

K E R A T O C O N U S AUSTRALIA

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FROM THE PRESIDENT

The world of keratoconus was never much more than a backwater in eye healthcare until recently. So after years of very little evolution in the treatments available to manage this disease, which affects us in so many ways, it almost comes as a surprise to see change suddenly occurring everywhere.

In 2010-11, Keratoconus Australia continued to play its part in what is becoming a revolution as the introduction of corneal collagen crosslinking gathered pace in ophthalmologic circles. Contact lenses for keratoconus are also being refined and more options are available today than ever before. Our new partnership with the University of Melbourne's EyeCare Clinic aims to reduce the cost of these complex lenses to patients while training more optometrists in how to fit them.

The international press is filled with new procedures and treatments – most still experimental and unproven – giving hope that one day keratoconus will be no more than a minor irritation for our children (or more realistically, our grandchildren).

But we are still a long way from that situation, and despite our best efforts and those of a committed group of ophthalmologists and optometrists specialising in this field, much more work needs to be done.

Change has also touched the Association. Our hardworking, omnipresent secretary, Belinda Cerritelli, is leaving the committee to take up new challenges after a decade of dedicated service to the keratoconus community. Belinda has been the face of



Belinda Cerritelli

Keratoconus Australia in so many forums and in so many roles that it is hard to imagine how the Association will function without her. She has worked tirelessly as a volunteer to the cause through much upheaval in her personal and professional life – and she has always performed her tasks with verve, insight and a big smile. Belinda's work for the Association in the areas of research and advocacy has been exceptional and was responsible for Keratoconus Australia becoming a respected player in vision-related healthcare.

Her contribution is greatly valued and she will be sorely missed. We wish her all the best in her post-KA endeavours.

Belinda leaves a huge hole to fill – but fill it we must. We therefore urge all members, especially those in our home state of Victoria, to consider joining the Association's committee of management and to help us maintain and build on the work Belinda has undertaken for so many years.

Larry Kornhauser
December 2011

Support for people with keratoconus and their families remains our primary mission, and one we take very seriously. Nobody wants to be diagnosed with a degenerative eye disease and it is perhaps even harder when it affects your child. Much of the support we provide revolves around the three stages of keratoconus:

- Initial diagnosis
- When glasses fail to provide adequate vision
- When contact lenses no longer seem to work

Generally, when people reach any of these stages, they need to be directed to a specialist contact lens fitter for keratoconus as their problems relate to issues which practitioners less experienced in keratoconus are unable to resolve.

However when a person seeks assistance at these stages, it could be a sign that their keratoconus is progressing too. That means their eye-carers may also need to consider whether or not they are a candidate for corneal collagen crosslinking (CXL), a relatively new procedure that aims to halt further progression by stiffening the cornea through a combination of riboflavin and ultra-violet light exposure.

The Association is gradually building up a list of corneal surgeons who are performing crosslinking around Australia and when necessary, we can direct people considering the operation to appropriate clinics.

However, crosslinking remains a largely experimental procedure (the world's longest randomised CXL trial in Melbourne has results for only 4 years) and many surgeons still believe that it should be offered only to patients showing clear progression. Furthermore, there have been no randomised trials on patients under the age of 16 years, who often suffer the most aggressive forms of keratoconus.

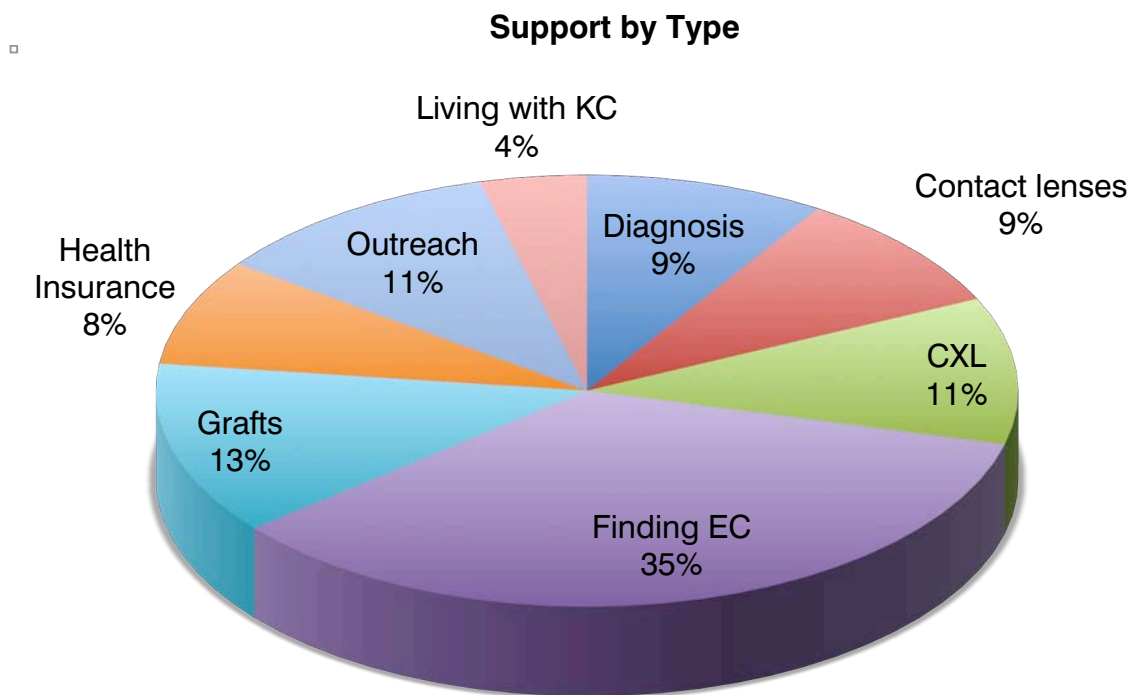
We therefore believe that the decision on crosslinking needs to be taken by the patient's optometrist in conjunction with a corneal surgeon to ensure that is the appropriate treatment. The Association has a short summary of the current view of crosslinking, which we generally distribute to patients and/or their parents to give them a clearer understanding of the issues involved in this procedure.

