ANNUAL REPORT

KERATOCONUS AUSTRALIA

2022

KERATOCONUS AUSTRALIA

ANNUAL REPORT

KERATOCONUS AUSTRALIA

2022

MISSION STATEMENT

MISSION STATEMENT

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

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

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

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

(1) raising the awareness and understanding in the medical, optometric and general community of keratoconus, its signs, symptoms and effects;

(2) promoting research into the causes, prevention and control of keratoconus; and

(3) acting as a representative body on behalf of Australians with keratoconus and providing, where necessary, counselling, support and referrals to the people with keratoconus and their families.

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

We are also:

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

KERATOCONUS AUSTRALIA INC ABN 80 683 325 208 A0039546H
PO Box 1109 Hawksburn VIC 3142 Australia
PHONE 0409 644 811 **EMAIL** info@keratoconus.org.au
WEB www.keratoconus.org.au

TABLE OF CONTENTS

ANNUAL REPORT

KERATOCONUS AUSTRALIA

2022

FROM THE PRESIDENT

FROM THE PRESIDENT

COVID-19 has severely limited people's access to timely treatments over the past three years, contributing to worse outcomes and mental anguish. But it couldn't prevent Australian researchers publishing some of the most important findings to date about the true burden of keratoconus on patients and their families.

At the start of 2022, the Save Sight Keratoconus Registry published new research findings that showed keratoconus led to worse quality of life outcomes for patients than macular degeneration and other retinal disease. A range of factors were implicated, including the young age of people affected and poor vision quality (ghosting, halos, light sensitivity and other visual aberrations) rather than low visual acuity (what you can read on an eye chart).

In 2020 and 2021, the Centre for Eye Research Australia published two ground-breaking studies showing that the prevalence of keratoconus was far higher than previously thought. The first study, conducted in Western Australia, indicated a prevalence of possibly 1 in 84, pointing to an Australian keratoconus population of over 300,000 and not 15,000 as implied by the generally-accepted figure of 1 in 2000 (arising from an old 1986 American population study). The second study focused on the economic burden of keratoconus and estimated that keratoconus patients face annual eye-care costs at least 30 times higher than the general population. Suddenly, the vision sector realised keratoconus was much more damaging and widespread than ever thought.

Keratoconus is a young person's disease, starting at puberty, and worsening (often quickly) through the teenage years until it tends to stabilize in a person's 40s. These are the prime years for education, social maturation, employment opportunities and child rearing.

The World Health Organization (WHO) highlights the consequences of vision impairment for young individuals:

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

There are also impacts for care givers who are required to engage in extra support for household activities, school, accessing medical services, etc., often at the expense of their own physical and mental health.

The cost to society is high too. The global costs of productivity losses from vision impairment are estimated at US$410.7 billion annually by Lancet researchers. There is no global

information on the specific economic cost of keratoconus to society. Keratoconus is not even referenced in the WHO or Lancet reports and rarely rates a mention in any study of global eye health.

Corneal collagen crosslinking has been used successfully to slow or halt progression since the late 2000s. But corneal surgeons report that many young patients still arrive in their surgeries either after suffering significant, irreversible vision impairment or too late to have crosslinking done on their thin corneas.

That often condemns these patients and their families to a lifetime of excessive expense on contact lenses and eye care, one or perhaps more rounds of corneal transplantation and/or other corneal surgery. If they can even afford or access quality treatments.

The primary role of Keratoconus Australia is to support the keratoconus community. But we also advocate on its behalf. We give keratoconus patients a voice. We tell the vision and research sectors what WE want and need, we advocate for change, greater affordability and access to treatments, we help train new clinicians and we are not dependent on anybody for our existence – except our members.

A recent National Keratoconus Foundation survey of keratoconus patient support groups found that apart from the Australian and UK groups, all the others they identified were run by medical institutes, research centres and hospitals. Those groups lecture their members about keratoconus but were not equipped to *listen* to patient feedback. That is why we need a patient-run support group like Keratoconus Australia.

And therein lies the difficulty today. Our volunteer-based model is failing us. Volunteering Australia says volunteering dropped by two-thirds in 2020-22 and is still 10% below pre-COVID-19 levels and remains on a downward trend. Keratoconus Australia has not been immune to that trend and despite the best will of our committee (including myself), COVID-19 has prevented us from devoting as much time to the Association as we once did.

Research shows that single-disease, volunteer-based groups that are donor funded generally do not survive. It would be a shame if we also become a footnote of history because, as I said in my KeraClub22 presentation, perhaps the most important contribution we make to the keratoconus community is simply to exist. A source of information, a safe haven to come to when nobody else understands and place to get a virtual hug when no one else cares.

The time has come for a strategic review of Keratoconus Australia and how it will operate in the future. We need your help.

So if you want Keratoconus Australia to be here in another 20 years, to paraphrase the immortal words of US president, John F Kennedy in 1961, "Ask not what your Association can do for you - ask what you can do for your Association."

Larry Kornhauser OAM
president@keratoconus.org.au
November 2022

ANNUAL REPORT

KERATOCONUS AUSTRALIA

2022

SUPPORT

SUPPORT

INTRODUCTION

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

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

What we do have is long experience with living with keratoconus. In other words, we provide peer group support to patients and information about keratoconus. We talk to patients and family members about our own experiences with keratoconus. We have access to a range of experienced optometrists and corneal surgeons working in the field of keratoconus and all medical questions are directed to these eye-carers for their expert opinion.

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

Never delay seeking medical advice if your vision is changing.

TRENDS IN SUPPORT

Support offered by the Association to people with keratoconus and their families remained fairly steady in the 2021-22 compared to the previous corresponding period. Contacts logged by Keratoconus Australia totalled around 490, up by 5% on the previous year's total of 466.

But the small overall change masked some quite significant differences in the type of support provided to the keratoconus community.

- Support provided to people who had been recently diagnosed with keratoconus more than doubled
- Concerns about contact lenses – particularly the larger semi-scleral lenses - more than quadrupled
- Support requests for issues relating to corneal collagen crosslinking remained fairly stable
- However, support inquiries relating to other surgery such as corneal transplantation and intra-stromal rings, intra-ocular lenses etc fell by around a quarter
- After a big jump noted in 2021, questions relating to health insurance and the cost of treatments fell back again last year

The bulk of our support work involves helping patients and their carers find clinicians in their local area to best assist them in treating and managing their keratoconus. Over recent years, direct requests for information about clinicians specialising in keratoconus averaged over 40% of our support contacts and this was again true in 2022. The Association assisted a number of members who moved to regional and country areas for work or to avoid COVID lockdowns in the major capitals and requested assistance in finding new eye-carers, in particular contact lens fitters experienced in keratoconus.

As we noted last year, many requests for assistance in finding an expert fitter of speciality contact lenses for keratoconus arise from an affordability issue, with the patient seeking an eye-carer who will bulk bill or who works in a clinic offering discounted or subsidised contact lenses.

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

Accessibility and affordability remain the key barriers to patients obtaining best-practice care for their keratoconus and the Association will continue to advocate for solutions to these problems which bedevil many other areas of eye disease too. Patients living in country and remote areas and those experiencing economic and social disadvantage suffer the most because of these two obstacles to proper eye-care. (See **Advocacy**)

Finally, in addition to these direct requests for help in locating proficient keratoconus clinicians or more affordable treatment options, most other support interactions, for whatever initial reason, end with us helping patients to find an expert keratoconus practitioner.

As we noted in our 2021 Annual Report, increasing numbers of patients – young and old – are displaying signs of depression and anxiety about their ability to manage their vision impairment. While COVID-19 and the associated restrictions on access to eye-carers had an impact (see below), the Association received a number of calls from people simply worried about how they would be able physically to manage their vision impairment in the future.

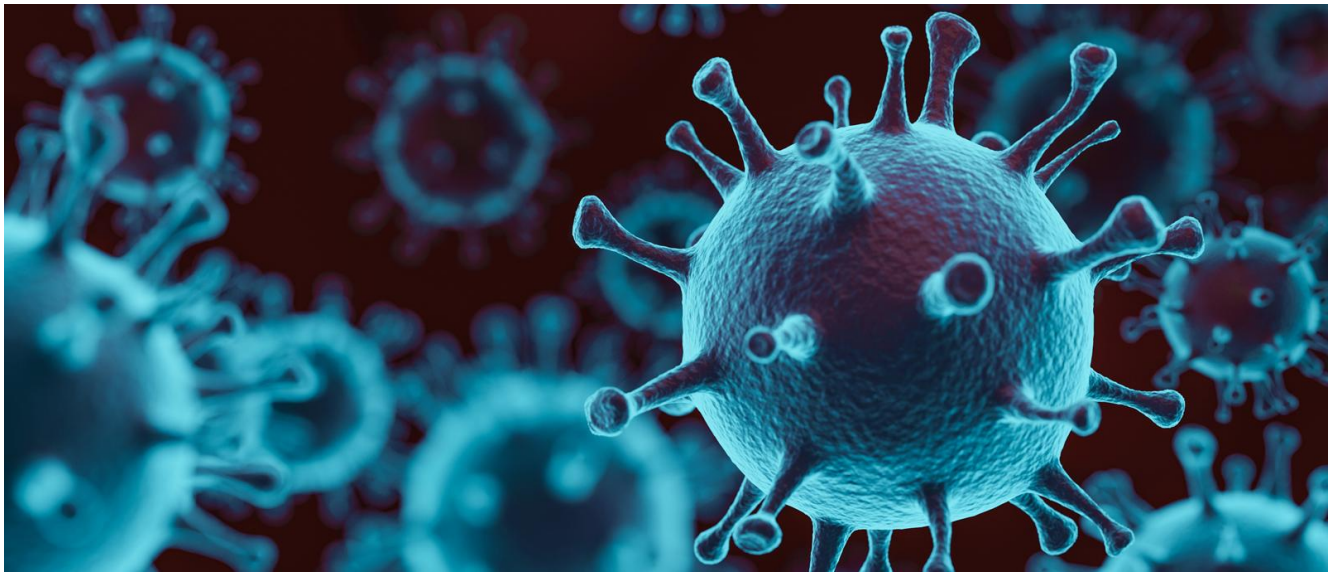
Some older members expressed concern about their on-going ability to manage contact lenses as they aged, in particular those wearing the larger semi-scleral lenses which can be difficult to insert and remove. Other older patients asked about the prospects for replacing failing grafts and whether they would be suitable candidates for backup glasses to assist them while travelling overseas, for example.

