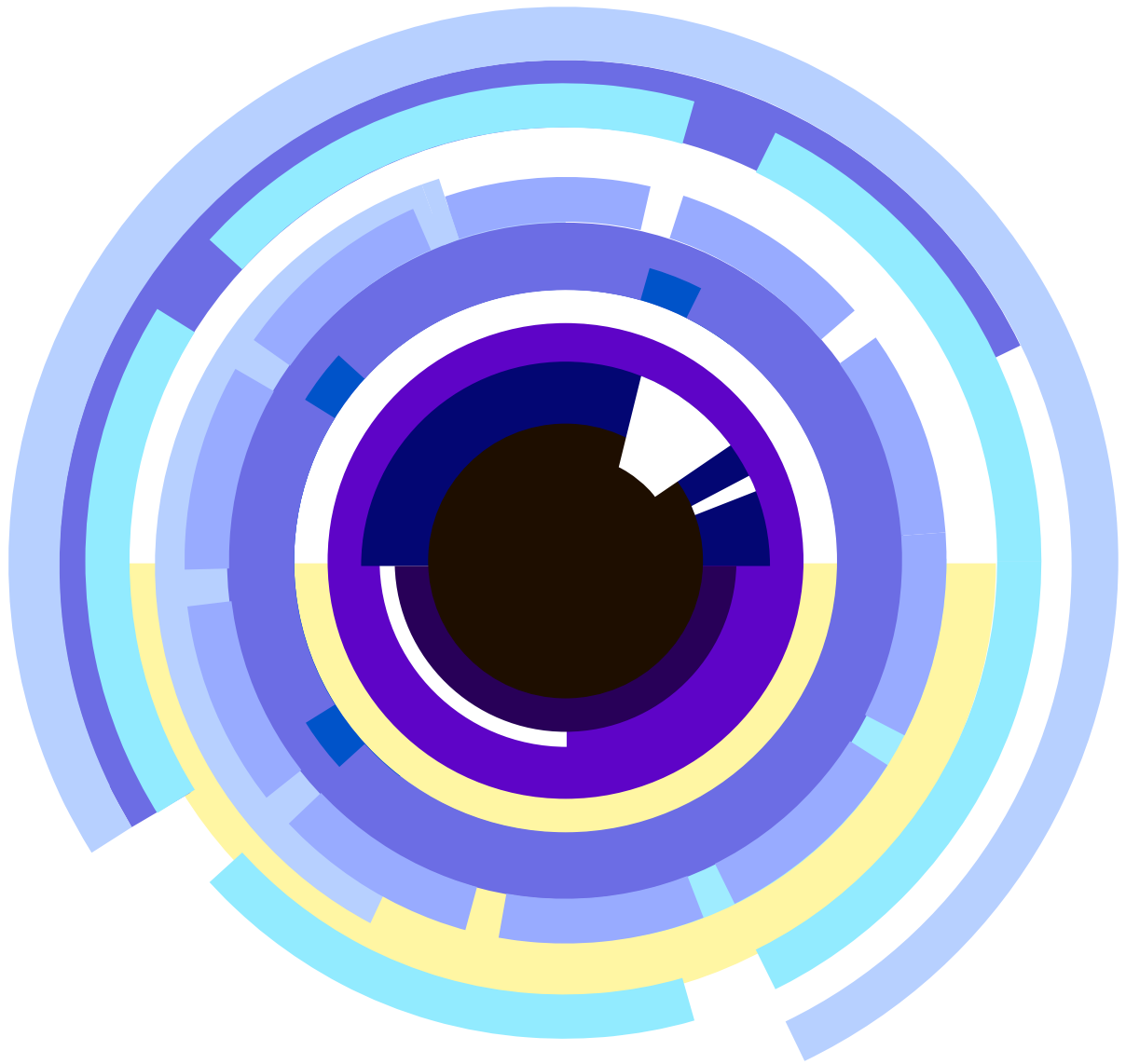

ANNUAL REPORT

2019



KERATOCONUS
AUSTRALIA





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KERATOCONUS
AUSTRALIA

From the president

Recently, I had taken out my contact lenses and was preparing to go to sleep when my son came into the bedroom for a late night chat. He sat at the end of the bed and as such was less than two metres away. As he spoke to me, my mind drifted to the thought that although I could hear him clearly and recognise his voice, I couldn't actually see him. In fact, his head was little more than a smudge in the dim light.

It was a stark reminder that although low vision from keratoconus can be corrected very well with contact lenses and acceptable and often functional vision can be obtained with spectacles, it causes a very serious disability without these corrective aids.

With my contact lenses, I have very good functional vision and never feel that I am handicapped by the eye disease I have lived with since adolescence. Without them, I am effectively disabled. Fortunately, even as my keratoconus has advanced, for most of my life I have been able to find solutions to my low vision thanks to progress in contact lens technology.

There is a wide range of contact lenses available today to correct low vision from keratoconus. These vary from simple rigid gas permeable lenses, mini-sclerals to complex hybrid lenses and full scleral lenses. They combine a range of materials to provide solutions for most situations. Prices for these can vary widely and wildly depending on the type of lens and the optometrist and laboratory supplying them.

Unfortunately for people with keratoconus and their families, the cost of these lenses has soared in recent years. This is partly due to rising optometrist fees, partly to the materials being used, and partly due to the limited number of laboratories manufacturing these specialised lenses raising their prices.

Keratoconus Australia has been trying for many years to find solutions to the cost pressure on patients.

