

THE ASSOCIATION

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

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

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

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

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

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

We are also:

- Assisting people to find optometrists and ophthalmologists / corneal surgeons experienced in treating keratoconus
- Helping to develop a network of support groups throughout Australia
- Publishing a regular electronic newsletter with information on a wide range of issues affecting people with keratoconus
- Acting as a representative group for keratoconus patients to improve health rebates for treatments (contact lens and solutions, glasses) and corneal surgery, and to obtain higher funding for local research into the condition
- Supporting the development of a national registry and database on Australian keratoconus patients designed to assist in networking individuals and groups within Australia, and to form a basis for future research work
- Supporting efforts to increase organ donations and in particular to reduce waiting times for corneal graft

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FROM THE PRESIDENT

Ironically and happily, I was sitting with Professor Stephanie Watson in Sydney talking about the Save Sight Keratoconus Registry when word came through that the Australian Department of Health had approved the inclusion of corneal collagen crosslinking on to the Medicare Benefits Scheme.

It was fantastic news for everyone with progressive keratoconus who had being trying to find a way to pay for this expensive procedure, which is the only treatment shown to be safe and effective in slowing or halting the advance of keratoconus.

It was a satisfying moment for both of us because the Government's advisory committee had made it clear last year that in the absence of strong evidence from randomised clinical trials, it had relied on data from the Save Sight Keratoconus Registry to support its recommendation that crosslinking be reimbursed under Medicare.

Professor Watson and her team worked hard to create the Save Sight Keratoconus Registry – a world first. Keratoconus Australia and I provided support and funding to launch the registry, thereby enabling it to collect critical data to track outcomes from crosslinking performed in Australia and overseas. Well done us and everyone else involved.

As we explain in this report, there is still much work to be done and many questions to be answered. Hopefully you will continue to support the Registry by ensuring your eyecarers join this ground-breaking project.

Last year, I devoted this page to describing my recent eye surgery, its impact on my life over the following 10 months and the lessons learnt about the importance of support from family, friends and those who have taken that rocky road before us.

Last week, I attended the third meeting of the KeraClub in Sydney. KeraClub is the joint initiative of Keratoconus Australia and Save Sight Institute to inform our NSW members and the local keratoconus community of the latest research and treatments in the keratoconus world. It also provides a forum for keratoconus patients to narrate their stories.

Although I have listened to your many and varied stories for the past 18 years, last year I was reminded that no matter how similar they may seem, each person's journey is unique. Each of us has a tale of coping, setbacks, triumph and yes, failures too. And of course, an endless collection of anecdotes about our encounters with the optometrists and clinicians who care for our vision.

Last week at the KeraClub, Mary-Ann horrified us all by explaining how hospital staff once levered off a mini-scleral from her eye using the edge of scissors when they could not find a contact lens plunger. Feisty 70-year young Joy calmly recounted how she "died" during a corneal transplant. Although she didn't actually say what happened next, we assumed

that her doctors managed to revive her because there she was standing onstage smiling and telling us about her travails as a keratoconus and multiple transplant patient.

These sorts of stories appall yet inspire us. We all have them.

Last week, I also spoke to young Oliver who was recently diagnosed with keratoconus in his final school year, his whole life ahead of him. He'd just completed his HSC exams and was worried about the future. I said basically step forth with courage because you must never let keratoconus stop your life. It might slow you down for a while but you mustn't let it defeat you. Avoid surgery if possible, find yourself a great specialist contact lens fitter for keratoconus, and then pursue your goals. Study, play sport, travel, work, enjoy family and friends, be joyful and don't let your eyes fill with tears because of your conical corneas. That's what the rest of us do and so should you. He left smiling and hopefully encouraged.

The eye-carers attending last week's KeraClub also learned much from hearing these patient stories. In their practices, they rarely have time to let patients say more than what brought them in.

The connections we create through Keratoconus Australia and our forums like the KeraClub make us all stronger. Our stories reassure us and remind us that, yes, we can actually die and still somehow live to tell the tale. Aren't we amazing!

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 2017-18

Support contacts logged by the Association were significantly higher in 2017-18, rising over 43% from 266 in 2017 to 381 last year.

It is almost impossible to know exactly why the level of support requests from the keratoconus community fluctuations from one year to another. Declines in support requests over previous years may have been attributable to better access to information about keratoconus online; this year's increase may reflect the upgrade in Keratoconus Australia's website which offers more direct access to our support helpline.

A breakdown of the types of support requested provides some insight. For some years now, we have identified a trend towards higher costs for keratoconus treatments – especially since optometrists' fees were uncapped by the Australian government. This has led to higher costs for consultations and for contact lenses. The rising cost of contact lenses has hit many patients hard and sent them searching for ways of reducing their treatment costs.

Last year, there was a significant jump in requests for information about the cost of treatments and how Medicare or private health insurance could help defray these costs. Many of the requests for assistance in finding eye-carers related to the need to find practitioners who bulk bill for appointments and clinics that offer discounted contact lenses and spectacles. That trend is continuing in the current year.

However, we expect the decision by the Australia Government to offer a rebate on crosslinking procedures done for progressive keratoconus from May 1, 2018 (see Advocacy) should help alleviate financial pressure on individuals with keratoconus and their families.

Overall, requests for support in 2017-18 were focused on requests for:

- 1. Assistance in finding specialist contact lens fitters and corneal surgeons for keratoconus either after diagnosis or for second opinions after disappointing experiences with an initial eye-carer.
- 2. Information about corneal collagen crosslinking the only treatment shown to slow or halt progression in keratoconus
- 3. Assistance in finding access to low cost treatments for keratoconus including contact lenses and surgery.

Other areas of concern related to support for people recently diagnosed with keratoconus, those having problems with contact lenses and vision generally, and patients facing surgery – notably corneal transplantation.

The question of **how and where to find a keratoconus specialist** has dominated requests for support ever since the creation of Keratoconus Australia in 2000. Quite often people are diagnosed with keratoconus after going along to their local optometrist because of a perceived deterioration in their vision. Assuming they make a correct diagnosis and despite often having little or no experience with keratoconus, these optometrists try to fit glasses or contact lenses – with mixed success. Patients can become frustrated with both the cost of these vision aids and their inability to correct their vision adequately and/or comfortably. Some persist in trying more lenses at significant cost, others seek help elsewhere while many simply give up and try to struggle through their daily lives with reduced vision.

People contact the Association with a range of issues. But most of them boil down to inadequate treatments and care from their current eye-carer. As a result, regardless of the initial reason for the call for help, the vast majority of our support is focused on directing patients and their families to the appropriate specialist in their area to assist with their problem.

Corneal collagen crosslinking remains the only treatment that has been shown to slow or halt keratoconus and is now being offered to most patients soon after diagnosis. Not surprisingly, patients and their families are concerned by the prospect of eye surgery and often contact the Association for further information about the procedure, its success rate, whether they really need it and who is the best surgeon to perform it.

Our new website offers more complete information on crosslinking than previously and attempts to provide general answers to many of these questions. In July 2018, we completed a patient brochure on crosslinking in conjunction with Save Sight Institute which is now available for download on the website. The brochure is also being sent to all new members as part of their welcome kit.

As explained in the brochure, crosslinking is not a risk-free operation and should be offered only to patients with progressive keratoconus as crosslinking is not a cure for keratoconus – its purpose is to harden the cornea and thereby slow or halt progression in the disease.

Patients with the following conditions are unsuitable candidates for crosslinking:

- Corneal thickness of less than 400 microns
- Herpetic keratitis
- Concurrent ocular infection

- Severe scarring
- Neurotrophia
- History of poor corneal wound healing
- Severe dry eye
- Pregnancy
- Autoimmune disorders

About 3 out of every 100 patients having CXL will have worsening vision due to corneal haze, scarring, surface shape irregularities or infection. In the uncommon cases where the cornea becomes scarred affecting the vision, a corneal transplant may be required to restore a patient's vision. Hazing of vision is very common after crosslinking with some studies showing up to 90% of patients having haze after one year. However this generally clears up over time.

Because of these risks, which tend to be higher in younger patients, eye-carers prefer to monitor a patient for 3-6 months to determine whether crosslinking is required. This especially true for patients over 30 years as keratoconus tends to slow or stabilize after this time anyway.

The Association offers information on the procedure itself, and what to expect afterwards. It also puts patients in contact with others who have had the operation. Finally, we have videos on our YouTube channel which explain the procedure and the latest research into crosslinking.

The so–called Dresden protocol which involves removing the epithelium from the cornea, bathing the eye in riboflavin for about 30 minutes and then irradiating the cornea with ultraviolet A light for 30-40 minutes, has a success rate of 70-90%. It remains the "gold standard" in crosslinking and appears safe and effective in most patients.

We urge all patients considering crosslinking to ask the following key questions to their corneal surgeon

- Is my eye suffering from progressive keratoconus?
- If so, what type of crosslinking are you proposing. Is it the Dresden protocol (the current gold standard based on randomized clinical studies) or some other protocol?
- If the Dresden protocol is not being used, could you explain in detail what you propose to do?
- What evidence is there to support the use of this protocol and what results have been achieved to date?
- Are you submitting your results to the Save Sight Keratoconus Registry which began operating in late 2015? If not, why not?
 If so, will I be given the patient quality of life survey to complete to ensure my feedback on the operation and post-operative vision is properly reported and tracked?

As discussed earlier, the **cost** of crosslinking has been a major concern for people with keratoconus and their families: a crosslinking operation done privately by a corneal surgeon

averages around \$2,500-\$3,500 per eye, although some corneal surgeons charge significantly higher fees.

Since May 1, 2018, crosslinking for *progressive* keratoconus has been added to the Medicare Benefits Schedule and will be subject to a \$1,200 rebate. This means public patients will be able to access crosslinking for no out-of-pocket expense and significantly reduces the gap for crosslinking for privately insured and other patients.

Hopefully this will ensure that all patients requiring crosslinking will have access to the procedure at an affordable cost in the future.

Patients need to be wary of corneal surgeons raising fees to absorb the rebate and/or performing crosslinking on patients with stable keratoconus or an older patient whose risk profile for progression is much lower than adolescents and young adults.

The other major issue of **cost** raised by patients contacting the Association in 2017-18 relates to contact lenses. Larger more complex lenses, new materials, uncapped fees for optometric services have all driven up the cost to patients of obtaining contact lenses. Even if a person's keratoconus can be stabilized with crosslinking, these lenses are still often required for life by patients who have already lost significant vision before having the procedure.

Apart from patients being unable to afford these lenses now, we believe their high cost is making more patients seek out corneal surgeons for ill-advised surgery in the hope of "curing" their keratoconus. This surgery is being seen as "cheap" compared to a lifetime costs of replacing a lens every year or two at \$700-\$1,500 a pair or more. Although many corneal surgeons promise much from surgery, the outcomes in terms of improved vision are generally imprecise, rarely provide a long-term solution and often lead to further eye surgery later in life etc.

The Association maintains that contact lenses will generally provide the best long term corrected vision for people with keratoconus, if they can be fitted properly.

Last year we said we hoped to investigate why contact lens costs are spiraling upwards and what can be done. Our efforts in this regard are discussed in the Research and Advocacy sections of this report.

We will try to pursue this issue in 2019 – all assistance from members would be appreciated.

In the meantime, members should be aware that discounted contact lenses can be obtained in the Eastern states from the contact lens clinics at the major optometry teaching institutions – the Australian College of Optometry (Melbourne), the University of Melbourne, University of NSW (Sydney) and Queensland University of Technology (Brisbane) as well as at eye hospitals like the Eye and Ear Hospital in East Melbourne.

Finally, the Association is receiving regular requests from people around the world for information on research published some time ago regarding drops being trialed on animals which apparently have the potential to halt progression in keratoconus – something like crosslinking but without the exposure to UV light or other surgical intervention. We have no particular information about this research or when it might be trialed on humans. We will endeavor to find out more about this research and post information online in due course.

Support by example

Below we have listed some examples of the questions posed by members last year and outcomes.

- Prior to the introduction of the \$1,200 Medicare rebate for crosslinking, we fielded
 multiple requests from individuals and families looking for cheaper alternatives to
 full cost crosslinking by private practice ophthalmologists. We were able to provide
 information to these patients about the free crosslinking on offer in hospitals in the
 major capital cities.
- Tried to assist a woman whose keratoconus had progressed in one eye beyond the safe limit for crosslinking and who was looking for some way of restoring her vision. Unfortunately, after discussions with her eye-carers, it became clear she had refused crosslinking when it was still possible and now had little alternative other than contact lenses or ultimately a corneal transplant.
- Advised numerous newly diagnosed patients to beware of eye rubbing and to try to halt this habit if possible. Note: all new members receive a flyer on eye rubbing, why it is dangerous and how to treat eye allergies
- Assisted a family whose adult son with Down Syndrome had been diagnosed with hydrops and was looking for a corneal surgeon able to treat him. Provided the names of local corneal surgeons specializing in keratoconus and advised of the need to control eye rubbing if possible.
- Tried to assist another distressed patient of Dr Jim McAlister who had corneal transplants which failed to improve his sight. Provided some counselling and the names of alternate corneal surgeons and of specialist contact lens fitters.
- Assisted an older patient (60 years +) who wanted crosslinking to deal with his eye issues. He had been advised it wasn't suitable for older patients but wanted a second opinion. Sent a list of local specialist contact lens fitters for keratoconus for a full review to see if there were other issues affecting his vision.
- A patient with one graft and contact lenses was having trouble on hot windy days. Advised to wear wraparound sunglasses and sweat bands to protect his eyes.
- Provided booklet on corneal transplantation to numerous people awaiting a graft.
- Assisted a family whose son was having trouble using scleral lenses after crosslinking.
 Pointed them to a video showing how to insert and remove the lenses. Also
 suggested trying different lenses for sport and glasses as necessary if sclerals can't be
 managed. Discussed eye rubbing and obtaining a second opinion on the contact
 lenses.
- Sought information for a patient interested in trying ortho-k contact lenses on keratoconus. Consulted two specialist contact lens fitters for keratoconus who both agreed these were really not suitable for people with keratoconus as they worked by pressing down on the central cornea. This is usually thinnest in keratoconus patients.
- Assisted an international student having trouble with his contact lenses after crosslinking. We provided a list of contact lens fitters for keratoconus for a full review of their lenses.