The internet remains the principal vehicle for support, with over 90% of support requests coming via email. Most of these are directed through the Online Forum page of our website at www.keratoconus.asn.au. The majority of these inquiries are handled by email initially, often with follow up via telephone or meetings. While emails can provide a brief outline of a problem, it usually requires a conversation before the real underlying issues can be identified and resolved.

Against this background, much of the support work done by the Association remains focused on helping people find experienced eye-carers in their area or region.

In 2010-11, individual support cases logged by the Association numbered almost 180, down from the 2009-10 record high of 230. However, many of these cases required multiple contacts with the persons concerned and the total number of support interactions with persons contacting the Association was closer to 400 last year.

Below is a percentage breakdown of support provided in 2010-11 by type



Help in Finding Eye-Carers

As in previous years, assisting members find experienced eye-carers was by far the largest single area of support in 2010-11 at 35%. However support provided by the Association in other areas notably contact lenses, diagnosis and surgery often resulted in patients seeking a second opinion from a keratoconus specialist, and the actual percentage of assistance in finding eye-carers in total support was therefore closer to 70%.

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.

Cases Studies

In the Association's 10th anniversary annual report presented to last year's AGM, we outlined in detail the guiding principles behind our support work and the different types of support provided to members and others who contact Keratoconus Australia for assistance.

Members wishing to gain a better understanding of these principles and types of support should refer to this report which can be downloaded from our website or will be sent to you on request.

This year we thought we would describe our work by outlining a few case studies from support provided over the past 12 months.

Case 1


Anthea, the mother of a 14 year old boy in regional Queensland contacted the Association in June 2010 after her son was diagnosed with keratoconus. She asked if there was financial support available to pay for contact lenses. We said no, other than obtaining the lenses through a government sponsored contact lens clinic. We sent information on contact lenses for keratoconus and corneal collagen crosslinking (as this may become an issue) and asked her to register her details with us.

In August 2010, Anthea emailed again to say her son now could not wear glasses or contact lenses and needed a corneal transplant in Brisbane. She asked about waiting times in the public system as she was concerned how long it would be until he could see again. She was under the impression from her corneal surgeon that it could be 12 months until the operation. "It's the worse thing for a mother to not be able to fix her child right away," she wrote.

As this rapid deterioration seemed unusual, the Association first contacted the Queensland Eye Bank which said that corneal tissue was generally available and that waiting times usually depended on the availability of operating theatres and other facilities at the public hospitals.

We then rang Anthea to explain this and discuss her son's situation and treatment to date. We discovered that the boy had been seen only by a local optometrist with no real knowledge or experience in fitting contact lenses for keratoconus. Based on his inability to fit contact lenses, the boy had been referred to a corneal surgeon for a corneal transplant.

Given the serious and irreversible nature of a corneal transplant and that the boy had been diagnosed only two months earlier, we suggested the family go to Brisbane to see a specialist contact lens fitter for keratoconus for a second opinion. We sent the family information on how to obtain a financial assistance grant under the Queensland Patient Travel Subsidy Scheme to facilitate that trip. We also helped Anthea arrange their appointment with the Brisbane contact lens fitter.



Two weeks later, an excited Anthea rang us just after seeing the optometrist to say that her son *could* be fitted for contact lenses after all and would not require a corneal transplant. The optometrist had also referred him on to a corneal surgeon who would consider corneal collagen crosslinking. We didn't hear anything from the family for some time thereafter.

In June 2011, Anthea contacted us again and asked how she could share her experience to help others. She said that her son had crosslinking done on his eyes in November 2010 and was doing very well with contact lenses. They were hopeful he would be able to get his learner's driving permit next year, "which is just fabulous as we had many tears over that issue early on," she said....

"I will be forever grateful for the support you gave me."

Case 2

Rebecca contacted us as she was expecting to have a corneal transplant and wanted more information than provided by her corneal surgeon. We sent her the excellent free booklet on corneal transplants supplied to us by the US Keratoconus Foundation.

She recontacted us a short while later because of problems with her contact lens on the other eye and to speak to someone about the corneal transplant. We suggested she obtain a 2nd opinion on her contact lenses prior to the surgery to ensure she had good sight in that eye and sent her the names of some contact lens fitters in her area. We also sent a list of KA members who have had corneal transplants with whom she could discuss the operation and the recovery period.


Case 3

Cathy contacted us about her son's vision problems. Like all concerned parents, she asked for names of the "best" eye-carers to treat him. As it wasn't clear what he required, we asked for further information. However she was confused as to whether he needed contact lenses or something she had heard about called corneal collagen crosslinking. We explained that contact lenses were required to correct vision and that crosslinking would not do that – rather it would hopefully halt any further deterioration in his vision. In the end, we sent her the names of some contact lens fitters in her area and told her they could assess her son and refer him on to a corneal surgeon to consider crosslinking if necessary.