However, the situation is becoming alarming for many patients as evidenced by the rising number of support calls from patients unable to pay for the contact lenses they require to maintain functional vision. In some cases we have dealt with, highly qualified people have lost their jobs because of their inability to afford corrective lenses. But everyone is being affected including students who are finding it difficult to complete the studies and work experience that will allow them to pursue their dreams. Hardest hit are those outside of the capital cities who are unable to access qualified contact lens fitters who could assist them in obtaining contact lenses under the state-based spectacle subsidy schemes.

These schemes provide some hope for patients close to the major optometrist teaching hospitals. But they are really designed for people requiring spectacles and simple contact lenses rather than those with keratoconus and their complex contact lens needs. The keratoconus community now needs help from the eye-carers - especially optometrists - to ensure that everyone with keratoconus has access to a qualified contact lens fitter for keratoconus and contact lenses to correct their low vision.

Keratoconus rarely causes irremediable vision loss. So everyone with this eye disease should have access to a proper education, the employment market, and the ability to enjoy a social and family life. Nobody should be left unable to see their child's face.

Larry Kornhauser

September 10, 2019

SUPPORT

Introduction

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

The Association is operated by people with keratoconus; we do not have medical qualifications or training nor do we provide medical advice.

What we do is talk to patients and family members about our own experiences with keratoconus. We have access to a range of specialists working in the field of keratoconus and all medical questions are directed to these eye-carers for their expert opinion.

However, a full examination of a patient's eye is required before even a medical practitioner will provide clear and considered advice on keratoconus treatment and management options. Which is why any advice coming via Keratoconus Australia will always be generalized, with the caveat that the patient needs to be reviewed by a keratoconus specialist.

Trends In 2018-19

Support provided by the Association to people with keratoconus and their families soared in 2018-19. Contacts logged by the Association totalled 867, the highest ever recorded by the Association and more than double those logged last year.

A breakdown of the type of support sought from the Association provides an insight into the issues facing most people with keratoconus and their families. As in the past, the overwhelming need for support was to assist people with keratoconus and their families in locating keratoconus specialists able to deal with their specific issues.

Support in helping find eye-carers thereby accounted for 60% of all the contacts logged by the Association and totalled 524 last year. This compared to 121 in the previous year.

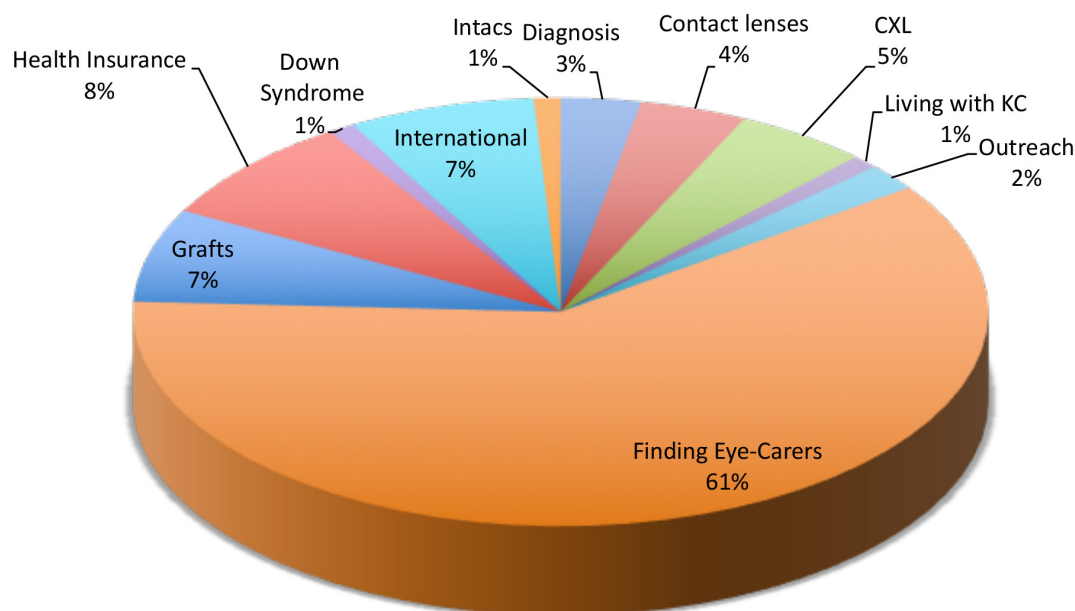
This is a statistical aberration to some extent as explained in previous reports.

People contact the Association for a variety of reasons. But in most cases, they essentially have received inadequate treatment for their keratoconus from the first eye-carer they contacted or who diagnosed the disease and feel they need specialist care or a second opinion. So regardless of the specific issue that brings them to the Association, in most cases the best we can do is to assist them in finding an appropriate optometrist or corneal surgeon in their area.

Other trends in support requests to the Association in 2018-19 included:

- the spiralling cost of treatments for keratoconus and especially contact lenses and optometric services. Demands for advice on how to obtain cheaper contact lenses and other treatments, including surgery, more than doubled again last year. This continued the worrying trend seen over recent years and highlighted in the 2018 Annual Report.
- Requests for information about non-crosslinking related surgery almost tripled last year,
- Support for contact lens-related issues almost doubled,
- Corneal crosslinking was less of an issue for people seeking support and support related to this issue was down by almost 60% in 2018-19.
- The introduction of the Medicare rebate for crosslinking may have been a factor in this decline.
- The information seminars organised by the Association and Save Sight Institute would have also helped in this regard.
- Finally, last year the Association began distribution of its new patient brochure on crosslinking to all new members as part of its upgraded new members welcome kit. The brochure was also made available for download in pdf format on the Association's website.

