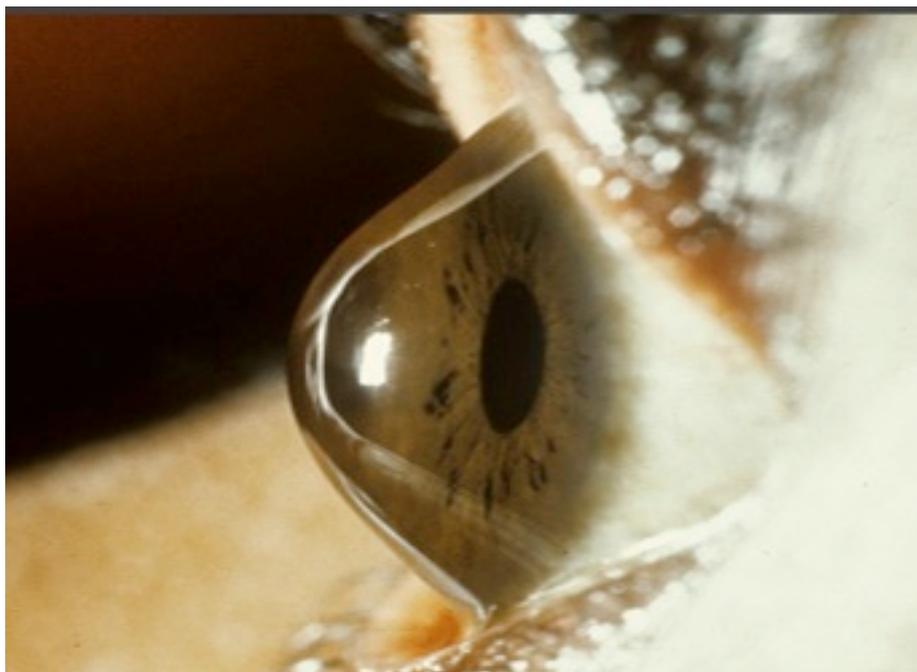


KERATOCONUS Australia



2014
ANNUAL
REPORT

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. 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 counseling 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
- Developing 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

Volunteer-operated charitable organizations like Keratoconus Australia are different. Not only do they operate for the sole benefit of those they serve, they do so without the goal of earning a profit on their activities. Not only do those working for such organizations do so out of commitment to an ideal, they do so without expectation of financial reward. That is what makes these organizations so special. That is also what makes these organizations so difficult to sustain.

Keratoconus Australia is now in its 15th year – a remarkable achievement for a tiny organization born in a Camberwell café in the hope of improving the existence of people with keratoconus. Many of us back then had struggled all our lives with poor vision, never meeting another person with keratoconus and with very little information about the disease and the treatments being offered to us. We trusted our eye-carers although they took little time to explain what they were doing. We soldiered on in our daily lives, at school, at university, in the workplace and while socializing with friends and family – mostly without complaint but not without difficulty. Invariably we were asked why we could not wear glasses when we had problems with our contact lenses.

Fifteen years on so much has changed thanks to the volunteers who assist Keratoconus Australia. Patients and their families now have access to clear and detailed information about keratoconus and its treatments via many media, they can obtain support by internet, phone and in person, they can attend regular public information seminars presented by specialist practitioners and researchers and they know that the Association is promoting research into the origins of keratoconus and the safety and effectiveness of new treatments being offered to them like corneal collagen crosslinking.

Yet the problem with a volunteer-based organization is that it cannot demand or even expect things from those offering to assist. It is vulnerable to the vagaries of its volunteers' availability and commitment and these can vary widely according to their personal and professional circumstances. That is perfectly normal. My own situation has changed considerably over the past two years and this has reduced my availability to help implement the many projects and policies we have on the drawing board.

In the past, I have sought more assistance from volunteers and some of you have kindly offered to help. But the lack of a volunteers' coordinator and the non specific nature of assistance offered has made it difficult for us to respond effectively. While we would like members to organize their own social functions for others with keratoconus to chat, what the Association requires today are motivated people with specialist skills in certain areas who are able to initiate and implement projects independently.



Ideally, we would like to find someone with the time and experience to act as a coordinator to manage these volunteers.

You do not need to have keratoconus to participate in the Association. Anyone with an interest in assisting people with keratoconus can join us. Harnessing the skills of the wider keratoconus community i.e. family and friends will be vital in the Association's survival and progressing its aims over the next 15 years.

Despite the challenges all of us faced during 2014, as you will see from this report we continue to achieve much. We could do so much more with a larger, committed group of volunteers.

Please consider taking on a bigger, long-term role in supporting people with keratoconus.

Larry Kornhauser
November 2014

Support for people with keratoconus and their families remains the Association's primary focus. Despite difficulties during the 2013-14 financial year in maintaining our effort in other areas, we have continued to try to respond to all requests for support with a few days. Overall, we think we have succeeded.

As discussed in previous reports, Keratoconus Australia is a support group operated by people with keratoconus; we do not provide medical advice. What we can 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.

As in the past, support issues tended to remain concentrated on the main issues faced by most keratoconus patients and their families: diagnosis and prognosis, initial visual correction, decisions about corneal collagen crosslinking to halt further progression and other surgery like corneal transplantation and some of the less conventional surgery now being offered by corneal surgeons.

Requests for support rose again in the 12 months to June 30, 2014 as did the number of interactions required to deal with these requests. Overall, the Association logged almost 400 contacts with patients and their families in the 2013-14 financial year. This represented an increase of 28% over the number of contacts logged in the previous corresponding period.

Finding a specialist eye-carer

As Keratoconus Australia does not provide medical advice and most questions from patients and their families relate to specific issues around keratoconus, much of our support work continues to be dedicated to helping people find specialist eye-carers for keratoconus.