Case 4

Like some of our members, Andrew wanted to buy his contact lenses online, as he thought they were too expensive to buy from his optometrist. We have discussed this issue endlessly with optometrists, health funds and government and have been trying to find a way to lower the cost of lenses to patients.

However in the meantime, there are good reasons not to buy rigid gas permeable (RGP) lenses for keratoconus online. Perhaps the most compelling is that these often complex lenses can be hard to fit. Often it takes several adjustments to get the right fit. Contact lenses bought through reputable optometrists specialising in



keratoconus cost more because they generally come with a warranty that enables the optometrist to make several adjustments to a prescription over a 3-6 period. This is designed to maximize the chances that the patient will end up with a best-fit contact lens at the end of the process. Wearing a poorly-fitted lens can seriously damage an already fragile keratoconic cornea and we always urge patients to stop wearing an RGP lens that feels uncomfortable or makes their eye turn red.

Furthermore, complex lenses for keratoconus can be difficult to manufacture. It is therefore imperative that an optometrist verifies a lens on delivery to ensure it conforms to the prescription and is comfortable and stable. We passed on this information to Andrew who acknowledged its wisdom. However he then added he was considering the online purchase to replace a pair of soft contact lenses, which are more commonly purchased on the internet.

Case 5

Tanya's son had corneal collagen crosslinking done 12 months earlier. Unfortunately the result was not good. His vision remained hazy (a common short term side effect of the treatment) and the keratoconus had continued to progress making his vision worse overall. She was very distressed and wanted to know what the family could do now.

We are often confronted by situations like this where people come to the Association seeking medical advice after failed surgery. However we are simple people with keratoconus – not medical practitioners – and we cannot give advice on medical issues.

We tried to reassure Tanya and offered to assist the family in obtaining a 2nd opinion from another corneal surgeon working in crosslinking.

But the simple fact is that crosslinking is still a largely experimental procedure and does have risks. It appears to have up to a 25% failure rate in aggressive cases of keratoconus and patients considering this procedure need to understand these risks.


Case 6

Leah contacted the Association to ask if having keratoconus and being legally blind meant a person could qualify for a disability pension.

We explained that legal blindness refers to corrected not uncorrected vision. Hence most people with keratoconus can get good corrected vision, with glasses, contact lenses or a corneal transplant and so very few would be defined as legally blind. We suggested she contact Vision Australia or Centrelink for further information and provided contact numbers.

Outreach

Being able to discuss your concerns with others who have had the same experience is an essential part of the support process. The Association has a growing list of members who are available to discuss their wide range of experiences as a person



with keratoconus. We give particular assistance to those facing the difficult issue of surgery, such as corneal transplantation and corneal collagen crosslinking. People wishing to know more about this service can contact the Association by phone or email.

We again thank the many members who are kind enough to participate in our outreach service.

Study and Work

Since joining the committee in 2009, Heidi Littleford has made a significant contribution to our support work with her unique skills in advising people with vision-related issues in education and the workplace. Heidi has assisted adolescents and their families in meeting their special needs in secondary and tertiary education and has offered invaluable advice to patients on how to cope with the daily stresses of working with keratoconus.

International

Many people from overseas contact the Association for support via our online forum page. Last year, we received requests from Indonesia, New Zealand, the US, and our Jordanian friend Nedal who works in Algeria and may need a corneal transplant now.

In some cases, we suggested that the person post their request on the NKCF's kc-link international email list (<http://www.nkcf.org/resources/kc-link.html>). Cathy Warren at the NKCF continues to cooperate with the Association on international support and in some cases has sent information on keratoconus directly to patients on our behalf. We continue to assist people in New Zealand in finding eye-carers for keratoconus in the absence of a support group in that country.

Research remains a key focus point for Keratoconus Australia and the Association was involved in a number of initiatives during 2010-11. We note that Keratoconus Australia does not conduct its own research work.

CERA study into Corneal collagen crosslinking

Keratoconus Australia has been a key partner of the randomized controlled trial of the corneal collagen crosslinking procedure being conducted by the Centre for Eye Research Australia (CERA) at the Royal Victorian Eye and Ear Hospital (RVEEH) since 2006. The Association continues to provide financial and logistical support to the trial, which is the longest running randomised trial of crosslinking in the world.

Last year, this included Secretary Belinda Cerritelli offering her services to help check data being compiled as part of the study.

One of the trial investigators, Dr Christine Wittig-Silva, was a keynote speaker at the 6th International Congress of Collagen Cross Linking in Milan in January 2011. There she presented the trial's four year results, which show that treated patients continue to remain stable or show slight improvements in their vision, with no side effects. Dr Wittig-Silva's summary of her presentation to the Congress can be found in the annexes to this report. Dr Wittig-Silva and Associate Professor Grant Snibson presented their findings at a public seminar organized by Keratoconus Australia in June 2011 (see **Events**).

The CERA trial is continuing and is being expanded to include a pilot study of crosslinking on thin corneas.