Support by numbers



Support by example

Below are just some examples of the support requests received by the Association last year and how we handled them.

- Jenny was having shoulder surgery and asked if there was anything to help her insert and remove her contact lenses. We were unable to assist but directed her to online patient forums where others may have some ideas
- Cameron was diagnosed with keratoconus and told to wait for a 6 month review before considering action eg. crosslinking. Mum was concerned that could be too late. We provided information on crosslinking and the names of other corneal surgeons to consult for a second opinion
- Julie, an older patient, was also concerned about waiting for a review. But at her age, wait and see seemed a better alternative.

Suggested she return to her eye-carer if she noticed any further deterioration in her vision.

- Violet was having trouble with her eye-carers and was dissatisfied with the service. Helped her find some alternative eye-carers.
- Sharon's son had bilateral crosslinking and was now looking for information on kerarings. Sent her some information on these rings but suggested they see a specialist contact lens fitter for keratoconus. Names were provided in her area.
- Craig had progressed to the point where contact lenses were no longer providing useable vision. Looking for information on the cost of a corneal transplant. Provided information and indicated how he could have the operation via the public system.
- Joshua saw online that contact lenses for keratoconus could cost \$4000 and was discouraged from seeking treatment. We advised him on other options and helped him find a contact lens fitter in his area.
- Tyler was another patient who had a poor experience with a surgeon in Brisbane and was seeking advice on whether he needed to pay upfront for his operation and contact lenses. We told him to go elsewhere and provided him with the names of alternate eye-carers.
- Ishana was seeking information on corneal transplants and costs. We provided both.
- Tammy asked about the Medicare benefit for crosslinking - we provided the requested information.
- Robert asked whether Medicare covers the cost of contact lenses. It doesn't. Many other people contacted the Association with the same question.
- Linda was worried her 14 year old son might have keratoconus. Wanted to know if he should have crosslinking immediately. Told her to wait until there was a definite diagnosis of progressive keratoconus.

- Sam needed a corneal transplant but couldn't afford to have it done privately. Was looking for options. We explained how he could have it done through the public system or pay for private health insurance.
- The Association fielded many questions about so called reshaping drops for keratoconus which have been touted on the internet. As we tell everyone we have no particular information about this research or whether it is likely to lead to an outcome.
- Natalie's daughter had crosslinking and is now having trouble wearing contact lenses. Looking for advice. Suggested she might want a second opinion on the quality of the fit of the contact lenses. Sent some names of other specialist contact lens fitters for keratoconus.
- Jessica was concerned about the cost of crosslinking which was about double the norm. Suggested the names of some alternate corneal surgeons to consult.
- Zoe's partner had a poor experience with a male corneal surgeon and was looking for a female ophthalmologist for treatment. Suggested an alternative and a female contact lens fitter if necessary.
- Tina required information on corneal transplants. We sent her a free booklet on the operation.
- Sandra read that the lifespan of a corneal transplant was around 20 years and was wondering if hers needed to be redone. We suggested she see her corneal surgeon for a full review and then decide based on what she can see rather than on the age of the graft.
- Nicolas was diagnosed with keratoconus but can't afford crosslinking. Was looking for ways to deal with the situation. Suggested he seek assistance through the public system.
- Roslyn was having trouble with itchy eyes and looking for relief. Suggested two types of eye drops which might help. Emphasised not to rub eyes.

International support

Keratoconus Australia provides support primarily to persons residing in Australia. However every year we receive requests for support from overseas. Last year we fielded questions from Pakistan, Russia, Zambia, Iran, Britain, Jordan, Switzerland, India, Brazil, South Africa, Malaysia and several people from the USA.

We try to provide information as best we can to these people or refer then to international forums where others may be able to provide assistance specific to their country and needs.



RESEARCH

One of the key purposes of Keratoconus Australia is to promote research into the causes, prevention and control of keratoconus. The Association surveys its members for basic information about their keratoconus to assist researchers identify particular areas of interest. Although it does not conduct formal research itself at this time, it does support research projects in various ways including funding, collection of information and assistance in the recruitment of participants.

Save Sight Institute (SSI), Sydney Eye Hospital

The Save Sight Institute's Keratoconus Registry (SSKR) project continues to act as a source of information on the outcomes of corneal collagen crosslinking treatments done in Australia and overseas.

Keratoconus Australia is a key partner in the registry project, having provided core funding and support for the research initiative. For full details of the project and its background, please see the 2018 Annual Report.

Last June, the SSKR provided the following report on its activities which was subsequently sent to all Keratoconus Australia members.

The advisory committee of the Save Sight Keratoconus Registry (SSKR) met on the 20th May 2019. The SSKR is part of the Fight Corneal Blindness! Project. Members including Mr Larry Kornhauser from Keratoconus Australia, Dr Laura Downie and A/Prof Gregory Harper from the University of Melbourne, and representatives from the Therapeutic Goods Administration and Save Sight Registries team, focussed on ensuring the registry met patient needs during the meeting.

Professor Stephanie Watson, Chief Investigator for the SSKR provided an update on the registry. 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.

