



**KERATOCONUS  
AUSTRALIA**

# **ANNUAL REPORT 2020**

**DECEMBER 2020**





## 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 completely 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
- Publishing a regular electronic newsletter with information on a wide range of issues affecting people with keratoconus
- Acting as a representative group for keratoconus patients to improve health rebates for treatments (contact lens and solutions, glasses) and corneal surgery, and to obtain higher funding for local research into the condition

- Supporting the development of a national registry and database on Australian keratoconus patients designed to assist in networking individuals and groups within Australia, and to form a basis for future research work
- Supporting efforts to increase organ donations and in particular to reduce waiting times for corneal graft

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## FROM THE PRESIDENT ... 20 YEARS ON

20/20 is the imperial measure of normal visual acuity. Yet there was nothing imperial or normal about 2020, the year in which COVID-19 made the world lose sight of its future.

Ironically it was exactly 20 years ago that 20 short sighted visionaries created Keratoconus Australia.

Back in 1999 when the Association's founding mothers and fathers sat down to create Australia's first keratoconus support group, we had no idea of what we were doing. But after exchanging war stories of life in the keratoconus trenches, we knew something had to be done to support those of us who couldn't find competent eye-carers much less our contact lenses when they popped out, those of us who were sick of pressing books to our noses to read, those of us who couldn't explain to others why spectacles were useless for keratoconus, and all of us who were dazzled by oncoming headlights when we tried to drive at night.

Actually, none of us had much idea about keratoconus either. And there was nothing on the Internet to enlighten us.

We had no money or government grants or wealthy donors or any experience in finding them. We just made it up as we went along.

We did have the internet and email and a vague notion that the two could be combined to offer a support service to people anywhere in Australia without incurring exorbitant long distance and mobile phone bills to communicate with them.

So in 2000, Keratoconus Australia was born as a virtual support group operating from a home office. We were connected to the country by email and an Online Forum web page through which people could send their questions, comments and complaints.

We've never had a real office filled with staff; yet we've always been available to anyone needing our help via email and phone. We used the postal service to distribute information booklets on keratoconus and corneal transplants. We recorded our Demystifying Keratoconus information forums and made them available to those unable to attend via our video cassettes, then DVDs and now YouTube. We've met with people whenever possible, but we've found that even without face-to-face contact we can make a big difference to people's lives just by talking to them online.

It wasn't fashionable back then to run a virtual support group but strangely it worked. Why? Probably because keratoconus patients and their families had been ignored and even disparaged for so long that they were delighted and relieved to gain a voice in any way possible.

Last year, we added a live webinar option to our KeraClub meeting in Sydney which I watched in awe in my pyjamas from a bedroom in Paris.

So when the pandemic hit a few months later, Keratoconus Australia really didn't change a thing. We had no costs to trim as we've always operated with volunteers off the smell of an oily rag, we had 20 years' experience of working over the Internet out of a home office and we'd already made the switch to online meetings via Zoom. In the future, we'll be using teleconferencing to offer you direct support.

Whether by accident or design, we had structured an organisation that was perfectly adapted to weather a global pandemic. We were COVID-19 ready.

But organizations need people for purpose and meaning.

As lockdowns spread across the country in March 2020 and people were forced to work and educate their children from home, the Association's phones stopped ringing and our email in-box stopped dinging. People even stopped accessing our website and Facebook pages as their focus turned from their eye health to basics like finding food (and toilet paper). Support requests logged by the Association almost dried up over that period.

It took time for everyone to adjust to the new reality and for eye-carers to win back the confidence of patients by creating COVID safe environments.

Today we thank all our amazing, dedicated health practitioners and officials for making Australia almost COVID-19-free once again.

Now it's time to look after your eyes. Keratoconus is a progressive disease and like a virus, it can move fast.

Larry Kornhauser  
president@keratoconus.org.au  
December 2020



# 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 specialists 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.*

## TRENDS IN 2019-20

After an abnormal rise in contacts logged by the Association in 2018-19, support provided to patients and their families returned to more long-term trend levels in the 2019-2020 financial year.

Total support contacts logged by the Association last year were 260 - almost 70% lower than the previous period (867). The method of recording support contacts reflects both the actual number of people assisted as well as the complexity of issues being discussed. So last year's high support number highlighted more repeat contacts with individuals and families rather than a sharp rise in the actual number of people assisted by the Association.

The eruption of COVID-19 in March 2020 and the subsequent lockdowns and restrictions on movement across the country also heavily impacted support requests, which almost dried up completely from mid-March until June 2020. Support contacts logged in that period fell to around 20 - well down from the 130 logged in the same period in 2018-19. This was a trend noted across the health sector as people avoided what were perceived as high-risk places like medical and optometrist practices and hospitals.

People with keratoconus and their families contact the Association for many reasons - usually stemming from a lack of information about keratoconus and its management and/or inadequate treatment from their current eye-carers. The vast majority of these support contacts culminate with the Association assisting patients

and their families to find local eye-carers specialising in keratoconus to resolve their underlying issue.

Directing patients to keratoconus specialists accounted for 45% of the Association's support work in the 2019-2020 financial year, which was down on the previous year (60%) but still higher than the long-term average of around 35%.

The high and rising cost of treatments - especially contact lenses and surgical procedures is an ongoing concern. The Association receives a constant stream of requests from patients and their families for advice on how to access low cost or subsidised contact lenses in particular. Support in this area accounted for 9% of contacts logged last year - a similar level to the past few years.

The Association has compiled a special section on the **Resources** page of its website 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 supporting research into the cost burden of keratoconus to highlight the additional impost on patients of the current situation.

Other trends from last year included:

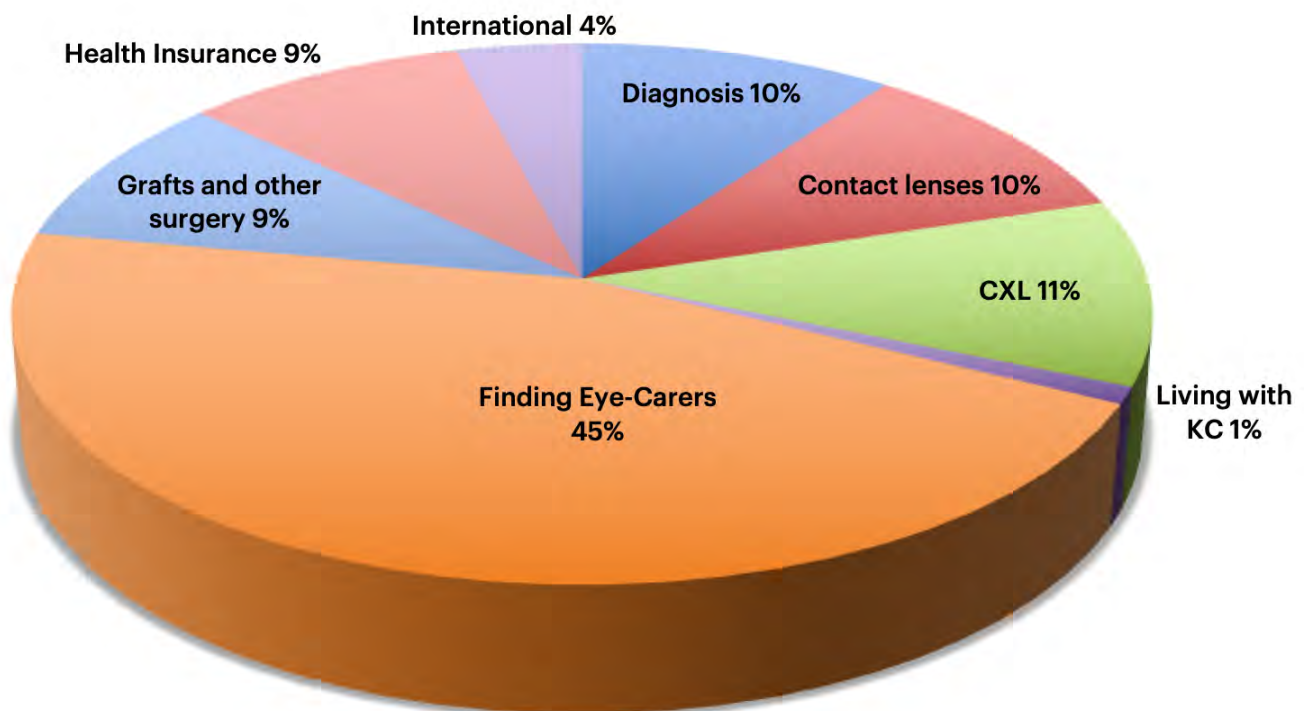
- Corneal collagen crosslinking remained the primary surgical procedure of concern to patients and their families. Many worried parents of keratoconus-affected adolescents contact the Association to seek reassurance about the safety and efficacy of crosslinking and the impact of keratoconus on their 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 straight after diagnosis of their keratoconus jumped significantly last year to around 10% of total support provided by the Association. In some cases, this reflected the lack of clear information about keratoconus provided to them by their eye-carer while in others, it resulted in advice from us to seek a second opinion from a keratoconus specialist.
- Requests about non-crosslinking related surgery and notably corneal transplantation remained significant last year (10% of total support), although there were no specific inquiries about intracorneal rings such as Intacs.