Around 32% of all requests for support last year were from people seeking a keratoconus specialist to assist them in managing or treating some aspect of their condition. However most support requests from people seeking assistance after a diagnosis, or who were seeking information about contact lenses or surgery also ended up as requests for specialist eye-carers for keratoconus. This meant that in anything up to 90% of all requests for support, the Association also provided the

patient with information to help them find a keratoconus specialist optometrist or corneal surgeon.

Please note that Keratoconus Australia does not make recommendations about these eye-carers or the quality of service patients will receive from them. Nor can the Association write patient referrals to ophthalmologists – this is something that can be done only by optometrists or general practitioners. Finally, Keratoconus Australia has no financial interest in providing information to patients about eye-carers.

Crosslinking

Crosslinking – which under the standard protocol involves stiffening the cornea by first scraping off the outer epithelium layer of the cornea and then soaking it in riboflavin and then irradiating it with ultra violet light for about 30-40 minutes – is the only treatment currently available to keratoconus patients that offers the prospect of halting progression in their keratoconus.

However there is an increasing range of variations of this procedure and patients and their families continue to be bewildered by the array of options being offered by corneal surgeons in Australia. Many do not realize that there is a standard protocol that has been tested over more than a decade now around the world and a range of adaptations now available – the most notable being the procedure which leaves on the outer epithelium layer of the cornea (epi-on) and an accelerated crosslinking which uses a higher intensity UV light source for a shorter period of time. Little information on the comparative results of these other types of crosslinking are made available to patients and their families prior to the treatment to allow them to properly give their informed consent to these operations.

As a result, corneal collagen crosslinking remains an ongoing source of mystery and concern for many patients. Some 15% of all support requests last year related to crosslinking and the quality of the information patients and their families were receiving from their surgeons.

We note again what Dr Elsie Chan from the Centre for Eye Research Australia said at our September 2013 seminar on crosslinking i.e. that there is still no evidence that crosslinking is beneficial to patients who are not experiencing demonstrable progression in their keratoconus. She also pointed to the mixed results from studies into “accelerated” crosslinking as the high intensity-short exposure crosslinking is known. Dr Chan is a researcher on CERA’s crosslinking investigation which is the world’s longest running randomised trial into that procedure, (A free audio podcast of Dr Chan’s presentation is available on the Keratoconus Australia website).

The decision to have crosslinking should not be taken lightly as at this stage there are questions as to whether a second dose of crosslinking can be effective.

The Association is now working with the Sydney Eye Hospital’s Save Sight Institute to develop a crosslinking registry to track the outcomes of crosslinking based on type of crosslinking performed. Hopefully in time, this information will provide clearly information for patients on what type of crosslinking they should consider.

See also [Research](#)

Outreach and Study and Work resources

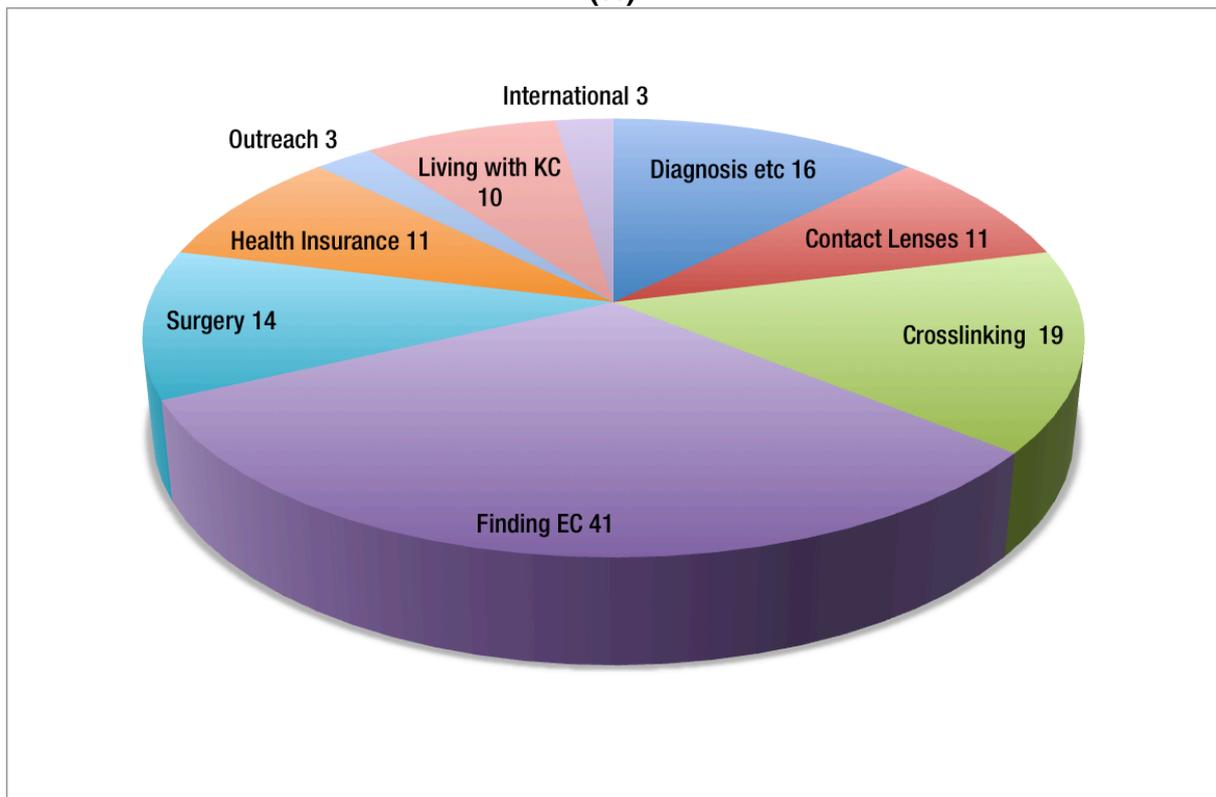
Outreach is an important adjunct to these support activities and we have a large number of members who are willing to discuss their experiences with patients facing the hard decisions around surgery like crosslinking and corneal transplantation. Although outreach accounted for only about 2% of all support last year, we believe patients should consider making direct contact with others to discuss their concerns and fears in preference to using social media like Facebook, Twitter etc which can limit the scope and depth of a discussion.