Finally, eye rubbing and treatment of allergies remains an issue for many people with keratoconus. The Association is constantly reminding members and posting to its socials about the dangers of eye rubbing which is the only patient-controllable factor in the progression of keratoconus. Some ophthalmologists even believe eye rubbing is the fundamental cause of keratoconus and that stopping can have almost the same impact on progression as corneal collagen crosslinking.

New data collated by Keratoconus Australia shows that **64% or almost two-thirds of our new members since 2015 admit they either rub their vigorously or have done so in the past**. Folks, you really need to stop.

COVID-19 IMPACT

Once again, COVID-19 and the resulting lockdowns across Australia provided the biggest challenge to both the Association and the keratoconus community in 2021-22. Prolonged hard lockdowns from July to October 2021 in NSW and Victoria exacerbated the problem for many people with keratoconus-related issues. Patients in other states also faced shorter periods of restricted movement and access to eye-carers and treatments, especially elective surgery, during the reporting period. This was a trend noted across the entire health sector as people avoided what were perceived as high-risk places like medical and optometrist practices and hospitals.



Despite the widespread take-up of COVID-19 vaccines in the second half of 2021, a fourth, more deadly wave of the Omicron variant swept across Australia in the first half of 2022. This led to further restrictions within the health system, aggravated the backlog for surgery and notably corneal collagen crosslinking and corneal transplantation and caused renewed trepidation amongst patients about consulting optometrists for their regular reviews.

During that stressful period, the Association repeatedly reminded patients that keratoconus is a progressive disease and that it was important they see their eye-carer if they noticed any change in their vision to avoid irreversible loss of sight.

Treatments like corneal collagen crosslinking are only effective when performed before the cornea becomes too thin. However, patients were understandably concerned about being exposed to COVID-19 and often would tell us they would wait until COVID infection rates fell before seeing their eye-carer. Unfortunately, the backlog in surgery due to COVID-19 means that many people who delayed seeking treatment are now facing long waits for corneal collagen crosslinking and corneal transplants.

Another issue that emerged from COVID was the quality of patient interactions within the health system – especially at public clinics. Some patients reported encountering unfriendly service staff in busy clinics who failed to recognize the stress and difficulties being experienced by many vision-impaired patients who were forced to spend long periods in crowded waiting areas. This reportedly caused particular anxiety for patients from country and regional areas who in addition spend many hours traveling to and from appointments.

Based on current government health advice, we believe that if you are fully vaccinated and your eye-carer is too and adopts COVID-safe practices (notably mask wearing in consultations), then you really should seriously consider having your eyes and contact lenses checked to avoid long term damage to your corneas and loss of vision. And if you have children over the age of 10 years, they should have regular check-ups too.

MENTAL HEALTH

A diagnosis of keratoconus with its associated risk of a significant and possibly rapid loss of vision is obviously upsetting and a trigger for stress and anxiety. After three years of managing COVID-19 and a disease leading to progressive vision impairment, we are all pretty frazzled.

Everyone involved with Keratoconus Australia has keratoconus and so we understand that feeling. But with early diagnosis and treatment (in particular corneal collagen crosslinking), keratoconus can be stabilised and vision loss improved dramatically with contact lenses. Keratoconus Australia was founded to help reassure patients, support them as they traverse the stages of keratoconus and direct them to the eye-carers who can restore and maintain their vision. Most people can then return to a fairly normal life.

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

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

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

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

Young people – especially outside of metropolitan centres - continue to be particularly affected by the combination of COVID-19 restrictions and limited access to experienced keratoconus clinicians. Once again, the Association spent many hours talking to adolescents and young adults about their difficulties with contact lenses and their vision and their prospects for the future. Sadly, in some cases the vision of these adolescents cannot be corrected to their satisfaction and they face the unpalatable choice of managing with either sub-optimal contact lenses or spectacles or having to consider a corneal transplant.

PATIENT INFORMATION

Keratoconus Australia sends new members a range information material about keratoconus and specific treatments and issues such as corneal collagen crosslinking and eye rubbing. COVID-19 prevented us from sending hard copies of this material, so we have been providing members with electronic versions in pdf format. With the lifting of restrictions in Victoria in 2022, we again have hard copy supplies of these booklets and brochures available for those

who prefer the information in that format. We urge members to request this free information material from us in whatever format they prefer.

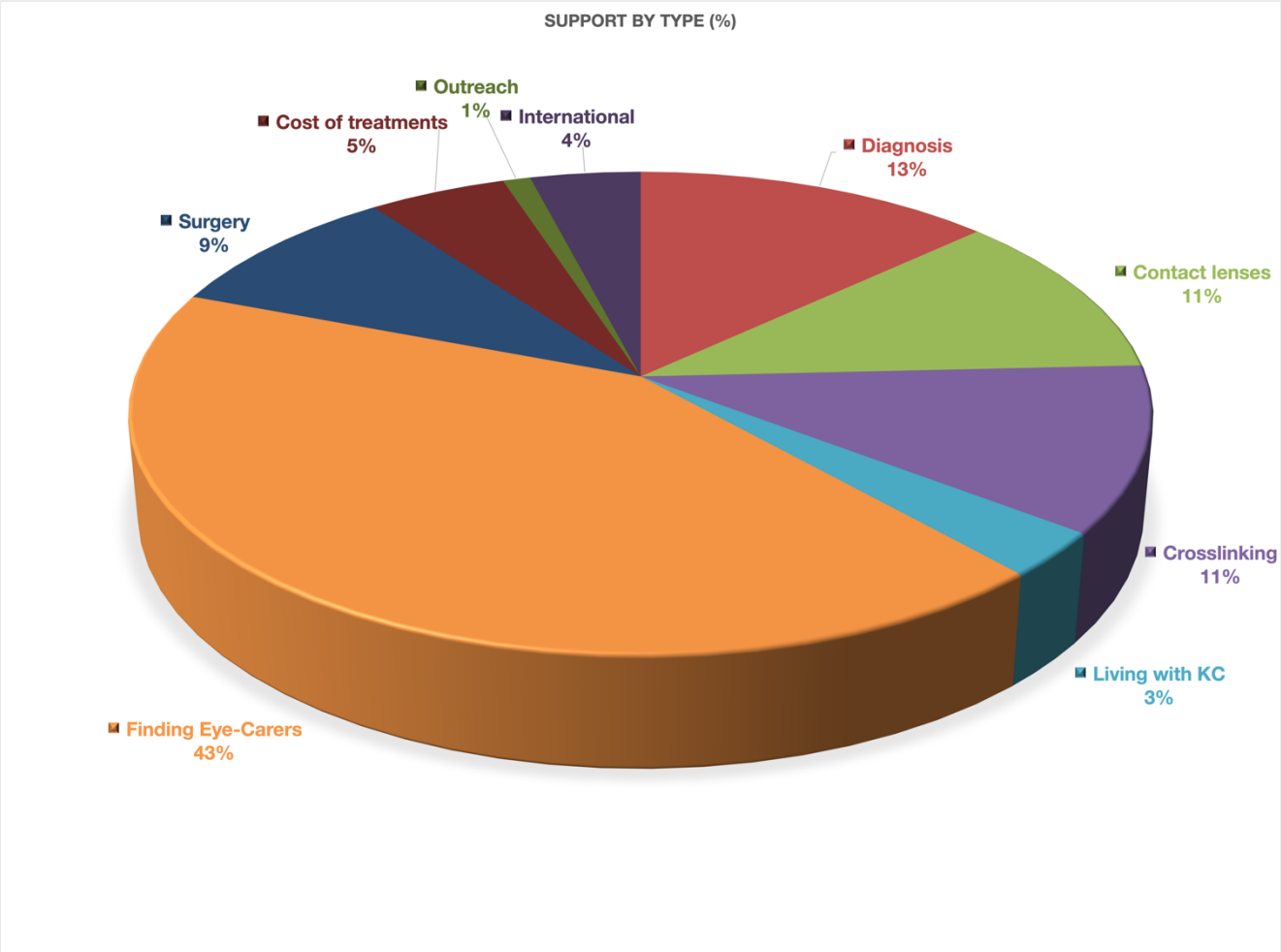
Many of the answers to patient questions can also be found on the Treatments and FAQ pages our website.

SUPPORT BY NUMBERS

After the wild swings noted in 2020 and 2021, total support contacts logged by the Association steadied at around 490, a 5% increase over the same period in 2021 and almost triple the lows recorded during the national lockdowns of 2020.

The method of recording support contacts reflects both the actual number of people assisted as well as the complexity of issues being discussed. Last year, the Association assisted over 130 individuals with many requiring multiple interactions to resolve the issues being confronted by the patient or family.

The pie chart below highlights the Association's support activities in 2021-22 by type of support given to patients.



SUPPORT BY EXAMPLE

Keratoconus Australia offers members and anybody with keratoconus free support. We listen to what people are saying to us and then try to respond in a way that best meets their needs.

Everyone with keratoconus is told to avoid eye rubbing if possible, as this could potentially worsen their condition.

Below are some examples of support we provided in 2021-22.

- Vidhyashini is a disability case officer with a patient suffering from severe light sensitivity who needed help. We said that if the patient was unable to wear sunglasses it could be difficult. We sent the name of an expert fitter of speciality contact lenses for keratoconus in Melbourne who could review the patient and see what options were available.

- Laura was dissatisfied with the contact lenses fitted for her at the public optometry clinic in Melbourne. We suggested she see the head of the clinic as the lenses were still under warranty. However, in the end, she decided to see a contact lens fitter in private practice. We also provided advice about treating her allergies and on having her children checked for keratoconus.

- Angela was a Colombian student caught up in COVID-19 lockdowns and needing help with her contact lenses. She hardly spoke English, so our Colombian board member contacted her, provided details of the UNSW contact lens clinic and other private practitioners. Unfortunately, at the time she was unable to see anyone due to the COVID-19 restrictions.