- Issues with contact lenses also accounted for 10% of total support. Some of these requests arose from problems with more complex contact lenses and often resulted in the patient being advised to seek a second opinion from a specialist contact lens fitter for keratoconus.

In recent years, 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. During the COVID-19 lockdowns, we switched from sending hard copies of this material to electronic versions in pdf format. With the lifting of restrictions in Victoria, we again have hard copy supplies of these booklets and brochures. We urge members to request this free information material from us in whatever format they prefer.

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

## SUPPORT BY NUMBERS



## SUPPORT 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 2019-20.

- Joshua was told he needed a corneal transplant and asked us for some information about the operation. We offered to send him our booklet on corneal transplantation supplied by the US National Keratoconus Foundation (NKCF). We also said that corneal transplants were life changing and that he should get a second opinion on his contact lenses from a specialist contact lens fitter for keratoconus (he wasn't seeing one). We sent him a list of contact lens fitters in his area.
- Stuart now 29 was looking for a solution to his keratoconus. He had consulted two optometrists already. He had one bad eye, one "okay." Thinking of contact lenses and crosslinking. Asked if epithelium grows back after crosslinking? Looking for advice on next steps  
We said we are not doctors and answered in general terms with some background on crosslinking. Suggested he see a specialist contact lens fitter for keratoconus for a full review and assessment of his suitability for contact lenses. The optometrist also could monitor for progression and see if crosslinking would be helpful. And yes, the epithelium does grow back a few days after CXL.
- Laura has a 15 year old son with keratoconus and was considering crosslinking. But was very concerned about epithelium off crosslinking and cited a US study showing serious side effects of this procedure. The same study promoted an epithelium-on method of crosslinking involving the "use of a 'patent-pending sterile sponge' that saturated the epithelium with proparacaine to increase penetration of the riboflavin formula into the corneal stroma without harming the epithelium. They also used a 'new riboflavin formulation', the details of which they do not reveal (although they mention riboflavin containing vitamin E has been tested but not reported on yet for CXL). Laura sent a copy of the study asked if there were any corneal surgeons in Australia using this apparently safer method of epi-on crosslinking.

Not being ophthalmologists, we sent the article to Professor Stephanie Watson who heads the Save Sight Keratoconus Registry for her opinion. We also sent Laura recent studies on paediatric patients that showed a clear benefit over a three-year period in using epi-off to halt progression

rather than epi-on. Finally, we noted in the study fine print that the authors had a financial interest in the technology they were promoting as safe and effective.

Professor Watson replied as follows:

*The main things to note about this study are:*

- 1. They included a range of patients not just those with keratoconus*
- 2. They did not have progressive disease as an inclusion criteria ie if the patients were not progressing in the first instance then it is hard to say the treatment has stopped progression. Note the average age is 30 years - this is typically an age where there is a very low risk of progression*
- 3. Proprietary products were used - these are not available for general clinical use and therefore likely have not been FDA approved aside from a trial*
- 4. The abundance of evidence still says that epi on is less effective*

Laura was extremely grateful for the responses from Professor Watson and the Association and said she would be taking her son for the operation via the public system. We also provided her with low-cost options for contact lenses in the Melbourne area.

- John's 19 year old son was booked for crosslinking despite showing no signs of progression. His son was very anxious about the operation and they wanted advice. In the absence of progression, we suggested they seek a second opinion from a specialist contact lens fitter for keratoconus. We provided the name of a local contact lens fitter and they subsequently decided to postpone the procedure on his advice and monitor the situation. John's son subsequently decided to have both eyes crosslinked in early 2020 for peace of mind about the future. John has since talked to other parents whose children are having crosslinking.
- Sam is a student and has progressive keratoconus. He would like crosslinking but can't afford it. He asked where he could go in Melbourne to have it done as a public patient. We provided him with details of the two main hospitals offering crosslinking to public patients.
- Tony lives in the United Kingdom and is considering a move to Australia and wanted to know if he can source silicon hydrogel contact lenses here. We asked one of our consulting optometrists Richard Vojlay who replied: *Silicon Hydrogel are available in Australia, they can be off-the-shelf lenses - i.e. disposable lenses - with or without astigmatism, they can also be manufactured in a custom design.*  
*Custom-designed silicon hydrogel lenses can be required if the shape of*

*the eye requires an unusual design - i.e. a very flat or very steep curve, or if the patient has a very high prescription - once again with or without astigmatism, laboratories these days can just make almost any design. Custom made lenses come with a warranty so that we can fine tune the design to maximize comfort and vision.*

*Also if he can't tolerate rigid gas permeable lenses - hybrid lenses are available, or even scleral lenses - both of these options can be significantly more comfortable than standard RGP.*

*Some patients often feel that their scleral lenses are more comfortable than a soft lens. Lots of options are available.*

- Sandy was very angry that her contact lens fitter talked her into trying a second set of scleral lenses after a first set failed. The second failed too and she was out of pocket to the tune of \$3,200 plus costs for solutions, drops, ointments etc. She had also paid for two crosslinking operations and now her vision was worse than ever. She was being told to try another set of lenses by her optometrist and Intacs by her corneal surgeon (also at a high cost). She wanted advice on what to do next.

We told her that the situation with the optometrists was simply unacceptable. We found her the name of more experienced contact lens fitter for keratoconus in the same practice who subsequently offered to try another set of scleral lenses at no cost to her if they too failed. We also provided advice from our consulting optometrists on how to resolve the fogging issues she had experienced with the scleral lenses. We advised her that Intacs too were fraught with issues and may be best avoided if a contact lens-based solution could be found.

Finally, we told her that some Melbourne optometrists were offering 50% refunds on unsuccessful contact lens fits.

Sandy tried the third pair of lenses with the third optometrist and was doing well with these.

*We note that this and a very similar case were the basis of a subsequent approach to Optometry Australia about the highly unsatisfactory situation facing patients regarding warranties and refunds on unsuccessful fits (see Advocacy).*

- Kerry was moving to Tweed Heads and was looking for a local contact lens fitter for keratoconus. We sent her a list of the optometrists specialising in keratoconus in her area.
- David has two corneal transplants and a lens implant and was wondering about the impact of wearing a scleral lens long term over a graft. He asked if there were any studies on this.  
One of our consulting optometrists sent through 4 articles on the topic

which we passed on to David.

Another optometrist replied saying there is work being done on the issue in the US. He said the general consensus was that sclerals are not suited to grafts as hypoxia or oxygen deprivation is definitely a major issue. He said he fits mini sclerals only when absolutely necessary and even then, monitors grafts closely and often tells patients to wear the lens either every second day or only as necessary. He added this is particularly true for older grafts and full thickness grafts. Partial thickness grafts or DALKs where the patient still has their own endothelium perform better with sclerals. The smaller lenses are definitely his preferred option for post graft patients. But he acknowledges these may be difficult to fit on uneven corneas.

- Finally, we have received many questions from around the world about a trial of drops at Auckland University that would purportedly reshape a keratoconic cornea. We tell people we have no information about this trial and they should contact the researchers directly. Our own efforts to contact the researchers have drawn a blank.

## NOTES OF APPRECIATION

Volunteers at Keratoconus Australia offer our 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.

- From Jacqui who we helped find a specialist for her son

*I'll make some calls tomorrow and see where we go from here. The unknown aspect is what we're finding the hardest at the moment. It will be interesting to see what a specialist in keratoconus has to say... Thanks so much for all your help and time...it's very much appreciated!*

- We sent a list of eye-carers to Mary who was looking for second opinions on her keratoconus in the Melbourne area

*Thank you very much for the below information and for taking the time to chat with me about my concerns... You have been very helpful and it was lovely chatting with you also.*

- Paul, 60, had suffered with keratoconus in one eye and was now being told he needed surgery by a surgeon without much experience in keratoconus. He wanted second opinions on his contact lenses and prospects. We sent him the names of specialists in his local area and arranged an initial appointment at minimal cost. We subsequently had

several discussions to reassure him about his prospects.