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

Other CERA projects

Keratoconus Australia also received a request from CERA researchers for assistance in recruiting people with keratoconus for their *genes in keratoconus and myopia study* being conducted by Associate Professor Paul Baird and Ms Srujana Sahebjada. After some delays caused by the need to verify ethics clearances, emails were sent to members in early November 2011.

Department of Ophthalmology at Flinders University, Adelaide

During 2010-11, Keratoconus Australia sought to develop further ties with the Department of Ophthalmology at Flinders University in Adelaide on a range of keratoconus-related projects.



As discussed in the 2009 report, KA and Flinders has been seeking government funding for studies

- To investigate patients' attitudes to their disease and to available treatment options, using focus groups and qualitative research procedures.
- To evaluate the evidence base for the efficacy of the various treatments for keratoconus by the use of a systematic review coupled with meta-analysis.
- To assist Keratoconus Australia to develop a national registry of Australians with keratoconus, using the University's experience with the Australian Corneal Graft Registry.

Two joint applications for funding for these projects have been rejected by the Australian Government's National Health and Medical Research Council (NHMRC - Australia's peak body for supporting health and medical research).

Given the ongoing interest in these projects, Larry Kornhauser and Belinda Cerritelli flew to Adelaide in early December 2010 for discussions with the heads of the Department of Ophthalmology, Professors Doug Coster and Keryn Williams. As a result of those discussions, it was agreed by the parties to continue to seek funding for joint research projects.

Keratoconus Australia applied for a funding grant from Perpetual Philanthropic Services in early 2011 to partially fund these projects. However this application was not successful.


Meanwhile, Prof Coster's group has already begun work to obtain ethical approval for the review of the efficacy of keratoconus treatments. The Association also provided information to enable Flinders to start preliminary work on the investigation of patients' attitudes to their disease. Further updates on these projects will be posted as we receive them.

In the meantime, Keratoconus Australia did assist Flinders University in launching one smaller project. This project entitled "*Metrics of optical quality predictive of visual performance in eye disease*" is being led by Prof. Konrad Pesudovs and Ms Serena Hawes of Optometry and Vision Science, Flinders University and Flinders Medical Centre. The aim of the research is to learn more about the relationship between the optics of the eye (how well the eye focuses light) and how well people see. The Association emailed members with keratoconus in South Australia to recruit participants. That research is now proceeding.

University of NSW stem cell research

The Association received an update from the University of NSW on its research into the use of stem cells on contact lenses to restore sight in people suffering from corneal damage. Members have asked for updates on when this procedure might be used to halt progression in keratoconus or reverse damage from the condition.

In response to a request from Keratoconus Australia for more information, Associate



Professor Nick Di Girolamo, Director of Ocular Research at the School of Medical Sciences, University of New South Wales indicated that there are no plans at this stage to extend the research into dealing with abnormalities in the stroma layer of the cornea which cause keratoconus. But Associate Professor Di Girolamo did say his team have submitted a research proposal to the National Health and Medical Research Council of Australia. If funded, the research plan involves developing novel strategies for treating patients with corneal scarring, including those with keratoconus.

Member surveys

New members receive two survey forms along with other material about the Association and keratoconus when they join Keratoconus Australia. After encountering multiple hurdles in finding an appropriate means to analyse the results of these surveys, we now have a system in place from which we hope to obtain preliminary data later in the current financial year.

We will keep you posted on the outcome of this work.

University of Melbourne DOSV Optometrist training clinics

During September and October 2010, Keratoconus Australia in collaboration with the University of Melbourne's Department of Optometry and Vision Sciences (DOVS) and Associate Professor Richard Vojlay, conducted the 5th annual keratoconus teaching clinics and lecture for final year optometry students. Three clinics for contact lens fits on keratoconus patients were held along with two post-graft contact lens fitting clinics.

As in previous years, Keratoconus Australia members responded magnificently to the call for volunteers to attend these clinics so that the students could attempt fits on a wide range of keratoconus and corneal transplants.

Larry and Belinda again presented information about keratoconus and the Association's activities at the special lecture to the final year students on keratoconus, which follows these clinics. Under a new format, Larry discussed his own experience with keratoconus, the importance of contact lenses to patients and what optometrists can do to improve care for keratoconus patients in general. Once again, the lecture was well received by the students and we are hoping one or two will decide to join one of Melbourne's optometry practices specialising in keratoconus.


This unique collaboration aimed at growing the pool of specialist contact lens fitters for keratoconus remains one of the Association's most important achievements and we thank all members who support this initiative every year. Perhaps best of all, it provides an opportunity for all members to participate actively in the effort to improve their own eye care into the future.

Other eye-carer matters

The Association held a range of discussions with various ophthalmologists and optometrists interested in keratoconus during 2010-11.

In particular, committee members met with representatives of the Corneal and Contact Lens Society of Australia during the year and we will continue to explore opportunities for cooperation in the future. Options discussed included extending the optometrist training clinics at the University of Melbourne to the Queensland University of Technology and to extend the contact lens subsidy scheme in South Australia to give better access to keratoconus patients.

As always, we thank the many eye-carers who support the work being done by Keratoconus Australia and who give their time to assist our members and to offer



advice and guidance to the Committee on a range of issues affecting people with keratoconus and their families.

Finally, an increasing number of eye-carer practices have been in contact with Keratoconus Australia to obtain information resources for their patients. The Association is pleased to offer this material to eye-carers at a nominal cost to cover our expenses.