Currently, the SSKR has 68 users (doctors) from 65 sites in Australia, New Zealand, Spain, Italy, France and Switzerland. The registry consists of data from more than 20,000 visits for 4,200 eyes of 2,300 patients. It is an extremely useful tool for monitoring patient outcomes, clinical events, adverse events, and for conducting research and educating patients. To find out more visit <https://www.keratoconus.org.au/treatments/australian-crosslinking-registry/>



Left to right: Dr Suzanne Habjan, Mr Dymow Barbosa Jr., Professor Stephanie Watson, Mr Larry Kornhauser, and Dr Himel Kandel

Talented researcher joins Save Sight Registry team

Dr Himel Kandel joined the SSKR as a Kornhauser Research associate in January 2019. His full time-position for three years is funded by the Kornhauser fellowship, a philanthropic donation from

Mr Larry Kornhauser – the president of the Keratoconus Australia. Dr Kandel has completed his PhD from Flinders University, Adelaide on measuring quality-of-life impact of eye diseases. He has received several awards including the Vice-Chancellor's Prize for Doctoral Thesis Excellence, the South Australian International Student of the Year, and the South Australian Academic Excellence Award – Postgraduate research category. Dr Kandel has published his work in several scientific journals and presented at several national and international conferences, including the Association for Research in Vision and Ophthalmology (ARVO) annual meetings. He has been selected to present his work on quality-of-life impact of keratoconus at the 10th EUCornea Congress, Paris in September 2019.

Research updates: What is new in keratoconus?

Dr Alex Ferdi, PhD student, looked through 4,000 studies and combined the data from 41 of these to find out about the natural course of keratoconus. Children under 17 years old and people with steeply shaped eyes were at higher risk of their disease worsening over a year.

“It was surprising how little modern research has been done investigating what happens to keratoconus over a lifetime” said Dr. Ferdi. “Yet knowing this is crucial in evaluating if patients need procedures such as corneal cross-linking”.

Dr Ferdi also found that Middle Eastern patients are at higher risk of progression than Europeans or East Asians.

Dr. Ferdi advised ophthalmologists to keep in mind age, corneal curvature, and background when evaluating progression risk, and the risks and benefits of cross-linking.

However, much remains unknown on what happens to patients with keratoconus in the long term, what treatments they need, how



Doctor Alex Ferdi, PhD Candidate with his First Prize certificate and Pauline Khoo, PhD Candidate and symposium organiser

Ferdi at the Annual Save Sight Institute, The University of Sydney Higher Degree Research Symposium for his presentation on this work.

The links to the recently published papers from the SSKR team are provided here: Natural history of keratoconus, Vision related quality of life in keratoconus, Registries in Ophthalmology, and Outcomes of cross-linking.

they respond to treatment, and the benefit to the patient of treatment. The answer to these questions can come from 'real world data'. That is information from medical practice that has in the past not been collected or analysed. With the SSKR we are now able to learn from everyday practice. Patients should ask their optometrist and/or ophthalmologist register them on the SSKR (<https://frb-research.org>).

"Our study has demonstrated the urgent need to log more data from people with keratoconus, so we can better understand not only the natural history, but also how people respond after cross-linking" Dr Ferdi said.

First prize was awarded to Dr

Optometry joins the Save Sight Keratoconus Registry

One of the most exciting news about the SSKR is that it will soon be available to optometrists. This will enable optometrists to track the outcomes of keratoconus patients collecting more information regarding the optometric care including the contact lens-related parameters. The optometrists and ophthalmologists will be able to refer patient data to each through the registry system.

University of NSW

In May 2019, Keratoconus Australia was contacted by optometrist Alan Ared who is currently conducting research into eye rubbing and its impact on the cornea. After receiving the relevant ethic approvals documentation from the university, the committee considered our participation in the project and gave its approval.

The Association subsequently did a mailout of an invitation to participate to all NSW members. A follow up email was sent in July.

Mr Ared expressed his thanks for support from Keratoconus Australia and will give us appropriate credit in his final paper. We also anticipate receiving a summary of the study results for distribution.

Deakin University

Dr Serap Azizoglu contacted the Association in late 2018 to discuss her project to study the prevalence of keratoconus in Victorian schools. One issue of concern to the Association was the support that will be provided to students and their families in the event of a positive diagnosis of keratoconus.

The Association sent Dr Azizoglu some materials on keratoconus, corneal collagen crosslinking and the dangers of eye rubbing. We expect to remain in contact and have offered to assist as possible in the future.



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.

These informal contacts continued during 2018-19 and the Association thanks all the eye-carers who offer their time and expertise to assist Keratoconus Australia and the keratoconus community. Issues canvassed include:

- Occasional feedback or discussion on patients' progress who have seen an eye-carer at our suggestion (obviously with the patient's permission);
- Introduction to eye-carers on behalf of patients;
- Ad hoc discussions about issues affecting patients like crosslinking, cost of treatments, availability of treatments;
- Suggestions on where to find eye-carers able to treat keratoconus in regional and more remote areas;
- Calls to local eye-carers to canvass their suitability to treat a patient – generally for members outside of the metropolitan areas;
- Seeking advice from eye-carers on how to access low cost services for patients outside capital cities. This has enabled patients to find contact lens fitters prepared to bulk bill low income patients;
- Providing eye-carers with information booklets, flyers and brochures on keratoconus- related issues;
- The Association also assists with media requests and comments for articles on keratoconus.

Crosslinking Information Brochure

As discussed earlier in the Annual Report, Keratoconus Australia and Save Sight Institute have produced a patient's guide corneal collagen crosslinking. The brochure is designed to answer a range of frequently asked questions concerning crosslinking including:

- What is crosslinking?
- Does it work?
- What are the risks?
- Are the risks worth taking?
- Do both eyes need to be treated?
- What are the long-term effects of crosslinking?
- What are the risks of waiting too long?
- What are the different types of crosslinking?
- How is the operation performed?
- What are the post-operative effects? Pain levels etc?
- What are the Impacts on lifestyle and work?
- Crosslinking and children.
- What is the role of the Save Sight Keratoconus Registry?