*Very much appreciated*

- Nafay was scared of having epithelium off crosslinking after reading about the perceived risks and discomfort on the Internet of this protocol relative to the epithelium-on method. Could not understand why he should not get the less invasive procedure.

We explained that epithelium-off protocol was considered the gold standard for crosslinking and worked well whereas epithelium-on might be less painful initially but was less effective. We also provided recent studies and evidence from the Save Sight Keratoconus Registry to that effect.

Nafay replied as follows:

*Humbled for the time you took to follow up and provide me with this information. You guys are doing great work. In the process of researching for Keratoconus - I found a real skew in the availability of information. Surgeons had different reviews often vs non biased sources. So I really appreciate the work you guys have done - super important in bridging the gap and helping people understand the condition and how to live with it. Would love to support/collaborate on this cause in anyway I can... Let me know how I can support. Would be honored to do so.*

- Patty was having repeat issues with her contact lenses and was quite distraught about her next steps. We advised her to continue with her current contact lens fitter who is highly experienced in the field  
*Your words are comforting and it helps a lot when this source of information is available to me.*
- Finally, from Sandy (see above) who we helped negotiate a third set of scleral lenses on a no-success, no-cost basis.

*I had no idea what to do next and was waiting for intacs to be inserted as a last option. (You) advised me to trial another optometrist and give scleral lenses another thorough exploration before surgery. I was very skeptical, but thought I would always regret not taking (your) advice. My new optometrist advised me that if these lenses did not succeed, I would be refunded, so I had nothing to lose. I have had a couple of different fittings but have successfully been wearing these new sclerals for 4 weeks now and wanted to send on my extreme gratitude and thanks to (Keratoconus Australia) for your support and advice.*



## 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 Japan, Uganda, India, 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.

We even received a request from a Portuguese woman sailing around the world who was stuck for 7 months in the Solomon Islands by COVID-19. She needed urgent assistance and was inquiring about eye-carers she could consult in the Brisbane area. We sent her a list of specialist contact lens fitters for keratoconus and wished her *fair winds*.

## SPEAK UP!

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 is a very tricky eye disease to treat and fitting contact lenses on a keratoconic eye is considered an art rather than 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, 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.

**Warranties and refund policies should be disclosed by eye-carers to patients 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

*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**

*The SSKR is critically important because it allows us to conduct research to better understand keratoconus and learn new research that helps clinical decision-making and ultimately discover better outcomes for patients.*

*In August 2020, the SSKR database had accumulated data from more than 29,000 clinic visits of patients with keratoconus. The visits were from more than 6,000 eyes of 3,257 patients, 87 ophthalmologists from 78 sites across multiple countries including Australia, New Zealand, France, Italy, Germany, Switzerland, and Spain. The registry has also tracked the outcomes of approximately 3,100 corneal crosslinking procedures.*

*Dr Himal Kandel is the Registry Research Associate, whose responsibilities include implementing the SSKR and managing its day-to-day activities. As part of this role, he engages with the SSKR development team to enhance the database.*

*Until recently, the registry was primarily tracking corneal cross-linking outcomes only, along with the natural history data. Dr Kandel has since prepared new fields to be included in the registry after a comprehensive literature review. This will allow for other treatments to be monitored such as corneal transplant, intrastromal corneal ring segments, and photorefractive keratectomy.*

## **OPTOMETRY MODULE**

*One of the most significant developments since Dr Kandel's appointment has been the development and launch of the optometry module.*

*This valuable addition enables an ophthalmologist to share their patients' data with an optometrist and vice-versa, allowing for seamless patient care.*

*Optometrists can track and share the outcomes with the patient directly, as well as benchmark their practice with their peers. Additionally, the outcomes of contact lens management for keratoconus patients can also be audited.*

*The module ultimately gives the SSKR more data and opportunities to research keratoconus care.*

*Additionally, Dr Kandel has prepared an application for Continuing Professional Development (CPD) accreditation for Australian optometrists using the keratoconus registry from the Optometry Board of Australia. This accreditation will increase the attraction of optometrists to use the registry.*

*(Optometry Australia published a long article on the Registry optometry module in its November 2019 edition at*



**Associate Professor Laura Downie and Dr Himal Kandel promoting the Save Sight Keratoconus Registry at the International Cornea and Contact Lens (ICCLC) conference, Noosa, 2019**

<https://www.optometry.org.au/patient-care-management/optometrists-to-record-patient-outcomes-on-online-keratoconus-registry/>

## QUALITY OF LIFE RESEARCH

*Quality of life is an incredibly important area of research, our goal is to improve functioning, relieve symptoms, and raise the overall standard of general wellbeing for people with keratoconus.*

*Alongside the standard clinical tests, in recent years there has been growing interest in measuring quality of life directly from the patient's own perspective. This shift ensures that patient's wishes are the priority of healthcare and the outcomes strived for are the ones most valuable to them.*

*In 2020, Dr Kandel published two papers focused on quality of life for keratoconus patients. These were both published in the prestigious Cornea journal – a leading research journal in this field.*

Keratoconus Australia is hoping that analysis of this QOL data can lead to changes in clinical practice and treatments to improve patient outcomes. We note how the Dutch researchers have used QOL data to better target candidates for crosslinking and thereby reduce crosslinking procedures by 20% (see our website for details).

## SAVE SIGHT KERATOCONUS REGISTRY ADVISORY COMMITTEE

The advisory committee of the Save Sight Keratoconus Registry (SSKR) met on the 20<sup>th</sup> May 2020 via Zoom. The SSKR is part of the Fight Corneal Blindness! Project. Members including Mr Larry Kornhauser and Associate Professor Gregory Harper from Keratoconus Australia, Dr Laura Downie from the University of Melbourne's Department of Optometry and Vision Sciences, and representatives from the Therapeutic Goods Administration, the optometric industry and Save Sight Registries team, focused on ensuring the registry met patient needs during the meeting.

Discussion at the 2020 Registry meeting centred around:

- A review of the 2019 KeraClub meeting. KeraClub is a NSW-based joint Save Sight Institute-Keratoconus Australia initiative. It holds annual meetings to highlight the latest developments in the Registry project and keratoconus research and treatments. KeraClub also provides a forum for people with keratoconus to share their experiences with the wider keratoconus community.
- The new Registry module to enable optometrists to track their patients
- A review of the SSI-KA crosslinking brochure to ensure it remained up-to-date
- Progress in the Registry data entries and control. Finalized data is now 95% of all saved data.



- Future funding options
- Initiatives to use the Registry in NSW hospitals to analyse treatments outcomes. Keratoconus Australia asked that other state health services and notably Victoria also be approached
- SSKR Research Associate Dr Himel Kandel described the publications and presentations over the past year.  
In 2019-2020, the SSKR team published 6 papers: 2 in *Ophthalmology* and 4 in *Cornea* journals. Currently, 3 papers are in submission and 4 other manuscripts have been drafted. He reported some of the key findings from



Dr Himel Kandel, Kornhauser Research associate at the Save Sight Institute, presenting about the Save Sight Keratoconus Registry at the International Cornea and Contact Lens (ICCLC) conference, Noosa, 2019

these unpublished papers including standard vs accelerated cross-linking outcomes, long-term outcomes of cross-linking, the quality-of-life impact of keratoconus, and impact of COVID-19 on the SSKR uptake. Finally, he presented on the recent conference proceedings and presentations from the SSKR. (Summaries and links to these papers can be found in the **Annex**)

- There was also discussion around corneal flattening noted after crosslinking

- It was decided that promotion of the Optometry module should commence once the COVID-19 crisis had eased - hopefully now in 2021
- Keratoconus Australia also noted that large swathes of patient data had still not been entered in the Registry.

We also expressed concern that the Save Sight Registry website still does not provide all the names of participating keratoconus specialists nor does it highlight which eye-carers are actually participating in the Keratoconus registry module. We are hoping this will be rectified in the near future to enable patients to choose corneal surgeons committed to improving their outcomes via the Registry data.

## **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**

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 deepened by Dr Sahebjada and her fellow researchers.

The CERA team recently published a final paper entitled *Economic impact of keratoconus using a health expenditure questionnaire: A patient perspective*

Based on patient survey data, Dr Sahebjada and her colleagues said “the calculated median out-of-pocket cost was \$3365 over 12 months, which included costs for medical care, visual aids, private health insurance, productivity losses, transportation and indirect costs. The median total cost of KC was \$3400 while the average household optical expenditure was \$145 per annum (Australian households report 2008).

**This suggests KC patients are paying 30-fold more than the general population on the care of their eyes.** Thus, the financial impact on the individual is important to consider in understanding the impact of this diagnosis. Individuals with KC have a higher utilization of eye care services than the general population.”