- Guillermo was a new arrival in Australia and looking for a contact lens fitter in the Wollongong area. We provided him with a list of contact lens fitters.

- Jordan was struggling with school because of his declining vision and his mother asked us to provide some options in a public clinic. They lived two hours out of Melbourne. For more than a year now, we have tried to support Jordan and help him find a solution to his ghosted vision. Sadly, he is a classic example of someone with keratoconus who can achieve good visual acuity with contact lenses but still has poor vision quality due to high-order aberrations that cause ghosting.

- Brett was seeking information on new procedures that could help improve his vision. After hearing about his problems and seeking advice from our consulting ophthalmologist, we told him there was nothing really beyond corneal collagen crosslinking and corneal transplantation. Offered to find him a corneal surgeon locally if he wanted to pursue the issue.

- We had two young patients from disadvantaged families in the Perth area who were suffering significant vision impairment due to keratoconus but could not afford to see a contact lens fitter privately. After making inquiries, we ascertained that there were no public contact lens clinics in Perth. In both cases, we managed to find a contact lens fitter prepared to offer heavily discounted treatment to both boys in the hope that it could get them back into their studies and the workforce.

Not all support contacts led to the desired outcome. In a number of cases, patients were unable to afford treatments with private practitioners (especially contact lens fitters) - and had no access to subsidised clinics. COVID-19 restrictions also prevented patients from travelling for treatments. In other cases, contact lenses were unable to correct vision sufficiently to eliminate the ghosting and halos that impact quality of life. A number of younger patients found themselves quite despondent because their vision impairment could not be corrected sufficiently.

Finally, we have received many questions from around the world about a trial of IVMED-80 drops that would purportedly reshape a keratoconic cornea. We understand that these trials were stopped during the height of COVID-19 but have resumed. Anyone interested in learning more should contact Glaukos, the company that recently bought the license to the treatment.

NOTES OF APPRECIATION

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

- Peter from Sydney had been quoted over $3600 for a pair of contact lenses and simply could not afford to pay that much. He asked for our assistance. We directed him to another contact lens fitter who managed to fit him with lenses for significantly less.

  "Yesterday I saw (the suggested contact lens fitter) who saved me nearly $2000 for exactly the same process as I was quoted $3600. He fitted them and gave me a great understanding of the new lenses. Thanks again for your support and time."

- In 2021, we helped Ben find a new contact lens fitter when he was very depressed about his vision. Last year, he asked whether he could access Wavefront Guided Optic Sclerals in Melbourne which he thought were available in Adelaide. After making some inquiries we told him that our information was they were not available in either Melbourne or Adelaide. Apparently, they are very hard to make correctly and very expensive. The Adelaide laboratory said they are working on another version that will give both excellent vision at around the same cost as other sclerals. They said the only alternative currently is to source them from the USA at a cost of around $8000 EACH. Finally, we told Ben that there was an optometrist in Warrnambool who was using similar equipment and we provided his details.

  Thanks for getting back to me so promptly, this is extremely informative and I appreciate you looking into it. Wavefront guided lenses and similar have always

seemed like such a distant goal, but now it seems they're becoming more available, especially in other countries. The technology is cool and I look forward to it being introduced here in Melbourne, whenever that is. I truly believe they're worth it and would change the lives of many. I'm glad we're searching for the best economic approach as the prices can be ridiculous.
Progress with Dr C is going well, Hybrid lenses are a fantastic treatment option for my particular eyes, the RGP centre closer to the cornea helps.
Hope all is well during these times.

- Jose was looking for a Sydney-based contact lens fitter. We sent a list of expert contact lens fitters.

  Thank you so much. Big help!

- Chris was after information on corneal grafts. We sent her our booklet from the US National Keratoconus Foundation on corneal transplants.

  I have recently received your booklet on corneal transplantation. Thank you so much for sending this. It was very helpful.

- Stephen moved from Melbourne to Sydney and needed help with his contact lenses. We sent him a list of contact lens fitters including information about the public clinic at the UNSW as he had previously been obtaining his lenses through a public clinic in Melbourne.

  I would like to thank you for your help with the list below and advice provided on the phone. I have since been treated at the optometry clinic - UNSW, who have been great. Furthermore, I have met with David Pye and he really is very well versed with Keratoconus. I would definitely recommend the Clinic, even though, the KC Clinic at UNSW only operates on a Wednesday morning, making booking appointments a little tricky and patients should be prepared to be seen by students as well. Regardless, I have been wearing contact lenses for the last few weeks, and happily I say, I have been doing so comfortably again. Sincerely (and thank you a million times over).

- Adam was having issues after cataract operations and we suggested he seek a second opinion from a Brisbane based corneal surgeon. We sent him a list of corneal surgeons there.

  I went and saw one of the doctors listed below. Such good advice from him and a better explanation. So left eye cataracts put on hold. I have really good vision in that eye. He said the eye and brain had found the sweet spot. Cataract op in right eye had just missed to spot and a secondary's bulge of the cornea is involved. They are going to put in a piggyback Toric lens. I had a amazing appointment with this practices optometrist so different. A whole different power. Can't remember my other Dr doing a power test for the lens he put in so thanks for the

recommendations I have learnt a lot more. I feel they are fiddling in the dark sometimes.

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.

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

Phone: 1800 800 110 (8:00am – 8:00pm Monday – Friday)
Email: enquiries@ndis.gov.au
Website: www.ndis.gov.au
Postal Address: GPO Box 700, Canberra ACT 2601

INTERNATIONAL SUPPORT

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

Jan asked for information about keratoconus and the cost of treatments for friends living in Kenya. We sent information and directed her to some of the international online chat groups where her friends could possibly obtain help in locating expert eye-carers. Brett is a pilot living in Hong Kong and requested information on the latest treatments, especially to improve night vision. We directed him to our Treatments page and gave some information on the latest contact lenses and surgery for keratoconus.

We also used our contacts in New Zealand to help locate a contact lens fitter for a family in Dunedin.

SPEAK UP TO SUPPORT YOURSELF!

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

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

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

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

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

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

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

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

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

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

ANNUAL REPORT

KERATOCONUS AUSTRALIA

2022

RESEARCH

RESEARCH

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

SAVE SIGHT KERATOCONUS REGISTRY UPDATE

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

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

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

Following the disruptions of the pandemic, the past year has been very productive for Professor Stephanie Watson and the Kornhauser Research Associate, Dr Himal Kandel.

Between 2021 and 2022, 18 research papers were published in reputed scientific journals. These papers discovered new knowledge that has changed clinical practice and eye care professionals and patients.

Similarly, 20 studies were presented at local, national, regional and global conferences. This ensured the ophthalmic clinicians and researchers were informed of the SSKR's research outcomes and could incorporate the findings into their clinical practice.

KeraClub 2021 and 2022 were also well-received and widely covered in the media and the team had valuable feedback from the attendees.

Regarding their teaching activities, nine students from various degrees including students from the Doctor of Medicine, Master of Medicine

Professor Stephanie Watson OAM

(Ophthalmic Science), Master of Optometry, and Higher Degree by Research were trained for conducting keratoconus research.

International collaborations
Currently, clinicians in Australia, New Zealand, Spain, Italy, France, Switzerland and Germany are contributing to the registry. There is also a major collaboration currently in progress with the Kensington Eye Institute at the University of Toronto, Canada. In doing so, the University of Toronto aims to have clinicians complete and insert patient medical information into the registry. As a co-ordinating centre, it would also be responsible for recruiting participating sites in Canada. The team, led by Professor Neera Singal, has already obtained ethics approval and is currently reviewing the agreement.

RECENT RESEARCH PUBLICATIONS

The Save Sight Keratoconus Registry published !8 new research papers in the past two years and a number of papers are currently under review. (References of recent papers can be found in the Annex of this report).

Among the most important papers published were:

- **Five-year corneal cross-linking outcomes**
  This study, the largest of its kind to date, evaluated the outcomes of cross-linking data from 41 centres across five countries. The registry found that the overall visual acuity after cross-linking improved steadily over five years and that Kmax flattens significantly at one year and is then sustained. However, some patients responded poorly to corneal cross-linking with 4.1 percent to 7.5 percent of eyes failing to stabilise, not only by one year but also at five years. Clinically significant adverse events (haze, scarring, persistent epithelial defects, and recurrent erosions) persisting at five years were between 0.6%-3% of eyes crosslinked.

  This important outcome should reassure patients that crosslinking is generally both safe and effective.

- **Efficacy and safety of standard corneal cross-linking procedures performed with short vs standard riboflavin inductions.**

  This study compared the efficacy and safety of two common corneal cross-linking protocols, standard (long) and accelerated (short). The results demonstrated that both procedures improved visual and corneal-shape outcomes. However, the findings supported that the shorter method may be better for the clinician and patient time, convenience and comfort. This is important as our up-to-date evidence supports clinicians in performing short corneal cross-linking.

- **Oxygen in Corneal Collagen Cross-linking to treat Keratoconus: A Systematic Review and Meta-analysis**.

  This study demonstrated that increasing oxygen during epithelium-on cross-linking improved vision and produced corneal flattening without any serious adverse events in patients with keratoconus.

- **Quality of life (QoL) impact of eye diseases**

  This large-scale, open-access study compared the QoL of four common eye conditions - keratoconus, age-related macular degeneration, diabetic macular oedema, and retinal vein occlusion for patients using real-world data from the SSR.

  The findings of this study highlighted that keratoconus patients have poorer QoL scores than patients with retinal diseases such as macular degeneration. This reflected the low correlation between visual acuity and patient-reported QoL outcomes. This is significant because the relative impact of eye diseases on QoL is useful for prioritisation, appropriate resource allocation and policymaking.

- **Patient-reported outcomes in keratoconus: a Save Sight Keratoconus Registry study**

  Utilising the SSKR data, this study was conducted to understand patient-reported outcomes in keratoconus. A validated keratoconus-specific questionnaire was used to evaluate the QoL impact.

Above: Dr Himal Kandel (far left) receiving his Early Career Alumni Award at Flinders University

The team also sought to find the relationship between QoL data with the standard clinical variables like vision, which is more routinely evaluated in clinics.