The brochure was finalised in July 2018. The layout was completed by committee member Alejandro Molano and we thank him for his excellent work.

The brochure was subsequently posted to the Crosslinking page of Keratoconus Australia website in pdf format. A printed copy is also being distributed to all new members of the Association as part of their welcome kit.

Save Sight Institute is also distributing the brochure and making it available to other ophthalmologists and hospitals.

We hope to keep the brochure updated to reflect the latest findings of the Save Sight Keratoconus Registry as they become available.

University of Melbourne –Department of Optometry and Vision Sciences (DOVS)

Since 2006, Keratoconus Australia and the University of Melbourne's Department of Optometry and Vision Sciences (DOVS) have been conducting keratoconus training clinics for optometry students. These clinics provide optometry students with a unique opportunity to fit contact lenses onto keratoconus and 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.

In early 2019, the Association emailed members to ask for 8 volunteers with keratoconus and corneal transplants to attend the keratoconus and post graft contact lens fitting clinics conducted in mid-March and April for 3rd and 4th year optometry students at the University's DOVS.

Our Victorian members again responded to the call and kindly offered their time to ensure these clinics were a success. Thanks were received from Dr Laura Downie who conducts the clinics.



Keratoconus, contact lenses and hospital care

In September 2018, the Association received an email from member Julie, drawing attention to the poor training of medical and nursing staff in hospitals and aged care facilities in regard to patients using contact lenses.

Julie explained that she had suffered considerable distress during a long procedure because of the staff's lack of understanding of a keratoconus patient's need to have access to facilities to clean and rinse contact lenses safely and that without contact lenses a patient would be effectively disabled.

The Association has passed on this information to senior optometrists and we hope that the Optometry Association will take steps in the future to engage with hospitals and aged care operators to improve training in contact lens handling for staff.

We see this as a serious issue and would appreciate assistance from members in pursuing a solution to the problem.

VISION 2020

In August 2018, Association President Larry Kornhauser met with Vision 2020 Australia CEO, Judith Abbott to discuss keratoconus and the Association. The discussion centred around past failures to implement promised actions and how we would still like assistance for our campaign to lower the cost of contact lenses.

Ms Abbott is an optometrist by training and understands well the issue. But she says that Vision 2020 Australia can help to only a limited degree. She will raise this issue with the Optometrist Association and The College of Ophthalmology and that of keratoconus in general to see if this can be advanced in future.

Follow up talks were subsequently held in July 2019 and Ms Abbott has initiated contacts with other Vision2020 members about the cost of contact lenses and how low income patients can access cheaper options.

State Spectacle and Contact Lens Subsidy Schemes

The rising cost of treatments – and especially contact lenses – is preventing many patients from receiving the specialist care and vision correction they require.

In June 2019, Keratoconus Australia compiled a list of Federal and State based schemes and clinics which provide subsidies to people with low incomes, students, health and pensioner cards who require visual aids.

This list was sent to all members.

We noted that fitting contact lenses on moderate to severe keratoconus is a specialist-only area. While these clinics can provide low cost services, they may not be staffed by specialist contact lens fitters for keratoconus.

A poorly fitted contact lens can do further damage to a thinning keratoconic cornea, causing scarring and possibly leading to a premature corneal transplant.

We urged members to ask for an optometrist at these clinics with keratoconus training and experience.

We have also included a list of state-based patient travel assistance schemes which provide funding for patients requiring treatment outside of their local areas. These can assist patients to travel to capital cities where keratoconus specialists are more easily found.

The lists may not be complete and we would appreciate members contacting us with any information that could assist people with keratoconus obtain lower cost specialist treatments.

You can always ask your eye-carer about bulk billing and deferred payment plans if you are in financial difficulty.

Write to your Private Health Fund!

As always, we repeat our suggestion that members put pressure on their private health funds to recognise the special nature of contact lenses for keratoconus and to provide higher rebates on claims for these specialised and indispensable lenses. With the assistance of the US Keratoconus Foundation, we have prepared a letter, which members can download, modify and print, to send along with their contact lens claims to their private health fund.

Please send this letter to your health fund EVERY TIME you submit a claim for a rebate on your new contact lenses. The letter to request a higher rebate from your health fund can be downloaded in Word format off our website at

<https://www.keratoconus.org.au/wp-content/uploads/2018/01/KA-Insurance-letter.pdf>

THE ASSOCIATION

At 30 June 2019, Keratoconus Australia had 2,501 registered members. This represented an increase of 2.7% (adjusted) above the 2,436 members registered one year earlier.

Of the larger states, membership grew fastest in NSW reaching 662, up 3.6% compared to the same time last year (639 members). Similar growth rates were recorded in Victoria (+3.5% to 893 members) and Western Australia where membership rose 3.1% to 233 members. The largest percentage gains (albeit off a very small base) was made in Tasmania, where membership was up 5% to 42 (see graph)