**Dr Srujana Sahebjada**

The authors therefore concluded “The results of this study highlight the economic impact of KC on individuals. KC usually has its onset during the teenage years, progressing throughout an individual’s core education, prime earning and child-rearing years. We have previously reported that the vision-related quality of life utility value is lower in individuals with KC compared to those with diabetic retinopathy or age-related macular degeneration. **With both impaired vision-related quality of life and a significant economic impact, KC represents a public health concern.**” (See Annexes for a full abstract of this paper)

This is critical research that hopefully can be used to argue for greater subsidisation of costly treatments, notably complex contact lenses - the primary treatment option for vision loss caused by keratoconus.

CERA is currently a partner in the Save Sight Keratoconus Registry project to prove the safety and efficacy of collagen crosslinking and other keratoconus treatments. CERA is also working on :

- Identifying clinical, environmental and genetic risk factors that contribute to keratoconus. This research aims to find the underlying cause of the condition. It includes a study looking at the genes involved in the diseased corneal tissue discarded after corneal transplant.



- Using artificial intelligence to fill in gaps in the clinical understanding of keratoconus. This includes detecting subclinical keratoconus and predicting disease progression.
- CERA has also created the Keratoconus International Consortium to enhance international collaboration and data-sharing to improve understanding of the disease.
- Dr Chan published a paper 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 participants.

Keratoconus Australia is currently in discussions with Dr Sahebzada around ongoing surveys of the keratoconus population and ways of improving patient outcomes.

## UNIVERSITY OF NSW

As reported in last year's Annual Report, Keratoconus Australia agreed to support research by optometrist Alan Ared into eye rubbing and its impact on the cornea.

The Association subsequently did a mail-out to invite NSW members to participate. A follow up email was sent in July 2019.

Mr Ared has found it difficult to recruit volunteers for the study. However, he kindly provided a very informative presentation to our KeraClub 2020 on eye rubbing and its impact on the cornea and keratoconus. A link to all the KeraClub presentations can be found on the **Resources** page of our website.

## DEAKIN UNIVERSITY

Dr Serap Azizoglu contacted the Association in late 2018 to discuss her project to study the prevalence of keratoconus in Victorian schools. The Association sent Dr Azizoglu some materials on keratoconus, corneal collagen crosslinking and the dangers of eye rubbing.

Dr Azizoglu kindly provided us with an update in mid-2020 on her progress along



Dr Azizoglu (2nd from left) and her team

with some photos of her team.

She said the project was initially hampered by a lack of adequate screening equipment but this had now been overcome. Screening started in spring 2018 and some data was collected. Dr Azizoglu talks to the students about eye-rubbing, and sends every student who has had their eyes tested information about eye rubbing, along with the full report of their outcomes. However, COVID-19 shut down the project temporarily.

## 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)

Keratoconus Australia and the University of Melbourne's Department of Optometry and Vision Sciences (DOVS) have been conducting keratoconus training clinics for 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.

Dr Laura Downie contacted us again in early 2020 to seek volunteers for this year's clinics. Unfortunately, due to COVID-19 and the lockdowns implemented in Victoria, the clinics were cancelled.

The University's Melbourne Eyecare Clinic remained open for emergency consultations during university semesters. Keratoconus Australia members continue to have access to bulk billed consultations and 30% discounts on contact lens fittings and ancillary services through the keratoconus clinic.

### 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.

Last year, we were able to assist patients encountering fogging problems with scleral lenses based on advice from some of Australia's senior contact lens fitters. We also were able to provide research papers to another patient concerned about the impact of using these lenses on corneal transplants.

Corneal collagen crosslinking causes much angst amongst patients and their families and our crosslinking brochure written and updated in collaboration with the Save Sight Keratoconus Registry has helped eased concerns. Professor Watson

from the Registry has also provided reassuring advice on crosslinking to a number of patients - especially on the epithelium-on vs epithelium-off dilemma.

We also have been approached by a number of medical practitioners and health care workers for advice and assistance with their patients. One such request came from the Danila Dilba Aboriginal Health Service in the Northern Territory who were seeking advice on a keratoconus patient's eligibility for funding under the National Disability Insurance Scheme (NDIS). This a vague area and we sought advice from Vision 2020 Australia. Policy and Advocacy Coordinator Georgia Taylor provided us with a detailed response and a list of contacts which were able to pass on to the Aboriginal Health Service. This information has now been added to the **Resources** page of the Association's website.

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

Keratoconus Australia acts as a support body for people with keratoconus and their families and the wider keratoconus community. That role includes acting as an advocate 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.

### VISION 2020 AUSTRALIA

One of our key partners in our advocacy work is Australia's peak eye health body, Vision 2020 Australia. Keratoconus Australia participates in its Prevention & Early Intervention Committee (PEIC). Vice President Greg Harper has been nominated as the delegate with Larry Kornhauser as his proxy.

Greg Harper provided the following report on his involvement in the PEIC:

#### **Vision 2020, PEIC work**

I have now attended two significant meetings of the PEIC. Copies of the agenda and minutes have been circulated by Vision 2020 Australia secretariat, and are available upon request. The February 2020 meeting covered the establishment of the new Committee and there was a good deal of discussion about its priorities. The September meeting covered a substantial agenda and here are some of the items that I thought relevant to KA, and conclusions from my perspective.

1. *Research project outline - Economic contribution of the eye sector.* There was debate about the value of previous attempts to estimate the community costs of poor vision, and hence the potential benefits of eye care interventions. There were a number of important precedents and survey design issues that would help this work get further.

2. *Second National Eye Health Survey.* The first National Eye Health Survey was conducted in 2015, and provided valuable information regarding the visual status of the Australian population and the prevalence of a range of eye conditions. The Australian Government's Department of Health awarded the work to the University of Sydney. Professor Paul Mitchell. While a précis of the consortia's proposal for the survey will be circulated to Committee members when available, he has indicated that the second National Eye Health Survey will have some differences from the previous survey, including:

a. Increased emphasis on identifying the impacts of vision impairment on the Australian community

b. A more comprehensive eye examination to help identify eye disease. The current intention is to conduct dilated fundus examinations on all participants, to take a range of biometric measurements (e.g. height, weight, blood pressure), to seek additional information about risk factors (such as smoking),

c. and to conduct a wider range of diagnostic tests including wide field retinal photograph, OCT and OCT-A, expanded assessment of visual acuity measurement and refraction, as well as increased participation of people aged 75+.

3. *Federal Budget Submission 2021-22.* Many matters to be included in this submission but on our behalf I added extra emphasis around the proposition that there should be a focus on innovation, and particularly how it relates to piloting new models for enhanced service delivery, (e.g. contain future costs, generate better outcomes, increase relevance/broader public appeal.)

Keratoconus Australia officers also held talks with Vision 2020 Australia CEO Judith Abbott in July 2019 and September 2020 to discuss a range of issues including the cost of contact lenses, collaboration with other smaller eye health organisations, analysis of Medicare data on crosslinking to see the impact (if any) on corneal transplantation rates and the use of contact lenses.

One area of particular concern is the lack of mental health support for people with keratoconus and low vision in general. We are hoping Vision 2020 Australia can assist in creating a common resource specialising in psychological support for the vision sector.

Keratoconus Australia also participated in the workshop for a vision sector submission into the development of the Australian government's National Preventative Health Strategy. Larry Kornhauser attended the workshop on behalf of the Association.

As a result, the final submission to the government included a reference to keratoconus as an example of how screening in older children can help prevent vision loss.

## OPTOMETRY AUSTRALIA

The Association sought talks with Optometry Australia (OA) in early 2020 following a number of complaints from patients about the lack of refunds on offer after repeat unsuccessful fits of expensive scleral contact lenses. These lenses can cost over \$1000 each. The patients in question complained they had no recourse against optometrists despite being urged to continue trying these lenses after successive failures. These patients incurred costs of \$3000-4000 and still ended up without contact lenses.

Preliminary discussions with OA National Professional Services Manager Luke Arundel indicated that the issue of warranties and refunds on unsuccessful contact lens fits had been raised before in other areas of optometry practice and that it needed to be addressed in keratoconus too.

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 COVID-19 lockdowns in Victoria. We intend pursuing this issue in 2021. 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. This is disappointing and we hope these decisions will be reversed in due course.

Some private optometrists are trying to fill the gap created by the cancellations by offering limited contact lens services to Centrelink card holders.