However requests from eye-carers to publicize their practices and clinics working in the field of keratoconus are refused, as the Association does not wish to become involved in marketing or endorsing individual practitioners or products and treatments for keratoconus.

Access to cheaper Contact Lenses, Melbourne EyeCare Clinic (and even better Optometrist Training too!)

Without question, one of the most exciting developments for Keratoconus Australia in 2010-11 was the success of its submission in April 2011 to the University of Melbourne's Department of Optometrist and Vision Sciences (DOVS) seeking greater emphasis on keratoconus as part of its redevelopment of the University's Melbourne EyeCare Clinic .

The submission to the DOSV arose from reflections by Committee on how to find a more lateral solution to reducing the cost of contact lenses, once it became evident that further approaches to the private health funds and federal and state governments were unlikely to bear fruit in the current economic climate.


We agreed that we could kick two goals at once if we could convince the DOVS to expand its keratoconus services through its Melbourne EyeCare Clinic, which has access to cheaper contact lenses and can offer them to patients at subsidised rates.

The clinic also serves as the primary teaching facility for optometry students, enabling them to secure hands on experience in treating patients. An expanded keratoconus clinic would therefore allow students to perform full keratoconus contact lens fits from start to delivery.

In short, the students could have a deeper training experience with contact lenses for keratoconus prior to graduation, while patients attending the clinics could be fitted with contact lenses under the guidance of leading keratoconus specialists at cheaper prices than available from visiting those specialists in their own practices.

Fortunately the DOSV agreed with us and immediately set about incorporating an enlarged keratoconus service into its planned extension of the Melbourne EyeCare Clinic. The expanded clinic opened in July 2011. Belinda attended the opening, which received coverage in the local media. A video of the new clinic launch and its new keratoconus services (including an interview with Belinda) can be viewed at <http://visions.unimelb.edu.au/episode/124>.

The clinic, located on Swanston St, Carlton, provides optometry services to students and employees of the University of Melbourne, and is also open to the general public. As it is a training facility for the DOSV, patients wishing to take advantage of the possibility of obtaining cheaper contact lenses there will have to allow students to perform the fits under supervision. As this will take much longer than a normal consultation, the Melbourne EyeCare Clinic option is really only designed for those people who cannot afford to obtain their lenses from a normal optometry practice.



We plan to send an email in early 2012 outlining all the services for keratoconus patients, once we have finalised arrangements with the DOSV over access for Keratoconus Australia members to the clinic.

Finally, the submission put to the DOSV included a proposal for a prize or scholarship to enable postgraduate optometrists to engage in further training in fitting complex contact lenses for keratoconus. We hope to pursue that proposal in 2012. Anyone who would like to help fund the scholarship should contact the Association.

Action on Contact Lens Rebates

The Association devoted a considerable amount of time again last year to the wider issue of lowering the cost of contact lenses for keratoconus. While the Melbourne EyeCare clinic option could provide a model for other states, it is far from the perfect solution.

Belinda held a range of discussions with representatives of Vision 2020 in a bid to advance this issue. These discussions led to contacts with officials at the Department of Health and Ageing and the Therapeutic Goods Administration over the possibility of reclassifying contact lenses for keratoconus as a medical device. These talks will continue in 2012. However there are no clear outcomes on the horizon at this stage.

The Association also sent a submission about keratoconus and the need for better access to cheaper contact lenses to Vision 2020, for inclusion in that organisation's submission on eye health in response to the Productivity Commission's draft report into Disability Care & Support. KA's draft submission can be found in the annexes to this report.

Over the past few months, talks with the private health funds have also thrown up some new possibilities, which the Association will continue to pursue.

Once again, in the absence of progress in this matter, 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 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 off our website at http://www.keratoconus.asn.au/Resources-F/KA_Insurance_letter.pdf.

Keratoconus Australia held four Demystifying Keratoconus events during 2010-11: three in Melbourne and the first ever seminar in Brisbane, in conjunction with the Queensland Eye Institute.

Keratoconus: research, new treatments and making the right choices

Keynote Speaker - Prof Doug Coster, Flinders University
September 1, 2010

Professor Coster examined different aspects of keratoconus including current and future research, corneal collagen crosslinking and other new treatments. He also discussed evidence-based medicine and how patients can assess the suitability of these treatments and when to have them.

A spirited debate followed the presentation with a variety of views being presented by patients and eye-carers about corneal collagen crosslinking and the risks of the treatment in the absence of any long term or large scale clinical studies regarding its safety and effectiveness. Prof Coster summarised his approach to keratoconus management in one sentence: find the best contact lens fitter you can, and have as little surgery as possible.

Prof Doug Coster is an internationally-recognized expert in keratoconus research and treatments with over 35 years experience in Australia and overseas. He currently holds a range of distinguished positions including Lions Professor of Ophthalmology at Flinders University (SA), Senior Director of Ophthalmology, Flinders Medical Centre, is editorial board member of several international ophthalmology publications and serves on a number of government advisory committees.




Professor Coster

Prof Coster also created the Australian Corneal Graft Registry which tracks the outcomes of some 15,000 corneal transplants Australia-wide. He has a profound insight into the risk factors for keratoconus and best-practice management of this condition.