The results found that the QoL scores were weakly correlated with visual acuity, corneal curvature and corneal thickness. Factors like gender, contact lens wear, reduced visual acuity and higher disease severity were associated with worse visual function and symptoms. Similarly, the younger the patient was, the results suggested they had a higher QoL impact.

Patients' lived experience of this condition is extremely useful to understand its impact and how to improve outcomes.

These findings suggest that clinicians should not solely rely on visual acuity and corneal curvature data, but they should also consider the factors that may be associated with reduced QoL when treating patients. For example, men may be more likely to cope better with keratoconus than women or older patients fare better than young ones.

SAVE SIGHT KERATOCONUS REGISTRY – THE FUTURE

According to Professor Watson, one of the team's priorities in the next twelve months is to utilise SSKR data to address common challenges in keratoconus management. Its immediate plan is to finalise the following publications:

- Comparison of standard versus accelerated corneal collagen cross-linking for keratoconus: five-year outcomes from the SSKR
- Long-term outcomes of corneal cross-linking
- Efficient capture of data on corneal cross-linking from routine clinical practice
- Outcomes of CXL in thin corneas with keratoconus
- Mental health impacts of keratoconus and QoL
- Keratoconus, eye rubbing and allergy
- Contact lens wear in keratoconus.

EXPANSION OF RESEARCH THEMES

The SSKR has become a crucial resource for conducting research in keratoconus. Other research themes it will focus on include:

- Identifying adverse events of corneal cross-linking
- Determining the effectiveness of the corneal cross-linking variations
- Isolating the factors associated with better or worse outcomes
- Understanding the mental health impact of the condition on patients.

The Association commends Professor Watson and Dr Kandel on their work – particularly in the area of quality-of-life assessments. This is proving critical in highlighting the serious impact of keratoconus on patients, especially younger ones. This ground-breaking research is finally providing scientific evidence of the need for clinicians and policymakers to look beyond simple visual acuity test outcomes to gauge the effect of this disease on patient welfare.

SAVE SIGHT KERATOCONUS REGISTRY ADVISORY COMMITTEE

Keratoconus Australia President, Larry Kornhauser and Vice President, Greg Harper attended the Save Sight Keratoconus Registry Advisory Committee meeting held on August 9, 2021. The committee heard reports on the latest research from the registry, recruitment of users to the Optometry Module, collaborations with NSW and VicHealth, Quality of Life data and on events including the ARVO webinar, a webinar organised for clinical optometrists and the KeraClub 20 meeting for patients and other interested parties.

STOP PRESS.

Seven years after its creation, the Save Sight Keratoconus Registry has just published a list of ophthalmologists and optometrists contributing data anonymously to the registry. The list can be found on the SSKR website at https://savesightregistries.org/clinicians/

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

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

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

STEM CELL RESEARCH

Professor Watson is also working with a multi-disciplinary team from the University of Sydney on projects to use nano bioengineering to develop stem cell treatments for keratoconus and other corneal disease. Professor Watson sought letters of support from Keratoconus Australia for funding applications to various bodies for the project. If successful, the team has committed to include Keratoconus Australia on its advisory board and to produce educational materials to update patients on advances in these potential stem cell treatments. More details on this exciting project can found in the KeraClub 22 presentation by team member, Dr Yogambha Ramaswamy, group leader in the School of Biomedical Engineering at Sydney University.

CENTRE FOR EYE RESEARCH AUSTRALIA

The Centre for Eye Research Australia (CERA) is 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.

LATEST RESEARCH

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

The problem of keratoconus is gaining increasing attention all over the world as the newer diagnostic approaches make it possible to recognize this disease earlier and better. Keratoconus is now considered the most common ectatic disorder of the cornea. Multiple factors contribute to the causation of keratoconus— genetic, mechanical, and other factors.

Considering we have worked with international research groups and conducted multi ethnic genetic studies (2021), this year we concentrated our research on non-genetic risk factors for keratoconus. We did systematic reviews and identified several environmental risk factors (eye rubbing, atopy, asthma and eczema) which play a crucial role in the susceptibility of KC. We further did a meta-analysis and showed eye rubbing to be associated with KC. Additional cause-effect relationship needs to be determined, and further large-scale longitudinal studies are needed to understand the mechanisms between environmental risk factors and keratoconus. Both will be our focus for next year.

I was honoured to be invited to write a book chapter on the Etiology and risk factors of keratoconus, published by Springer Nature where I discuss all the known associated factors for KC.

Directing the Keratoconus International Consortium (KIC), I worked closely with our collaborators in India to present the demographic and clinical profile of KC in pre-teens. This study identifies severe keratoconus in pre-teens and considers the condition as an important diagnostic entity when a refractive error is diagnosed. These results clearly suggest the increasing prevalence of keratoconus in children and directs us to look at it a separate entity in diagnosis and management.

Our other focus was on using corneal images and artificial intelligence (AI) to detect early keratoconus. Again, we conducted a review to synthesize available data on the use of machine learning to evaluate its accuracy in detecting keratoconus, and measure reporting completeness of machine learning models in keratoconus. Presently, the machine learning models perform poorly in identifying early KC from control eyes and many previous research studies did not follow established reporting standards, thus resulting in the failure of the clinical translation of these machine learning models.

To address this, we investigated the complete Pentacam corneal topography parameters (~1700) and developed models to identify subclinical keratoconus. Again, I plan to continue this work to build further AI models that could be used as an automated diagnostic tool for KC. (A full summary of CERA's recent keratoconus research papers can be found in the Annex of this report).

COST OF CONTACT LENSES

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.

In 2020, Dr Srujana Sahebjada and her CERA team published a landmark paper entitled *Economic impact of keratoconus using a health expenditure questionnaire: A patient perspective,* which estimated that keratoconus patients are paying an average $3365 over 12 months or 30-times what the general population spend on eye care.

As foreshadowed in last year's report, we have been working with Dr Sahebjada to conduct further research into the spiralling cost of contact lenses and optometrist charges which are forcing many patients out of the private system into public eye clinics to source their contact lenses. The switch away from rigid gas permeable lenses to the larger semi-scleral lenses has seen contact lenses costs to patients more than triple over the past 5 years.

After many COVID-19 related delays, Keratoconus Australia and Dr Sahebjada are now developing a survey of Australian optometrists to gather information about their contact lens usage and pricing. The survey will also examine the attitudes of local optometrists to keratoconus and its management. The Association hopes we can advance this study in the coming 12 months.

Last year, we mentioned that CERA researcher Dr Elsie Chan had made a big splash in the keratoconus world with the paper she and other researchers published in mid-2020 showing a much higher incidence of keratoconus than previously thought with a prevalence rate of 1 in 84 among the 20-year-old West Australian participants. That paper continues to rock the eye health community and has sparked an enormous upsurge of interest in our perennially ignored eye disease.

PROFESSOR DOUGLAS COSTER

Keratoconus Australia president, Larry Kornhauser was privileged to have a long discussion in November 2021 with Professor Douglas Coster. Professor Coster is a legendary figure in keratoconus research, having created the world's first corneal graft registry at Flinders

University in 1985. Today the registry has information on over 33,000 grafts (a third of which were performed for keratoconus) and is the global reference for information on corneal transplant outcomes.

Professor Coster, now retired, has strong views on evidence-based medicine and has been a long-time sceptic of corneal collagen crosslinking. In a wide-ranging discussion, Professor Coster gave his views on the value of the Save Sight Keratoconus Registry to prove claims about crosslinking and other surgical procedures, patient reported outcome measures (PROM) and quality of life studies, and the use of device-driven surgery for keratoconus.

Professor Coster is also a painter and for those interested, he gave a fascinating presentation in 2016 on "The Art of Seeing and the Seeing of Art" which can be found on YouTube at https://tinyurl.com/3pt7wsk

ANNUAL REPORT

KERATOCONUS AUSTRALIA

2022

EYE CARERS

EYE-CARERS

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

OPTOMETRISTS

Last year, we reported on the creation of a working party with University of Melbourne optometrists and academics to discuss ways of promoting young optometrists to take an interest in keratoconus and to replace the aging cohort of expert fitters of speciality contact lenses for keratoconus, many who are approaching retirement. Once again, COVID-19 interfered with the group's ability to gain continuity in its deliberations.

One issue of particular concern to the group was the question of what was being done to upskill post graduate optometrists in fitting of speciality contact lenses for keratoconus.

Since then, the situation has evolved significantly as the new leadership of Optometry Australia (OA), the industry body covering optometrists, moves to implement its Optometry 2040 report. This report found that the profession was facing serious challenges unless it adapted to the introduction of new technologies and artificial intelligence. One of the recommendations of that report was the need for optometrists to engage in greater specialisation.

In recent talks with new OA President, Margaret Lam, herself an optometrist with a large keratoconus practice, it was revealed that her association had finally acknowledged a need for a special accreditation for optometrists fitting speciality contact lenses. She expected that could begin in the next 12 months.

Keratoconus Australia considers this a long overdue development and hopes that once implemented, it will reduce the number of optometrists who "dabble" in contact lens on keratoconus patients – often to their detriment. Time will tell.

It also offers the hope for patients that a registry of accredited contact lens fitters will finally be created to assist patients in finding an expert fitter of speciality contact lenses for keratoconus in their area.

cornea & contact lens SOCIETY OF AUSTRALIA

Both the OA and the Cornea & Contact Lens Society Australia (CCLSA) have recently upgraded their Find an Optometrist online search engines after repeated requests from Keratoconus Australia. The CCLSA database probably works best now as the OA search

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

In addition, Keratoconus Australia has been able to form an ad-hoc group with both OA and CCLSA optometrists who have been aiding the Association to find contact lens fitters for keratoconus in regional and country areas. This has been of immense benefit to patients outside of the metropolitan centres who suffer additional disadvantage and long travel times because of poor access to expert eye-carers. We thank everyone involved for their kind assistance.

MELBOURNE EYECARE CLINIC

One of the key issues discussed last year by the Melbourne University working party was the operation of the weekly keratoconus clinic which was supposed to provide training for students in fitting contact lenses for keratoconus while offering discounts to Keratoconus Australia members. A key problem with the MEC is the pricing of contact lenses. Although the MEC offers a 30% discount on lenses, its retail price is so high that some practitioners working at MEC said they could supply the same lenses cheaper through their own private practices even after the MEC discount.