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

## MEMBERSHIP

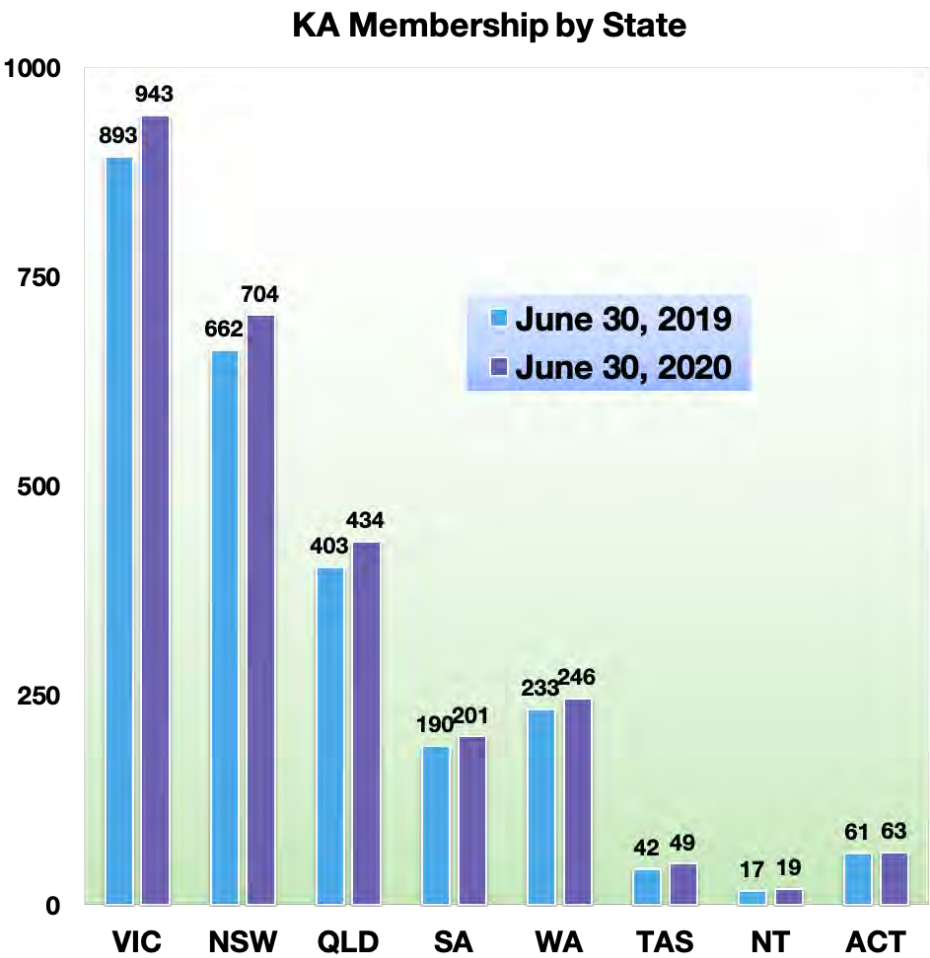
Keratoconus Australia enjoyed its strongest growth in membership since 2013-14 in the latest financial year, with the number of people joining the Association up by 6.3% to a total of 2,659. This was despite (or perhaps due to) Australia-wide COVID-19 restrictions for much of the second half of the reporting period. In fact, the majority of the Association’s 158 new members did join between January and June 2020 when the country was living under the spectre of the coronavirus and many people were afraid of visiting their eye-carers.

The rise in membership was spread across all states with Queensland membership up almost 8%

compared to last year to a total of 434 members on June 30, 2020. NSW (704 members), South Australia (201), Western Australia (246) and Victoria (943) also recorded large increases of around 6% respectively. Of the smaller states and territories, Tasmania added 7 new members (+17%) to a total of 49 (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 (8%).

(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 2019-20, 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 must go to the US National Keratoconus Foundation which provides the Association with its patient booklets on keratoconus and corneal transplants. These have been provided at nominal cost since 2000 and have greatly benefited both patients and eye-carers in disseminating information about keratoconus. Last year, 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 NKCF for establishing a **World Keratoconus Day** on November 10 as a means of spreading word about this disease that affects so many people. Keratoconus Australia celebrated WKD this year with videos made by committee member Alejandro Molano which are 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 including the Save Sight Keratoconus Registry, the NSW 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 her team 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 has also participated in patient forums to keep our members updated on data from the Keratoconus Registry and answers 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 and Laurie Downie who oversee contact lens fits by student optometrists, and offer discounts of up to 30% 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 are also providing 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 2019-20 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>.

## LOCAL AND STATE GROUPS

### **New South Wales KeraClub**

The NSW KeraClub - our keratoconus patient support group launched in October 2016 with the assistance of Keratoconus Australia member Michelle Pritchard and the Save Sight Institute - continues to provide a meeting place for Sydney-based Keratoconus Australia members and others interested in keratoconus.. The group offers a forum for an exchange of interesting stories by members and updates on

the latest research by the Save Sight Institute. It also enables members to hear about topics of interest from keratoconus specialists.



**A full house for the 4th annual KeraClub meeting**

Last year, the 4th annual KeraClub community meeting was held on October 24, 2019 in Sydney and for the first time was broadcast live to the world via Zoom. Save Sight Keratoconus Registry director, Professor Stephanie Watson, provided an update on the latest registry research and development in keratoconus treatments, and Sydney optometrist Dr Jim Kokkinakis discussed contact lenses for keratoconus and how to manage them in every situation (*but don't try and climb Mount Everest in them*). Patients Joy Alleyne and Ana Sandoval (who flew up from Melbourne), also had their say about their experiences with keratoconus and how it affects their lives. The meeting concluded with a lively Q&A session.

A video of the 2019 meeting is available on the Keratoconus Australia and Save Sight Institute websites. A full report on the meeting is also included in the **Annexes**.



The introduction of a simultaneous webinar format in 2019 has made the KeraClub meetings accessible to members around the country (and the world) and linked with Zoom has enabled the Association to function almost normally throughout the COVID-19 shutdowns.

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.

## WEBSITE

As discussed in the President's report (see above), Google Analytics data for the Association's website highlighted some fascinating trends in usage in 2019-20 as COVID-19 super across Australia.

At 41,000, total website page views in 2019-20 were almost steady (-1%) compared

**Key website statistics 2019-20**



to 2018-19. However, the unchanged number of visits hid sharp swings that occurred during the past year compared to 2018-19. In particular, visits to the site plunged in March 2020 as COVID-19 restrictions and lockdowns were imposed across the country. It would appear that like everybody, keratoconus patients went

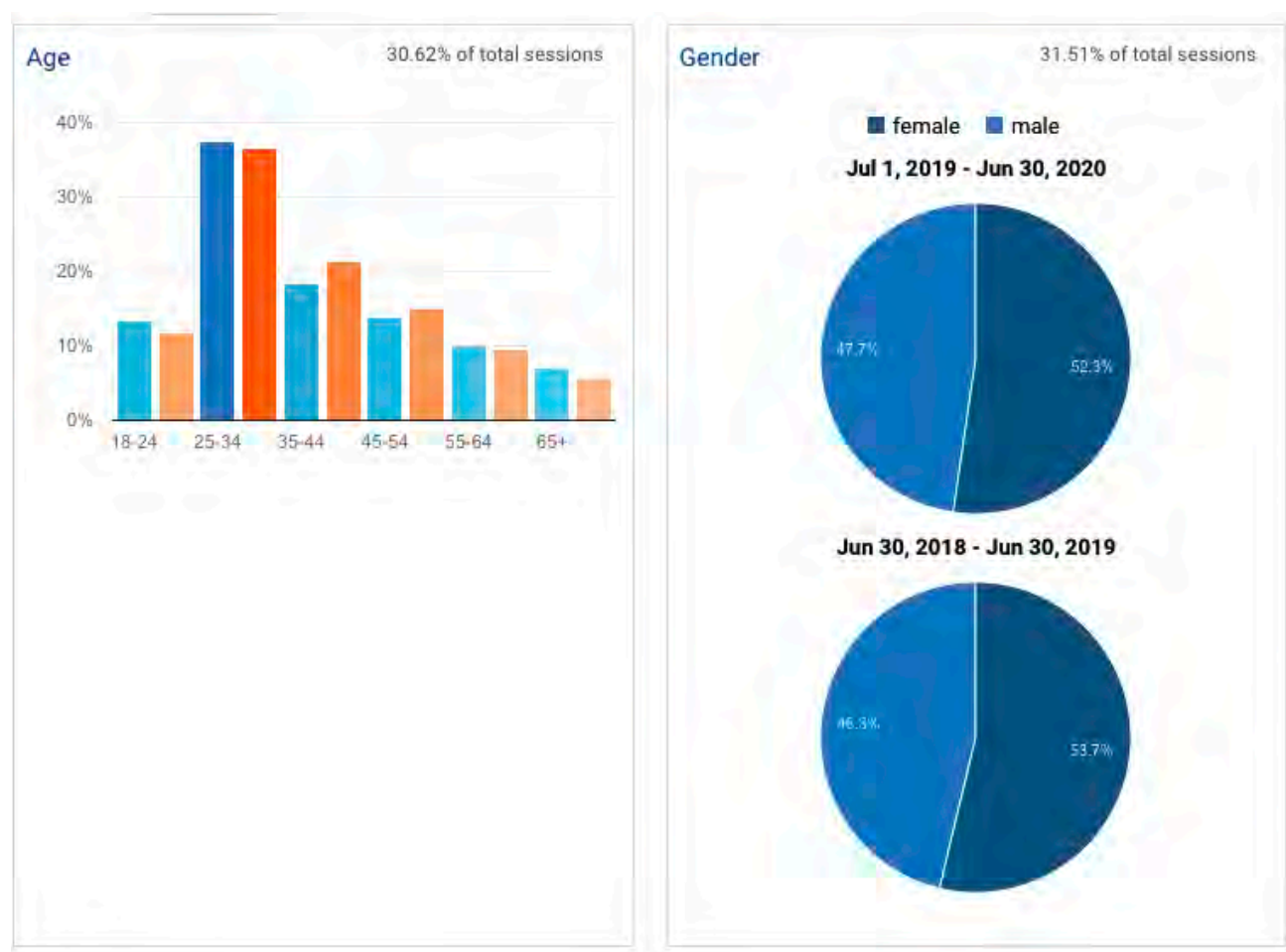
into survival mode by avoiding health carers because of the perceived risk of catching the virus and hunkered down at home to focus on their work, education and family needs. Visits to the Association's website climbed back sharply as restrictions on movement were lifted in May-June and actually peaked in mid-August just as the Victorian Stage 4 lockdown was imposed.