Brisbane keratoconus information seminar

Keynote Speakers Dr Jim McAlister, corneal surgeon
John Mountford, contact lens fitter
Saturday November 6, 2010

Keratoconus Australia, in association with the Queensland Eye Institute held a very successful information day on keratoconus in Brisbane on Saturday November 6, 2010 at the Des O'Callaghan Auditorium, Mater Public Hospital, South Brisbane.



Keynote speakers were corneal surgeon and researcher Dr Jim McAlister who presented on surgical options for keratoconus and current research into treatments notably corneal collagen crosslinking. Contact lens expert, John Mountford, gave a fascinating presentation on the history of contact lens and the latest developments in contact lens technology for keratoconus. We hope to organise a seminar with Mr Mountford in Melbourne soon.

Keratoconus Australia president, Larry Kornhauser, outlined his experiences with keratoconus and described the work done by the Association to improve life for people with keratoconus.

Over 100 people attended the event, which included lively discussion on the new treatment options for keratoconus like corneal collagen crosslinking and mini-scleral contact lenses.

Larry used this opportunity to meet a number of KA's Queensland members to whom we have provided support over many years.

Special thanks to Camilla Ciarna, a longtime member of the Association, for acting as the driving force behind this seminar.

Melbourne: Living with Keratoconus information roundtable

Keynote speaker Heidi Littleford, educator for sight-impaired students
Thursday November 25, 2010

Living with keratoconus is not always easy. Although glasses and contact lenses can improve vision, studying and working for long periods on computers and in difficult environments can be challenging. Life after a corneal transplant can be even more complicated.

Heidi Littleford, an educator for sight-impaired students and KA committee member, discussed her experience as a bilateral corneal transplant recipient and some of the issues which face students with keratoconus and their parents, along with strategies for dealing with them. The roundtable format provided an intimate environment for open discussion of the attendees' varied experiences in coping with keratoconus in their daily lives and occupations.

Corneal crosslinking: the latest evidence and trends and a family's view

Speakers Associate Professor Grant Snibson, Dr Christine Wittig-Silva
Tuesday 28 June 2011

Corneal collagen crosslinking (CXL) is the only treatment that provides hope of halting progressive keratoconus. Introduced into Australia in 2005, it is becoming the procedure of choice for most corneal surgeons and their keratoconus patients. Young adolescents, with often the most aggressive form of keratoconus, are also being offered CXL today in increasing numbers.

What evidence is there to support this new treatment?

Associate Professor Grant Snibson and Dr Christine Wittig-Silva, principal investigators on Melbourne's world-leading randomized control trial of corneal



Dr Wittig-Silva and A/Prof Snibson

collagen crosslinking presented their most recent results supporting the view that crosslinking is safe and effective and discussed trends in crosslinking here and in other countries. These include efforts to reduce treatment times and modify the procedure to achieve better results in a wider range of patients.

Ben Johnson, now 22, was 18 years of age when he entered the CXL trial. Ben and his mum Georgie Munro, spoke about their experiences in deciding to have crosslinking done and the effect on their lives.

All speakers answered questions from the audience.

Videos

Videos of the Coster and Snibson presentations can be purchased from the Association.

COMMUNITY RELATIONS

One of Keratoconus Australia's key missions is to publicize keratoconus and its effects on individuals and families in the wider community.

As discussed last year, one of the most important ways we do this is through our partnership with Vision 2020 Australia, the umbrella body for all eye healthcare organisations in Australia. Belinda's work with Vision 2020 has raised the Association's profile within the eye health community and has led to cooperation with other vision-related support groups.

Committee members also conduct regular meetings with ophthalmologists and optometrists working in the field of keratoconus to provide feedback from patients and their families and to highlight areas of concern. We also draw on their experience and knowledge to ensure that members receive up-to-date information on treatments and management strategies for vision loss caused by keratoconus.

We mentioned last year that we were collaborating with a group of eye-carers on a patient booklet, which was planned for publication in 2011. This is now expected to be released in 2012.

The Association also cooperates with the Optometrist Association of Australia to provide information on its activities and a number of articles about Keratoconus Australia and its seminars were published in the OAA monthly newsletter Australian Optometry in 2010-11.


RANZCO's JuIEYE 2011

Following our Brisbane seminar in November 2010, we were asked about holding a Keratoconus Awareness Day. The Committee discussed the possibility and while not adverse to the idea, decided that we did not have the resources, volunteers or time to organize such an event at present.

However, we decided that we would explore the possibility of joining up with existing eye health promotions like those run by Vision 2020 Australia and the annual JuIEYE campaign organised by The Eye Foundation.

The Eye Foundation was founded in 2002 as the fundraising arm of The Royal Australian and New Zealand College of Ophthalmologists (RANZCO) and The Ophthalmic Research Institute of Australia (ORIA). JuIEYE is The Eye Foundation's eye health awareness month that takes place during July each year. JuIEYE has three core aims:

- to raise community awareness of eye health issues

- 
- to raise funding for research projects into the causes and cures of vision impairment and blindness
 - to support international development projects whose goals are aligned with those of The Foundation.

Belinda contacted The Eye Foundation in early 2011 to request that keratoconus be given greater prominence during their JulEYE month. The Foundation agreed immediately. Keratoconus was promoted during the JulEYE 2011 campaign and can be seen at <http://www.eyefoundation.org.au/news-a-events/news/257-1-juleye-2011>.

The Association will continue to seek ways to promote keratoconus in partnership with other eye health organisations in the future.