 Counselled a distraught family whose 14 year old son had just been diagnosed with keratoconus and was seeking the best medical help. Provided some names of corneal surgeons for crosslinking. Received a lovely thank you note saying that the corneal surgeon was fantastic and they were much relieved and looking forward to a good outcome.

International Support

Every year, the Association receives requests from people experiencing issues with keratoconus in overseas countries.

- Last year, we had a request from a young woman from South Africa who was looking to share her experience with others. We directed her to the US National Keratoconus Foundation chat group kc-link which has an international following.
- A teacher in the Philippines requested information as to where her colleague could obtain free crosslinking. We suggested they try a local eye hospital or again seek assistance from the kc-link.
- A Chinese student living in Australia asked a series of questions about keratoconus
 on behalf of a cousin living in China. These related to the possibilities of obtaining
 treatment in Australia, the value of intracorneal rings, whether he would need to halt
 school to prevent progression and whether he could come to Australia for a corneal
 transplant. We did our best to answer these questions and sent our flyer on eye
 rubbing to explain how stopping this behavior could assist in slowing progression.
- A mother in Zimbabwe asked if glasses would be sufficient to correct her 15 year old daughter's vision as she was having issues with contact lenses. We suggested she have the contact lenses checked and that glasses were a useful backup.
 Another Zimbabwean girl was concerned about progression in her keratoconus and asked what she should do. We referred her to our treatments page and suggested she seek corneal collagen crosslinking.
- A man in the US asked about finding a corneal surgeon who would assess his eye records and evaluate his suitability for surgery. We were bemused by this request and told him America had excellent keratoconus surgeons but added we would help him find eye-carers should he plan to move to Australia. In the meantime, we told him to contact the US National Keratoconus Foundation for help in finding local specialists.
- A man in Nigeria asked for visa entry information under the mistaken belief Keratoconus Australia was a hospital that could perform surgery on his eye scarred by a glass injury. We were unable to help.
- Women from India and Sri Lanka also asked what to do about progression in their keratoconus. Again, we referred them to our Treatments pages and suggested they seek crosslinking.

Support by numbers

There was a sharp increase in support provided to people seeking assistance with crosslinking related issues. These tripled in number and accounted for 28% of total support logged in 2018 compared to only 12% of the total in 2017. As indicated above, requests

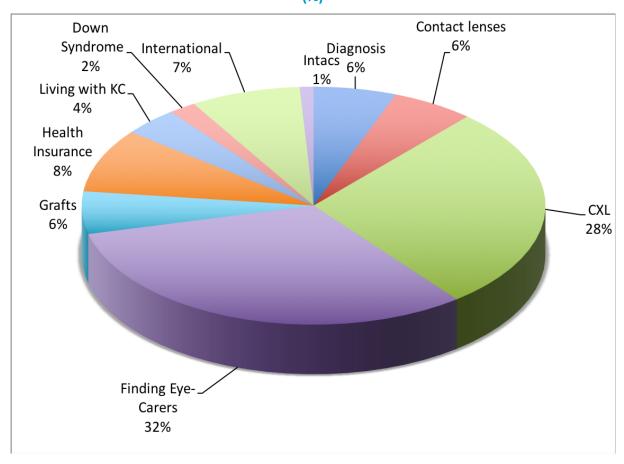
concerning crosslinking ranged from information about the procedure and after care, to costs, success rates, side effects and suitability for patients of different ages. Many of these people also were seeking information on specialists to perform the operation.

Direct requests for assistance in finding specialist eye-carers for keratoconus fell by around 21% from last year but still remained the largest single type of support provided to members. These requests accounted for around 32% of the total support contacts logged by the Association – down from 38% in 2017. As in previous years, most support provided by the Association resulted in us offering the names of local eye-carers to ensure patients received the highest quality care for their particular issue.

As noted above, the support relating to the cost of treatments and health insurance tripled in 2018 and accounted for 9% of total support contacts logged in 2018. There were significantly more requests for help with surgery related matters too, and these accounted for 6% of last year's total.

Requests for assistance after a keratoconus diagnosis were down by 37% last year while support for contact lens related issues was also down by one-third.

Support by Type 2017-18 (%)



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

Save Sight Keratoconus Registry

Keratoconus Australia has been a key partner in the development and expansion of the Save Sight Keratoconus Registry, which launched its crosslinking module in late 2015. The registry is the first of its kind in the world and will eventually allow clinicians to monitor and track a patient's treatment journey from diagnosis through use of spectacles and contact lenses to surgery, such as corneal collagen crosslinking and corneal transplantation and other emerging therapies. It also includes a patient quality of life survey for keratoconus patients, developed at Flinders University with the assistance of Keratoconus Australia.

The registry allows the collection of data via a web-based software tool developed as part of the Save Sight Institute's earlier Fight Retinal Blindness Registry project. The registry includes high-quality data on outcomes from keratoconus interventions and will help determine clinical effectiveness and safety of existing and emerging therapies and surgical techniques. It will also enable eye-carers to evaluate their own performance against national and international benchmarks. The use of patient quality of life data will assess whether these treatments are actually improving life for the patient.

Patient data entered into the registry is unidentifiable while an eye-carer's data is identifiable only by the treating eye-carer.

Although still focused on tracking crosslinking and its outcomes at this stage, agreements with the Australian Optometrists Association were initiated in 2017-18 at the request of Keratoconus Australia to ensure keratoconus data could be tracked before and after a patient is under the care of a corneal surgeon. This is critical to ensuring a lifetime picture of a patient's keratoconus and the outcome of treatments can be monitored.

We have helped fund the registry project and have a partnership agreement to share results from the registry's data analysis with the keratoconus community via information updates, brochures and public meetings. The Association also has representatives on the registry Advisory Committee. The first of these community updates came in October and November 2017, when the head of the registry, Professor Stephanie Watson, presented the early results from the registry to meetings of patients and eye-carers in Sydney and Melbourne (see Events).

Slides from these presentations can be found on the Keratoconus Australia website and in the Annex section of this report.

The second major advance in 2017-18 came from a request made by Keratoconus Australia in March 2017 to the registry team for a brochure that explained crosslinking in simple terms and also outlined the purpose of the Save Sight Keratoconus Registry to engage patients in the project and its objectives.

We thought it would be a simple task that could draw on existing material available at SSI and the Sydney Eye Hospital. As it turned out, there was no such information readily available and we turned to Moorfield's Eye Hospital in London for their guide to crosslinking. After many redrafts, a final version was completed in July 2018 and was loaded on to the Crosslinking page of our website for download. It is also being sent to all new members as part of their welcome kit.

Considerable progress has been already made by the Save Sight Keratoconus Registry in collecting and analyzing data on crosslinking procedures being performed in Australia and overseas.

These early results played an important role in gaining approval from the Australian Government for the inclusion of crosslinking on the Medicare Benefits Scheme – a critical outcome that patients and eye-carers had been advocating for years and which will now benefit thousands of Australian keratoconus patients (see Advocacy).

Yet more needs to be done from a patient perspective.

Since the outset of the Registry project, Keratoconus Australia has been advocating for the publication of the names of participating eye-carers to provide patients with an easy means of checking if their ophthalmologist was participating in this groundbreaking research project and benchmarking their own performance against best practice treatments. We argued that transparency by Save Sight Keratoconus Registry around the doctors participating in the registry can act as both carrot and stick to push more ophthalmologists (and later, optometrists too) into the registry as it will be seen as a positive for them to be involved. That in turn should benefit everybody by augmenting the data flow into and out of the registry. Finally, as more eye-carers join the registry, there is less justification for others to remain outside of it.

[Indeed, the government's Medical Services Advisory Committee which made the recommendation for a \$1,200 fee for crosslinking went much further: it recommended **mandatory** reporting by ophthalmologists to a registry and a review of crosslinking data collected after two years. (See Advocacy)]

So far, there has been considerable resistance to this idea on grounds of privacy. However, we fully intend to pursue this demand as it was a key part of our initial partnership understanding with SSI. At this stage, SSI is offering to include the participating eye-carers on their Save Sight Registry webpage, which already includes the names of ophthalmologists participating in other Save Sight Registry projects. They also say participating eye-carers can display a Save Sight Keratoconus Registry branding logo. This could provide an acceptable compromise. The Association will pursue this issue to conclusion, hopefully in 2019.

The second area of concern with the current functioning of the registry relates to the collection of patient quality-of-life information. As noted above, this is being collected via the excellent quality-of-life survey developed by Flinders University. The questionnaire is web-based and is offered to patients to fill out on an iPad/tablet in ophthalmologists' practices during regular eye reviews. However, by mid-2018 it was apparent that the

number of quality-of-life surveys being completed was currently well below the number of patient visits being recorded by the registry and there is still inadequate analysis of those surveys being done.

Keratoconus Australia believes these quality-of-life surveys are an essential ingredient in research into the safety and efficacy of any treatment or therapy. Many a patient has been told a corneal transplant has been a success in surgical terms, only for the patient to later complain they can't see much out of it and/or can't be fitted with comfortable contact lenses to improve their best corrected vision.

Similarly, a majority of crosslinking patients suffer from post operation haze – often significant - which can cause a deterioration in their vision for long periods of time – in spite of a stabilization in their actual keratoconus.

So, we believe validated patient feedback on how they are faring after a procedure must be a part of any research project aimed at scientifically assessing the safety and efficacy of that procedure.

One idea floated by the Association was the development of a **smartphone application** to enable patients to enter their own quality-of-life data from their phones more frequently and as the need arose. This would require further development of the registry. But it could offer additional benefits in patient-eye-carer interactions if patient feedback could be monitored in real time to ensure certain critical thresholds were being respected.

Talks were held in July and August 2018 about developing such an app but to date a project has not been defined. As noted in Fundraising, the Association applied unsuccessfully in 2017-18 for a \$5,000 Transurban Community grant to fund this smartphone app development and has reapplied in the December 2018 funding round.

Finally, at the end of the 2017-18, the Save Sight Keratoconus Registry received a large private donation to allow it to engage a **full-time research fellow**. Professor Stephanie Watson says this researcher is currently being engaged and should supercharge the registry's ability to engage with eye-carers and patient groups, collect and analyze data, and publish research papers.

We look forward to a wealth of information from the Registry in the near future.

Centre of Eye Research Australia (CERA)

During 2017-18, Keratoconus Australia held a series of informal meetings and exchanges with researchers from the Centre of Eye Research Australia (CERA) concerning proposals for keratoconus-related research.

As indicated in last year's annual report, CERA has launched a **Keratoconus International Consortium (KIC)** – "a global collaborative initiative – to act as an overarching vehicle that consolidates all research within the field and generates collaborative opportunities to address key issues faced by keratoconus patients" according to the CERA website. "KIC has over 20 national and international corneal specialists, willing to collect and share data with the overarching goal of expanding our knowledge about keratoconus. KIC will generate more data from a larger number of patients than can be achieved by a single research team, enabling more effective testing of hypotheses and treatments for keratoconus."

CERA told Keratoconus Australia in a paper sent in August 2017 that "the KIC project has been designed along the lines of The Lowy Medical Research Institute's MacTel Project

Consortium – an international research collaboration among clinicians and bench scientists to study idiopathic Macular Telangiectasia Type 2 (MacTel). The MacTel project aims to improve clinical understanding, raise awareness of the disease, and identify causes and appropriate treatments. Prior to the creation of the MacTel project in 2005, there was little research into the condition despite it being identified in 1977. In the decade since, the project has enormously progressed research bringing a potential therapy to clinical trial."

At the time, CERA said "A key feature of CERA's KIC involvement will be patient engagement – both in the studies and trials as well as providing a resource centre for people with keratoconus. Resources will include publications as well as regular forums for direct patient engagement. CERA is keen to work with groups such as Keratoconus Australia to design a patient engagement framework." We have not been contacted by CERA about this project yet.

CERA is engaged in other corneal and keratoconus research relating to stem cells (culture of endothelium and epithelium cells for transplantation into diseased and damaged eyes), modification of riboflavin for more effective use in crosslinking and assessment of accelerated or flash crosslinking for faster procedures.

Keratoconus Australia was not directly involved in these initiatives in 2017-18 but remains open to collaboration as required.

In early 2018, the Association did meet with **Dr Srujana Sahebjada**, CERA's Post-Doctoral Research Fellow/ Optometrist, Ocular Genetics Unit who has conducted research in the past into different aspects of keratoconus in conjunction with Keratoconus Australia.

We discussed launching joint research to update Dr Sahebjada's early work on the economic cost of keratoconus to examine the causes of the recent jump in contact lens costs and impacts on patients. The Association believes this research is a critical step towards mounting a campaign to lower the cost of contact lenses in Australia.

Dr Sahebjada has suggested doing a study on economic burden of keratoconus and its management on the patients, mainly on the mild to moderate cases wherein the contact lens costs are high.

She is also considering a study on the impact of keratoconus on quality of life of the subjects, focusing on the main aspects of vision and daily life activities, rather than mere clinical information like corneal curvature. This is important and hasn't been looked at in children.

Dr Sahebjada plans to prepare an information flyer for the Association to distribute to invite members to participate in these important studies. She is also seeking to link up with eyecarers around Australia to help her gather relevant information for these studies.

Quality-of-life of older patients

One issue that emerged last year in discussions with Melbourne specialist contact lens fitter, Richard Lindsay, was how older patients are coping with keratoconus and managing treatments and contact lenses.

Mr Lindsay suggested that a collaborative effort with Associate Professor Konrad Psedovs from Flinders University in Adelaide who developed the quality-of-life questionnaire, now being used as part of the Save Sight Keratoconus Registry, could be a useful starting point for this type of study.

In October 2016, Vision 2020 Australia requested input from members regarding strategy on aged care. At that time, the Association responded as follows:

The issue for keratoconus patients is that the main form of long-term vision correction is rigid gas permeable contact lenses. These become harder to wear if dry eye develops with age. Care and insertion of these lenses can become problematic with age and particularly if older patients suffer from diseases that may impact on their ability to handle such small items e.g. arthritis etc. They may then require carers to assist with the insertion and removal of lenses.