Most users arrived on the site via the Home page, which accounted for 19% of the total site visits. Information on keratoconus treatments and corneal collagen crosslinking in particular, was again the most sought after, with visits to the various Treatments pages totalling a third of all visits to the website. Visitors also headed to information about the Association and the pages with general information about keratoconus and answers to frequently asked questions.

Most visitors came from Australia (74%) with almost one-third from Victoria, about 30% from NSW followed by Queensland (18%), WA and SA.

Keratoconus is a young person's disease and so not surprisingly, the bulk of visitors

#### Website visitors by age and gender



were in the 25-44 age group, the ages most affected by keratoconus. The gender split was 52-48 in favour of males (see above).

## FACEBOOK

We have continued to promote our Facebook page and currently have almost 500 followers. 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. 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.

## STRATEGIC PLANNING

While Keratoconus Australia had somewhat of a hiatus in 2020 because of COVID-19, some of us took the time to look towards the future. We have some ideas on how to progress the Association in 2021 and beyond and are reviewing surveys returned by members to discern other objectives.

We are hoping to conduct further surveys next year and hope you will support these to give us guidance on what you want from us. We are aiming to use results from these surveys to develop a strategic plan for future action. Please participate or simply send us your ideas directly.

Members wishing to launch and implement projects are welcome to contact the Association at any time.

## COMMITTEE OF MANAGEMENT

The Committee holds regular meetings to discuss the Association's plans and projects and to review its finances and procedures. In 2019-20, the committee met three times 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

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 liaise with Save Sight Institute in Sydney.

Greg Harper is now our Vision 2020 Australia representative and his work with the peak vision health body is greatly appreciated.

Wishing everyone a good and healthy 2021

The Keratoconus Australia Team



## FINANCIAL REPORTS 2019-20

Keratoconus Australia Inc. reported a net operating surplus of \$7,865, compared to \$8,813 in the 2018-19 financial year. This was 11% down on last year mainly due to a decline in donations. These fell from \$9,690 in 2018-19 to only \$7,430 last year (-23%). However a sharp increase in interest from term deposits to \$2,000 (\$771 in the previous period) enabled the Association to largely offset the fall in donation income.

The Association's presence on online giving portals such as GiveNow, MyCause and GoFundraise has assisted in reaching more donors over recent years despite the lack of major fundraising drives.

Thanks to the kind support of a number of organisations, our operating expenses remain low. Our major expense remains postage due to a persistently high number of members who fail to update their email addresses. Postage costs were again \$750 last year as the Association was required to mail out information to around 500 members. The only significant increase in costs noted was a jump in our Vision 2020 Australia membership fees to \$546 due to a timing issue. Other expenses remained fairly stable last year. Overall, total expenses in 2019-20 fell 12% to \$1,601.

The balance sheet as at 30 June, 2020 was showing net assets of \$121,931 compared to \$114,067, one year earlier. The Association holds the bulk of these assets in term deposits and continues to seek to maximize returns in the current low interest rate environment. Whilst some of this money will be retained to earn interest to cover on-going costs, the Committee is looking at other options for funding key research and advocacy projects to improve patient outcomes.

We thank Cameron Falt, previously of Deloitte Private for his assistance, both in preparing quarterly GST returns and finalising and reviewing our annual accounts. Cameron, who has been preparing the Keratoconus Australia accounts for some years now on a pro bono basis, left Deloitte in late 2019 and is now working at Slomoi Immerman Partners.

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

**KERATOCONUS AUSTRALIA INC**

**SPECIAL PURPOSE FINANCIAL REPORT**  
FOR THE YEAR ENDED 30 JUNE 2020

**KERATOCONUS AUSTRALIA INC**

**PUBLIC OFFICER'S DECLARATION**

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

The public officer declares that:

1. the financial statements presents fairly the incorporated association's financial position as at 30 June 2020 and its performance for the year ended on that date in accordance with the accounting policies described in Note 1 to the financial statements;
2. in the public officer's opinion there are reasonable grounds to believe that the incorporated association will be able to pay its debts as and when they become due and payable.

This declaration is made in accordance with a resolution of the public officer.

**Public Officer**



**Larry Kornhauser**



Slomoi Partners Pty Ltd

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Melbourne, VIC, 3001

Tel: +61 3 8376 1600  
admin@slomoipartners.com.au  
www.slomoipartners.com.au

## **COMPILATION REPORT TO KERATOCONUS AUSTRALIA INC**

We have assisted in the compilation of the accompanying special purpose financial statements of Keratoconus Australia Inc for the year ended 30 June 2020.

### *The Responsibility of the Public Officer*

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

### *Our Responsibility*

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

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

### *Assurance Disclaimer*

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

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

Slomoi Partners Pty Ltd

A handwritten signature in dark ink, appearing to read 'Cameron Falt', written over a light blue horizontal line.

Cameron Falt  
Director

Dated: 2 November 2020

**Keratoconus Australia Inc**

*PO Box 1109  
HAWKSBURN VIC 3142*

**Income Statement**

*July 2019 through June 2020*

	<b>This Year</b>	<b>Last Year</b>
	<b>\$</b>	<b>\$</b>
<b>Income</b>		
Donations	7,430	9,690
Booklet sales	0	68
Bank interest	36	99
Term Deposit interest	2,000	771
<b>Total Income</b>	<b>9,466</b>	<b>10,628</b>
<b>Expenses</b>		
Bank charges	(286)	5
Catering	19	0
Domain Name Registration	49	268
Dues & Subscriptions	0	272
License Fees	53	0
Meeting expenses	0	87
Postage	750	758
Printing	0	18
Photocopying	109	141
PO Box rental	134	130
Stationery	51	0
Telephone and Internet	78	90
Vision 2020	546	0
Website Hosting	98	46
<b>Total Expenses</b>	<b>1,601</b>	<b>1,815</b>
<b>Operating Profit</b>	<b>7,865</b>	<b>8,813</b>
<b>Other Expenses</b>		
Gifts / Contributions	0	0
<b>Total Other Expenses</b>	<b>0</b>	<b>0</b>
<b>Net Profit / (Loss)</b>	<b>7,865</b>	<b>8,813</b>