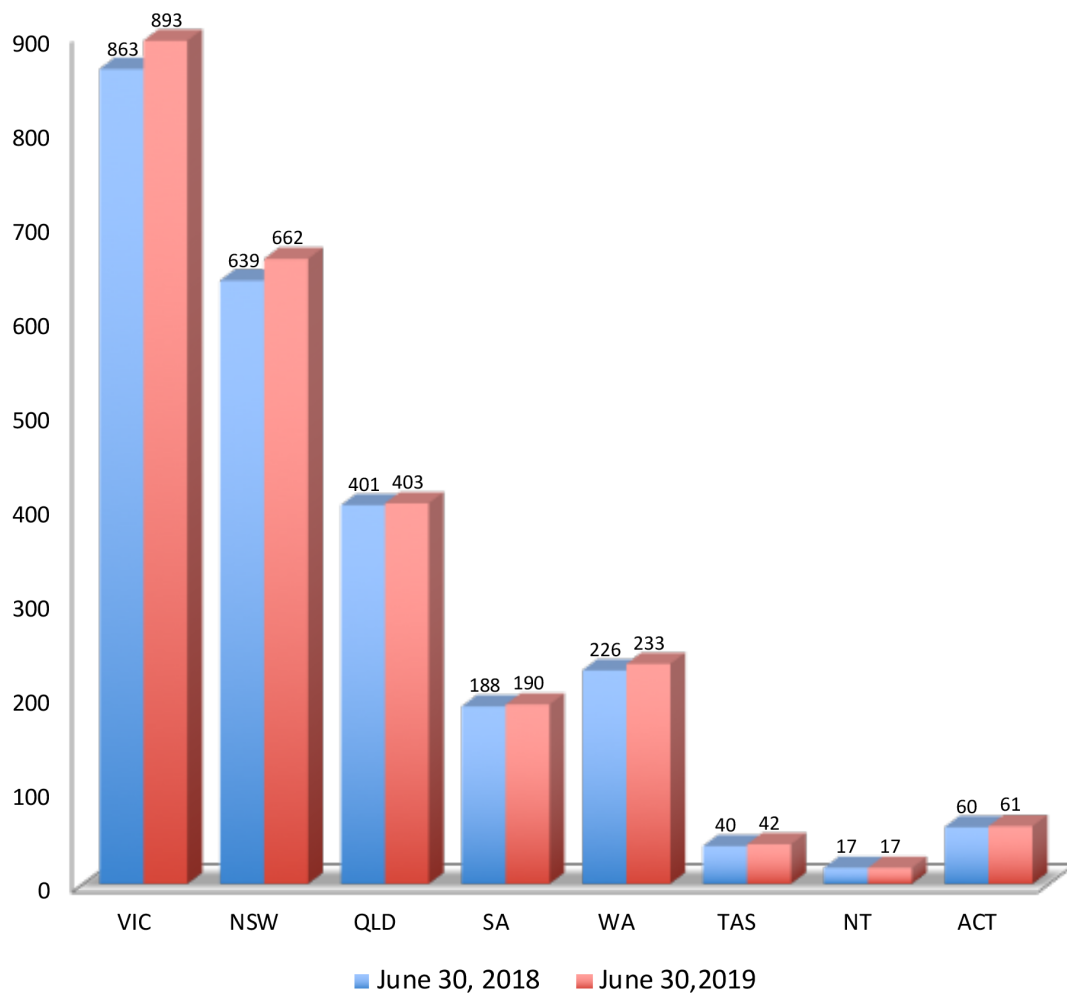
Victoria, the Association's home state, remained the Association's largest state accounting for 35.7% of the total membership at the end of the 2018-19 financial year. That proportion has remained largely unchanged over the past seven years. NSW continues to account for around 26.5% of the membership base, followed by Queensland at 16.1%, and WA at 9.3% slightly ahead of South Australia at 7.6%.

(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.)

Membership by State 2018-19

Supporters

A range of companies assist the Association in the form of free facilities for meetings and pro bono services. We thank all of these companies and institutions for their kind assistance again in 2018-19, notably Deloitte Private for accounting services, Viewgrow Capital Pty Ltd (meeting venue and administrative support services) and Herbert Smith Freehills for legal services. The US-based National Keratoconus Foundation provides the Association with patient booklets on keratoconus and corneal transplantation at a reduced cost. These are now being supplied in pdf format only.



As discussed previously, the University of Melbourne has backed Keratoconus Australia's efforts to improve access to cheap, well-fitted contact lenses for keratoconus patients through its EyeCare clinic, which runs regular keratoconus clinics. These clinics are staffed by specialist contact lens fitters for keratoconus 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.

Save Sight Institute is a key partner of Keratoconus Australia on a number of projects including the Save Sight Keratoconus Registry, the KeraClub and the Hands Off Eyes campaign to alert keratoconus patients of the dangers of eye rubbing. We have also collaborated to produce a patient brochure to explain crosslinking (see earlier).

Both the crosslinking brochure and the Hands Off Your Eyes poster are being sent to all new members as part of their welcome kit

along with a NKCF booklet on keratoconus. These are available to all members by contacting the Association.

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

Fundraising

We are registered as a charity on the GoFundraise platform should members wish to fundraise on behalf of Keratoconus Australia. <https://www.gofundraise.com.au/> and also at MyCause <https://www.mycase.com.au/>.

Donations

We thank all donors who made significant contributions during the 2018-19 financial year. Particular thanks again go to the Ray and Margaret Wilson Foundation, and to the Petard Tarax Charitable Trust for their ongoing and generous support of the Association.

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



Local and State groups

NSW

The NSW keratoconus patient group launched in October 2016 with the assistance of Keratoconus Australia member Michelle Urquart and the Save Sight Institute continues to flourish. The new group – called the Keratoconus Club or KeraClub – is providing a forum for an exchange of interesting stories by members and an update on the latest research by the Save Sight Institute. It is also offering an opportunity for members to learn about topics of interest from keratoconus specialists.

The third meeting of the Keraclub was held in Sydney on November 8, 2018. Members and eye-carers heard some fascinating stories from a range of lively speakers, while Professor Stephanie Watson discussed the development of the Save Sight Keratoconus Registry.