We would like to see a survey of our members to determine what their needs are as they age. As keratoconus generally stabilises by middle age and beyond, we would think that a general population survey of people using contact lenses in particular (or spectacles) may cover the requirements of older keratoconus patients too.

We would note that the introduction of corneal collagen crosslinking which aims to slow or halt progression at an early stage may in future reduce the number of people who arrive at old age with severe vision loss due to keratoconus.

Perhaps one question of interest would be to see if keratoconus patients have a higher rate of other eye disease (glaucoma, retinal, MD etc) later in life than the general population.

Vision 2020 Australia responded in July 2017 that it had referred our request for a survey of the needs of older patients to the Centre for Eye Research Australia, which would contact us about this. A follow up response from Vision 2020 Australia indicated that CERA's recent collection of epidemiological data from 400 keratoconus patients could be used to determine whether older keratoconus patients may suffer other eye disease.

The Committee of Management has noted this issue and hopes to examine the needs of older keratoconus patients in 2019. We recognize however, that data collected by the Save Sight Keratoconus Registry may cover this requirement for better quality-of-life information over the long term.

However, older patients generally have stable keratoconus and do not generally require interventions such as crosslinking or corneal transplantation (apart from regrafts). Therefore unless optometrists are entering their keratoconus data into the Save Sight Keratoconus Registry, a separate study of older patients may be required.

Deakin University

Keratoconus Australia also held brief talks with researchers from **Deakin University** in Victoria, who are planning to launch a large-scale screening program for keratoconus in Victorian schools. Dr Sahebjada says she would join up with this program as part of her quality-of-life study for children.

Keratoconus Australia told the Deakin researchers we would support this screening program but wanted to be sure that a proper support path was created to assist families whose children were diagnosed with the disease. In particular, we believe that all newly diagnosed patients should be referred to specialist eye-carers for keratoconus.

Deakin is also trying to conduct a study to determine the prevalence of keratoconus within the Australian community and to thereby identify markers for early detection. This could form part of a study emanating in Switzerland to obtain a global perspective of keratoconus.

The University of New South Wales (UNSW)

Researchers at the UNSW School of Optometry and Vision Science contacted Keratoconus Australia in September 2017 for assistance in recruiting 15 volunteer research participants for their study on the regional thickness changes within the cornea in keratoconus.

The study was designed "to compare the corneal thickness distribution between keratoconus patients and controls (both myopic and normal patients) to understand the progress of the disease and the influence of additional variables such as contact lens wear." Specifically that involved investigating "the relationship between the central corneal epithelial and stromal thickness compared to the peripheral corneal thickness in eyes with keratoconus to those without the disease."

After receiving the necessary documentation regarding study and design and ethics approval, the request was approved by the Committee of Management and letters calling for volunteers were sent to NSW members. Members responded generously and the necessary volunteers were recruited.

Maria Markoulli, Postgraduate Research Coordinator and our contact on the research project, informed us the study was completed in late 2017 and sent us a kind thank you letter and results poster in December (see below). Keratoconus Australia received appropriate acknowledgement of its assistance.

Key results from the study were:

- The MATLAB and CASIA measurements of corneal thickness were not comparable with the MATLAB program consistently overestimating corneal thickness across both layers.
- There is a moderate negative relationship between the stromal and epithelial thickness for keratoconus in the periphery. This was the only statistically significant relationship.
- A significant difference in stromal thickness between those with keratoconus and controls was found.
- Future studies are required to further develop the automation of the method and investigate the relationships found.
- Further research should aim to quantify the peripheral relationship to be used as a marker in the keratoconus cases which are harder to diagnose.

Thank you letter from UNSW

On behalf of our research group, I wanted to thank you for your assistance with our study recruitment this year. Please find attached a poster summarising this work. This work was undertaken as a collaborative effort between the School of Optometry and Vision Science (Vinod, Usha, Nick and myself) and the Save Sight Institute (Gerard Sutton and Jingjing You).

Wishing you a very merry Christmas and all the best for 2018.

Kind regards,

Maria Markoulli

PhD MOptom GradCertOcTher FBCLA FAAO

Senior Lecturer | Postgraduate Research Coordinator | School of Optometry and Vision Science Deputy Editor | Clinical and Experimental Optometry

UNSW Final Results Poster



Regional Corneal Thickness Variations in Eyes with Keratoconus



Usha Ranjitkumar, Nicholas Stanley, Dr. Maria Markoulli, Dr. Jingjing You, Dr. Vinod Maseedupally

INTRODUCTION

- Keratoconus is a progressive condition of the comea that causes a cone like protrusion, inducing significant blur for the individual
- Little is understood of the pathogenesis of Keratoconus and few have investigated the relationship between Stroma and Epithelium separately. Preliminary studies on excised eyes suggest a peripheral relationship which required further investigation.
- The Tomey CASIA SS-1000 is a swept-source OCT is an effective repeatable measure for corneal thickness which is quick and non-invasive.
- In order to better detect keratoconus in the early stages and understand the cause may better empower clinicians in the management of patients and family members with this condition.

• To investigate the relationship between the central corneal epithelial and stromal thickness compared to the peripheral corneal thickness in eyes with keratoconus to those without the disease.

SUBJECTS

- No retrieval

 Rx between +0.75DS and -6.00DS and corneal toricity ≤1.00D.

 No history of ocular trauma or surgery, including collagen cross linking

 No use of Ortho-Keratology contact lenses

 No pregnant or nursing mothers

 No evidence of ocular disease, excluding keratoconus.

- Contact lens wearers were advised to cease lens wear for at least 48 hours before study.

STUDY DESIGN

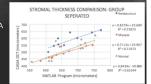
- Pre-Screening: questionnaire, auto-refraction, Medmont topography and slit lamp examination were performed to both check eligibility and catergorise the subjects into their appropriate sub-group.
- Medmont E300 (Placido-disc) Version 6 (Melbourne, Australia):
 - Composite maps were produced using the central topography scan along with the 4 directions of gaze
- Study Measurements: CASIA OCT 3D customised scans were performed only on eligible subjects

STUDY MEASUREMENTS

- Tomey CASIA OCT Version 6R.2 (Tomey Corp., Nagoya, Japan):
 3D customised scan taken which captures the whole cornea, line slices through 45°, 90°, 135° and 180° were exported
 - Customised Matlab (R2017b) program (CMP) used to detect the edge of the front surface of the epithelium, the back surface of the epithelium and the back surface of the endothelium-> best-fit Piecewise Cubic Hermite Interpolating Polynomial (PCHIP) was used to fit data points.
 - The central 8mm corneal diameter was analysed

ANALYSIS

- A comparison revealed the MATLAB consistently overestimated cornea thickness comparted to CASIA OCT. (Figure 1)
- Interestingly, Keratoconic corneas were more significantly affected compared to the control group. (Figure 2)



RESULTS

- 55 subjects categorised into two groups: Keratoconus and Control
 - Keratocons group (N=10) aged between 19 and 67 years (22.7 ± 4.0 years)
 - Control group (N=45) aged between 18 and 37 years (33.2 \pm 13.7 years)
- The relationship between peripheral stroma and epithelium in each group is given in Figure 3

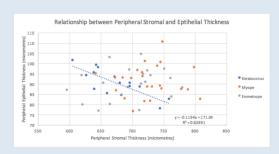


Figure 3. Relationship between stroma and epithelium in the periphery

• Box plots showing the stromal thickness between groups with Keratoconus being

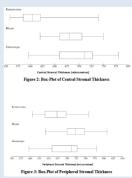


Figure 4. Stromal thickness across the three groups centrally and in the periphery

DISCUSSION & CONCLUSION

- The MATLAB and CASIA measurements of corneal thickness were not comparable with the MATLAB program consistently overestimating corneal thickness across both
- There is a moderate negative relationship between the stromal and epithelial thickness for keratoconus in the periphery. This was the only statistically significant relationship.
- A significant difference in stromal thickness between those with keratoconus and controls was found.
- Future studies are required to further develop the automation of the method and investigate the relationships found.
- · Further research should aim to quantify the peripheral relationship to be used as a marker in the keratoconus cases which are harder to diagnose

REFERENCES

Acknowledgments

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.

These informal contacts continued during 2017-18 and the Association thanks all the eyecarers 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;
- Providing eye-carers with information booklets, flyers and brochures on keratoconusrelated issues;
- The Association also assists with media requests and comments for articles on keratoconus

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 2018, 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.

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?

Keratoconus Clinics for non-health card holders

The University of Melbourne's Eyecare optometry teaching practice operates a keratoconus clinic that provides an avenue for all Keratoconus Australia members to obtain spectacles and contact lenses at steep discounts.

This Keratoconus Australia initiative provides an opportunity for optometry students to gain valuable experience in full fits of all types of contact lenses on keratoconus and post-graft patients under the supervision of specialist keratoconus contact lens fitters.

Appointments at Melbourne EyeCare are bulk billed and initial appointments generally take around two hours.

We urge our Victorian members seeking relief from the rising cost of contact lenses for keratoconus to consider the Eyecare keratoconus clinic.

The University of NSW offers a similar service at its Optometry Clinic as does Queensland University of Technology. (see Advocacy)

Consulting Eye-carers

We again recognise the invaluable contribution of many eye-carers in the keratoconus community who answer questions from our members and hold informal discussions with

committee members. These contacts are a two-way affair and enable us to provide feedback on our members' concerns. We have a range of information resources available for eyecarers and continue to provide these at a nominal cost to eye-carer practices.

We also maintain a list of these keratoconus specialists to assist members and their families in obtaining the best possible care in their area.

We thank Sydney optometrists Margaret Lam and Mark Koszek for providing us with their notes from their November 2017 KeraClub presentation on the pros and cons of large and small contact lenses

Eye-carer projects still in-waiting...

As discussed last year, the Association remains interested in launching two new projects in conjunction with keratoconus eye-carers in an attempt to improve the quality of care and treatment for people with keratoconus.

- One way of expanding and formalizing our links with eye-carers that has been canvassed is the creation of a scientific committee to advise Keratoconus Australia on all matters relating to keratoconus, its management and treatment and research in this field.
- Also still on the radar, the original submission to the University of Melbourne that led
 to the creation of the keratoconus clinic at UoM's Eyecare practice also included a
 proposal for the creation of a post-graduate scholarship to enable an outstanding
 optometry graduate the opportunity to further their studies in keratoconus.

Although in abeyance since put forward, further discussions were held in early 2018 to implement this part of the original proposal.

This initiative – if adopted – would involve providing an annual bursary to the candidate selected by a panel of optometrists in conjunction with Keratoconus Australia to enable him/her to travel around Australia to work in the leading keratoconus practices in each state. Funding will be an issue and hopefully cofunding with the optometry community can be negotiated.

Members and eye-carers experienced in keratoconus and interested in funding and assisting the Association in advancing these proposals should contact us.

ADVOCACY

Australian Government includes Crosslinking on Medicare Benefits Schedule

In a huge win for keratoconus patients and their families, the Australia Government has finally accepted patient advocate and eye-carer pleas to cover the cost of crosslinking under its Medicare Benefits Scheme (MBS).

The government's decision was announced in early April 2018 and came into force from May 1, 2018. The fee for a crosslinking procedure was set at \$1,200 per eye and will apply in cases where progressive keratoconus had been demonstrated. This was in line with the top end recommendation by the Australian Government's Medical Services Advisory Committee (MSAC), which reviewed an application by the Royal Australian and New Zealand College of Ophthalmologists for crosslinking to be included in the MBS.

No guidance was made about the particular crosslinking protocol subject to the fee. This reflected the MSAC recommendation that the MBS descriptor should not specify details of the crosslinking protocol "as this may limit clinicians' ability to use the most appropriate procedure according to the best available evidence." In this regard MSAC added "However, given that there are variations in both the complexity and duration of the procedure, MSAC recommended it would be appropriate to review the MBS fee for CCXL two years after MBS listing."

Given the difficulty of obtaining evidence on the safety and efficacy of crosslinking from clinical trials, MSAC had emphasized that MBS listing be linked with a requirement "for mandatory recording of the types of CCXL services provided and their outcomes in a CCXL register." It is not clear if mandatory reporting to a registry has been implemented at this stage.

In any event, the \$1,200 fee and the resulting benefit to most patients outside of the public system of \$900 (75% of fee), should reduce significantly out-of-pocket costs to patients who generally are charged by ophthalmologists \$2,500 to \$3,500 (or higher) per eye for crosslinking.

It also makes the operation available to public patients in eye hospitals for a minimal out-of-pocket cost.

The government's dependence on data from the Save Sight Keratoconus Registry for its decision to include crosslinking on the MBS fully justifies the decision by Save Sight Institute to create its Keratoconus Registry and for Keratoconus Australia and its members to provide it with significant funding and support.

More information needs to be gathered in the coming months on how the MBS fee will affect the numbers of crosslinking procedures done in Australia. Already many patients without clear progressive keratoconus were being crosslinked and some eye-carers fear an upsurge in these operations despite the risks to patients for no demonstrable benefit.

In its advice paper, MSAC had anticipated over 2,400 patients accessing crosslinking in the first year after a rebate was introduced, falling to under 400 by year 5. MSAC also expects the cost of crosslinking to the government will decline over time because of a reduced number of corneal transplantations being performed and lower costs of eye banking as a consequence of crosslinking. Actual savings are likely to be higher than its estimates, as MSAC did not include the costs of other vision aids which may be rendered unnecessary, such as spectacles and complex contact lenses, etc.

Now what?

Based on the findings and recommendations of MSAC, Keratoconus Australia believes some of the key issues to be elucidated include:

- Whether mandatory reporting of crosslinking procedures will be enforced as recommended by MSAC;
- Will RANZCO accept and support the mandatory reporting requirement?
- Whether there will be a two-year review of data and protocol safety and efficacy;
- If Save Sight Keratoconus Registry will receive government funding to support it now given its critical monitoring role. We note the Australian Corneal Graft Registry recently was awarded a \$500,000 grant from the Australian Government Organ and Tissue Authority (DonateLife);
- What is the average out-of-pocket gap experienced by patients.
- Other issues to be resolved:
- When is optometrist data going to be entered into the Save Sight Keratoconus Registry?
- Will data from the Australian Corneal Graft Registry be incorporated into the Save Sight Keratoconus Registry?
- Does the Save Sight Keratoconus Registry have the capacity to analyze whether keratoconus and crosslinking patients have higher rates of other eye disease later in life?
- What progress is there on the QOL app?