**Keratoconus Australia Inc**

PO Box 1109

HAWKSBURN VIC 3142

**Statement of Financial Position**

As of June 2020

	<b>This Year</b>	<b>Last Year</b>
	<b>\$</b>	<b>\$</b>
<b>Assets</b>		
<b>Current Assets</b>		
Cash On Hand		
Westpac DGF Account	15,381	7,378
Westpac Cash Reserve	23,642	23,617
<b>Total Cash On Hand</b>	<b>39,024</b>	<b>30,995</b>
Term Deposits	82,000	80,000
Funds received - not yet banked	0	3,000
Trade Debtors	0	38
GiveNow Receivables	880	310
<b>Total Current Assets</b>	<b>121,904</b>	<b>114,343</b>
<b>Intangible Assets</b>		
Website Development - at Cost	6,975	6,975
Accumulated Amortisation	(6,975)	(6,975)
<b>Total Intangible Assets</b>	<b>0</b>	<b>0</b>
<b>Total Assets</b>	<b>121,904</b>	<b>114,343</b>
<b>Liabilities</b>		
<b>Current Liabilities</b>		
Goods and Services Tax	(27)	277
<b>Total Current Liabilities</b>	<b>(27)</b>	<b>277</b>
<b>Total Liabilities</b>	<b>(27)</b>	<b>277</b>
<b>Net Assets</b>	<b>121,931</b>	<b>114,066</b>
<b>Equity</b>		
Retained Earnings	114,066	105,253
Current Year Earnings	7,865	8,813
<b>Total Equity</b>	<b>121,931</b>	<b>114,066</b>

**KERATOCONUS AUSTRALIA INC**

**NOTES TO THE FINANCIAL STATEMENTS  
FOR THE YEAR ENDED 30 JUNE 2020**

**1. SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES**

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

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

**(a) Revenue and Other Income**

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

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

**(b) Cash and Cash Equivalents**

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

These notes should be read in conjunction with the attached compilation report.





# ANNEXES

## 2019/2020 PUBLICATIONS FROM THE SAVE SIGHT KERATOCONUS REGISTRY

1. **Tan JCK, Nguyen V, Fenwick E, Ferdi A, Dinh A, Watson SL. Vision-related quality of life in keratoconus: A Save Sight Keratoconus Registry Study. *Cornea* 2019. 38(5):600-4**

This study evaluated the effect of keratoconus on patients using the Impact of Vision Questionnaire (IVI). The relationships between the IVI scores and the clinical variables such as vision, corneal shape and thickness, were also looked at. The study found that the vision in the 'better' eye had the strongest relationship with the ability to do day-to-day activities, whereas, vision in the 'worse' eye was strongly related to emotional well-being.

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

Although a person's overall day to day functioning is determined mainly by their 'better' eye, the vision in the 'worse' eye may influence the quality-of-life and well-being of a person with keratoconus. Clinicians should keep this in mind when treating keratoconus patients.

2. **Tan JCK, Ferdi A, Gillies M, Watson SL. Clinical registries in ophthalmology. *Ophthalmology*. 2019;126(5):655-662**

This study identified and described the existing registries in ophthalmology. A registry is an organized system for the collection of data on a health condition. They are used for tracking outcomes and monitoring adverse events from treatment.

A registry was found to be able to inform guidelines to make sure patients get the best treatments and overall improve health care. Registries were able to include anyone with the condition and allowed data collection over time, whereas clinical trials were short-term and had strict criteria for patients to be part of them. The number, size and scope of clinical registries had grown significantly in the last few decades. This trend is likely to continue as information technology improves. The challenges of maintaining a registry included having enough resources to support them and data quality.

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

The study findings showed clinicians and policymakers the benefits of adopting disease-focused, good-quality registries in clinical practice. The Save Sight Keratoconus Registry at Save Sight Institute, The University of Sydney was identified as a key web-based, international registry that aligned with the principles of the International Consortium for Health Outcome Measurements. This means that the registry can drive improvements in patient care.

3. **Ferdi A, Nguyen V, Gore DM, Allan BD, Rozema JJ, Watson SL. Keratoconus natural progression: A systematic review and meta-analysis of 11,529 eyes. *Ophthalmology*. 2019;126(7):935-945 [Featured in *Eyenet*, *American Academy of Ophthalmology*]**

The aim of this study was to help clinicians assess the risk of and monitor whether keratoconus was getting worse. This information is needed so that decisions can be made on whether treatments are needed. For example, corneal crosslinking can prevent keratoconus from getting worse but not everyone with keratoconus needs crosslinking as their eyes may be stable. This study included 11,529 eyes with keratoconus and was carried out to improve our understanding of the natural history of keratoconus. The study found that younger patients and those with steeper cornea had a greater risk of their keratoconus getting worse. The study also found that the corneal shape may be more sensitive for detecting keratoconus progression than vision, refraction and corneal thickness.

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

Closer follow-up and a lower threshold for cross-linking should be adopted in patients younger than 17 years and with steeper corneas. To tell if keratoconus is getting worse clinicians should monitor corneal shape.

#### **4. Ferdi A, Nguyen V, Samarawickma C, Hamilton A, Yeung S, Watson S. The impact on work patterns of implementing the Save Sight Keratoconus Registry in the hospital setting. 2019 Cornea [Epub ahead of print 2019.10.1]**

The use of clinical registries has the potential to improve outcomes for patients while reducing the costs of health care. The study sought to find out if using the Save Sight Keratoconus Registry in clinics would take clinicians more time. The timing of clinic consultations was recorded before and after registry use and clinicians were asked what they thought of the registry. The study found that the Save Sight Keratoconus Registry was able to be used in clinical practice without affecting the total consultation time, time spent directly interacting with patients, or use of patient records. Clinicians found the registry easy to use.

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

This study showed that the Save Sight Keratoconus Registry could be used easily in clinics allowing improvements in patient care to be made.

#### **5. Kandel H, Pesudovs K, Watson S. Measurement of quality-of-life in keratoconus. Cornea 2020;39(3):386-393**

Patients are the centre and priority of health care. Recently, there has been considerable interest in measuring the quality-of-life of patients from their own perspectives, along with the standard clinical tests. After all, the ultimate aim of health care is to improve functioning, relieve symptoms and uplift the quality-of-life of people with various health conditions. However, it was not known if there was a 'gold-standard' tool to evaluate quality-of-life in people with keratoconus.

A comprehensive review of what is already known on the impact of keratoconus on patients with the condition and the benefits of its treatments was done. The primary aim was to help clinicians decide how to measure quality-of-life in patients with keratoconus. 45 studies were reviewed and the quality of the existing quality-of-life questionnaires evaluated.

The Keratoconus Outcomes Research Questionnaire (KORQ) was found to be the only questionnaire designed for keratoconus that had been properly tested and had the best measurement properties. Overall, we found that keratoconus management methods (spectacles, contact lenses, and cross-linking in early stages, corneal transplantation in late stages) improved the quality-of-life of patients.

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

The best way to measure quality of life in patients with keratoconus is by using the KORQ. The KORQ is part of the Save Sight Keratoconus Registry. Using the KORQ, clinicians and researchers can determine the benefit of treatments to patients lives.

**6. Kandel H, Pesudovs P, Ferdi A, Mills R, Chen JY, Watson A, Poon A, Dwonie LE, Watson S. Psychometric properties of the Keratoconus Outcomes Research Questionnaire (KORQ): a Save Sight Keratoconus Registry study. Cornea 2020;39(3):303-310**

The Save Sight Keratoconus Registry collects information on the day-to-day functioning and symptoms from patients using the Keratoconus Outcomes Research Questionnaire (KORQ). The KORQ consists of 29 questions and was developed from an extensive literature review, and patient and expert interviews. It takes about two minutes to complete the questionnaire.'

This study found that the KORQ was a valid tool to collect meaningful patient-reported outcome data in the Save Sight Keratoconus Registry.

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

The findings suggested continued use of the KORQ to routinely collect, measure and monitor quality-of-life data in keratoconus patients in the Save Sight Keratoconus Registry.

### **Publication web-links:**

Publication 1: <https://www.ncbi.nlm.nih.gov/pubmed/30730335>

Publication 2: <https://www.ncbi.nlm.nih.gov/pubmed/30572076>

Publication 3: <https://www.ncbi.nlm.nih.gov/pubmed/30858022>

Publication 4: <https://www.ncbi.nlm.nih.gov/pubmed/31577627>

Publication 5: <https://www.ncbi.nlm.nih.gov/pubmed/31599780>

Publication 6: <https://www.ncbi.nlm.nih.gov/pubmed/31634230>

## KERACLUB 2019: 4<sup>TH</sup> ANNUAL KERATOCONUS COMMUNITY EVENT

The KeraClub links patients, researchers and clinicians on the topic of keratoconus.

KeraClub, a community event for patients with keratoconus and their friends and family was co-hosted by Save Sight Institute, The University of Sydney and Keratoconus Australia at the Sydney Eye Hospital on 24<sup>th</sup> October 2019. This annual event brought together over 40 patients with keratoconus, clinicians and researchers.