This year's Keraclub will be held on October 24 in Sydney and will look at how to manage contact lenses in daily life. Leading Sydney optometrist Jim Kokkinakis will be a keynote speaker.

TWEED/GOLD COAST

Tweed Coast member, Renee, has expressed an interest in launching a Keratoconus Support group on the Tweed/Gold Coast in 2020. Members interested in assisting Renee can email our assistant Mary Veal at admin@keratoconus.org.au over the coming months.



We will provide more information about the group once Renee notifies us of her availability.

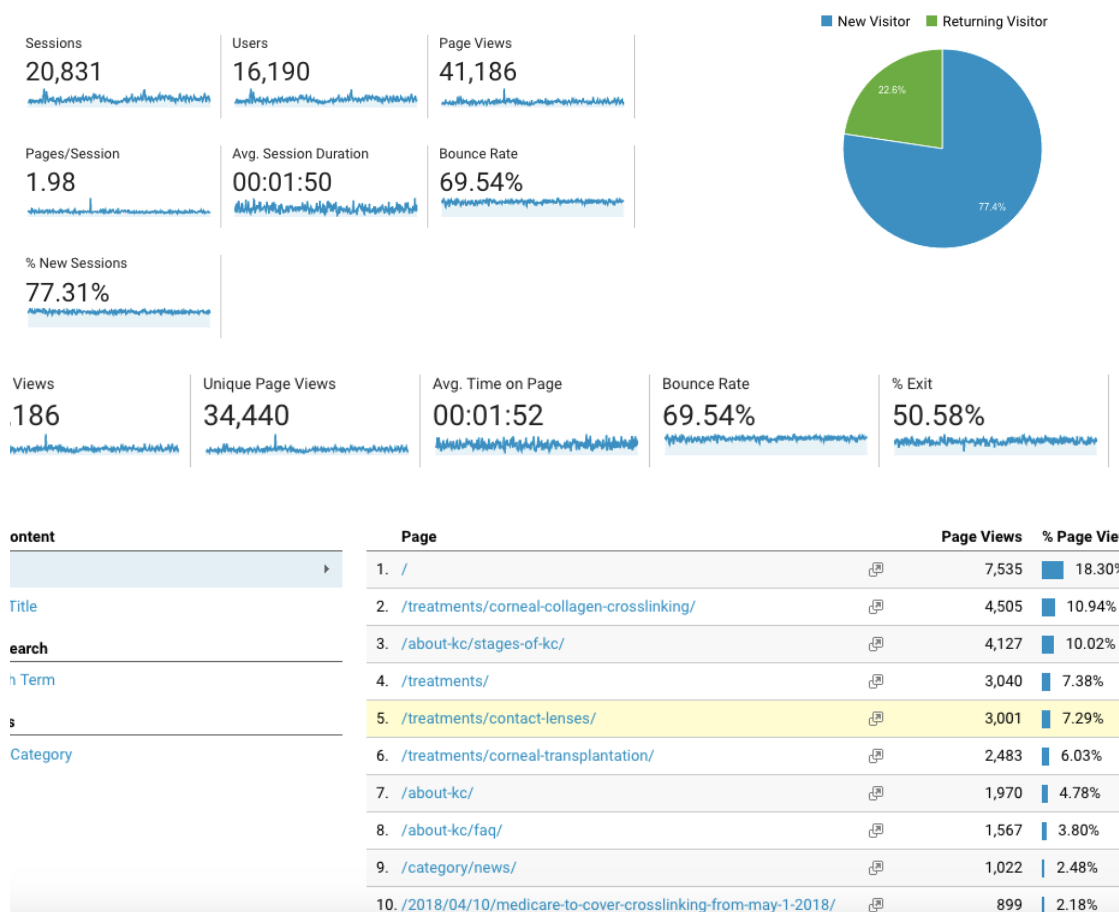
SA

Rebecca, a member from Adelaide has also been in touch and would like to facilitate a seminar and local support group for the Adelaide area. Some preliminary thoughts have been put together around what topics should be addressed. If you are interested in assisting, please contact us and we can pass on the details.

Website

The new Keratoconus Australia website continues to attract interest with over 40,000 page views over the past year. Google Analytics data show that visitors gravitated to pages concerning treatments for keratoconus. Information on corneal collagen crosslinking proved most popular, followed by the stages of keratoconus and contact lenses.

Some 16,000 people visited the site with a return rate of 22%. Over 50% of visitors accessed the site from a mobile device with another 41% accessing the site from a desktop computer. Interestingly,



Australian users were largely from NSW and Victoria (62%) with almost an even split between the two states. This seems to reflect the success of the KeraClub in raising the profile of Keratoconus Australia in NSW.

Facebook

The Association launched its Facebook page in mid-2019. The page will be used mainly to alert members of events being held by the Association and new developments in keratoconus research and treatments. **Please visit the page and give us a like.**

The Committee of Management

The Committee holds regular meetings to discuss the Association's plans and projects and to review its finances and procedures. In 2018-19, the committee met three times and held informal discussions on other occasions.

The committee last year comprised:

Larry Kornhauser, President

Neil McFarlane

Greg Harper

Rod Swift

Alejandro Molano

Michelle Urquart

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

FINANCIAL REPORT

Keratoconus Australia Inc. reported a net operating surplus of \$8,813 in 2018-19, compared to \$14,858 in the 2017-18 financial year. This was 41% down on last year mainly due to a sharp fall in donations. These fell from \$17,571 in 2107-2018 to only \$10,628 last year (-40%). In fact, donations actually remained fairly stable at around the \$10,000 mark because last year's figure included a double donation from Petard Tarax Charitable Trust that applied to the previous financial year.