Note: Keratoconus Australia made a submission to the MSAC inquiry into the RANZCO application. The Association supported a subsidy of around \$1500 per eye in the case of progressive keratoconus. Details of the Keratoconus Australia submission were published in the 2014-15 Annual Report.

Corneal collagen crosslinking is now a routine procedure recommended by ophthalmologists to all patients with progressive keratoconus under the age of about 50. Crosslinking costs range from about \$2,500 - \$3,500 per eye. Prior to the government's decision, the procedure was being offered free through a very limited number of hospitals in Australia.

In its submission to MSAC, the Association noted that keratoconus specialists currently urge patients to undergo crosslinking, causing many patients and their families to suffer distress because of the financial burden associated with this procedure. This adds to concerns over

deteriorating vision and the prospect of severe vision loss over time. With the cost of contact lenses spiraling upwards plus sundry expenses on solutions and regular checkups, a keratoconus diagnosis can be the start of an expensive journey for many – especially those with progressive keratoconus.

Corneal collagen crosslinking costs

For patients considering crosslinking outside the public health system, we again note that there can be wide discrepancies in the cost of corneal collagen crosslinking procedures. This is still of particular concern as patients may encounter significant variations in out-of-pocket costs depending on the ophthalmologist performing the operation.

A survey done by Keratoconus Australia indicates that reputable keratoconus specialists around the country are charging between \$2,500-\$3,500 per eye for crosslinking. These costs generally exclude an initial consultation and may vary depending on several factors – notably, how many follow-ups are included in the first 3-6 months after the operation.

However, many patients are being quoted much higher fees and it is important for patients to contact the Association if they think their ophthalmologist is quoting unreasonable fees for this critical procedure.

A better deal on contact lenses

There has been no significant change to report in 2017-18 in the situation facing wearers of contact lenses for keratoconus. Costs keep going up, making it harder for patients to access what most practitioners consider the gold standard treatment for the management of vision loss from keratoconus.

Optometrists claim rising costs are linked to larger, more complex lenses that assist patients in avoiding surgery like corneal transplantation, which would have been deemed mandatory with the types of lenses available 5-10 years.

Yet as previously reported, the perverse effect of the high recurring cost of lenses, which need to be replaced every 12-36 months, is that patients tend to seek help from corneal surgeons for other surgical therapies to reverse their vision loss. This often leads to otherwise unnecessary surgery which fails to yield the desired result and may need to be redone in the future. Many of these patients still require spectacles or contact lenses to achieve best visual acuity.

As reported in our Research section, we are trying to initiate studies into the economic burden of rising optometric costs and their impact on the quality-of-life of patients.

Unfortunately, research is a slow process requiring large grants and other funding – results can take years and reports are often ignored.

The Association therefore plans to continue its efforts to seek other ways around this high cost treatment regime. All ideas and assistance will be welcome.

In the absence of lower prices or higher rebates on contact lenses for keratoconus, Keratoconus Australia again notes that members can access cheaper lenses in a number of ways.

We have established an agreement with the University of Melbourne's Eyecare practice that offers a range of lenses for keratoconus at a 50% discount. The Eye and Ear Hospital in East

Melbourne has also opened a keratoconus clinic which is offering contact lenses and crosslinking at minimal cost to patients.

Similar services can be obtained through the Sydney Eye Hospital for crosslinking and the University of NSW eye clinic for contact lenses (although this is not a specialised service for keratoconus). Low income patients without health cards can obtain free services via the UNSW clinic on a means test basis.

In Brisbane, patients referred to the corneal clinic at Mater Hospital with a visual acuity of less than 6/12, can receive a script for contact lenses to be fitted by one of the local keratoconus specialists and billed to Mater. Queensland University of Technology (QUT) also offers a contact lens fitting service through its Optometry clinic.

These are just some of the options available to patients experiencing financial difficulty in purchasing contact lenses (and crosslinking) for keratoconus.

Patients can also request bulk billing of optometrist services when experiencing financial hardship. It never hurts to ask. Many optometrists have told us they can provide significant discounts on contact lenses in special cases.

Vision 2020 Australia

Keratoconus Australia is currently an associate member of Vision 2020 Australia, the peak body in Australia for all eye health related organizations. In support of its goal of eliminating avoidable blindness and vision loss in Australia, Vision 2020 Australia submits position papers to the Australian Government on vision related issues on behalf of the eye health community.

In June 2018, Judith Abbott, a former optometrist, took over as CEO of Vision 2020 Australia and requested an opportunity to meet with the Association and hear our views on issues important to our members. KA President, Larry Kornhauser, subsequently met with Ms Abbott who expressed a desire to assist with our campaign to make contact lenses more accessible to patients. We look forward to making progress with Vision 2020 Australia in the coming year.

Keratoconus Australia has a representative on the Vision 2020 Prevention and Early Intervention Committee.

We request that anybody else who is interested in assisting with patient surveys or eye health policy contact the Association to participate in the Vision 2020 Australia committees during 2018. Teleconferencing is available for members unable to attend the Melbourne meetings.

Last year, Keratoconus Australia expressed support for the Vision 2020 Australia position paper on aged care.

Optometrists

The Association has previously asked members to assist in lobbying Optometry Australia for support in its campaign over the cost of contact lenses. We urge members who have experience and time to engage in this type of advocacy to contact us immediately so that this matter can be progressed in 2019.

Write to your Private Health Fund!

As always, we repeat our suggestion that members put pressure on their private health funds to recognize the special nature of contact lenses for keratoconus and to provide higher rebates on claims for these specialized 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/2017/11/KA-Insurance-letter.pdf.

Tracking Outcomes of Crosslinking seminars

With the support of Keratoconus Australia, the Save Sight Institute launched the world's first Keratoconus Registry in 2015 to track outcomes of crosslinking performed on keratoconus patients in Australia. Crosslinking, which involves the use of riboflavin drops and ultra-violet light to stiffen the cornea, is the only treatment which offers a hope of slowing or halting progression in keratoconus.

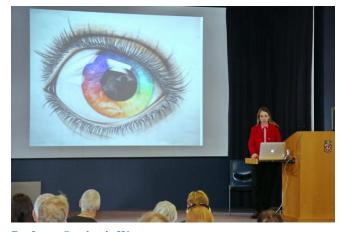
A key element in our partnership agreement with Save Sight Institute is the publication and dissemination of findings from the Save Sight Keratoconus Registry. This is being done in multiple ways.

As part of this effort, the head of the Save Sight Keratoconus Registry project, Professor Stephanie Watson, presented two fascinating seminars in Melbourne and Sydney last year on Tracking Outcomes of Crosslinking. Professor Watson outlined the early results from the

Registry and explained why it is important that all crosslinking patients become involved in the Registry project. She urged patients to ensure their corneal surgeons are reporting their surgery results and patient quality of life survey information to the Registry.

Professor Watson said that the registry had analysed data from almost 2,300 eyes of which over 1,000 had undergone crosslinking.

Ophthalmologists from 37 sites in



Professor Stephanie Watson

Australia, New Zealand and overseas had already joined the registry.

She explained that the registry hoped to provide a clearer picture of how different protocols (epithelium on or off, slow or accelerated irradiation, types of riboflavin used, types of ultra violet light used etc) affected outcomes.

She also revealed that the initial focus of the registry on collecting data on crosslinking outcomes had been widened to include data on patients' keratoconus from diagnosis to through contact lenses to surgery if necessary. The inclusion of data collected by optometrists will be the next stage in the registry's development.

The full video of her presentation at the Keratoconus Australia seminar held in Melbourne in late October 2017 can be viewed on the Keratoconus Australia YouTube channel. Slides from the presentation have been included in the Annex of this report.

Professor Watson presented a similar talk to the Kera Club in early November 2017. The



L-R Margaret Lam, Professor Stephanie Watson, Mark Koszek

Kera Club is a joint Keratoconus Australia-Save Sight Institute initiative to support people with keratoconus in NSW.

Patients attending her Sydney talk also heard from optometrists Margaret Lam and Mark Koszek who shared their extensive experience in contact lens fitting for keratoconus patients and engaged in an entertaining debate about the relative merits of big contact lenses vs smaller contact lenses for keratoconus patients.

A video of this meeting is available on the SSI

website. https://www.youtube.com/watch?v=6JoK9Alksug&feature=youtu.be

Ms Michelle Urquhart hosted the Keraclub session and is the contact point for NSW patients interested in receiving support and becoming involved in the NSW Keratoconus Club. Michelle can be contacted by email on info@keratoconus.org.au.

Members are welcome to contact the Association with their ideas for future information seminars and social meetings.

Free Audio and Video Podcasts

Free audio and video podcasts of recent Keratoconus Australia seminars are available on the Association's new website and YouTube channel.



Michelle Urquart

THE ASSOCIATION

Membership

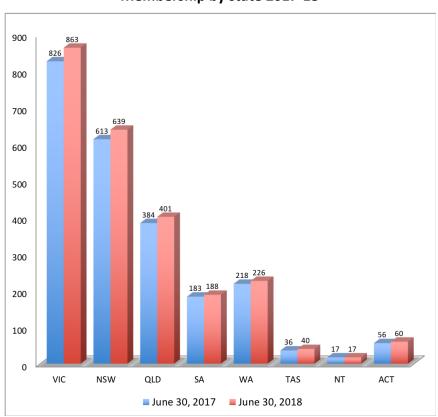
At 30 June 2018, Keratoconus Australia had 2,434 registered members. This represented an increase of 4.3% (adjusted) above the 2,335 members registered one year earlier.

Of the larger states, membership grew fastest in Victoria reaching 863, up 4.5% compared to the same time last year (826 members). Similar growth rates were recorded in NSW (+4.2% to 639 members) and Queensland where membership rose 4.4% to 401 members. The largest percentage gains (albeit off a very small base) were made in Tasmania, where membership was up 11% to 40 and ACT (+7% to 60 members), while in Western Australia a gain of 3.7% was recorded to 226 members. (see graph)

Victoria, the Association's home state, remained the Associations largest state accounting for 35.4% of the total membership at the end of the 2017-18 financial year. That proportion has remained largely unchanged over the past six years. NSW continues to account for around 26% of the membership base, followed by Queensland at 16.5%, and WA at 9.3% slightly ahead of South Australia at 7.7%.

(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 2017-18



Supporters

The Association receives benefits from a range of companies 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 2017-18, 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.

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 students optometrists.

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 Annex). This is now available for download on the crosslinking page of our website at https://www.keratoconus.org.au/wp-content/uploads/2018/08/KA-crosslinking-Brochure2018.pdf.

Both the crosslinking brochure and the Hands Off Your Eyes poster are being sent to all new members as part of their welcome kit and 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 now also 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.mycause.com.au/.

A number of members have taken advantage of this facility to run campaigns in support of Keratoconus Australia and its work.

Grants

In April 2018, the Association, in collaboration with Save Sight Institute, lodged an application for a \$5000 grant from the Transurban Community Grants program. The funds would be used to develop a smartphone application (APP) to track the benefit to patients of treatments for keratoconus.

The patient quality-of-life data collected via the APP would be used by the Save Sight Keratoconus Registry, an international web-based tool for outcomes data collection, to establish "best practise" treatment guidelines for keratoconus clinicians.

Transurban notified the Association on November 2, 2018 that the application was unsuccessful.

We have resubmitted the application for the current round of grants which closes in December 2018. We will keep members informed on progress in our latest bid for funding.

Donations

We would like to thank all donors who made significant contributions during the 2017-18 financial year. Particular thanks again go to the Ray and Margaret Wilson Foundation, and to the Petard Tarax Charitable Trust for their generous contributions to the Association.

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

Please give generously.

Local Groups

NSW

A long overdue NSW keratoconus patient group launched in October 2016 with the assistance of Keratoconus Australia member Michelle Urquart and the Save Sight Institute. The new group is called the Keratoconus Club or KeraClub. Already it is providing a forum for learning more about keratoconus from the professionals, exchanging stories and experiences about living with keratoconus and discussion around the issues that interest NSW members in particular.

A second meeting held in November 2017 was also well attended. Speakers included Professor Watson, who presented the latest results from the Crosslinking Registry and Sydney optometrists Margaret Lam and Mark Koszek who shared their extensive experience in contact lens fitting for keratoconus patients.

Ms Urquart is seeking ideas for future Sydney-based activities during 2019. We strongly urge Sydney-based members to contact us if they would like to assist Michelle in the coming 12 months.

Despite interest from members on the Gold Coast, Tasmania, SA, and the ACT in forming local groups, none have materialized. If you want to make a long-term commitment to organizing drinks or social events with other keratoconus patients, please contact us and we will assist in contacting other people in your area.

New Logo

As announced in our 2016-17 Annual Report, work on a new logo was completed in August 2017 and we launched our new logos and colours, designed by Jorge Tarzia of Yolk design.



Website

Also announced in last year's Annual Report was the launch of the Association's new website at www.keratoconus.org.au.

Despite a number of setbacks, this work was finalised in August 2017 with an enormous amount of advice and help from Matthew Blode. We acknowledge Matthew's assistance in fine tuning the site and thank him for his important contribution.

Website statistics

The new website is attracting increasing numbers of visitors. Since going online, the number of users has almost doubled from around 550/month in August 2017 to over 930 in June 2018. Page views have fluctuated in the range of 2,500 to 3,000 a month since inception. In total, 5,846 users have visited the site since September 1, 2017 (the first full month of operation) resulting in almost 20,000 page views, according to Google Analytics. Some 76% of users are new visitors.

As expected, the vast majority of visitors are located in Australia (71%) followed by the United States (9%), India (3.5%), Canada (2.7%) and the United Kingdom (1.6%). Within Australia, user location broadly follows the membership patterns noted above i.e. 25% are located in Melbourne, followed by Sydney (17%), Brisbane (9%), and Perth and Adelaide each around 4%.

The switch to a smartphone friendly layout was well justified: over 54% of users are accessing the new site on their phones.



