>	<b>-</b>	<b>-</b>
<b>Total Assets</b>	<b>125,542</b>	<b>121,931</b>
<b>Net Assets</b>	<b>125,542</b>	<b>121,931</b>
<b>Equity</b>		
Current Year Earnings	3,611	7,865
Retained Earnings	121,931	114,066
<b>Total Equity</b>	<b>125,542</b>	<b>121,931</b>

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 2021

#### 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.





# ANNEXES

## 2021 PUBLICATIONS FROM THE SAVE SIGHT KERATOCONUS REGISTRY

1. **Kandel H, Nguyen V, Ferdi AC, Gupta A, Abbondanza M, Sullivan L, Apel A, Watson SL. Comparative efficacy and safety of standard versus accelerated corneal cross-linking for keratoconus: one-year outcomes from the Save Sight Keratoconus Registry study. Cornea 2021;40(12):1581-589**

This study compared the efficacy and safety of two common corneal cross-linking protocols, standard (long) and accelerated (short). They found that both procedures improved visual and corneal-shape outcomes. However, the findings suggested that the shorter method may be better for the clinician and patient time, convenience, and comfort. To date, this study is the largest of its kind that has investigated this research question. The paper was published in the Cornea journal, the official journal of the Cornea Society.

### **Why is this important?**

The findings from this study have led clinicians to adopt short corneal cross-linking with higher confidence.

2. **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. Br J Ophthalmol 2021;105**

This registry study discovered that steeper Kmax and young age were the most clinically useful baseline predictors of keratoconus progression. This paper was published in the prestigious British Journal of Ophthalmology, the British Medical Journal's flagship ophthalmology journal.

### **Why is this important?**

The findings of this study will assist clinicians in decision making regarding when to undertake corneal cross-linking. Closer follow-up and a lower threshold for cross-linking should be adopted in younger patients and those with steeper corneas.

3. **Khoo P, Cabrera-Aguas M, Watson SL. Microbial keratitis after corneal collagen cross-linking for corneal ectasia. Asia Pac J Ophthalmol 2021;10(4):355-359**

Serious corneal infection is rare but possible after corneal cross-linking. This study looked at the largest cohort of patients with serious corneal infection after crosslinking.

### **Why is this important?**

The paper informs clinicians on what is the most likely cause of the infection after crosslinking and on how to prevent and manage serious infection after corneal cross-linking in keratoconus patients.

4. **Kandel H, Downie LE\*, Watson SL\*. The Save Sight Keratoconus Registry – Optometry Module: An opportunity to use real-world data to advance eye care. Clin Exp Optom 2021 <https://doi.org/10.1080/08164622.2021.1924626> \*Joint senior authors**

This paper describes and highlights the advantages the keratoconus registry may offer optometrists, a new tool in their management of patients with keratoconus. The optometry module in the SSKR is the only registry in the world dedicated to optometrists. It was published in the Clinical and Experimental Optometry, the official journal of Optometry Australia, the New Zealand Association of Optometrists, the Hong Kong Society of Professional Optometrists, and the Singapore Optometric Association.

**Why is this important?**

Optometrists are primary eye care providers and have a major role in providing clinical care to people with keratoconus, and the real-world data collected from the registry can help them to improve their clinical practice and patient care.

**Publication web-links:**

Publication 1: <https://pubmed.ncbi.nlm.nih.gov/33935236/>

Publication 2: <https://pubmed.ncbi.nlm.nih.gov/33785509/>

Publication 3: <https://pubmed.ncbi.nlm.nih.gov/33534235/>

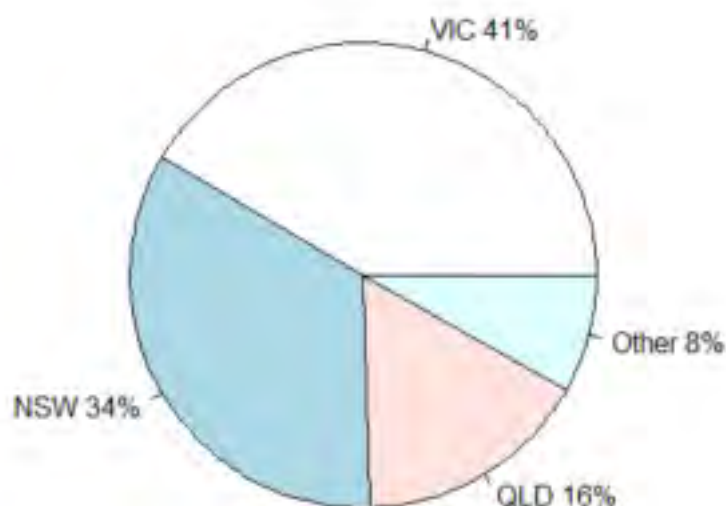
Publication 4: <https://pubmed.ncbi.nlm.nih.gov/34134600>

## KERACLUB 2020: 5<sup>TH</sup> ANNUAL KERATOCONUS COMMUNITY EVENT



The COVID-19 outbreak has impacted almost every aspect of our lives and KeraClub was no exception. This year, the fifth annual community event for people with keratoconus, 'KeraClub 2020', was organised solely as a webinar.