Our major donors enable us to offer support to larger research projects, while our general donations assist with financing our day to day operations. The Association's presence on online giving portals such as GiveNow, MyCause and GoFundraise has assisted in reaching more donors.

Despite having shifted funds into a bank term deposit in 2018, falling interest rates impacted this other major source of revenue. Interest revenue declined to only \$771 last year, down 28%.

Thanks to the kind support of a number of organisations, our

operating expenses remain low. The only significant increase in costs noted was a jump in domain name registration costs to \$272. Other expenses remained fairly stable last year. Overall, total expenses in 2018-19 fell 33% to \$1,815 with most of that directed to postage. This cost could be reduced further if members could supply us with the current email addresses.

The balance sheet as at 30 June, 2019 was showing net assets of \$114,067, compared to \$105,254 one year earlier. Whilst some of this money will be retained to earn interest to cover on-going costs, the Committee is looking at options for funding key research and advocacy projects to improve patient outcomes.

We thank Deloitte Private for their assistance, both in preparing quarterly GST returns and finalising and reviewing our annual accounts. Deloitte Private has continued to provide support to Keratoconus Australia Inc. on a pro bono basis.

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



FINANCIAL REPORT DOCUMENTS

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 2019.

The Responsibility of Public Officer

The public officer is solely responsible for the information contained in the special purpose financial statements.

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 significant accounting policies adopted as set out in APES 315: Compilation of Financial Information. The Balance Sheet and Profit and Loss Account information has been extracted from the MYOB accounting records which have been solely maintained by the public officer and management of the incorporated association.

Our procedures use accounting expertise to collect, classify and summarise the financial information, which the public officer provided, in compiling the financial statements. Our procedures do not include verification or validation procedures. In addition, these procedures do not include an assessment of the integrity of the MYOB file provided to us. No audit or review has been performed and accordingly no assurance is expressed.

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

Deloitte Private Pty Limited



Cameron Falt
Director

Dated: 5 September 2019

TO KERATOCONUS AUSTRALIA INC

PUBLIC OFFICER'S DECLARATION

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

The public officer of the incorporated association declares that:

1. the financial statements presents fairly the incorporated association's financial position as at 30 June 2019 and its performance for the year ended on that date in accordance with accounting policies;
2. in the public officer's opinion there are reasonable grounds to believe that the incorporated association will be able to pay its debts as and when they become due and payable.

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



Public Officer

Larry Kornhauser

Dated:

Keratoconus Australia

*PO Box 1109
HAWKSBURN VIC 3142*

Profit & Loss [Last Year Analysis]

July 2018 through June 2019

	This Year	Last Year
Income		
Donations	\$9,690	\$16,190
Booklet sales	\$68	\$134
Bank interest	\$99	\$178
Term Deposit interest	\$771	\$1,069
Total Income	\$10,628	\$17,571
Cost of Sales		
Gross Profit	\$10,628	\$17,571
Expenses		
Bank charges	\$5	\$2
Domain Name Registration	\$268	\$53
Dues & Subscriptions	\$272	\$242
License Fees	\$0	\$57
Meeting Expenses	\$87	\$0
Photocopying	\$141	\$113
PO Box rental	\$130	\$115
Postage	\$758	\$774
Printing	\$18	\$106
Seminar Expenses Melbourne	\$0	\$384
Stationery	\$0	\$520
Telephone and Internet	\$90	\$151
Website hosting	\$46	\$196
Total Expenses	\$1,815	\$2,713
Operating Profit	\$8,813	\$14,858
Other Expenses		
Gifts / Contributions	\$0	\$0
Gift - Save Sight Institute	\$0	\$0
Total Other Expenses	\$0	\$0
Net Profit / (Loss)	\$8,813	\$14,858

This report should be read in conjunction with the attached compilation report

Keratoconus Australia

PO Box 1109
HAWKSBURN VIC 3142

Balance Sheet [Last Year Analysis]

June 2019

	This Year	Last Year
Assets		
Current Assets		
Cash On Hand		
Westpac DGF Account	\$7,378	\$17,451
Westpac Max-iDirect	\$23,617	\$7,750
Total Cash On Hand	\$30,995	\$25,201
Term Deposit	\$80,000	\$80,000
Funds received - not yet banked	\$3,000	\$0
Trade debtors	\$38	\$0
GiveNow Receivables	\$310	\$300
Total Current Assets	\$114,343	\$105,501
Intangible Assets		
Website Development - At Cost	\$6,975	\$6,975
Accumulated Amortisation	(\$6,975)	(\$6,975)
Total Intangible Assets	\$0	\$0
Total Assets	\$114,343	\$105,501
Liabilities		
Current Liabilities		
GST Liabilities		
GST Collected	\$282	\$279
GST Paid	(\$6)	(\$31)
Total GST Liabilities	\$277	\$248
Total Current Liabilities	\$277	\$248
Total Liabilities	\$277	\$248
Net Assets	\$114,067	\$105,254
Equity		
Retained Earnings	\$105,254	\$90,396
Current Year Earnings	\$8,813	\$14,858
Total Equity	\$114,067	\$105,254

This report should be read in conjunction with the attached compilation report

KERATOCONUS AUSTRALIA INC

NOTES TO THE FINANCIAL STATEMENTS FOR THE YEAR ENDED 30 JUNE 2019

1. SUMMARY OF SIGNIFICANT ACCOUNTING POLICIES

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

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

(a) Revenue and Other Income

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

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

(b) Cash and Cash Equivalents

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

This report should be read in conjunction with the attached compilation report