Home page of new KA Website

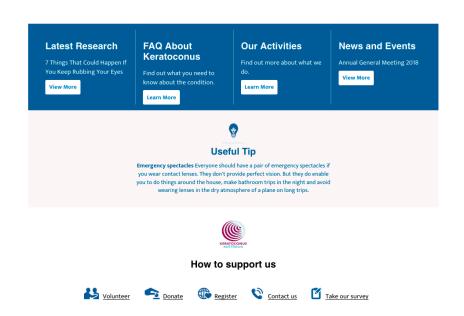


About Keratoconus

Keratoconus (KC) is a thinning of the central zone of the cornea. As this progresses, normal eye pressure causes the round shape of the cornea to distort and a cone-like bulge develops, resulting in significant visual impairment.

Symptoms blurring and shortsightedness, light sensitivity, halos and ghosting around light sources that can make night driving difficult.

Treatments spectacles in the early stages. Then contact lenses, usually rigid. Corneal crosslinking may slow or halt progression; corneal transplants used in a small number of severe cases.



YouTube channel

As part of the upgrade of our online services; the Association also created a YouTube channel in January 2018 to distribute videos of our recent seminars. At present, the channel incudes two presentations on crosslinking and the Save Sight Keratoconus Registry by Professor Stephanie Watson and Dr Elsie Chan and one by Associate Professor Mark Roth on allergies, dry eye and contact lenses.

The channel can be found at https://tinyurl.com/keratoconusau-youtube. Please subscribe.

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 2017-18, the committee met three times and held informal discussions on other occasions.

The committee last year comprised:

Larry Kornhauser, President Neil McFarlane Ryan Kaplan Rod Swift Alejandro Molano Tamalii Laloulu Michelle Urquart

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

Volunteers still required urgently

Since requesting assistance 12 months ago, a number of members have kindly offered to help us. We thank those members greatly for those offers. However, in most cases, we were unable to match up the desire to do something with the Association's specific needs.

We therefore renew our request noting that the Association urgently requires *highly skilled* volunteers who are self-motivated to assist with a variety of tasks. If you want to help, please understand we need people able to initiate, follow up and complete tasks as we are unable to provide advice and supervision in these specialist areas. These include:

Strategy and Management	• Experience in developing strategy and management policies for not for profit organizations
Volunteer coordinator	• experience in managing volunteers, allocating tasks, follow-up
Website	design, content development and maintenance
	 launch a Life With keratoconus section to gather stories of people's experiences with keratoconus
Social media	 formulate policy guidelines for Facebook and Twitter and other platforms
	 provide and monitor content and postings
Advocacy	 experience in writing submissions to government and other representative organizations

•	understanding of the Medicare system
•	representatives for the Save Sight Keratoconus Registry
Research •	ability to initiate, understand and evaluate research projects and ethics protocols in the health and medical field
•	coordinate with research teams
•	experience in writing submissions
Fundraising •	ability to develop and implement a fundraising strategy
•	event management
•	plan major fundraisers to support keratoconus research projects. Two are being considered for 2019
Treasurer •	ability to develop budgets and forecasts of funding requirements
•	manage research budgets

The Association will be closing for the summer holiday break in early December 2018. However, you can email us over the holiday period if you would be interested in contributing in 2019 to any of the above areas.

Please contact KA Administrative Assistant Mary Veal directly on 0409 644 811 if you wish to participate.

The Committee of Management would like to thank everyone who has supported the Association over the past 12 months.

With your assistance, we can do much more in the coming year. If you believe in patients having a voice in their own care and can provide some expertise in the areas we are targeting, please join us in improving the lives of people with keratoconus and their families.

The Committee of Management 13 November 2018

FINANCIAL REPORTS

Keratoconus Australia Inc. reported a net operating surplus of \$14,858 in the 2017-18 financial year. This was 67% higher than last year.

Again, the major source of income was from donations, and this year saw another major donor contribute to our important work. 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 number of general donations has again remained relatively consistent, although the amounts have reduced. The Association's presence on online giving portals such as GiveNow, MyCause and GoFundraise has assisted in reaching more donors.

A review of bank accounts resulted in \$80,000 being transferred to a Term Deposit to maximise interest income. This resulted in interest income almost doubling last year to \$1,069.

Thanks to the kind support of a number of organisations, our operating expenses have remained relatively low. Stationery costs jumped from \$25 in 2016-17 to \$520 last year, reflecting the need to renew our stock of stationary as part of the Association's rebranding exercise. This cost was largely offset by a sharp drop in webhosting expenses as we shifted our new website to a new internet provider to take advantage of cheaper hosting plans. Other expenses remained fairly stable last year. Overall, total expenses in 2017-18 fell 5% to \$2,713.

The balance sheet as at 30 June, 2018 was showing net assets of \$105,254, compared to \$90,396 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.

Deloitte. Private

Deloitte Private Pty Ltd ACN 120 167 455 550 Bourke Street Melbourne, VIC, 3000 Australia

Phone: +61 3 9671 7000 www.deloitte.com.au

COMPILATION REPORT TO KERATOCONUS AUSTRALIA INC

We have assisted in the compilation of the accompanying special purpose financial statements of Keratoconus Australia Inc for the year ended 30 June 2018.

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

Kevin Slomoi

Dated: 20/8/2018

Liability limited by a scheme approved under Professional Standards Legislation

Keratoconus Australia

PO Box 1109 HAWKSBURN VIC 3142

Profit & Loss [Last Year Analysis]

July 2017 through June 2018

	This Year	Last Year
Income		
Donations	\$16,190	\$9,040
Booklet sales	\$134	\$0
Bank interest	\$178	\$536
Term Deposit interest	\$1,069	\$0
Total Income	\$17,571	\$9,576
Cost of Sales		
Gross Profit	\$17,571	\$9,576
Expenses		
Advertising	\$0	\$36
Bank charges	\$2	\$61
Domain Name Registration	\$53	\$593
Dues & Subscriptions	\$242	\$241
Legal fees	\$0	\$230
License Fees	\$57	\$0
Photocopying	\$113	\$159
PO Box rental	\$115	\$124
Postage	\$774	\$839
Printing	\$106	\$0
Seminar Expenses Melbourne	\$384	\$0
Software	\$0	\$45
Stationery	\$520	\$25
Telephone and Internet	\$151	\$47
Website hosting	\$196	\$454
Total Expenses	\$2,713	\$2,854
Operating Profit	\$14,858	\$6,723
Other Expenses		
Gifts / Contributions	\$0	\$0
Gift - Save Sight Institute	\$0	\$0
Total Other Expenses	\$0	\$0
Net Profit / (Loss)	\$14,858	\$6,723

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 2018

	This Year	Last Year
Assets		
Current Assets		
Cash On Hand		
Westpac DGF Account	\$17,451	\$13,997
Westpac Max-iDirect	\$7,750	\$76,509
Total Cash On Hand	\$25,201	\$90,506
Term Deposit	\$80,000	\$0
GiveNow Receivables	\$300	\$10
Total Current Assets	\$105,501	\$90,516
Intangible Assets		
Website Development - At Cost	\$6,975	\$6,975
Accumulated Amortisation	(\$6,975)	(\$6,975)
Total Intangible Assets	\$0	\$0
Total Assets	\$105,501	\$90,516
Liabilities		
Current Liabilities		
GST Liabilities		
GST Collected	\$279	\$267
GST Paid	(\$31)	(\$148)
Total GST Liabilities	\$248	\$119
Total Current Liabilities	\$248	\$119
Total Liabilities	\$248	\$119
		7110
Net Assets	\$105,254	\$90,396
	\$105,254	
Equity		\$90,396
	\$105,254 \$90,396 \$14,858	

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 2018

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

ACKNOWLEGEMENTS

Keratoconus Australia would like to acknowledge the special contributions of the following people and organizations during 2017-18.

Associate Professor Richard Vojlay, optometrist

Audiovisual Solutions, Anatoly Vulikh

Belinda Cerritelli

Connecting Up

Centre for Eye Research Australia

Cameron Falt, Deloitte Private

Dr Laura Downie, optometrist

Dr Michael Loughnan, ophthalmologist

Dr Elsie Chan, ophthalmologist and researcher

Dr Srujana Sahebjada, optometrist and researcher

Herbert Smith Freehills

Jessica Chi, optometrist

Margaret Lam, optometrist

Mark Koszek, optometrist

Microsoft Philanthropies

National Keratoconus Foundation

Optometry Australia

Professor Mark Daniell, ophthalmologist and researcher CERA

Professor Charles McMonnies, optometrist and researcher

Professor Stephanie Watson, ophthalmologist and researcher

Richard Lindsay, optometrist

Save Sight Institute

The Australian College of Optometry

The Department of Optometry and Vision Sciences, University of Melbourne

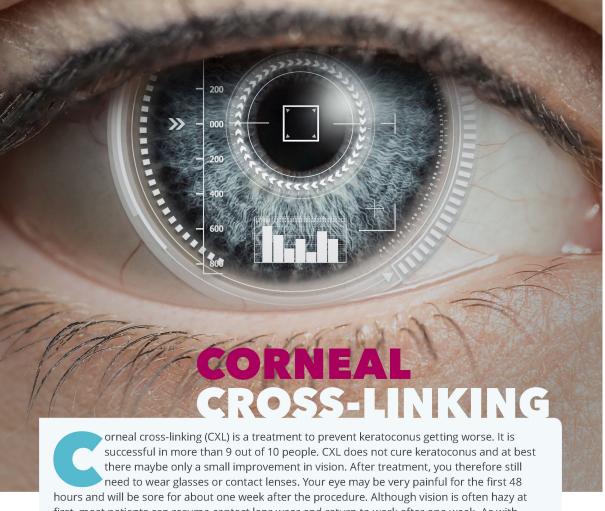
The Eye Foundation

Viewgrow Capital Pty Ltd

Vision 2020 Australia

ANNEXES

Patient brochure on corneal collagen crosslinking



first, most patients can resume contact lens wear and return to work after one week. As with all operations, there are risks: CXL is safe, but there is a small chance (about 1 patient in 30) of worse vision afterwards. As the treatment is not risk free, CXL is for patients whose keratoconus is progressing

What is Cross-linking?

Keratoconus gets worse because the cornea weakens and thins causing it to bulge into a cone. CXL, also known as C3R, uses ultraviolet light and vitamin B2 (riboflavin) drops to stiffen the cornea. Used together, they cause fibres within the cornea to cross-link - or bond more tightly. This treatment mimics the normal age-related stiffening of the cornea, which is known as natural crosslinking. Although there are several variations of CXL, the most commonly used and studied is the traditional method, called the Dresden epithelium-off technique and this is the method that we will refer to in this leaflet.

Will it work?

CXL is the only treatment currently available that appears to stop keratoconus from getting worse. Evidence from three big studies one year after CXL showed success in stopping keratoconus progression in more than 9 out of 10 patients, with more than 4 out of 10 people also gaining an improvement in corneal shape. Longer term results (up to five years) from a different study suggest a similarly high success rate in preventing keratoconus progression. Vision is slightly better after treatment than before in about half of the patients treated with CXL.

53

What are the risks?

In general, CXL is very safe, but like all operations your eye needs time to heal and problems do occasionally occur. About 3 out of every 100 patients having CXL will have worsening vision due to corneal haze, scarring, surface shape irregularities or infection. In the uncommon cases where the cornea becomes scarred affecting the vision, there are options to improve things. A transplant can be used to replace the cornea entirely if these complications occur, however, this is a much bigger operation with more risks and a long recovery.

Is it worth the risks?

Deciding to go ahead with an operation is a difficult decision for any patient. Studies on 'epithelial-off' CXL thus far have shown that CXL is effective at stopping keratoconus progressing. The complications from CXL appear largely minimal and temporary but it is still a relatively new procedure so long-term consequences are unknown.

An important part of weighing up if CXL is right for you is considering how fast your keratoconus is progressing and it is helpful to discuss this with your doctor to come to a decision.

Will I need to have both eyes treated?

Keratoconus typically affects both eyes. You may therefore need to have CXL on both eyes if the keratoconus is progressing in each eye. Treating both eyes in the same surgery however is not recommended due to the risks.

How will CXL affect my eyes long term?

CXL aims to stabilise keratoconus so in most cases your vision long term will remain the same. In a small proportion of patients their corneal shape improves after CXL resulting in a slight improvement in their vision. This small group who gains an improvement in their corneal shape may also notice their hard contact lenses fitting more comfortably onto their eye.

In some patients CXL will cause haze in their cornea, affecting the vision. This is usually at its worst after one month and remains the same until the third month when it begins to improve over the next year. The number of people who get corneal haze after CXL is unclear but has been found to be as high as 9 out of every 100 patients in some studies a year after the procedure.

What if I delay or do not have CXL?

Without CXL your keratoconus will progress as it would naturally. If your keratoconus is relatively stable it may be appropriate to monitor you instead of proceeding to CXL. This way you avoid unnecessary risks from the procedure for little gain. Even if you require CXL in one eye that is progressing, frequently the lesser affected eye is best just being monitored.

We know that keratoconus often stabilises after 30 years old so, if you are in this age bracket, again it may be more appropriate to monitor you instead of performing CXL.

If you do not require CXL or choose not to go ahead with it, it is important that you are still monitored regularly as if your keratoconus advances this decision may change. Crosslinking cannot be performed on a very thin cornea so regular reviews will ensure you are able to make up to date decisions on whether to have crosslinking before your cornea thins so much that it is no longer safe to have the procedure.

If your keratoconus is very advanced it may be too late for you to have CXL, but there may be other options such as a corneal transplant or specialised contact lenses.

Some patients may not be able to have CXL due to another eye condition such as herpes simplex keratitis, increasing the risk of complications.

THE CORNEAL CROSS-LINKING PROCEDURE

What are the different types of CXL?

There are many different ways, or "protocols", for doing CXL. One main variation is how the riboflavin is soaked onto the cornea. The surface skin of the cornea (epithelium) can be removed or left on (epithelium off vs epithelium on). The time that ultraviolet light is shone on the eye can also be varied - as rapid or classic. More experimental variations are being used in which other procedures such as laser or corneal ring operations are done at the same time as CXL.