MEC undertook a review of its fees, including consultations, ancillary testing, contact lenses and also its warranties and refunds on unsuccessful contact lens fits. However, at the time of writing, Keratoconus Australia had not received any information about a contact lens pricing structure for 2023. This is problematic for patients who wish to benefit from bulk billed consultations and testing at MEC but who may be paying excessive prices for their contact lenses.

FUTURE GOALS

Last year, we set out a series of objectives for the Melbourne University optometrist course and we think these are worth pursuing in 2023. The problem identified was that in the absence of further consolidation of their skills through additional training and exposure to keratoconus patients, post graduate and early career optometrists were losing their ability to treat and manage keratoconus patients effectively. The group identified a need for two programs:

1. Student scholarship for post graduates to develop skills in fitting speciality lenses for keratoconus. This would include external placements with experienced clinicians, local and interstate and even with contact lens manufacturing laboratories.

2. A co-management program to create a network of regional and country clinicians and practices to work with experienced keratoconus clinicians to co-manage keratoconus patients. Experienced practitioners could also attend these keratoconus practices for intensive training. Co-management sessions could also be integrated into MEC clinic times to allow clinicians to work together via zoom to minimise patient travel.

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

UNDERGRADUATE TRAINING

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

These clinics resumed in 2022 and Keratoconus Australia assisted in recruitment of volunteers for the post-graft fitting clinics.

EYE-CARER SUPPORT

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

ANNUAL REPORT

KERATOCONUS AUSTRALIA

2022

ADVOCACY

ADVOCACY

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

MENTAL HEALTH

Mental health remained a key focus of Keratoconus Australia again in 2022 as COVID-19 continued to cause disruption to patient's access to eye-carers and their ability to afford the ever-increasing cost of treatments. The Association has been a leader in the eye sector in raising the issue of vision impairment and its impact on mental health.

Keratoconus Australia is tackling the issue through two distinct strategies. First, through the Save Sight Keratoconus Registry which has now added questions around mental health to its Quality of Life survey at our request. The registry is planning to expand its mental health data gathering in 2023 and begin publishing research on the outcomes of its analysis.

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

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

Objective: *Preserving mental health or enhancing support for people with vision impairment due to keratoconus*

Representatives of Keratoconus Australia (Dr Gregory Harper and Mr Larry Kornhauser OAM) have maintained their engagement with Vision 2020 Australia during 2022, in seeking to derive maximum value from our organisational membership. Priorities for the engagement has been identifying, securing and disseminating information that will be valuable to the members of Keratoconus Australia. We have continued to work with a working group of interested Vision 2020 Australia members out-of-session to explore avenues for action.

These interested members include:

- NACCHO (National Aboriginal Community Controlled Health Organisation)
- Royal Victorian Eye and Ear Hospital
- Macular Disease Foundation Australia
- Guide Dogs Victoria
- VisAbility
- The Royal Society for the Blind

Key directions during 2022
Volunteer time is always limited but some of the initiatives progressed during the year include:

- Current gaps in data, training and resources available through Vision 2020 Australia members;
- Current support mechanisms, and particularly for eyecare providers confronted with the challenges of keratoconus;
- Recognition of the roles of low vision organisations and service providers, professional bodies, advocacy and peer support organisations, Mental Health Professionals and Organisations (e.g. BeyondBlue)
- Sourcing mental health first aid training for people within the above groups from providers such as Mental Health First Aid International, or St Johns Ambulance or the Australian Red Cross.

The issue remains how to raise awareness and how to provide training at scale, from the very limited resources of Keratoconus Australia.

Key opportunities for 2023
We propose to continue along these strategic directions and welcome sincerely, the support of any other members of Keratoconus Australia.

We think there will be value in bringing members together at informal gatherings to discuss their lived experience, make them aware of the resources that are available to them, and to share stories of other sufferers of keratoconus, and how they have overcome the challenges this disorder presents.

VISION 2020 AUSTRALIA

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

The Association was saddened by the departure of Vision 2020 Australia CEO Judith Abbott in late-2021 and congratulated her on her efforts to support the Association, notably by initiating the mental health working party at our request. Keratoconus Australia President, Larry Kornhauser, met with new Vision 2020 Australia CEO, Patricia Sparrow, in December 2021 for a wide-ranging review of issues affecting the keratoconus community. Ms Sparrow resigned from the organisation in October 2022.

Keratoconus Australia also participates in World Sight Day in October and publicises its activities through the organisation's Sector News e-newsletter which is distributed widely across the eye sector.

WARRANTIES AND REFUNDS

Preliminary discussions in early 2020 with Optometry Australia National Professional Services Manager, Luke Arundel over the issue of warranties and refunds on unsuccessful contact lens fits have not been progressed in the past 12 months.

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 have been delayed by repeat COVID-19 lockdowns in Victoria over the past 20 months. We wish to pursue the matter again in 2023 and seek assistance in pursuing this from interested members.

CONTACT LENS COSTS

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

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

Recently, the Association had opened discussions around this issue with a coalition of optometrists, ophthalmologists and industry experts to see how the situation could be ameliorated.

One suggestion put forward was that in the absence of a universal contact lens subsidy scheme for keratoconus as in New Zealand and the United Kingdom, disadvantaged patients should receive funding for their lenses and other unfunded treatments via the National Disability Insurance Scheme.

Ophthalmologists report that some patients with more serious cases of keratoconus are being accepted for NDIS funding but there are no clear guidelines for how keratoconus patients could or should be dealt with, which is leading to inconsistent outcomes for patient NDIS applications.

Keratoconus Australia recently signed up to participate in the NDIS review recently launched by the Australian government and we hope to provide a submission prior to the end-year deadline. Anyone wishing to assist with the submission should contact the Association.

MACULAR DISEASE FOUNDATION AUSTRALIA

Keratoconus Australia president, Larry Kornhauser held talks with Ms Dee Hopkins, CEO of the Macular Disease Foundation Australia in March 2022 to discuss how the Foundation operates and manages volunteers and corporate donations. The MDFA is quite a large organisation and covers some 1.8 million Australians who show signs of macular disease.

They operate a clear and informative website that could provide guidance for a revamp of our own on-line presence.

Ms Hopkins argued that the survival of small organisations like Keratoconus Australia depended on moving away from a volunteer-only model to an employee-based structure or face being absorbed into a larger vision support group.

Ms Hopkins resigned from her position at MDFA in mid-2022 and has offered to help with developing a strategic plan and policies for arms-length relationships with large donors and funders. She also offered to relate her Foundation's experience in working with the Black Dog charity on mental health.

There is a good opportunity in 2023 to form working partnerships with groups like MDFA with the assistance of Ms Hopkins. These could help with our own efforts to restructure the Association and improve our resources and advocacy work.

ANNUAL REPORT

KERATOCONUS AUSTRALIA

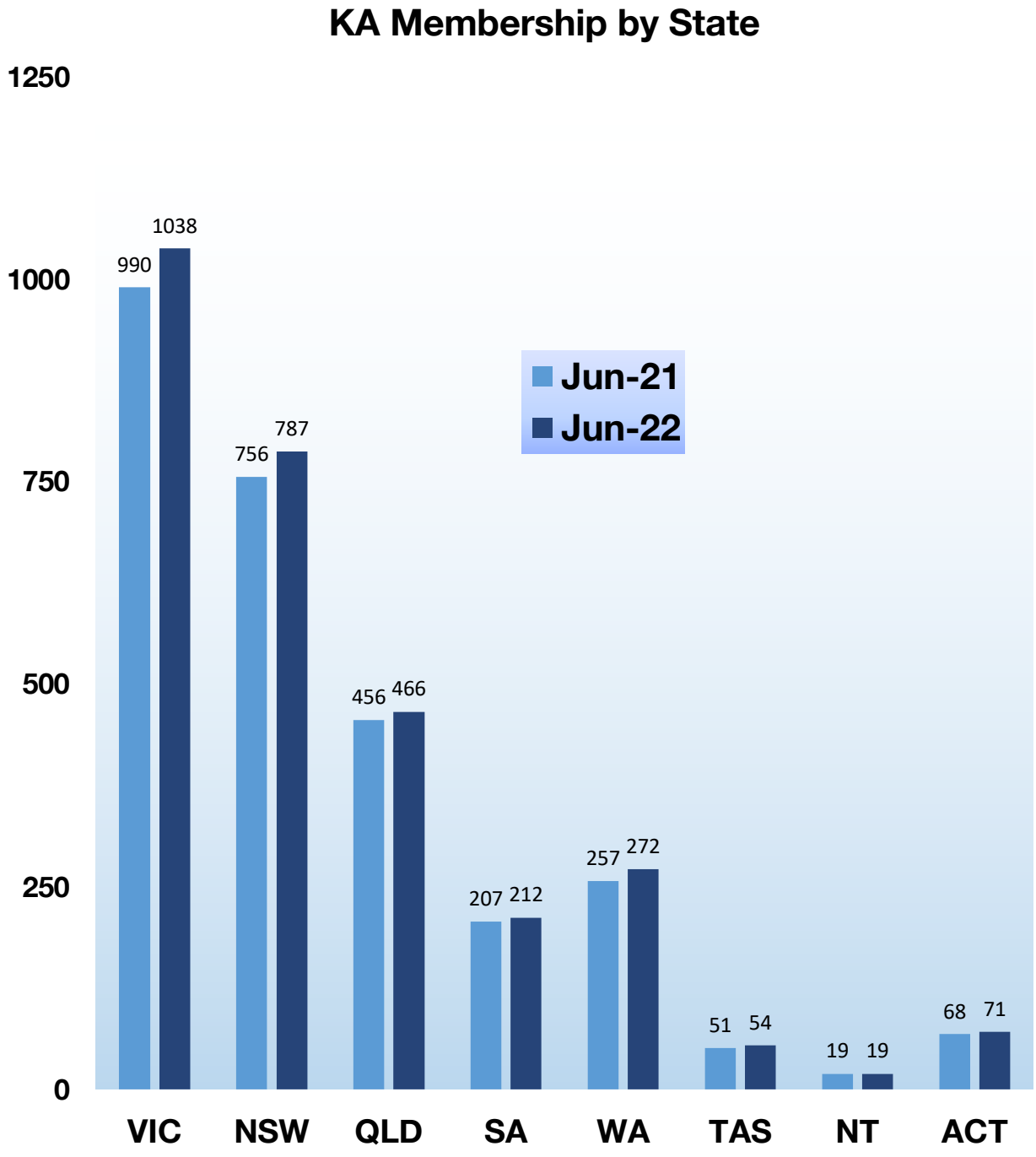
2022

THE ASSOCIATION

THE ASSOCIATION

MEMBERSHIP

Growth in Keratoconus Australia membership was solid in 2021-22, with total numbers rising by 4% to 2,919. This followed an increase of 5.5% in 2020-21. Membership was again affected by COVID-19 lockdowns in the second half of 2021 and the sharp rise in deadly infections in the first half of 2022 which left many worrying about things other than their keratoconus. While patients seemed reluctant to visit eye-carers unless absolutely necessary, patient support requests to the Association remained strong at slightly above 2021 levels (see **Support**). Membership growth generally mirrors shifts in support requests.