We also have an excellent [patient's guide to corneal transplantation](#) from the US National Keratoconus Foundation. It is free so contact us to obtain a copy.

Finally, we also have resources for those members having trouble with day-to-day life with keratoconus. Our [work-study expert Heidi Littleford](#) has counselled many patients – especially students - on how to deal with specific issues relating to computer use, long term study and coping with low vision in the workplace.

Below is a percentage breakdown of support logged in 2013-14 by type

Support by Type 2013-14
(%)



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 identifying particular areas of interest. Although it does not conduct formal research itself, it does provide support for research projects in various ways including funding, collection of information and assistance in the recruitment of participants.

Save Sight Institute, Sydney Eye Hospital

Australian Keratoconus Registry

Last year, the Association noted the profusion of protocols for performing corneal collagen crosslinking in Australia and the lack of clear, reliable information for patients about the safety and effectiveness of the various procedures being adopted by ophthalmologists. We said we would continue discussions with ophthalmologists about what could be done to rectify this situation to provide patients with greater transparency re the pros and cons of these protocols.

So without question, the most exciting Australian research project for keratoconus in recent years is the Australian Keratoconus Registry, which is being jointly developed by the Save Sight Institute (SSI) in Sydney and the Centre of Eye Research Australia (CERA) in Melbourne.

This project “will develop a national registry for keratoconus to collect high quality data outcomes from patients in clinical settings on the clinical effectiveness and safety of emerging therapies and surgical techniques”, according to the SSI proposal.

Corneal cross-linking, a relatively new treatment aimed to prevent keratoconus progression, will be the first therapy to be evaluated via the registry. The two research centres note that while many therapies, devices and surgical procedures have been developed to treat keratoconus, few have been evaluated using post-market surveillance. Further, there is no system in place to collect such data nationally.

SSI says the crosslinking registry aims to develop a module for its established anonymised data collection system, the Fight Retinal Blindness project, for patients with keratoconus. Using a specially developed keratoconus module, it will then

- investigate and evaluate the clinical effectiveness, cost-effectiveness and safety of emerging therapies for the treatment of keratoconus.
- develop strategies to ensure the use of evidenced based guidelines in the management of keratoconus.”



The project is being headed by Clinical Professor Stephanie Watson, of Save Sight Institute.

In May 2014, KA President Larry Kornhauser, went to Sydney to discuss the project with Professor Watson, Amparo Herrera-Bond of the Fight Retinal Blindness project team and the Director of SSI, Professor Peter McCluskey. Particular emphasis was given to how patient input would be integrated into the data collection process and how patients could be informed of the outcomes generated by the registry to enable them to make better informed decisions regarding surgery for keratoconus. Both issues have been dealt with under the registry proposal.

As a result of these discussions, Mr Kornhauser agreed to personally provide seed funding to launch the pilot registry project, which is now under development.

We expect the Association to become involved directly in this development process and perhaps to provide funding at a later date to help finance further stages aimed at spreading the registry to Melbourne and then nationwide.

Any Keratoconus Australia member who could assist in coordinating our involvement in this landmark project should contact the Association.

Centre for Eye Research Australia, Melbourne

Australian Keratoconus Study

For much of the 2013-14 financial year, Keratoconus Australia was in discussions with researchers at the Centre of Eye Research Australia (CERA) about a suite of projects relating to keratoconus under the umbrella of its new Australian Keratoconus Study (AKS). We commend CERA for this initiative, which will broaden its interest in keratoconus after establishing the world's first randomized trial into corneal collagen crosslinking in 2006. Three year follow-up data for that crosslinking project was published by CERA researchers in the journal *Ophthalmology* in January 2014. The Association has supported the crosslinking study since its inception.

As part of discussions around the AKS, Keratoconus Australia provided CERA researchers Ms Srujana Sahebjada and Dr Elsie Chan; with access to anonymous information collected by the Association on the economic cost of keratoconus to members. Ms Sahebjada provided the Association with a high level appraisal of the survey results. CERA has since used this information to develop its own questionnaire for an Economic Impact of Keratoconus study which it hopes to conduct in the near future as part of its AKS.

At this stage, Keratoconus Australia has not finalized an agreement with CERA over how it would continue to participate in the AKS. We will inform members in due course about progress in these discussions. However in the meantime, we note that Keratoconus Australia may provide limited funding to assist CERA with its keratoconus work. As in the past, the Association will also be pleased to use its resources for help recruit patients for the research if required.

Genes and Keratoconus trial

Ms Srujana Sahebjada presented the results of her Genes In Keratoconus and Myopia Study conducted along with Associate Professor Paul Baird at our September 2013 seminar on crosslinking held in Melbourne. Her presentation can be heard as part of the free audio podcast of proceedings on our website.

In March 2014, the Association sent out a special bulletin published by CERA outlining the preliminary results of their Australian Keratoconus Study (AKS). All members on email should have received a copy.

As noted in last year's Annual Report, the Association assisted in recruiting people with keratoconus for this research project. This study complemented other research being conducted by Flinders University into identifying the gene(s) that cause keratoconus.

New corneal collagen crosslinking research

Keratoconus Australia has been a partner in CERA's randomized controlled trial of the corneal collagen crosslinking procedure since its inception in 2006. The Association has provided funding and logistical support for the project over this period.