Epithelium off cross-linking is considered the traditional method. Currently the National Institute for Clinical Excellence (NICE UK) has evaluated studies done for the different protocols. They only recommend epithelium-off as it has good evidence that it works, whereas epithelium-on and combined procedures do not have sufficient studies to back them up yet. What happens in the 'epithelial-off' treatment is described next.

What happens on the day of surgery?

CXL is performed as a day-case procedure in the operating theatre or consulting rooms. Although the procedure takes less than 60 minutes, there is usually some waiting time before treatment and you will also need to stay for a short while afterwards so we can check that you have everything you need to go home.

You will be asked to lie flat on the treatment table. Anaesthetic drops are used to numb the surface of your eye before a small clip is placed to keep your eyelids open. The surface skin of your eye (epithelium) is gently brushed clear and riboflavin drops are applied every few minutes for at least 10 minutes.

Following this, the ultraviolet light is shone at your eye. A soft contact lens may be placed on your eye at the end of the procedure and acts as a bandage.

RECOVERY AFTER CROSS-LINKING

What is the pain like?

The anaesthetic drops will wear off later on the day of your procedure, and your eye will be gritty, red and sensitive to light for several days. Everyone's experience of pain is different, with some patients reporting very little discomfort and others describing the first few days as very painful. Your eyes could be sensitive to light and many patients find sunglasses helpful.

What is it like straight after CXL?

You will be given eye drops to use after the procedure. The soft 'bandage' contact lens will remain in your eye until the surface has healed (usually in under seven days). If the bandage lens falls out during this time, please throw it away – do not attempt to reinsert it.

Your vision will be quite blurred at first, but will clear gradually over the first few weeks.

It is normal to experience fluctuating pain within the first two days after surgery. However, if you experience increasing pain three or four days after the procedure this could indicate infection and you should seek emergency assessment straight away. Please note that infection is rare, affecting fewer than 1 in every 100 patients.

What should I do, or not do, after CXL?

It is important to put the eye drops in regularly as prescribed. Wash and shower normally, but try to avoid getting water in your eyes. You may exercise, but should not swim before the surface of your eye has healed.

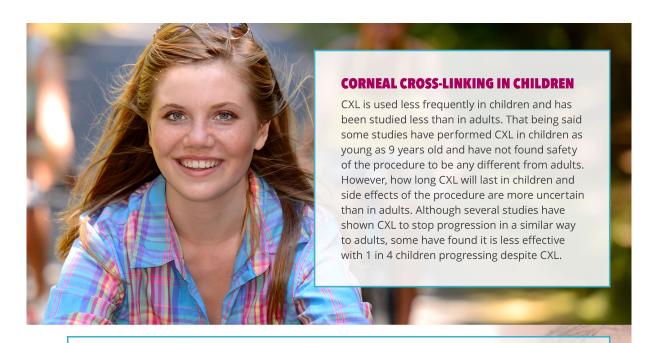
When can I drive again?

We will check your vision in the clinic within the week after your procedure to confirm if your vision is good enough to drive. It is normally safe to resume contact lens wear once the eye surface skin layer has healed. This typically happens around the end of the second week after your procedure.

Do I need to take time off?

Yes. You should allow at least one week off while most of the surface healing occurs, or two weeks if your job involves a lot of computer work, and the treatment is being done on your best eye. You will be putting eye drops in typically every four hours for the following days.

Day to day activities such as watching TV or using a computer will not do any damage to your eye, but you might find it more comfortable to rest with your eyes closed early on.



SAVE SIGHT KERATOCONUS REGISTRY

What is The Save Sight Keratoconus Registry (SSKR)?

The Save Sight Keratoconus Registry is part of the Fight Corneal Blindness! (FCB!) Project. It is a tool that allows you and your doctor to monitor your keratoconus and treatment journey including before and after CXL treatment as well as other treatments. Its innovative system collects data on your vision and eye shape at each clinic visit and stores it securely on a server at the University of Sydney.

A team comprised of clinicians and patients designed the Save Sight Registry and continually update and improve it with input from clinicians, patients and other stakeholders. The system is in use across Australia

How will the SSKR help you and your doctor?

The SSKR system can anonymously capture a lifetime record of your eye care. If CXL is needed, it then tracks your response to the treatment to determine if your eye remains stable as the effect of CXL may wear off over the years. It is also valuable for your safety as it can log any side-effects that you experience. SSKR is useful for your doctor; it assists them in tracking the progress and results of CXL for their patients, helping them improve the care they deliver. Only your doctor and their health care team can view your records to protect your privacy. The system also helps clinicians understand how keratoconus progresses and how it affects your day-to-day life. Understanding keratoconus and evaluating new treatments will help further research into finding a cure for keratoconus.

What can you do?

Ask your doctor if you can be a part of the registry to make sure you are receiving the best care.

Further information on the SSKR is available at

www.savesightregistries.org/registries/modules/fight-corneal-blindness







keratoconus.org.au

© 2018 Keratoconus Australia and Save Sight Institute

Tracking treatment outcomes in patients with keratoconus Professor Stephanie Watson October 2017

see the future



The Save Sight Keratoconus Registry:

Tracking treatment outcomes in patients with Keratoconus

Professor Stephanie Watson
Save Sight Institute
Bondi Junction

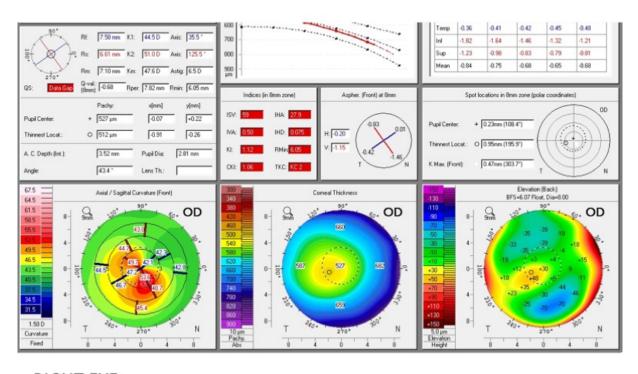


RESEARCH | TEACHING | PATIENT CARE



KERATOCONUS Affects 1 in 2000, progressively reduces vision Onset in childhood/young adult Life-long visual disability Evidence lacking on treatments aside from corneal transplantation ACGR thank you!

2007 2013 2015



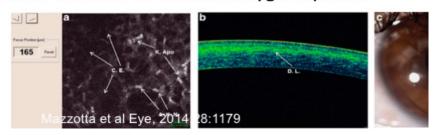
RIGHT EYE

CORNEAL CROSS-LINKING?



MECHANISMS OF ACTION

- Biological
 - Stimulation of keratocyte apoptosis and repopulation
- Mechanical
 - Increase in crosslinked collagen fibre diameter
 - · Increased resistance to degradation
- Chemical
 - Direct electron transfer or reactive oxygen species



HOW IS IT IT DONE?

- Riboflavin 0.1% in 20% Dextran
 - q 3 to 5 min for 30 min
- UV irradiation: 3 mW/cm² 30min
 - Riboflavin q 4 to 5 min

Spoerl E, et la Cornea 2007; 26: 385-389

PROTOCOL VARIATIONS

- · Treat thinner corneas
- · Avoid epithelial debridement
- 'Flash-linking'/AXL
- · Combined refractive surgery
- Iontophoresis





Ectasia progression

- consistent change in at least 2
- · magnitude of the change
 - · above the normal noise of the testing system:
 - Steepening of the anterior corneal surface
 - · Steepening of the posterior corneal surface
 - Thinning and/or an increase in the rate of corneal thickness change from the periphery to thinnest point

Gomes et al, Cornea 2015;34:359-369)

Ectasia progression

- Changes consistent over time and above the normal variability (ie, noise) of the measurement system (this will vary by system).
- Change in uncorrected visual acuity and BSCVA is not required to document progression

How accurate is topography?

Eyes (KC grade)	Kmax (D) 95% interobserver limits
Normal	0.78
All KC	1.51, 2.30
Early KC (1-2)	-0.90 to 1.01
Advanced KC (>2)	-3.71 to 3.86

Early KC K1, K2, or Kmax > 1D likely to be significant

Flynn, Sharma, Bunce, Wilkins. Br J Ophthalmol 2016;100:1183–1187 McAlinden et al. Invest Ophthalmol Vis Sci. 2011;52:7731–7737 Hashemi K *et al* Ophthalmology 2015;**122**:211–12. Epstein RL et al J Refract Surg 2012;**28**:890–4.

Topographic progression

- Same operator
- Same equipment
- Repeat unreliable measurements
- Adjust parameters depending the degree of ectasia

Contraindications

- Pachy < 400 microns
- Herpetic keratitis
- Concurrent ocular infection
- Severe scarring
- Neurotrophia
- History poor corneal wound healing
- Severe dry eye
- Pregnancy
- Autoimmune disorders

YOUR PATIENTS?







Peggy



Sally

ARTICLE IN PRESS



U.S. Multicenter Clinical Trial of Corneal Collagen Crosslinking for Treatment of Corneal Ectasia after Refractive Surgery

Peter S. Hersh, MD,^{1,2} R. Doyle Stulting, MD, PhD,³ David Muller, PhD,⁴ Daniel S. Durrie, MD,⁵ Rajesh K. Rajpal, MD,^{4,6} and the U.S. Crosslinking Study Group*

- Prospective, randomized, controlled clinical trial
- n = 179
- Corneal ectasia after previous refractive surgery
- Standard CXL vs riboflavin epithelium intact

Outcomes

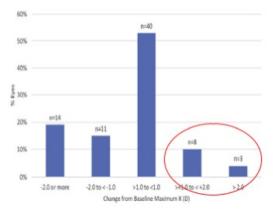


Figure 1. Change in maximum K in individual eyes between baseline and 12 months after crosslinking. D = diopters, K = keratometry.

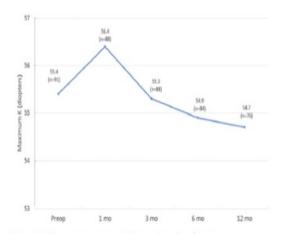
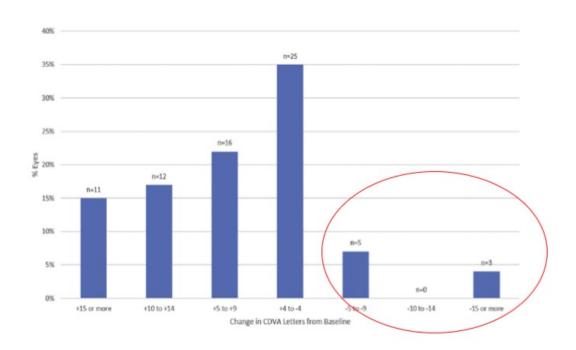


Figure 2. Change in maximum K over time. K = keratometry.

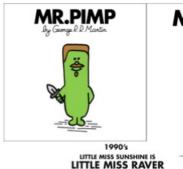
- Eyes with steeper Kmax > 55.0D
 - more likely to have > 2D or more of flattening

Corrected distance vision



Registries vs Clinical Trials

- Real world treatment
- Real world patients
 - Co-morbidities
- Large patient numbers







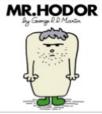












Save Sight Registries!

Aim

To establish a registry of outcomes of treatment of ocular diseases to determine whether these treatments work as well in the **real world** as they did in clinical trials

Method

Efficient Web-based software tool

Quality assurance measures

Sophisticated statistical back-end

Tracks outcomes that patients care about (vision, number of injections)



Save Sight Registries



Design Goals

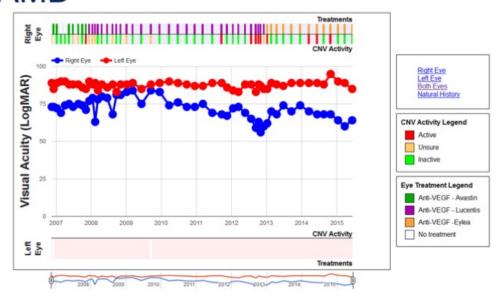
- Basic anonymised patient data management system
- Compatible with data entry in routine practice
 - Baseline visit entry: 30 sec
 - Follow up visit entry: 15 sec
- Generate graphs "on the fly" of vision, treatment and relevant audit-specific clinical markers
- Self audit tool



Consent, Anonymity and Ownership

- Opt out consent in Australia patient given a brochure
- Patient data remains unidentifiable
- Doctor's data is identifiable ONLY by the treating Doctor
- The copied data is owned by the collaboration but may be withdrawn at any time without notice or reason by the contributing practitioner

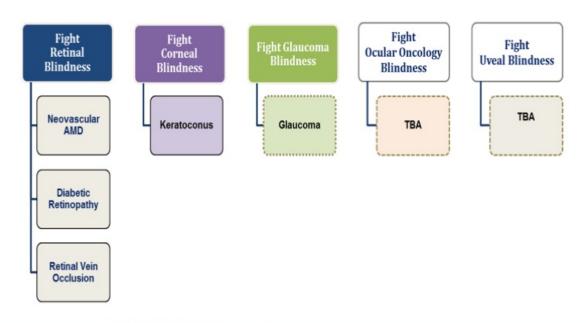
Tracking treatment outcomes in nAMD



FRB! Macular Degeneration



Save Sight Registries





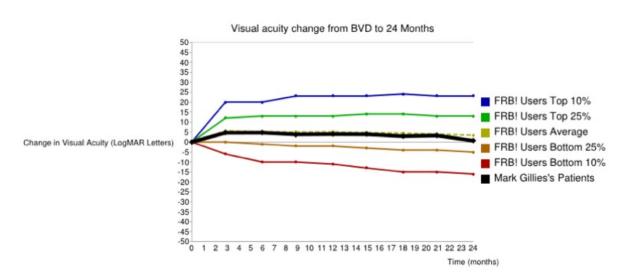
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FCB: KERATOCONUS

- National registry to
 - · Collect high quality data outcomes
 - Determine clinical effectiveness and safety of emerging therapies and surgical techniques
- · Patients in real life clinical settings
- Based on the national and international success of the FRB!
 Project developed by Prof Mark Gilles

FCB! Keratoconus

Quick comparison of clinical outcomes against peers





Generating Doctor's Activity Report

Patient treatment outcomes by doctor practice report:

- · informative report
- · self audit tool
- anonymously generated within the system upon request
- evaluating effectiveness of treatment





Save Sight Registries

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BENCHMARKING

	My patients	Other doctors' patients
Mean VA at time of first treatment (letters)	53.1	60.5
Mean change VA from first treatment (letters) at 6 months	-1.2	3.4
Mean change VA from first treatment (letters) at 12 months	1.8	0.8
Proportion of eyes with 6/12 vision at 12 months (%)	66.7%	41.7%

Adverse events - rate total audit			
	My patients	Other doctors' patients	
Persistent significant haze (after 12 months of treatment)	18.5%	3.3%	
Clinically significant haze (within 12 months of treatment)	49.2%	8.5%	
Microbial keratitis	3.3%	0.4%	

Patient journey



FCB! Keratoconus



































KORQ

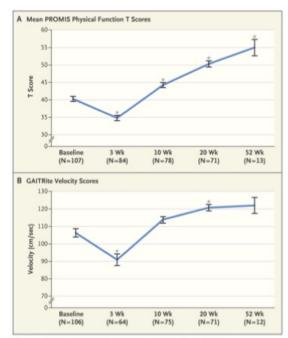
Benefit to patients
 of treatments



Patient-Reported Outcomes — Are They Living Up to Their Potential?