### Distribution of the Australian participants



Co-hosted by Save Sight Institute and Keratoconus Australia, KeraClub 2020 attracted over 230 participants, including patients with keratoconus and their carers from inter-state as well as participants from New Zealand, the Netherlands, Nepal, India, Pakistan, Brazil and Mexico. There were 147 Australian participants, the majority from New South Wales and Victoria.

With every challenge comes an opportunity, and in the case of KeraClub 2020, its presentation as a webinar enabled KeraClub to reach a broader audience.



This year's event included presentations on The Save Sight Keratoconus Registry, 'COVID and contact lenses', and 'Eye rubbing in keratoconus' by Professor Stephanie Watson and Dr Himel Kandel from the Save Sight Institute, The University of Sydney and optometrists Allan Ared and Jessica Chi. Musician Michelle (Urquhart) Pritchard, who has a lived experience of keratoconus, chaired the webinar and took the opportunity to highlight activities carried out by Keratoconus Australia to support keratoconus patients.

### Save Sight Keratoconus Registry

Professor Watson, head of the corneal research group at Save Sight Institute, and head of the corneal unit at Sydney Eye Hospital, presented updates from the Save Sight Keratoconus Registry, which tracks outcomes in patients with keratoconus. She highlighted the importance of the registry in evaluating the effectiveness and safety of new keratoconus treatment methods, such as cross-linking variants and advised that the Registry now has a module for optometrists. Since the launch of this module, optometrists and ophthalmologists have been able to share data for seamless patient care.

Professor Watson, acknowledged the support provided by Keratoconus Australia and its president Larry Kornhauser to the keratoconus registry.

### Invited Talks: COVID-19, Eye-rubbing, and Keratoconus

Melbourne-based optometrist Jessica Chi, who practises fitting specialised contact lenses, presented on 'COVID and contact lenses'. Ms Chi reminded the



audience that there is no evidence to support that contact lenses increase the risk of COVID-19 infection. However, she said it is important not to wear contact lenses if a person is sick or in doubt, and good hygiene when handling contact lenses is crucial. Information on showering and swimming with contact lenses was of particular interest to many attendees. Ms Chi also discussed different contact lens types available for keratoconus patients.

Allan Ared spoke on eye-rubbing, the subject of his PhD research. Mr Ared discussed the potential causes of eye rubbing, trauma from eye rubbing, and treatment options to stop rubbing. He highlighted the many gaps in knowledge when it comes to eye rubbing and keratoconus. Many participants related Mr Ared's discussion on eye rubbing behaviour to their own experiences.

"For me, I have always felt I do not rub my eyes overly much, however, I could relate to how I sleep and the pressure on the eyes – something I have really only noticed in more recent times," said one participant from Tasmania.

Dr Himal Kandel, the Kornhauser Research Associate at Save Sight Institute, presented interesting data from the Save Sight Keratoconus Registry. Dr Kandel shared key messages from the registry team's six recently published research papers. This included the implementation of the registry, the natural history of keratoconus, and the evaluation of the impact of keratoconus on quality of life. The research conducted at the Save Sight Keratoconus Registry aims to help clinical decision making and improve patient outcomes.

Presentations were followed by a Q&A session moderated by Professor Watson, and then panelists shared their perspectives on the future of keratoconus management. New contact lens types, cross-linking research at the registry, and quality-of-life research were thought to be some of the important impactful research and innovation areas. Professor Watson stressed that the patient and their needs must remain central to research efforts so that outcomes are meaningful to those affected.

### Positive Feedback

Feedback from KeraClub 2020 was very positive, with most saying the webinar was helpful, insightful, and full of information. One participant from New South Wales proclaimed that "everything (about the event) was useful and informative. It was brilliant. Each year I learn so much from everyone. I'm no longer alone".

Participants acknowledged the broad spread of topics and said that when presented as a webinar, KeraClub was easier to attend.

“I found it all interesting in different ways, I liked that there was a mix of practical information that users could apply combined with some interesting science and foundation information,” said a participant from New South Wales.

A participant from Western Australia said, “A webinar meant people in Western Australia like me could attend.”

“It was fabulous as I live in Brisbane and have never been able to ‘attend’ a meeting before. Please may this type of meeting be available in the future,” said a participant from Queensland.

Their suggestions for KeraClub 2021 included information on expected future developments, such as improvements in operations and lenses for patients with keratoconus.

As well as serving keratoconus patients and their carers, KeraClub has been a valuable platform for clinicians and researchers to learn from patients, whose perspectives may differ. For example, as clinicians we generally provide advice that swimming with contact lenses has a risk of infection. However, one Victorian participant said, “I feel the benefits of swimming (physical and mental health) may sometimes outweigh the risk from the incidence of problems. I have a severe back injury and swimming is one of the few activities I can engage in pain-free.”

Traditionally, participants and panelists gather for informal conversation at the end of KeraClub’s formal programme. The opportunity to do so was sadly missed this year however the success of the event has encouraged us to continue organising these types of community events for our patients, despite living in a strange and challenging COVID-19 environment.