CERA and Keratoconus Australia are now looking at funding new research into crosslinking relating to its long term safety and effectiveness and its effect on younger patients.

Funding to continue these CERA studies into crosslinking is urgently required. Please contact the Association or CERA directly if you can assist.

Mater Hospital, Brisbane

In last year's annual report, we noted that in November 2011 Keratoconus Australia became aware it had been linked with a trial of corneal collagen crosslinking on juveniles (children under the age of 16) without our knowledge. The trial entitled "Comparison of corneal cross linking treatment parameters for juvenile onset keratoconus" was being conducted under the auspices of the Mater Hospital by Dr Jim McAlister, formerly of the Queensland Eye Institute.

The Association advised members that we were not associated with this trial.

In July 2012, we wrote to the Mater Ethics Committee about the conduct of this trial and documentation linking the Association to it. The Ethics Committee informed us in early 2013 that it had reviewed the trial at our request and found deficiencies.

On 17 June 2014, The Chief Executive Officer of Mater Health Services, Dr John O'Connell, wrote to the Association saying that during a revision of the trial protocols to correct "deficiencies," Dr McAlister ended the trial and resigned from Mater Hospital. Dr O'Connell claimed there had been "no serious adverse events or study outcomes identified" by Mater as part of its investigation.



If you have any concerns about Dr McAlister's treatment of your child prior to his dismissal from Queensland Eye Institute or his resignation from Mater Hospital, please contact these hospitals directly.

University of Melbourne -

Department of Optometry and Vision Sciences (DOVS)

In February 2014, the Association and its members again helped organise the keratoconus training clinics conducted for 3rd and 4th year optometry students at the University of Melbourne's Department of Optometry and Vision Sciences (DOVS).

These clinics have been held in conjunction with the DOVS since 2006 and provide optometry students with a unique opportunity to fit contact lenses onto keratoconus and corneal transplant patients prior to graduating. They are the only keratoconus training clinics in Australia.

Keratoconus Australia members kindly volunteered their time and their corneas to ensure the clinics were again a success.

Optometrist Post Graduate Scholarship

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, moves are now afoot 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.

Anyone interested in helping fund this initiative should contact the Association.

Eye-carer scientific advisory committee

Keratoconus Australia recognises the invaluable contribution of many eye-carers in the keratoconus community in answering questions from our members and holding 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 eye-carers and continue to provide these at a nominal cost to eye-carer practices.

One way of expanding and formalizing these 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.



Members interested in assisting the Association in advancing this proposal should contact us.

UoM Eyecare Keratoconus Clinic

The University of Melbourne Eyecare's Keratoconus Clinic continues to offer an avenue for members to obtain contact lenses at up to a 50% discount. We continue to receive good reports from members who have used the clinic over the past year.

This Keratoconus Australia initiative also provides another opportunity for optometry students to gain valuable experience in full fits of all types of contact lenses on keratoconus and post-graft patients.

The Association will hold talks with the DOVS to see how arrangements for the keratoconus clinic can be improved for 2015. We also understand that additional qualified specialist contact lens fitters for keratoconus will be participating in the clinic which should enable Eyecare to provide more appointments for patients.

We again commend the DOVS on supporting this initiative and hope it can serve as a model for similar clinics in other states.

A better deal on contact lenses

We often feel like we are tilting at windmills, but still we plug away in our effort to reduce the cost of contact lenses for keratoconus to members and to improve rebates from private health insurers for these specialized lenses.

After the flurry of activity in 2012-13, most of our effort in the 2013-14 financial year centered around putting another submission to Optometry Australia (formerly the Optometrist Association of Australia) seeking support for a submission to the Australian Government prior to the May 2014 budget.

Optometrists

In last year's annual report, we noted that Melbourne optometrist, Richard Lindsay, had identified the fact that Medicare does not recognise keratoconus as an eye condition as one of the roadblocks to achieving higher rebates on contact lenses. His argument is that a key step towards a better deal for people with keratoconus will be recognition by the Australian Government that keratoconus actually exists!

The full text of a paper entitled *Why Medicare needs to recognize Keratoconus* that he wrote for the Association was included in the annexes to the 2012-13 annual report. In October 2013, we provided it to Vision 2020 Australia for inclusion in their submission to the Australian Government being prepared on behalf of Keratoconus Australia.

In parallel to that submission to Vision 2020 Australia, the Association reopened talks with Optometry Australia (OA) CEO, Genevieve Quilty, in the hope that she would take our submission to the OA board meeting in February 2014 for inclusion in their pre-budget submission to the Australian Government. Our submission to OA is included in the annexes. The OA board did not consider the contact lens issue but offered to assist us later in the year. Nothing has eventuated to date and this matter will be taken up again with the OA in 2015.

We note that this issue has become imperative now as OA did succeed in their bid to have the cap lifted on optometrist fees as from January 1, 2015. The cap on fees has always been cited as the reason contact lenses for keratoconus are so expensive as optometrists recoup the cost of time spent fitting them by charging extra for the lenses. Unfortunately there is no indication that higher service fees will now lead to a fall in the cost of contact lenses. At best, optometrists tell us that scheduled increases in the cost of lens may be postponed or limited.

This is a most unsatisfactory outcome for patients. We urge all patients experiencing higher fees next year for appointments to challenge their optometrists about the cost of the lenses they are fitting and why they have not been reduced.

Access to cheaper contact lenses

In the absence of lower prices or higher rebates on contact lenses for keratoconus, Keratoconus Australia 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).

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.

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.

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 http://www.keratoconus.asn.au/Resources-F/KA_Insurance_letter.pdf.

Corneal collagen crosslinking costs

As noted in last year's annual report, there can be wide discrepancies in the cost of corneal collagen crosslinking procedures. This is of particular concern as crosslinking is still not approved by Medicare and patients will need to meet the full cost of the operation regardless of whether they have private health insurance or not.