Judith F. Baumhauer, M.D., M.P.H.

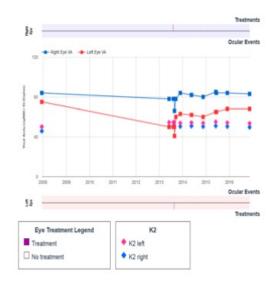
Orthopaedic centre
University of Rochester
Medical Centre
USA



Physical Function Assessments after Knee-Ligament Reconstruction.

IN THE CLINIC

- · Orthoptic review
 - Vision
 - Topography
 - Data entry
- KORQ completed on Ipad
- · Clinician consult
 - · Finalise data
 - Review
 - Discuss



RANZCO Approved CPD Audit

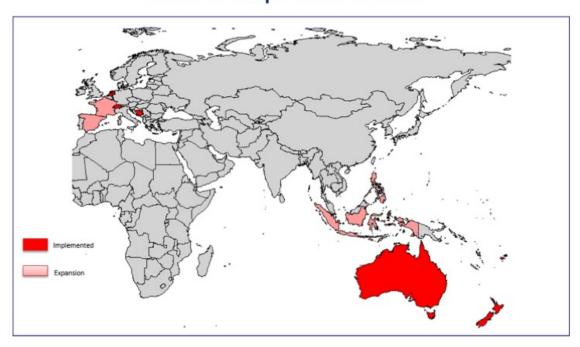
The Project is a RANZCO approved CPD Audit activity. Participating fellows are potentially able to claim 30 points in clinical expertise level 2.



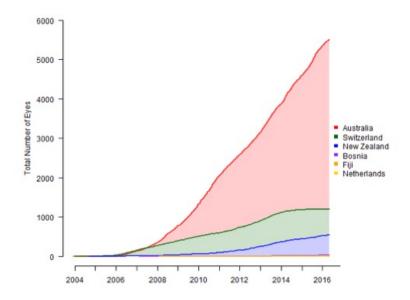
Publications accepted in following journals



Global Implementation

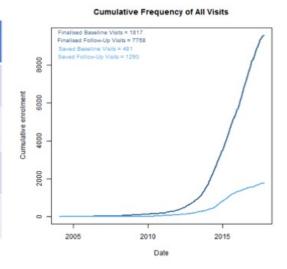


Recruitment Update



RECRUITMENT UPDATE

Eyes	2298
Patients	1228
All Visits Total	11349
Sites	37
w. P. T.	4050
X link	1062

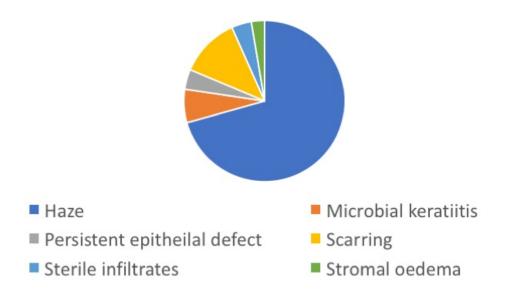




Save Sight Registries

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ADVERSE EVENTS



FCB! Keratoconus

COMPLICATIONS

- Loss ≥ 2 Snellen lines VA 2.9% (95% CI, 0.6%-8.5%).
 - · Risk factors
 - · Age older than 35 years and
 - Preop CDVA > 20/25
- Continued progression 8% 11%
 - · Risk factors

 - · Central cone

Koller et al J Cataract Refract Surg 2009; 35:1358-1362

HAZE

- Common
- Decreases in first year
- Extends to 60% depth (300 microns)
 - PRK haze is subepithelial

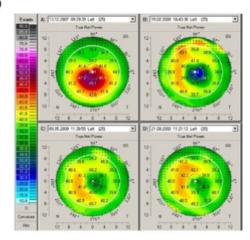
Koller et al J Cataract Refract Surg 2009; 35:1358–1362



SCARRING

• Central stromal scars in 2.8%



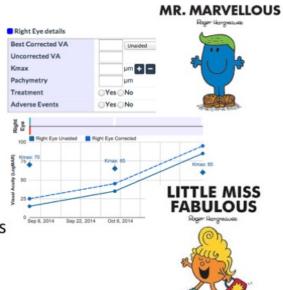


• Infection acquired post op

Koller et al J Cataract Refract Surg 2009; 35:1358-1362

BENEFITS FOR YOUR DOCTOR

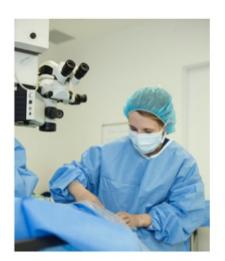
- Individualise patient treatment
- Patient data graphed
- Practice level summaries
- Contribute to development of national trends
- · Compare own data to benchmarks



FCB! Keratoconus

REGISTRY IN PRACTISE

- Individualise patient treatment
- · Patient data graphed
- Practice level summaries
- Compare own data to benchmarks
- Contribute to development of national trends



FCB! Keratoconus

BENEFITS TO YOU

- Track your treatment journey
- Contribute to best practise
- Impacts of keratoconus
- · Data referral



· Your data can be referred to another practitioner

FCB! Keratoconus

Keratoconus in a young adult

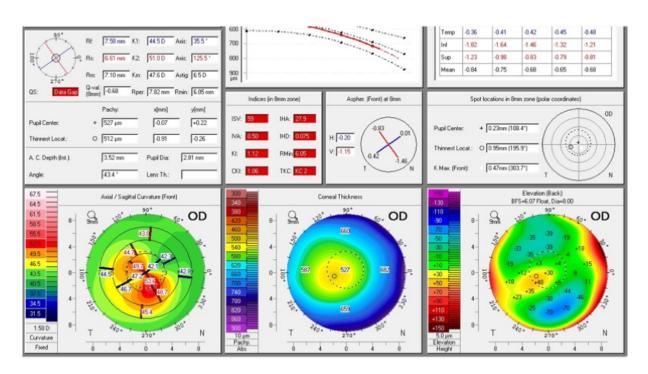
RIGHT EYE

Year	2007	2013	2015
Unaided	6/6	6/18	
Glasses		+0.25/-3.50 at 65º 6/7.5	+0.25/-3.50 at 70º 6/5

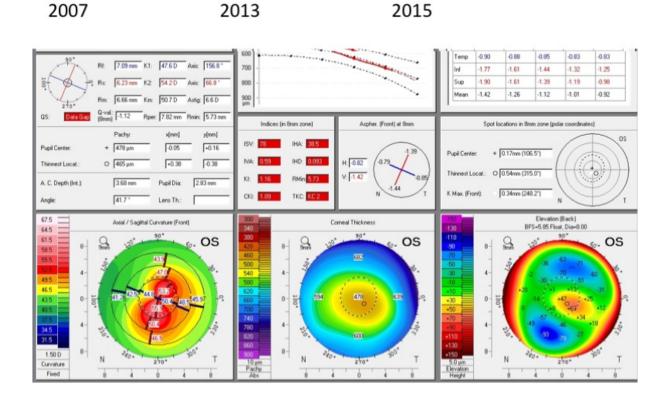
LEFT EYE

Year	2007	2013	2015
Unaided	6/36	6/18	
Glasses	- /-1.25 at 120 º 6/12	-1.50/-1.00 at 150º 6/30	-2.50/-3.50 at 135º 6/12

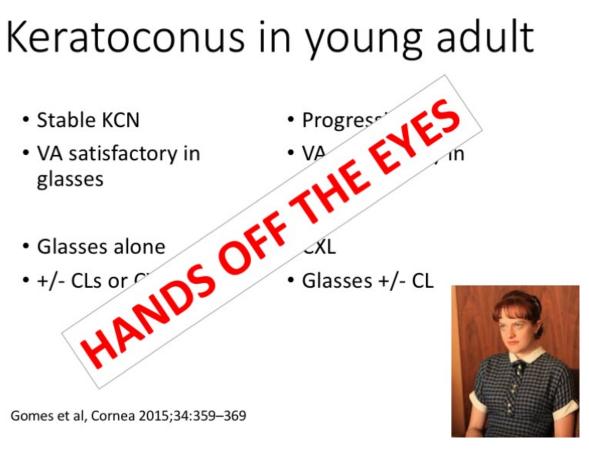
2007 2013 2015



RIGHT EYE



Keratoconus in young adult



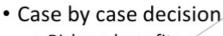
LEFT EYE

Keratoconus in a young child

- Progression can be rapid
- High quality evidence lacking
 - Case series show progression can be stopped
- Risks: progression
 - · Over 5 years: 25% may progress
 - Infection and scarring

Wisse RP, Godefrooij DA, Soeters N. Reply. Cornea. 2016; 35(11):e36.

Keratoconus in a young child





Mild cases

- VA 6/6
- Few*
- Consider CXL
- Asymmetric KCN
 - Monitor good eye

Keratoconus in an adult

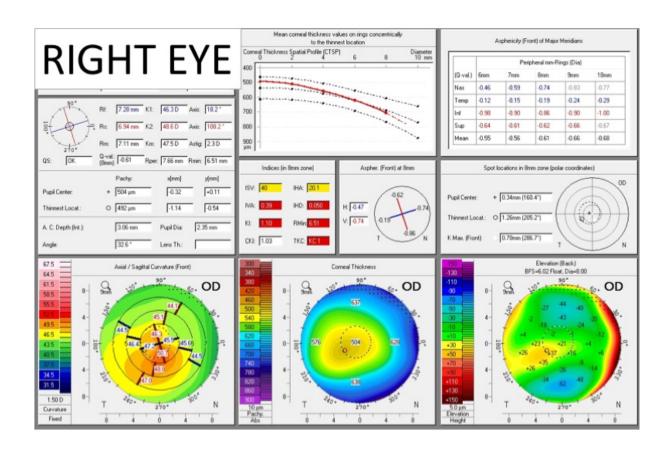
- 55 year old
- · c/o reduced vision
- Pohx:
 - · Glasses since teenager
 - · Use to rub eyes but has stopped

• RVA 6/12

LVA 6/12

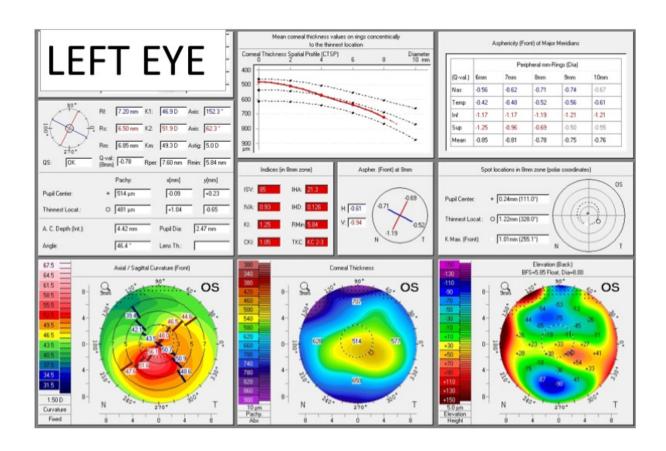
-1.50/-1.25 at 84 º

+0.25/-4.50 at 109 º

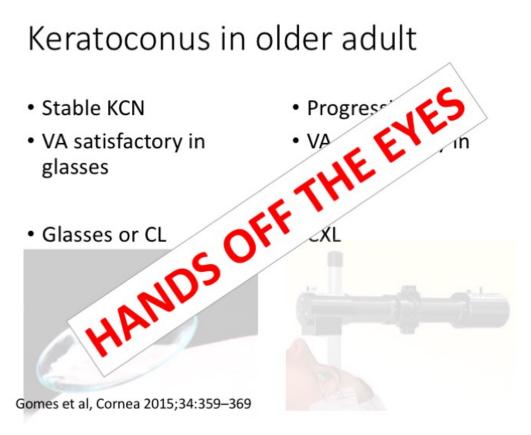








Keratoconus in older adult



CXL

- Currently only Rx able to halt progressive ectasia
- Evolving methods
- New indications
- Monitor outcomes



Chief Investigators Prof. Mark Gillies Prof. Stephanie Watson



CIB: Daniel Barthelmes

Project Manager: Amparo Herrera-Bond

Coordinators: Amanda Dinh

Biostatisticians: Vuong Phuc

Richard Walton

ENQUIRIES-amparo. her rerabond @sydney.edu. au



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Dr Martina Bosch Dr Andrew Apel

Dr John Males Dr Peter Beckingsale

Dr Yves Kerdraon

ORIA Keratoconus Australia Claffy Foundation



RESEARCH | TEACHING | PATIENT CARE



Position statement on meeting the needs of people who are blind or vision impaired within the aged care system

Executive Summary

As a result of reforms to disability, such as the roll out of the National Disability Insurance Scheme (NDIS), there will be a greater number of older Australians who are blind or vision impaired relying on the aged care system to receive the supports and services necessary to maintain their independence and live the life they choose. It is therefore critical that the aged care system is effective for people who are blind or vision impaired, given that the majority of this population group are aged over 65 years and will therefore be ineligible for support through the NDIS.