Western Australia and Tasmania recorded the largest percentage rises last year of just under 6% respectively. Victorian membership jumped by almost 5% to 1038 while NSW increased by 4% to 787 (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 27%, followed by Queensland (16%), WA (9%) and SA (7.3%).

(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 2021-22, notably Cameron Falt of Slomoi Partners for accounting services, Viewgrow Capital Pty Ltd (meeting venue and administrative support services) and Herbert Smith Freehills for legal services.

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

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

Save Sight Institute at the Sydney Eye Hospital is a key partner of Keratoconus Australia and collaborates with us on a number of projects. These include the Save Sight Keratoconus Registry, the KeraClub and the Hands Off Eyes campaign to alert keratoconus patients of the dangers of eye rubbing. The Save Sight Keratoconus Registry and Keratoconus Australia also distribute a patient brochure on crosslinking. We are currently preparing a new campaign to heighten awareness of the risks associated with regular eye rubbing.

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

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

We also acknowledge the University of Melbourne which continues to back the Association's efforts to improve access to well-fitted contact lenses for keratoconus patients through its Melbourne Eyecare Clinic, which runs regular keratoconus clinics. The clinics offer discounts of 30% to Keratoconus Australia members and are staffed by specialist contact lens fitters for keratoconus including Richard Vojlay, Luke Arundal, Jessica Chi, Jillian Campbell and Laurie Downie who oversee contact lens fits by student optometrists.

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

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

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

FUNDRAISING

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

DONATIONS

We thank all donors who made significant contributions during the 2021-22 financial year. Particular thanks again go to the Ray and Margaret Wilson Foundation for its long time and generous support of the Association.

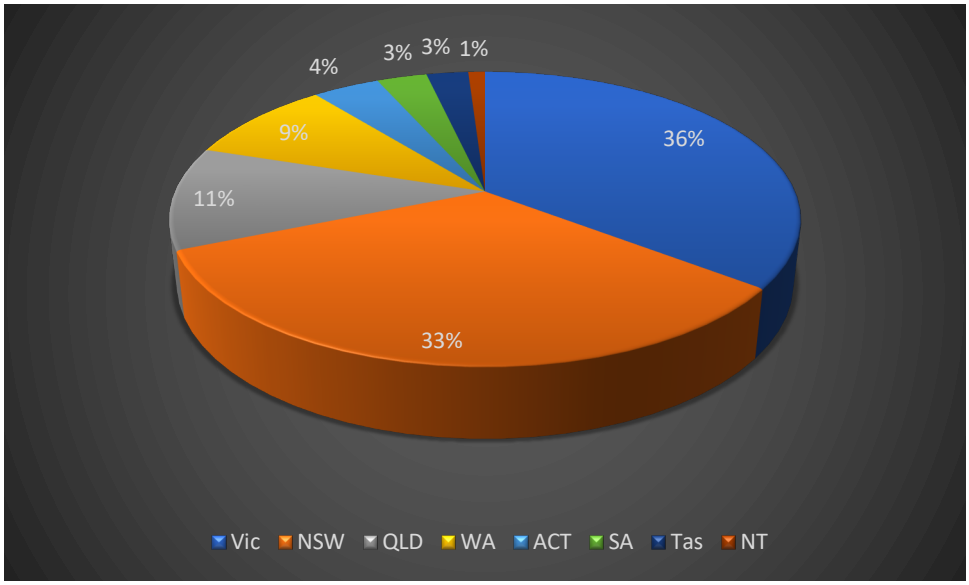
Donations to the Association can be made by credit card online via the Give Now website at https://www.givenow.com.au/keratoconusaustralia.

EVENTS

6TH KERACLUB PATIENT FORUM

KeraClub was launched in October 2016 as a joint initiative with the Save Sight Institute to provide a meeting place for Sydney-based Keratoconus Australia members and others interested in keratoconus. It has now become an online event making it accessible to people with keratoconus, eye-carers and other interested parties from around the world

KeraClub 21 attracted registrations from 319 people with almost 200 persons watching online. The event video clocked up about 400 watch-hours on YouTube. Attendees were located in 10 countries (Australia, New Zealand, UK, Ireland, Belgium, France, Netherlands, Nepal, Uganda, and India); with most from Australia. The age of the participants ranged from 33 to 78 years with a mean of 55 years.



The distribution of the Australian participants

The event was chaired by **Ms Michelle Pritchard**, a renowned musician – a violinist and violist. She has long experience of keratoconus with three corneal transplants and graft rejection episodes. Speakers at the event included:

Professor Stephanie Watson, head of the Corneal Unit at the Sydney Eye Hospital; head of the Corneal Research Group at Save Sight Institute. Professor Watson spoke of the challenges of managing keratoconus in the COVID-19 pandemic and reassured attendees that COVID-19 could not spread into the cornea. However, she noted that prolonged mask wearing could cause or exacerbate dry eye. Professor Watson also discussed some of the latest findings from the Save Sight Keratoconus Registry.

Associate Professor Mark Roth OAM who discussed dry eye, allergy and contact lens tips. He shared clinician perspectives and clinical advice on managing dry eye and allergy in keratoconus patients.

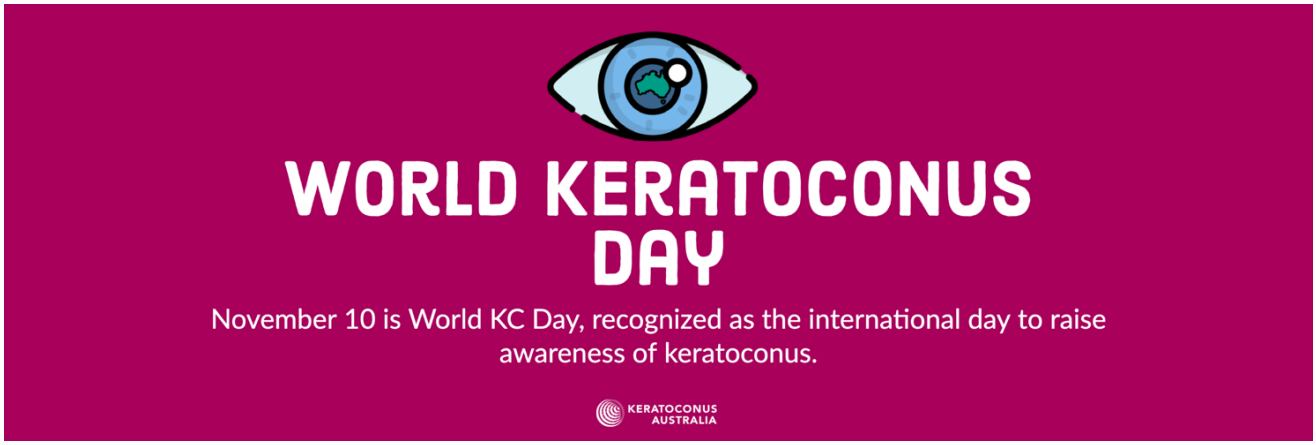
Keratoconus Australia President, Mr Larry Kornhauser OAM who described the activities of Keratoconus Australia in providing patient support, work being done by the Association in the area of mental health and how the Association was working towards improving affordability and accessibility of treatments for patients.

Ms Chloe Davies, a keratoconus patient, who outlined her lived experience with keratoconus from a young age and her coping strategies.

Dr Himal Kandel, the inaugural Kornhauser Research Associate at the Save Sight Institute, The University of Sydney. Dr Kandel spoke about the recent research papers published by the Save Sight Keratoconus Registry on different aspects of keratoconus and corneal collagen crosslinking.

The video of KeraClub 21 can be found via our website at https://tinyurl.com/3a4skbb7

WORLD KERATOCONUS DAY



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

Last year, the Association celebrated with video posts on Facebook created by committee member, Alejandro Molano which attracted enormous attention.