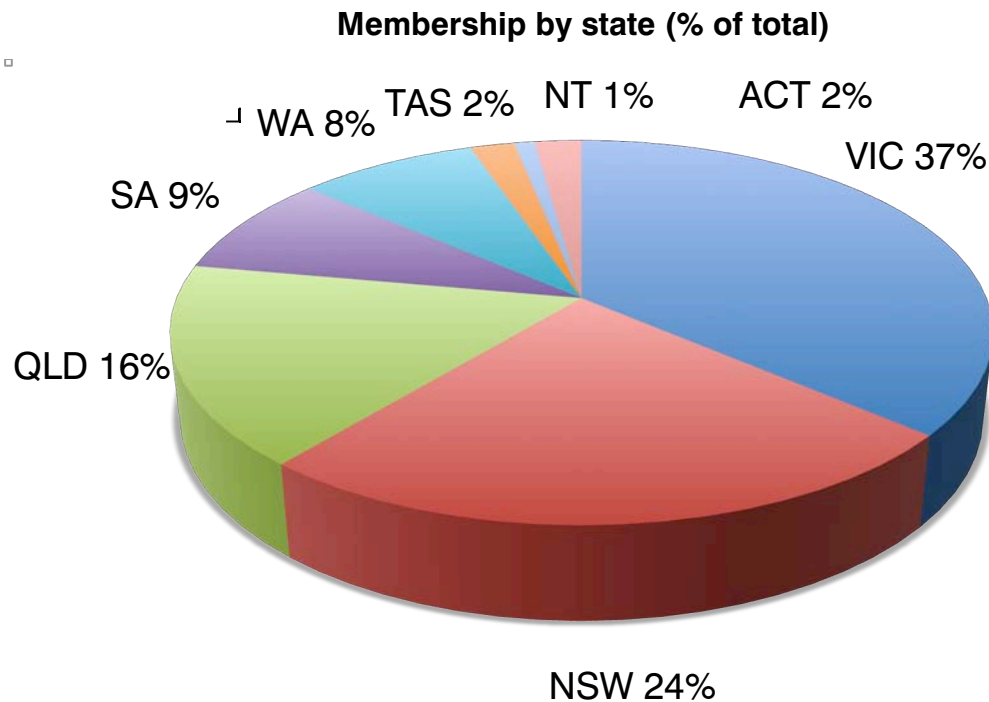
Members have also taken individual initiatives to promote keratoconus and the work of the Association in their workplaces by holding fundraisers. We greatly appreciate all of these efforts on our behalf (also see Fundraising).

THE ASSOCIATION

Membership

Keratoconus Australia had 1,688 registered members on 30 June 2011, compared to 1,510 members a year earlier. This represented an increase of 11.9% for the year.

Victoria (613 members) continues to account for over one-third (36.3% of the total at June 30, 2011) of the Association's total membership base. But the dominance of the Victorian membership base is slowly diminishing (from over 50% in 2004) as more people with keratoconus in NSW and Queensland join the Association. Membership in these latter states grew by 15% in NSW (to 417 members) and 16.5% in Queensland (284 members). South Australia and Western Australia both account for around 8.5% of total membership, while Tasmania and the ACT comprise about 2% each.



Supporters

A number of companies provide benefits to the Association in the form of free facilities for meetings and pro bono services. We thank all of these companies for their kind assistance in 2010-11, notably GMK (accounting), The Australian College of Optometry (seminar venue) and Viewgrow Capital Pty Ltd (meeting venue and administrative support services).

Fundraising and Grants

The Association received almost \$10,000 in donations during the 2010-11 financial year. Particular thanks goes to long time supporters The Ray and Margaret Wilson Foundation for continuing its generous donations to assist the Association and its work.

A number of members and supporters kindly donated funds raised at workplace charity events over the past year. We would like to acknowledge the efforts of George Ferteklis and David Shaw (BP) in this regard.

We also received a donation from the winners of BHP's Pirate Dry River Boat Race between its contractors. Thiess, the race victor, chose to donate the \$1,000 prize money to Keratoconus Australia.

Finally, a number of members who volunteered to attend the DOSV keratoconus student training clinics kindly donated their \$25 travel allowance to the Association.

We thank everyone who thought of the Association when making their charitable donations last year. It is very much appreciated. We would be pleased to offer assistance to anybody considering a fundraiser to raise awareness of keratoconus and to help finance the Association's activities.

The Association also applied for two grants in 2010-11.

In January 2011, we sought a \$68,000 grant from Perpetual Philanthropic Services to help fund the development of an online patient register in conjunction with Flinders University. This application was unsuccessful.

In March 2011, we applied for a \$23,500 grant from the Melbourne Lord Mayor's Charitable Foundation to help defray set up costs for the installation of a keratoconus clinic in the University of Melbourne's EyeCare Clinic. The application was also refused. However in the end, the Department of Optometry and Vision Science assumed most of the establishment costs thanks to internal University grants and funding.

Website

The Committee launched a redevelopment of the Association's website during the year following a number of suggestions and ideas received from members. Work on the website is continuing and we hope to have the new site operating in 2012. In the meantime, the site can still be found at www.keratoconus.asn.au.

The website averaged about 1,500 hits a month in 2010-11. Apart from the home page, the most popular pages on the site were FAQs on keratoconus, our resources page and the outline of corneal collagen crosslinking and the results of the CERA randomized control trial into crosslinking. The online forum, through which members can pose questions about keratoconus and its management, also proved popular.