A quick survey done by Keratoconus Australia indicates that keratoconus specialists in Sydney and Melbourne are charging between \$1,800-\$2,600 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.

The Association hopes that the crosslinking registry project will help standardize protocols for best practice crosslinking and normalize costs in the future.

Crosslinking seminar

Keratoconus Australia held one seminar during the 2013-14 financial year.

All about corneal crosslinking

Tuesday September 10, 2013

Speaker **Dr Elsie Chan**, researcher Centre for Eye Research Australia

Over the past decade, corneal collagen cross-linking has become commonplace as a treatment option for people diagnosed with progressive keratoconus. Results have shown that cross-linking slows and may even halt the progression of keratoconus, with a small risk of complications. More recently, variations to the cross-linking procedure have been performed.

In her talk, Dr Chan reviewed the theory, different treatment regimes and the clinical results of cross-linking. She also presented an update of the results from the Melbourne trial and other upcoming research projects.

A DVD of the presentation is available from the Association for those members who were unable to attend and a free audio podcast is also available on our website.

Free Audio Podcasts

Free audio podcasts of recent Keratoconus Australia seminars are now available on the Association's website.

Membership

At 30 June 2014, Keratoconus Australia had 2,026 registered members. This represented an increase of 6.9% above the 1,896 members registered one year earlier.

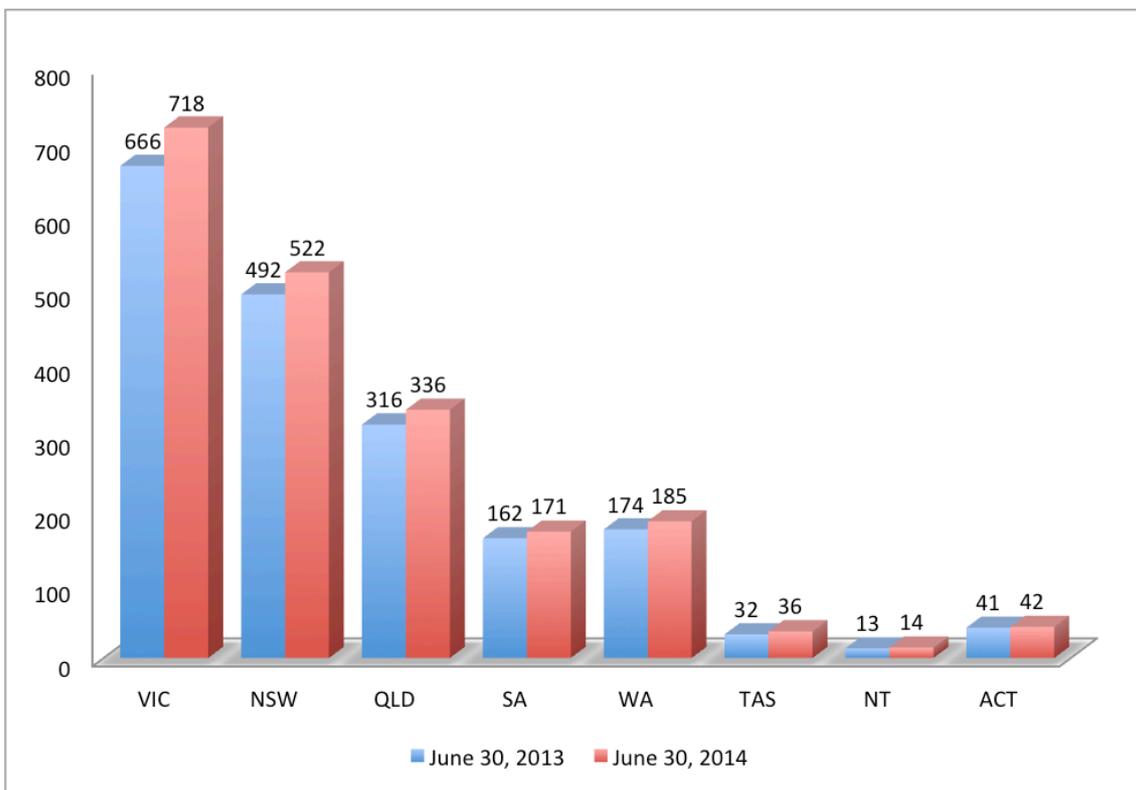
Victoria (718 members, +7.8%) experienced strong growth last year and continues to account for more than one-third (35.4% at June 30, 2014) of the Association's total membership base. Membership in NSW grew more slowly in 2014 (+6.1%) to 522 and accounted for 26% of the total.

Queensland remains the third largest state in the Association's membership base (16.6% of the total); members there now total 336, +6.3% on the previous year.

Membership also increased in Western Australia by over 6% to 185 members in 2014 (9.1% of the total), followed by South Australia at 171 members or 8.4% of the total at June 30, 2014.

(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



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 for their kind assistance again in 2014, notably GMK (accounting), The Australian College of Optometry (seminar venue) and Viewgrow Capital Pty Ltd (meeting venue and administrative support services) and Herbert Smith Freehills for legal services.

As discussed previously, the University of Melbourne has strongly backed Keratoconus Australia's efforts to improve access to cheap, well-fitted contact lenses for keratoconus patients.

Review of rules

The committee initiated a review of the Association's constitution and rules to ensure it conformed with recent legislative changes relating to associations and charities. Changes will be required by new provisions of either the *Associations Incorporation Reform Act 2012 (Act)* or the *Australian Charities and Not-for-Profits Commission Act 2012 (ACNC Act)*. We engaged Herbert Smith Freehills which has in the past acted on behalf of the Association on a pro bono basis. This review is still underway. However a preliminary report from HSF indicates that only minor changes to our constitution should be required. The Committee is taking this opportunity to review its privacy policy, social media policy and membership rules.