The US National Keratoconus Foundation, which launched World Keratoconus Day, Chair, asked the Association to co-host a photographic competition "*Keratoconus through my Eyes*" for the 2021 event, in conjunction with the UK Keratoconus support group. The winning photos can be seen below. (Full details at https://tinyurl.com/56nsy3r6)

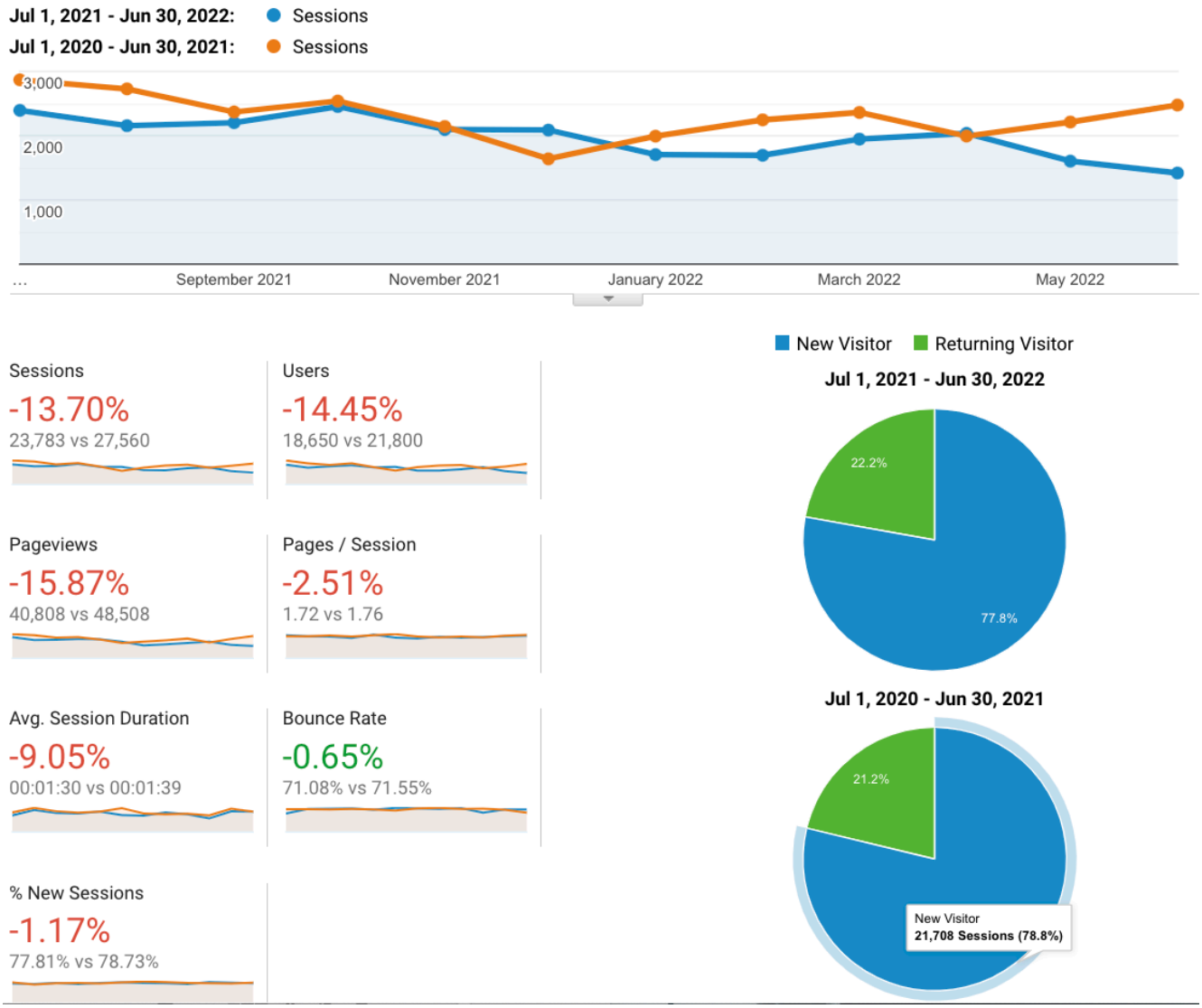
Please let us know if you have ideas for how the Association can mark World Keratoconus Day 2023.

LOCAL AND STATE GROUPS

COVID-19 heavily impacted efforts to start new local groups and hopefully members will try to organise local meetings in 2023 now that the fears about COVID-19 seem to be receding.

We are always available to assist you start a local coffee catchup or wine and cheese event or information forum. In the meantime, we encourage you to use zoom for group catchups.

WEBSITE

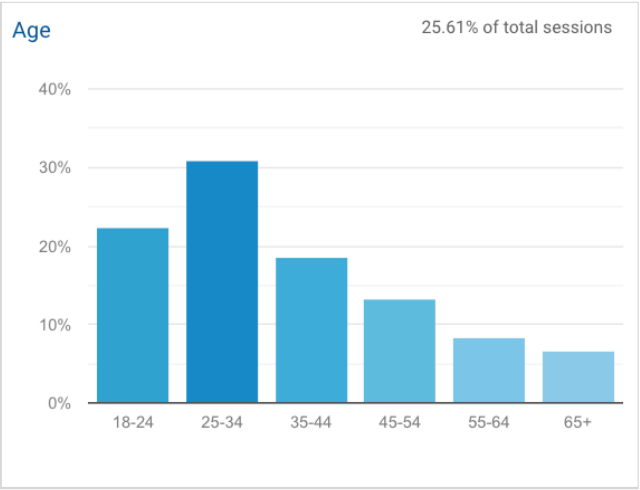


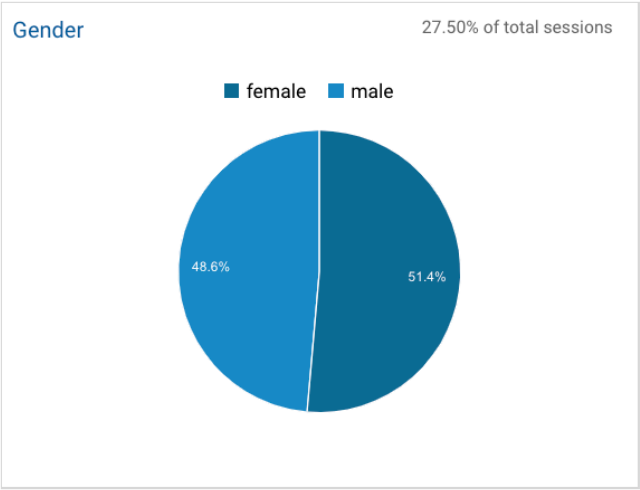
The Association's website remains a popular source of information about keratoconus. Visits over the last year appeared to follow the rhythm of COVID-19 and the associated lockdowns, rising when people were confined to their homes and spending time online and then falling again as the pandemic eased. All key metrics for the site were down in 2021-22 compared to the previous year, with sessions 14% lower to around 24,000, page views falling 16% to 41,000 while the number of users also declined by 14.5% to 18,650.

Looking across the whole period of the pandemic, visits have gradually declined as users have drifted away from using websites to find information and towards social media sites – a trend that is affecting many websites today.

Most users arrived on the site via the Home page, which accounted for 20% of the total site visits. Information on the stages of keratoconus accounted for 16% of page views, followed by pages on corneal transplantation, corneal collagen crosslinking and the Treatments home page (8% each), then contact lenses (7%), and the About Keratoconus page. (4%).

Visitors came from Australia (68%) with almost an even split between those from Victoria and NSW (around 30% each) followed by Queensland (16%), Western Australia and South Australia. Some 10% of users came the United States and 4% from India.





Keratoconus is a young person's disease and so not surprisingly, the bulk of visitors were in the 25-34 age group (31%), the ages most affected by keratoconus. Almost 72% of visitors were in the 18-44 age groups. The gender split was 52-48 in favour of females – a reversal of the 2020-21 result.

FACEBOOK

We have continued to promote and post to our Facebook page and currently have almost 830 followers, up 20% from one year earlier (690). The Association uses Facebook to promote our events like KeraClub. We are also using Facebook to post articles on keratoconus, new research and information on eye-care in general. Last year, our most popular post by far were the post and video created by Alejandro Molano for World Keratoconus Day on November 10 with over 5,000 views. The announcement of the Order of Australia awarded to Professor Stephanie Watson received 1,500 views, with the surprise third place going to the Australia

Electoral Commission post about how to vote by telephone at the May 2022 Federal Election if you were vision-impaired.

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

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

COMMITTEE OF MANAGEMENT

The Committee holds regular meetings to discuss the Association's plans and projects and to review its finances and procedures. In 2021-22, the committee met twice and held informal discussions on other occasions.

The committee last year comprised:
Larry Kornhauser, President
Greg Harper, Vice President
Erica Blake
Alice Delaney
Sarah Flynn
Neil McFarlane
Justine McLaughlin
Alejandro Molano
Michelle Pritchard
Rod Swift

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

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

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

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

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

We wish everyone a safe holiday season and good and healthy 2023.

The Keratoconus Australia Team

ANNUAL REPORT

KERATOCONUS AUSTRALIA

2022

FINANCIAL REPORT

FINANCIAL REPORTS 2021-22

Keratoconus Australia Inc. reported a net operating surplus of $5,341 , up 36% on the surplus of $3,611 recorded in the 2020-21 financial year. The increase was largely attributable to a significant rise in donations during the year. These were up by 41% to $6,222 ($4,075 previously). However low interest rates, at almost zero, also impacted interest revenue from term deposits which again fell sharply to only $385 last year, or 69% down on the previous year ($1,239).

Lower interest income was somewhat offset by a decline in total expenses, which were down by 33% to $1,266 (1,879 previously), mainly due to lower office expenses ($52) and in particular, zero printing costs ($547 in 2020-21). In 2020, the National Keratoconus Foundation stopped supplying us with its booklets on keratoconus in printed form as it moved to digital copies. The Association decided to have the booklets printed locally to ensure access to hard copies for distribution to both patients and eye-carers. Printing was unnecessary last year as we held sufficient stocks of these hard copy booklets and decided to switch to digital distribution of our information booklets and flyers until COVID-19 lockdowns ended. The Association is again distributing both hard and digital copies of these resources.

Postage costs remained steady at only $238 ($265 in 2020-21) as more material was sent to members via email and social media. COVID-19 restrictions in Melbourne closed our offices for much of the reporting period and made it difficult for the Association to conduct mail outs to members not on email or who have failed to inform us of their new email addresses.

The balance sheet as at 30 June, 2022 was showing net assets of $130,883 compared to $125,542, one year earlier. The Association holds the bulk of these assets in term deposits and recently rolled these to take advantage of higher interest rates.

The Committee will examine options in 2023 to raise funds for research and at starting a fund to assist low income members in financing treatments. A full strategic review of the Association’s funding and management is also planned.

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

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

Slomoi Immerman Partners
Chartered Accountants & Advisers

Special Purpose Financial Report

Keratoconus Australia Inc
For the year ended 30 June 2022

Prepared by Slomoi Partners Pty Ltd

Slomoi Immerman Partners
Chartered Accountants & Advisers

Contents

Public Officer's Declaration

Keratoconus Australia Inc
For the year ended 30 June 2022

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 2022 and its performance for the year ended on that date in accordance with the accounting policies described in Note 1 to the financial statements;

2. in the public officer's opinion there are reasonable grounds to believe that the incorporated association will be able to pay its debts as and when they become due and payable.