There is therefore a need for greater Government recognition and investment to address blindness and vision impairment as an issue predominately affecting older Australians. Given the link between ageing and the increased incidence of blindness and vision loss, ensuring access to funded specialist blindness and vision impairment services for older Australians is a crucial aspect of improving the aged care system and ensuring that consumers have equal access to the right services and supports.

Vision 2020 Australia therefore considers it critical that the Australian Government address the issue of access to aged care for people who are over the age of 65 and who are blind or vision impaired by implementing the following measures:

- 1. Amend the *Aged Care (Living Longer Living Better) Act 2013* to include people with disability, including people who are blind or vision impaired as a special needs group.
- 2. Appropriately resource and inform aged care assessment to identify and respond to the needs of people who are blind or vision impaired and people with disability more broadly.
- 3. Ensure that co-payments do not create a barrier for people who are blind or vision impaired in accessing the most appropriate supports and services they need to remain independent and engaged in their community.
- 4. Develop a National Aids and Equipment Scheme for older Australians to redress the current inequitable access to aids and equipment and assistive technology.

Vision 2020 Australia position

1. Amend the *Aged Care (Living Longer Living Better) Act 2013* to include people with disability, including people who are blind or vision impaired as a special needs group.

For many years, the eye health and vision care sector has expressed concern that people with disability, including people who are blind or vision impaired, are not explicitly recognised as a special needs group within the Aged Care Legislation.

Clause 1 of Schedule 1, section 11-3 (definition of people with special needs) of the *Aged Care Living Longer Living Better Act* (the Act) defines a person with special needs as the following:

a. people from Aboriginal and Torres Strait Islander communities;

- b. people from culturally and linguistically diverse backgrounds;
- c. people who live in rural or remote areas;
- d. people who are financially or socially disadvantaged;
- e. veterans:
- f. people who are homeless or at risk of becoming homeless;
- g. care leavers;
- h. parents separated from their children by forced adoption or removal;
- i. lesbian, gay, bisexual, transgender and intersex people;
- j. people of a kind (if any) specified in the Allocation Principles.

In the current definitions specified in the Act, disability acquired in older age is perceived as frailty, rather than disability. The focus on frailty creates a barrier to accessing necessary supports and services for people who are blind or vision impaired, as they are often not frail but require support relating to their requirements and their wish to remain independent.

Amending the Act to include people with disability, including people who are blind or vision impaired as a special needs group, will not only ensure that places in the Commonwealth Home Support Program (CHSP), Home Care Packages Program and residential aged care could be allocated to meet their specialist needs, but will also allow for them to be matched to professionals who hold expertise specific to the holistic needs of the individual.

2. Appropriately resource and inform aged care assessment to identify and respond to the needs of people who are blind or vision impaired and people with disability more broadly.

Regional Assessment Services (RAS) or Aged Care Assessment Teams (ACATs) assess the needs of those who wish to access aged care services in order to determine the level of support required by the individual. Given the circumstances, RAS and ACATs are accustomed to assessing the needs of those who are frail, rather than the needs of a person with disability. Assessors are therefore often not equipped with specific expertise in determining the types of services and support required for a person who is blind or vision impaired, and may not consider whether a person would benefit from specialised blindness and vision impairment services, such as orientation and mobility, literacy aids, library services or assistive technology training.

Furthermore, the National Screening and Assessment Program (NSAF) is itself limited in its capacity to respond to the needs of older people who are blind or vision impaired and people with disability more broadly. While disability is identified as a health condition that may prompt referral to an allied health professional, there is no trigger to refer an individual to specialised support services, such as providers of blindness and vision impairment services. In relation to blindness and vision impairment, NSAF instructs assessors to refer the person to an optometrist if the person has had changes to their vision in the last three months, and does not seek any information on underlying vision impairment or consider the need for specialised blindness and vision impairment services.

It is therefore essential that specialist knowledge regarding individual need is available once an individual presents to the My Aged Care portal, the website through which available services can be identified. A specific trigger mechanism that identifies applicants who are blind or vision impaired will ensure an effective passage through the My Aged Care portal, by providing the option for a specialist assessment, undertaken by a specialist service provider in blindness and vision impairment, to substantiate the correct services and supports to meet the identified needs.

3. Ensure that co-payments do not create a barrier for people who are blind or vision impaired in accessing the most appropriate supports and services they need to remain independent and engaged in their community.

While aged care services are subsidised by the Australian Government, there is also an expectation that individuals over the age of 65 accessing the aged care system will contribute to the cost of the services that they require if they are able to do so. The amount that an individual will contribute towards their required services and supports is determined through negotiations with the service provider, and may also involve income or other forms of means testing.

As outlined by the Productivity Commission in their 2011 inquiry report on *Disability Care and Support*, the major goal of the aged care system is to minimise the loss of autonomy of those accessing it, and to allow people to live as independently and as fully as possible. This approach also recognises that people over the age of 65 have generally had lived a 'full life' to accumulate wealth during their lifetime, which can therefore be used to fund the costs of the care that they require.

However, this approach assumes that those accessing the aged care system will have had the *opportunity* to live a full life. While this assumption may be applicable to people who acquire disability, including vision loss, after the age of 65, individuals who were born with or acquired disability early in life have often experienced discrimination and exclusion through their lifetimes, and have therefore not had the same opportunities for wealth accumulation.¹

Given that the aged care system is currently structured to accommodate the support needs of Australia's ageing population, commonly funded mainstream services that may sometimes cross over with those that are required by people who are blind or vision impaired do not sufficiently cater to the requirements of this group. As the requirements of people who are blind or vision impaired have the potential to be more cost prohibitive than those of the average older person, it can be expected that co-payments paid by a person who is blind or vision impaired would be higher due to their higher support needs.

Consideration of the rules for co-payment under My Aged Care should therefore be taken, with acknowledgement of the fact that co-payments can, for some, create a barrier to the specialist services and supports uniquely required by people with disability. Exemptions to specialist services and supports required by people with permanent and severe disability could also be considered, and may include such services as mobility and support training, or adaptive technology training among others.

4. Develop a National Aids and Equipment Scheme for older Australians to redress the current inequitable access to aids and equipment and assistive technology.

Services and supports for people who are blind or vision impaired may range from assistance with orientation and mobility, training in using acentric viewing methods, training in braille or adaptive technology for literacy, occupational therapy, peer or emotional support to deal with vision loss, as well as a range of aids and equipment to assist with their mobility or literacy.² Under the NDIS, participants can access fully funded aids and equipment if they are eligible for a package that is individually funded.³ However, people who acquire a disability

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¹ BCA submission? Or email?

² National Aged Care Alliance, Improving the Interface between the Aged Care and Disability Sectors, August 2017

³ Ihid

over the age of 65 are not eligible for individually funded NDIS packages, and would be expected to access these supports through the aged care system.⁴

Further, while Home Care Packages offer some aids and equipment, as well as assistive technology, only a limited number of packages, which are often not prioritised for people who are blind or vision impaired, are available.⁵ In addition, the CHSP, through which individuals can access entry-level support while on the waiting list for a Home Care Package, is not adequately funded to offer aids and equipment supports and services. It is therefore imperative that My Aged Care staff are made aware of the range of services and supports people who are blind or vision impaired may require, but also of the existing inequities that may present a barrier to accessing these supports.

Therefore, as per the recommendation put forward by the National Aged Care Alliance, the development of a National Aids and Equipment Scheme for older people, aligned with the NDIS Assistive Technology Scheme, would redress the current inequitable access to aids, equipment and assistive technology.⁶ Further, a federally funded scheme with harmonised and streamlined eligibility, access and co-payment requirements across all jurisdictions would provide information and support to allow consumers to make informed choices about the aids, equipment and assistive technologies available and the related services.

Policy context

The proportion of people aged 65 and over in the Australian population is increasing, with the number tripling over 50 years to 3.4 million in 2014.⁷ Of the total Australian population, it is estimated that more than 453,000 people are living with vision impairment or blindness, and that the majority are over the age of 65.⁸ In 2010, Access Economics projected that the number of people over the age of 40 who are vision impaired will rise to almost 801,000 by 2020. It was also projected that the number of people over the age of 65 who are blind will rise to 102,750.⁹ This rise reflects the ageing population and the fact that the prevalence of vision impairment and blindness doubles with each decade over the age of 60.¹⁰

It is estimated that on average, supporting people who are blind or vision impaired over the age of 65 requires less frequent interventions than their younger counterparts, and that they can remain engaged in their communities and live in their own homes for longer, with relatively little intervention.

However, despite the benefits associated with supporting people who are blind or vision impaired and over the age of 65, only a fraction of funding for blindness and vision impairment services is derived from Government-funded aged care streams. For example, according to the 2015 *Snapshot of Blindness and Low Vision Services in Australia* (the Snapshot Survey) conducted by Vision 2020 Australia, the National Disability Services and the Australian Blindness Forum, funding for the blindness and vision impairment services

⁴ Ibid

⁵ BCA submission? Or email?

⁶ Ibid

⁷ http://www.aihw.gov.au/ageing/

⁸ Foreman, J., et al, 2016, The National Eye Health Survey Report 2016, The Centre for Eye Research Australia and Vision 2020 Australia, Melbourne

⁹ Vision 2020 Australia by Access Economics Pty Limited, Clear Focus: The Economic Impact of Vision Loss in Australia in 2009, June 2010.

¹⁰ Foreman, J., et al, 2016, The National Eye Health Survey Report 2016, The Centre for Eye Research Australia and Vision 2020 Australia, Melbourne

sector generated from all government sources amounted to only 30 per cent of all funding, or \$56 million in 2013.¹¹

Government funding streams for the sector are spread across disability, aged care, health and education, however the greatest proportion of funding for the blindness and vision impairment services sector is generated by fundraising and bequests at 43 per cent (nearly \$81 million). 12 A further 18 per cent is derived from sales (\$34.4 million) and nine per cent (\$17.1 million) from investments, grants and other sources.¹³

As a result, many organisations within the blindness and vision impairment services sectors, who are registered providers of aged care, are only partly funded through the aged care sector. These organisations therefore provide services which are not funded from aged care to people aged 65 years and older living with blindness and vision impairment. These services include low vision clinics, information and library services, alternative formats, assistive technology training and advocacy services. Furthermore, the provision of specialist blindness and vision impairment services by these organisations is only made possible through philanthropic funding, a cost that has not been borne by the Government or aged care providers.

According to the results of the Snapshot Survey, more than one-quarter (27 per cent) of organisations reported that they have had to refuse services to clients. ¹⁴ For organisations that reported that they had not been able to meet demands, the main impediments were cited as a lack of financial resources to hire staff or being unable to pay staff to work longer hours. Furthermore, with no current mechanism in place for residential aged care providers and other generalist aged care organisations to refer or pay for specialist blindness and vision impairment services, unmet demand for specialist services within nursing homes and residential care is hidden.

Reforms to aged care

Introduced in July 2012, Living Longer, Living Better is a ten year reform program intended to establish a flexible and seamless aged care system. The aim of the Living Longer, Living Better reform program is to ensure that Australians aged over 65 years have easier access to services and supports, with a focus on a model of consumer directed care that puts choice and control in the hands of consumers. Under the Living Longer, Living Better reform package, a number of initiatives have been introduced or expanded upon, including:

My Aged Care

My Aged Care was introduced in July 2013 and provides an entry point to the aged care system, offering information to consumers, service providers, as well as family members and carers. In 2015, My Aged Care was expanded to include a central client record, adoption of the National Screening and Assessment Form (NSAF) and a web-based My Aged Care portal for clients, assessors and service providers.

National Screening and Assessment Form

The NSAF is a tool used to determine eligibility level and to inform the development of support plans within the Aged Care system. In relation to eye health and vision care, the NSAF instructs assessors to refer the patient to an optometrist if they have had changes to their vision in the last three months.

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¹¹ B. Ah Tong, G. Duff, G. Mullen and M. O'Neill, August 2015, A Snapshot of Blindness and Low Vision Services in Australia, Vision 2020 Australia, National Disability Services, Australian Blindness Forum, Sydney, page 13 ¹² B. Ah Tong, G. Duff, G. Mullen and M. O'Neill, August 2015, A Snapshot of Blindness and Low Vision Services in Australia, Vision 2020 Australia, National Disability Services, Australian Blindness Forum, Sydney, page 13 ¹³ B. Ah Tong, G. Duff, G. Mullen and M. O'Neill, August 2015, A Snapshot of Blindness and Low Vision Services in Australia, Vision 2020 Australia, National Disability Services, Australian Blindness Forum, Sydney.
¹⁴ Reference required

The Commonwealth Home Support Program

The Commonwealth Home Support Program (CHSP) is a consolidated program that provides entry-level home support for older Australians who wish to live independently at home, but may require assistance. These supports include nursing, allied health, assistive technology, home modifications, home maintenance, food services, domestic services, personal care, social support and specialised support.

Home Care Packages

The Home Care Packages Program provides more complex support for older people who wish to stay at home, offering access to a range of ongoing personal services, support services and clinical care that can provide assistance with day-to-day activities. Under the Living Longer, Living Better reforms, the Home Care Packages Program was modified to mandate that all home care packages be delivered on a consumer directed care basis, ensuring that consumers have a choice in the types of care and services they access, how and when the services are delivered and by whom.

Vision 2020 Australia

Established in October 2000, Vision 2020 Australia is part of *VISION 2020: The Right to Sight*, a global initiative of the World Health Organisation and the International Agency for the Prevention of Blindness. Vision 2020 Australia is the peak body for the eye health and vision care sector, representing around 50 member organisations involved in local and global eye care, health promotion, low vision support, vision rehabilitation, eye research, professional assistance and community support.

The Vision 2020 Australia Independence and Participation Committee

Vision 2020 Australia's Independence and Participation Committee (the Committee) brings together a diverse group of members providing services and supports to people who are blind or vision impaired across Australia; enabling an unique platform for stakeholders to collaborate, foster consensus and develop a shared understanding on matters of significance affecting member organisations and consumers. Through drawing on the knowledge, experience, and resources of the Committee's broad and inclusive membership, the Committee is central to supporting one of Vision 2020 Australia's key roles as an effective conduit to government, offering a unified and consistent voice.