Fundraising and Grants

We would like to thank all donors who made significant contributions during 2013-14 financial year.

No grants were sought or received during the year.

Local Groups

A long-time member and supporter of Keratoconus Australia, George Ferteklis, contacted the Association during the 2013-14 financial year about creating a local support group in the [Adelaide](#) area. The Association notified all our South Australia members about George's interest in creating the group. Please contact the Association if you would like further information about George's group.

Members on the Gold Coast, Tasmania, ACT and NSW have also expressed interest in forming local groups. 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.

Website and Social Media

Due to changes with our hosting arrangements, we do not have statistics on the website usage this year. We hope to reintegrate that function into the new website which is again on track and hopefully will be online in 2015.

We also hope to start using Facebook, Twitter and other social media in 2015 (yes, its about time!) to post articles on keratoconus and keratoconus-related research that constantly appear.

We note that a number of members have created keratoconus-related Facebook pages for Australians with keratoconus and dry eye syndrome. While we are assisting some of these members with their pages, the Association is not directly involved in any of these Facebook or other support sites.

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 2013-14, the committee met twice and held informal discussions on other occasions.

The committee last year comprised:

Larry Kornhauser, President
Neil McFarlane, Secretary
Jennifer Toom,
Heidi Littleford
Aghi Di Maio
Mila Maisano

Mary Veal acts as the Association's Administrative Assistant 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:

- | | |
|------------------------------|--|
| Volunteer coordinator | <ul style="list-style-type: none">• experience in managing volunteers, allocating tasks, follow-up |
| Website | <ul style="list-style-type: none">• design, content development and maintenance |
| Social media | <ul style="list-style-type: none">• formulate policy guidelines for Facebook and Twitter and other platforms• provide and monitor content and postings |
| Advocacy | <ul style="list-style-type: none">• experience in writing submissions to government and other representative organizations• understanding of the Medicare system |
| Research | <ul style="list-style-type: none">• 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 | <ul style="list-style-type: none">• ability to develop and implement a fundraising strategy |


Treasurer

- event management
- ability to develop budgets and forecasts of funding requirements
- manage research budgets

Design

- assist in the design and preparation of templates for invitations, newsletters, brochures and other printed and electronic materials for distribution

The Association will be winding down its activities over the summer by early December. However, you can email us over the holiday period if you would be interested in contributing in 2015 in any of the above areas.

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

Once again, the Committee of Management would like to thank everyone who has assisted the Association over the past 12 months. Despite all the limitations on our resources, we are trying hard to improve the lives of everyone with keratoconus and their families. We believe we are making a difference. Please consider joining us in our endeavours in 2015.

24 November 2014




FINANCIAL REPORTS

The Association reported a **net profit** in the 2013-14 financial year of \$5,000. This was down 16.7% on the previous year's net profit of \$6,006.

The lower result largely reflected lower video sales on the income side and higher mailing charges (stationary, postage and photocopying on the expenses side. Total income for the year fell 3% to \$10,588 compared to \$10,917 in 2012-13. Donations in the absence of a major fundraiser remained almost steady at \$8,499 (\$8,489 previously)

Overall expenses rose by 13.8% to \$5,588 up from \$4,912 in 2013-14.

The **balance sheet** for on June 30, 2014 showed net assets of \$83,137, or 6.4% higher than one year earlier (\$78,137). End-year assets totalled \$83,380 (\$78,324 on June 30, 2013), held mostly in cash (\$81,881). Some \$71,350 of this is being held in a high interest bearing deposit account at Westpac. Liabilities totalled \$243 at the end of the 2013-14 financial year – these related to GST.

The accounts have been finalized and reviewed by our accountants, GMK Partners, who work for the Association on a pro bono basis.

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

**COMPILATION REPORT
TO KERATOCONUS AUSTRALIA INC**

We have assisted in the compilation of the accompanying special purpose financial statements of Keratoconus Australia Inc.

The Responsibility of Director

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

Our Responsibility

On the basis of information provided by the director, 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 director and management of the company.

Our procedures use accounting expertise to collect, classify and summarise the financial information, which the director 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 director of Keratoconus Australia Inc. We do not accept responsibility to any other person for the contents of the special purpose financial statements.

Melbourne

Date: 12 November 2014

Directors

Norman Metz
Sydney Kahn
Kevin Slomoi
Eugene Berkovic
John Mabilia
Antony Barnett
Laurence Slomoi
Chris Wookey
Gary Immerman
Cameron Falt
Ranjan Manoranjan
Snehal Shah

Associates

Paul Pui
Deirdré Buckley
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Linkmann Xavier
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under Professional
Standards Legislation

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Keratoconus Australia

PO Box 1109
HAWKSBURN VIC 3142

Profit & Loss [Last Year Analysis]

July 2013 through June 2014

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	This Year	Last Year
Income		
Donations	\$8,499	\$8,489
Seminar Entrance Fees	\$1	\$51
Video Sales	\$105	\$468
Booklet sales	\$91	\$68
Bank Interest	\$1,893	\$1,841
Total Income	<u>\$10,588</u>	<u>\$10,917</u>
Cost of Sales		
Gross Profit	<u>\$10,588</u>	<u>\$10,917</u>
Expenses		
Domain Name Registration	\$107	\$54
Bank Charges	\$4	\$6
Catering	\$18	\$41
Stationery	\$714	\$208
Depreciation Expense	\$1,388	\$2,092
Dues & Subscriptions	\$222	\$217
Legal Fees	\$0	\$44
Postage	\$1,177	\$887
Photocopying	\$431	\$170
Booklets	\$189	\$79
Seminar Expenses Melbourne	\$102	\$103
PO Box Rental	\$107	\$99
Video Recording	\$439	\$439
Website Hosting	\$303	\$327
Telephone and Internet	\$69	\$70
Software Purchased	\$168	\$0
Sundry expenses	\$151	\$76
Total Expenses	<u>\$5,588</u>	<u>\$4,912</u>
Operating Profit	<u>\$5,000</u>	<u>\$6,006</u>
Other Expenses		
Net Profit / (Loss)	<u>\$5,000</u>	<u>\$6,006</u>