The event was chaired by Ms Michelle Urquhart, an internationally lauded violinist who has keratoconus. The speakers included Professor Stephanie Watson, Dr Jim Kokkinakis, and patients with keratoconus, Ms Joy Alleyne and Ms Ana Sandoval.



**Ms Michelle Urquhart speaking at the KeraClub 2019**

Ms Joy Alleyne kicked off the evening with a rendering of her personal experience with keratoconus. She recounted her shock when she was diagnosed in her youth, and the difficult, yet worthwhile adjustment to living with contact lenses. She wore piggyback lenses (hard contact lenses over soft contact lenses), which proved *“hard at the beginning but the vision with contact lenses is so good, there is no other*

*way to compare it. With contact lenses, you have hand-eye coordination, peripheral vision, and depth perception.” Additionally, she found wearing the lenses prevented her from rubbing her eyes. However, alongside their merits, the lenses came with a share of inconveniences: they were easy to lose, burdensome to clean, and finding an optometrist with experience in keratoconus management was a challenge. After sharing a wealth of experience with keratoconus and contact lenses, she advised, ‘Don’t let keratoconus define you, you decide what you are going to be. There are times when things are difficult. I once hailed a truck instead of a bus by accident! You just have to do what you can to get around’*

Joy’s talk was followed by a presentation from Professor Stephanie Watson, the head of the Corneal Research group at the Save Sight Institute, a corneal surgeon and an innovator. Prof Watson detailed recent research, clinical care and current teaching activities conducted by her team at Save Sight Institute, an institute of The University of Sydney.

She acknowledged the contribution of Keratoconus Australia and its president Mr Larry Kornhauser as *“a great source of support for keratoconus research and the KeraClub event since it started.”*

In presenting her research on keratoconus, Prof Watson showcased a recent finding from her team. They found that younger people and those with more advanced keratoconus have the greatest risk of changes in the steepest

part of their cornea. Dr Alex Ferdi, a PhD student in Prof Watson’s research group, pointed to the importance of this work in helping clinicians decide who requires corneal cross-linking.

Prof Watson also reported on the progress the **Save Sight Keratoconus Registry**. This registry tracks outcomes of keratoconus using the real-world clinical data in over 2,600 patients. With sites in Australia, New Zealand and Europe, there is now data from over 23,000 patient visits. Clinicians receive benchmarking reports comparing the condition of their patients with other users of the registry. The registry system generates graphs ‘on the fly,’ which help monitor visual acuity, corneal shape and keratoconus treatments. Patients, too, benefit from the registry, as the graphs aptly illustrate their individual keratoconus journey.

Patient-reported outcomes are collected using the ‘Keratoconus Outcomes Research Questionnaire’ developed by Professor Konrad Pesudovs. Dr Himel Kandel’s project found that this is a valid tool to measure the quality-of-life impact in keratoconus and the benefits of keratoconus treatment methods.

Prof Watson was pleased to announce the launch of the new “Optometry module” for the Save Sight Keratoconus Registry. This module developed with Dr Laura



Downie, School of Optometry, The University of Melbourne, will track the continuity of care from ophthalmologists and optometrists for keratoconus patients, including contact lenses.

“Improving outcomes of people with keratoconus can’t be done alone,” said Prof Watson. “Collaborations within Australia and abroad for basic science, clinical and translational research and collaborations with registry users and stakeholders



**Professor Stephanie Watson speaking at the KeraClub 2019**

including patients with keratoconus and Keratoconus Australia, are all needed to deliver research that matters.”

The insightful talk from Prof Watson was followed by an informative presentation from Dr Jim Kokkinakis. Dr Kokkinakis has over 30 years of experience of managing keratoconus patients with various types of contact lenses. He is an optometrist at The Eye Practice, Sydney, and an adjunct senior lecturer at the School of

Optometry and Vision Science at the University of New South Wales. “Managing contact lens in ‘extreme ’conditions’” was a key topic on this year’s event.



**Dr Jim Kokkinakis speaking at the KeraClub 2019**

Dr Kokkinakis highlighted that every keratoconus patient is unique: they have their own clinical profile, challenges, and expectations. He discussed common misconceptions, providing reassurance that people with keratoconus could do most things in contact lenses... aside from climbing Mt Everest! In addition to the broad range of capabilities, however, he underscored the risks of swimming or showering in contact lenses, rinsing contact lenses in tap water and sleeping in contact lenses.

Ms Michelle Urquhart shared her experience with scleral lenses. After undergoing corneal graft surgery, she now wears scleral lenses very comfortably. “It’s brightened up my life. I’m driving at night-time again; touring; playing music, reading all those tiny little dots on the page. I now feel I am a very fortunate person.” - Michelle Urquhart

The final speaker, Ms Ana Sandoval, flew from Melbourne to Sydney for the event to share her experiences and meet other people who have lived with keratoconus over different phases of their lives. She stressed the emotional toll of living with keratoconus, stating, “I knew absolutely no one with keratoconus... and it felt so lonely... When I wore my first contact lenses, I felt I was missing out on so much... the leaves, flowers and every little detail.”

Ana recently underwent cross-linking in both eyes. She affirmed that despite the pain and discomfort during the treatment, stabilising her keratoconus was



worthwhile.

The talks were followed by a panel discussion where participants actively engaged in discussions. The questions related to keratoconus risk factors, seeking appropriate services and managing keratoconus.

For the first time, the KeraClub was broadcast live this year making it accessible to the people who couldn't physically attend the event. The approach allowed us to have participants from Australia and abroad. The link to the recordings from the event is: <https://soundcloud.com/savesightinstitute/sets/keracub-2019>

Participants found the event advantageous, as it provided a forum to 'interact with people with up-to-date information on the latest advancements in keratoconus treatments and research developments.'

Dr Himal Kandel, the Kornhauser Research Associate working at the Save Sight Keratoconus Registry, announced KeraClub as an established annual event, with next year's session being held early in 2020.



Dr Himal Kandel and Dr Alex Ferdi provided support for the educational segment of the meeting. Save Sight Institute staff, Janet Bunn and Becky Lim were of invaluable help during the informal social gathering.

## ABSTRACT OF CERA RESEARCH PAPER

### *Economic impact of Keratoconus -a patient's perspective*

Elsie Chan FRANZCO <sup>1,2,3</sup> | Paul N. Baird PhD <sup>1,2</sup> | Sara Vogrin MBiostat <sup>2,4</sup> | Vijaya Sundararajan MD <sup>4,5</sup> | Mark D. Daniell FRANZCO <sup>1,2,3</sup> | Srujana Sahebjada PhD <sup>1,2</sup>

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#### **Importance**

This is the first study to estimate the lifetime costs associated with keratoconus based on a questionnaire completed by patients and highlights the significant economic burden of the disease. As keratoconus affects individuals from a young age, the study highlights keratoconus as a public health concern.

#### **Background**

Keratoconus is a disorder characterized by corneal steepening and thinning, leading to reduced visual acuity. To date, there have been no studies evaluating the economic costs of keratoconus from a patient's perspective.

#### **Design**

A randomized cross-sectional study undertaken in Australia where keratoconus subjects were recruited from public and private ophthalmology and optometry clinics.

#### **Participants**

A total of 100 participants completed the questionnaire: median age was 31 years and 57% were males.

#### **Methods**

A keratoconus health expenditure questionnaire was designed to assess direct and indirect expenditures for each individual.

#### **Main Outcome Measures**

Total direct and indirect costs associated with the condition were calculated along with the estimated lifetime per capita costs.

#### **Results**

The median and IQR for the total cost of spectacles, contact lenses, contact lens solutions, eye drops and other equipment was AUD 1087.50 (650, 1885) per year; the cost of health visits to optometrists/ophthalmologists, hospital and other health services was AUD 378 (100, 1779); the cost of transportation to health visits was AUD 125 (45-300). The total cost related to direct and indirect care was estimated to be AUD 3365.

Our findings suggest that keratoconus patients are paying 30-fold more than the general population for their eye care. The estimated lifetime per capita cost ranged from AUD 3400 for those with a <1 year duration of keratoconus to AUD 85,000 for those with 25 years 'duration.

By applying our cost data to keratoconus prevalence data for the Australian population, the total cost is estimated to be approximately AUD 44.7 million per year in Australia.

### **Conclusions and Relevance**

Our results show that the costs associated with the diagnosis and management of keratoconus represent a significant cost to patients. An understanding of this is important not only to individuals and their families, but also health care providers, health insurers and the wider health system. As keratoconus affects individuals from a young age, the study highlights keratoconus as a public health concern.

### **KEYWORDS**

cornea, corneal graft, corneal transplantation, keratoconus