Public Officer: _____

Larry Kornhauser

Date: 26 October 2022

Slomoi Immerman Partners
Chartered Accountants & Advisers

Compilation Report

Keratoconus Australia Inc
For the year ended 30 June 2022

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 2022.

The Responsibility of the Public Officer

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

Our Responsibility

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

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

Assurance Disclaimer

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

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

Slomoi Partners Pty Ltd

Cameron Falt

Director

Dated: 26 October 2022

Income Statement

Keratoconus Australia Inc
For the year ended 30 June 2022

Income Statement

	2022	2021
Income		
Donations Received	6,222	4,075
Interest Received	385	1,252
Other Revenue	-	163
Total Income	**6,607**	**5,490**
Total Income	**6,607**	**5,490**
Expenses		
Bank Charges	6	5
Domain Name Registration	454	312
Office Expenses	52	526
Postage	238	265
Printing & Stationery	-	547
Subscriptions	282	-
Telephone & Internet	103	119
Website Hosting	131	105
Total Expenses	**1,266**	**1,879**
Profit/(Loss) for the year	**5,341**	**3,611**
Undistributed Income	**5,341**	**3,611**

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

Statement of Financial Position

Keratoconus Australia Inc
As at 30 June 2022

Statement of Financial Position

	30 JUN 2022	30 JUN 2021
Assets		
Current Assets		
Bank Accounts	20,657	32,326
Term Deposits	110,000	93,011
Goods and Services Tax	47	75
GiveNow Receivables	178	130
Total Current Assets	**130,883**	**125,542**
Non-Current Assets		
Intangible Assets		
Website Development - at Cost	6,975	6,975
Less: Accumulated Depreciation	(6,975)	(6,975)
Total Intangible Assets	**-**	**-**
Total Non-Current Assets	**-**	**-**
Total Assets	**130,883**	**125,542**
Net Assets	**130,883**	**125,542**
Equity		
Current Year Earnings	5,341	3,611
Retained Earnings	125,542	121,931
Total Equity	**130,883**	**125,542**

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

Notes to the Financial Statements

Keratoconus Australia Inc
For the year ended 30 June 2022

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 show 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.

ANNUAL REPORT

KERATOCONUS AUSTRALIA

2022

ANNEXES

ANNEXES

2021-22 RESEARCH PUBLICATIONS

THE SAVE SIGHT KERATOCONUS REGISTRY

2021 AND 2022 PUBLISHED PAPERS

Kandel H, Pesudovs K, Nguyen V, Chen JY, Poon A, Mills RL, Watson SL. Patient-reported outcomes in keratoconus: a Save Sight Keratoconus Registry study. Cornea 2022 https://doi.org/10.1097/ICO.0000000000003119

Borchert GA, Watson SL*, Kandel H*. Oxygen in Corneal Collagen Crosslinking to treat Keratoconus: A Systematic Review and Meta-analysis. Asia-Pac J Ophthalmol [Provisionally accepted in June 2022] *Equal senior authors

Benito-Pascual B*, Kandel H*, Abbondanza M, Mills R, Sullivan L, Watson SL. Efficacy and safety of standard corneal cross-linking procedures performed with short vs standard riboflavin induction: a Save Sight Keratoconus Registry study Cornea 2022 https://doi.org/10.1097/ico.0000000000003058 *Joint first authors

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

Kandel H, Downie LE*, Watson SL*. The Save Sight Keratoconus Registry – Optometry Module: An opportunity to use real-world data to advance eye care. Clin Exp Optom 2022;105(1):96-99 *Joint senior authors

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

Ferdi AC, Nguyen V, Kandel H, Tan J, Arnalich-Montiel F, Abbondanza M, Watson SL. Predictors of progression in untreated keratoconus: A Save Sight Keratoconus Registry study. Br J Ophthalmol 2021;105 http://dx.doi.org/10.1136/bjophthalmol-2020-317547

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

Kandel H, Nguyen V, Ferdi AC, Gupta A, Abbondanza M, Sullivan L, Apel A, Watson SL. Comparative efficacy and safety of standard versus accelerated corneal cross-linking for keratoconus: one-year outcomes from the Save Sight Keratoconus Registry study. Cornea. 2021;40(12):1581-9

Kandel H, Khadka J, Watson S, Fenwick E, Pesudovs K. Item banks for measurement of refractive error-specific quality-of-life. Ophthalmic Physiol Opt. 2021;41(3):591-602

Kandel H, Watson SL. Quality-of-life researchers in ocular allergy may benefit from the newer methods. The Journal of Allergy and Clinical Immunology: In Practice 2021. 1: 595-6.

Kandel H, Watson SL. Comparison of standard versus accelerated corneal collagen crosslinking for keratoconus: 5-year outcomes from the Save Sight Keratoconus Registry. Invest Ophthalmol Vis Sci. 2022;63:2381 – A0184

Kandel H, Howes F, Abbondanza M, Watson SL. The outcomes of transepithelial corneal cross-linking: Real-world one-year outcomes from the save sight keratoconus registry. Clinical and Experimental Ophthalmology 2022;49(8):863-4

Watson SL, Gupta A, Abbondanza M, Sullivan L, Apel A, Kandel H. Comparison of standard versus accelerated corneal collagen cross-linking for keratoconus: Two-year outcomes from the save sight keratoconus registry. Clinical and Experimental Ophthalmology 2022;49(8):864

Ling ML, Kandel H, Ferdi AC, Watson SL. Riboflavin for corneal collagen cross-linking. Clinical and Experimental Ophthalmology 2022;49(8):891

Kandel H, Nguyen V, Gillies MC, Watson SL. Quality of life impact of eye diseases: a Save Sight Registries study. Investigative Ophthalmology & Visual Science. 2021;21;62(8):3495

THE CENTRE FOR EYE RESEARCH AUSTRALIA

Non-genetic risk factors for keratoconus

Minji Song 1, Qing Yi Fang 1, Ishith Seth 1, Paul N Baird 2, Mark D Daniell 1, Srujana Sahebjada 1 Affiliations expand

PMID: 35504720 DOI: 10.1080/08164622.2022.2062222

Abstract

Keratoconus is a complex and multifactorial disease and its exact aetiology remains unknown. This current study examined the important environmental risk factors and their association with keratoconus. This study was registered in the PROSPERO International Prospective Register of systematic reviews under registration number CRD42021256792 in 2021. Scopus, Web of Science, PubMed, and Cochrane CENTRAL databases were searched for all relevant articles published from 1 January 1900 to 31 July 2021. National Institutes of Health Quality Assessment Tool was used to assess the methodological quality of the studies. The assessment for statistical heterogeneity was assessed using the Z-statistics on RevMan v5.4. P-value of <0.05 was considered as statistically significant and I^2 < 25% as homogenous. Thirty studies were included in this meta-analysis. Pooled odds ratio was calculated with 95% CI. The pooled odds ratio (OR) of eye rubbing, atopy, asthma, and eczema was 3.64 (95% CI, 2.02, 6.57), 1.90 (95% CI, 1.22, 2.94), 1.36 (95% CI, 1.15, 1.61) and 1.90 (95% CI, 1.22, 2.94), respectively. The OR for diabetes was 0.86 (95% CI 0.73, 1.02), and use of sunglasses, contact

lens, allergic conjunctivitis, side sleep position and prone sleep position was 0.40 (95% CI, 0.16, 0.99), 1.68 (0.70, 4.00), 2.24 (95% CI, 0.68, 7.36), 3.81 (95% CI, 0.31, 46.23), 12.76 (95% CI, 0.27, 598.58), respectively. Twenty studies were considered to be of high quality, nine to be moderate and one to be low. Environmental risk factors have been identified to play a role in the susceptibility of keratoconus. However, further large-scale longitudinal studies are needed to understand the mechanisms between environmental risk factors and keratoconus.

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

doi: 10.1007/s00417-021-05081-8. Epub 2021 Jan 23.

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

Srujana Sahebjada [#1 2 3], Haitham H Al-Mahrouqi [4], Sophia Moshegov [5 6], Sathiya M Panchatcharam [7], Elsie Chan [5 6 8], Mark Daniell [5 6 8], Paul N Baird [5]

Affiliations expand

- PMID: 33484296 DOI: 10.1007/s00417-021-05081-8

Abstract

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

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

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

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

intricate relationship of eye rubbing and its induction, ongoing progression, and severity of keratoconus.

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

Keratoconus in pre-teen children: Demographics and clinical profile

Bhava Tharini [1], Srujana Sahebjada [2], Maria Agustina Borrone [1], Pravin Vaddavalli [1], Hasnat Ali [1], Jagadesh C Reddy [1]

Affiliations expand PMID: 36190036 DOI: 10.4103/ijo.IJO_2579_21

Abstract

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

Methods: This was a retrospective case series conducted as a single-institutional study at a tertiary eye center in India. A total of 586 eyes from 294 KC patients (aged 12 years or less) without any active comorbid conditions of the eye were included in the study. Slit-lamp biomicroscopy was used to document the clinical signs of KC. Information on age; gender; reason for consultation; family history; history of allergy, atopy, and eye rubbing; manifest refraction; uncorrected and best-corrected distance visual acuity (UCVA and BCVA, respectively); clinical presentation; and contact lens usage were also analyzed, along with data on types of medical and surgical treatments for KC and their outcomes.

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

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

Comput Biol Med . 2021 Nov;138:104884. doi: 10.1016/j.compbiomed.2021.104884. Epub 2021 Sep 28.

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

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

Ke Cao [1 2], Karin Verspoor [3 4], Srujana Sahebjada [1 2], Paul N Baird [2]

Affiliations expand
PMID: 35159930
PMCID: PMC8836961
DOI: 10.3390/jcm11030478
Free PMC article

Abstract

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

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

Ke Cao [1], Karin Verspoor [2], Elsie Chan [3], Mark Daniell [3], Srujana Sahebjada [1], Paul N Baird [4]

Affiliations expand
- PMID: 34607273
- DOI: 10.1016/j.compbiomed.2021.104884

Free article

Abstract

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

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

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

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