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 2014

12/11/20
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	This Year	Last Year
Assets		
Current Assets		
Cash On Hand		
Westpac DGF Account	\$10,531	\$10,951
Westpac Max-iDirect	\$71,350	\$64,474
Total Cash On Hand	\$81,881	\$75,425
Trade Debtors	\$100	\$0
Total Current Assets	\$81,981	\$75,425
Other Assets		
Sundry Debtors	\$0	\$113
Total Other Assets	\$0	\$113
Property & Equipment		
Clubhouse		
Website	\$6,255	\$6,255
Accumulated Depreciation	-\$4,855	-\$3,468
Total Clubhouse	\$1,399	\$2,787
Total Property & Equipment	\$1,399	\$2,787
Total Assets	\$83,380	\$78,324
Liabilities		
Current Liabilities		
GST Liabilities		
GST Collected	\$267	\$270
GST Paid	-\$25	-\$83
Total GST Liabilities	\$243	\$187
Total Current Liabilities	\$243	\$187
Total Liabilities	\$243	\$187
Net Assets	\$83,137	\$78,137
Equity		
Retained Earnings	\$78,137	\$72,131
Current Year Earnings	\$5,000	\$6,006
Total Equity	\$83,137	\$78,137

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




ACKNOWLEDGEMENTS

Keratoconus Australia would like to acknowledge the special contributions of the following people and organizations during 2013-14.

Associate Professor Richard Vojlay

Audio Visual Solutions

Centre for Eye Research Australia

Save Sight Institute

Dr Michael Loughnan

Dr Jacqueline Beltz

Associate Professor Stephanie Watson

Dr Elsie Chan

Dr Srujana Sahebjada

Belinda Cerritelli

GMK Partners

Herbert Smith Freehills

Minuteman Press

Optometry Australia

Richard Lindsay

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



Genevieve Quilty
Chief Executive Officer
Optometrists Association of Australia
Level 6, 39 London Circuit,
Canberra, ACT 2601

06 February 2014

Dear Ms Quilty,

Keratoconus Australia (KA) would like to thank you for agreeing to submit our request for proper recognition of keratoconus under the Australian Government's Medicare scheme to the Board of the Optometrists Association of Australia (OAA).

We appreciate that the OAA has a number of competing priorities and this issue is one of many for your Association to consider. However, over the past 10 years, our Association's repeated attempts to provide people with keratoconus access to better treatment options at an affordable cost have had little success. Government ministers and officials, private health insurance fund representatives, ophthalmologists and optometrists have all expressed concern – but done little else - about the plight of the many keratoconus patients whose education, work and family lives are severely impacted by their inability to access affordable treatments to correct their often severe vision loss.

As a result, patients are sent for corneal transplants they would not require if they had access to affordable and properly fitted contact lenses. Yet, most will still require vision correction including contact lenses after this irreversible operation. This is hardly what either optometrists or ophthalmologists could consider best practice medicine. Far from it.

We and specialist keratoconus optometrists believe that a key hurdle to better outcomes for keratoconus patients is the failure of Medicare to recognize keratoconus as a condition under its optometric schedules. This issue has been explained in detail in the accompanying submission '*Medicare recognition of keratoconus*' which was prepared in conjunction with Richard Lindsay, a leading optometrist in this field, Vision 2020 Australia, KA and the OAA. We are hoping the OAA Board will consider this matter serious enough to take it up with the Medical Services Advisory Committee.

Keratoconus Australia believes that proper recognition of keratoconus in the Medicare optometric schedules would have a flow on effect beyond just ensuring that keratoconus patients received better rebates on optometrist consultation fees. It should also ensure that optometrists could be better recompensed for the time they spend treating difficult cases of keratoconus and should therefore increase the pool of optometrists specializing in this field. It would also assist in convincing the private health funds to recognize that complex contact lenses used for keratoconus are as important to keratoconus patients as hearing aids are to hearing impaired persons and should therefore be considered as a medical device – not a lifestyle choice.

Optometrists have always been the primary carers for keratoconus patients and will be for many years to come. If anything meaningful is to be done to assist keratoconus patients, we will need your support. We therefore urge the OAA Board to give serious consideration to our submissions.

We look forward to your reply.

Yours sincerely

Mr Larry Kornhauser

President

Keratoconus Australia Inc

Keratoconus Australia Inc (KA) is a not-for-profit association created to prevent and control the eye disease, keratoconus, and visual impairment caused by keratoconus. The Association currently has 2000 members Australia-wide. All members either have keratoconus or are parents or guardians of children with keratoconus.

Keratoconus Australia Inc.

PO Box 1109, Hawksburn, VIC 3142

T 0409 644 811 **E** info@keratoconus.asn.au **W** www.keratoconus.asn.au

ABN 80 683 325 208 A0039546H

Medicare recognition of keratoconus

Keratoconus is a progressive eye disease that affects at least 14,000 Australians and even as many as 40,000

Keratoconus is a thinning of the central zone of the cornea, the front surface of the eye. As a result of this thinning, the normally round shape of the cornea is distorted and a cone-like bulge develops. In the majority of cases it causes significant visual impairment which can only be rectified by the fitting of specific, custom-made contact lenses.

The social cost of keratoconus

As there are no apparent physical signs of this disease, family, friends and colleagues of people with keratoconus find it difficult to understand the ramifications of this condition.

The early onset of keratoconus and its often rapid advance during these first years means keratoconus can impact heavily on a person's ability to study, obtain or maintain employment, cope with the demands of raising a family and in extreme cases, to perform basic self-care functions. Even when a person's keratoconus is well managed by an experienced optometrist, complications and implications of contact lens wear are numerous. Examples include:

- people face a lifetime of expensive contact lenses, countless visits to the optometrist, risk of developing contact lens intolerance and the prospect of a corneal transplant with limited guarantee of success
- complex cases of keratoconus can require many appointments often impacting on a person's work/ study
- if contact lenses are not able to be worn (one or both) for some reason - eye irritation, the lens getting lost or breaking - this usually means the person is not able to work/ study until the crisis is resolved. Albeit in a short term capacity (can be up to three weeks), this often results in loss of income or ability to study etc.

Medicare

Medicare recognition of keratoconus, with a clearly defined item description that outlines the nature of the visual disability, would lead to a greater understanding and acceptance of this condition amongst the community.

Presently about 10-15% of the population are covered under Medicare for contact lens fitting. There are nine Medicare item numbers (10921 to 10929) which cover conditions such as high short sightedness, high long sightedness, high astigmatism, etc.

Although Item 10924 is intended for keratoconus, keratoconus is not actually mentioned in the item description. Item 10924 is classed as being for '*patients with irregular astigmatism in either eye, being a condition the existence of which has been confirmed by keratometric observation, where maximum VA obtainable with spectacle correction is worse than 6/12 and the corrected acuity can be improved by an additional one line by the use of a contact lens*'.

The issues with this item description are:

- it does not mention **keratoconus**
- it is an outdated definition (keratoconus is now easily diagnosed by use of corneal topography which is a significant advancement over keratometry)
- it applies to only 60-70% of patients with keratoconus

- the 6/12 criterion is just one measure of vision quality. It is inadequate in determining as to whether someone qualifies for financial assistance.

There are many people with keratoconus who achieve a visual acuity of better than 6/12 with spectacle correction – and hence are not eligible for item 10924 – however most of this group are still very much visually incapacitated with spectacles due to the poor quality of their optical image as a result of their keratoconus.

These people experience visual symptoms such as ghosting and monocular diplopia due to the high degree of corneal irregularity associated with the keratoconus. As such, these people are often not able to work or perform normal activities of daily living – even with spectacle correction – due to their visual impairment.

In this situation, patients will only achieve satisfactory vision with specially fitted custom made contact lenses. As these contact lenses are the only adequate means of correction for people with keratoconus, it goes without saying that the use of contact lenses is absolutely indicated clinically and so should be covered under Medicare.

The need for Medicare recognition

As the Government and Medicare does not recognise keratoconus as a specific disease (unlike in other countries such as the UK and NZ), private health funds also do not recognise the condition of keratoconus. Consequently, rebates from private health funds for keratoconic contact lenses are clearly inadequate given the specialized, custom-made nature of these lenses. People with keratoconus generally only receive rebates comparable to people with more routine ocular disorders such as short sightedness and long sightedness, leaving a significant out-of-pocket expense. It is not uncommon for people to travel vast distances to see their optometrist and be fitted correctly for these specialized lenses in order to achieve adequate vision to enable them to live their lives and contribute to society.

Existing schemes

It is acknowledged that subsidised contact lenses are available at the state level from some eye hospitals and optometry teaching colleges. However, these lenses are often fitted by eye health practitioners with limited experience with keratoconus and proper fitting of keratoconus specific contact lenses require more time than is often allocated. This can result in negative outcomes for the patient, for example, (1) poorly fitted lenses can cause ulcers eventually lead to scarring that can necessitate a premature corneal transplant and (2) poorly fitted lenses discourage people from wearing them and incorrectly persuade them there is no non-surgical solution to their vision problem.

People outside the major capital cities have virtually no access to either subsidised contact lenses or experienced contact lens fitters for keratoconus in their areas.

New treatments

There is now a promising new treatment that can be used for many people with keratoconus to stop the progression of the disease. The treatment, known as Corneal Collagen Cross Linking (CXL) has had very positive feedback from randomized double blind studies and results indicate that the treatment is effective in retarding the progression of keratoconus.

Should this surgical treatment be covered under Medicare, it will greatly reduce the number of people with keratoconus who go on to need corneal transplantation. This will result in tremendous savings in health care costs for the Government as well as costs associated with



people being incapacitated and unable to work due to advanced keratoconus.

Conclusion

The complexity of this matter is well understood. However, there are many immediate and obvious benefits for both the community and individuals suffering real disadvantage from a lack of access to affordable vision correction and optometrists experienced in fitting contact lenses to people with keratoconus. The costs and lack of productivity to this group of people with this vision impairment is very significant.

The recognition of keratoconus as a specific disease by Medicare will offer substantial social and economic benefits, such as:

- better visual outcomes for a large proportion of people diagnosed with keratoconus.
- a significant reduction in the number of people despondent about their chances of obtaining high quality and affordable non-surgical treatment options.
- better educational outcomes for adolescents (and others)
- greater potential for people to obtain and maintain regular employment. This should reduce welfare payments and increase income tax revenue
- lower workforce absentee costs by reducing the number of people who have recurring issues with their vision caused by inappropriate contact lenses or less than optimal outcomes from corneal transplants
- a reduction in the number of corneal transplants performed which may assist in reducing the long waiting lists for those in need of corneal surgery.

This submission was prepared by:

Keratoconus Australia

Richard Lindsay, optometrist, Richard Lindsay and Associates

Vision 2020 Australia

With input from:

Optometrists Association of Australia

Andrew Watkins, optometrist, Andrew Watkins Optometrist

January 2014