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 2010-11, the committee met six times and held informal discussions on numerous other occasions.

The committee last year comprised:

Larry Kornhauser, President
Belinda Cerritelli, Secretary
Heidi Littleford,
Marisa Cerritelli

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



KA Committee - past and future (from left: Heidi, Jennifer, Belinda, Larry, Marisa and Matt)

As already indicated at the start of this report, Belinda Cerritelli is retiring from the Committee and position of Secretary at the AGM 2011 after a decade of service to the Association. We thank Belinda for her enormous contribution to the Association and the keratoconus community in general. We will miss her and we wish her all the very best for the future.

Marisa Cerritelli also announced her retirement from the committee this year. Marisa has made a valuable contribution to the Association in a variety of ways over a long period. Prior to joining the committee, Marisa hosted Keratoconus Australia committee meetings at her house and kept us nourished with a range of wholesome snacks and beverages. She has been largely responsible for the professionalism and success of our Melbourne seminars virtually since their inception in the early noughties. Since discovering she had keratoconus and joining the committee, her insights and firsthand experience have added a new dimension to discussion of

many of the issues facing parents of children with keratoconus. We are very grateful for all her work on behalf of the Association and she too will be missed.

Matt Vaughan, a past vice president of the Association, has returned from his overseas travels and has decided to rejoin the committee. Matt previously concentrated on advocacy issues and intends taking over some of Belinda's tasks. Jennifer Toom has also joined the committee this year. Jennifer has past experience in working with the Citizens Advice Bureau in the UK. One her areas of interest is improving management of volunteers.

We welcome both Matt and Jennifer and look forward to working with them in the future.

New volunteers

All members of the Committee are unpaid volunteers, all of us have other full time jobs and all of us have keratoconus. We do our best with limited time and resources. But there is so much more we could do if we had more volunteers to assist us.

We urgently require new committee members to assist in developing and implementing the Association's projects and services. We are looking for dynamic people with new ideas and enthusiasm. Working for a not-for-profit is an extremely fulfilling pastime. Keratoconus often runs in families. So by working towards better outcomes for all of us with keratoconus, you may also be helping someone close to you too. Please contact KA Administrative Assistant Mary Veal directly on 0409 644 811 if you wish to participate.

In the coming year, we would also like to see a greater contribution from the members in their own hometowns. That could mean organizing a fundraiser or an information seminar. We would love to have a contact person for the Association in each city and town around Australia so that people with keratoconus could find someone locally with whom they could discuss and share their experiences. Again, let us know if you would like to be involved.

On behalf of the Committee of Management, thank you to everyone who has helped the Association over the past year. Perhaps we do not manage to do everything we would like. But the Committee can assure members, supporters and donors that with your backing, we are all making a difference to the lives of many people with keratoconus, their families and their children.



Larry Kornhauser,
President

1 December 2011




FINANCIAL REPORTS

The Association reported a net profit in 2010-11 of \$7,807. This was up 18% on the previous year's net profit of \$6,614.

The higher result reflected increased donations in 2010-11, which totaled \$9,785 (up 12% compared to \$8,770 in 2009-10). Bank interest also increased significantly to \$2,459 after renegotiating our banking arrangements with Westpac, yielding total income for the year of \$13,358.

Despite higher expenses associated with organizing four seminars in the 2010-11 financial year, total expenses actually fell 16% to \$5,551 last year (\$6,614 in the previous corresponding period). Postage more than doubled to \$1,184 and was the Association's single largest expense in 2010-11 - reflecting the ongoing costs of mail outs to members who have not provided the Association with current email addresses. Most other expenses were associated with the organization and videoing of the Demystifying Keratoconus seminars.

The balance sheet for 2010-11 showed net assets of \$65,728.71, or 13.5% higher than at June 30, 2010 (\$57,923). End-year assets totaled \$65,898 (\$58,108 on June 30, 2010), held entirely in cash. Around \$54,000 of this is being held in a high interest bearing deposit account at Westpac.

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.



K E R A T O C O N U S AUSTRALIA

ABN: 80 683 325 208 A:0039546H

Profit & Loss Statement

July 2010 through June 2011

Income

Donations	\$9,785.00	
Seminar Entrance Fees	\$488.20	
Video Sales	\$609.16	
Booklet Sales	\$13.64	
Miscellaneous Income	\$3.48	
Bank Interest	\$2,458.56	
Total Income		<u>\$13,358.04</u>

Cost of Sales

Gross Profit \$13,358.04

Expenses

Advertising	\$177.27	
Domain Name Registration	\$36.36	
Bank Charges	\$14.25	
Catering	\$166.99	
Stationery	\$381.23	
Dues & Subscriptions	\$253.83	
License Fees	\$218.95	
Postage	\$1,183.57	
Printing	\$605.08	
Seminar Expenses Melbourne	\$758.42	
Seminar Expenses - Brisbane	\$303.50	
PO Box Rental	\$275.84	
Video Recording	\$363.64	
Website Hosting	\$245.07	
Telephone and Internet	\$111.71	
Travel	\$455.18	
Total Expenses		<u>\$5,550.89</u>

Operating Profit \$7,807.15

Other Expenses

Net Profit / (Loss) \$7,807.15



K E R A T O C O N U S AUSTRALIA

ABN: 80 683 325 208 A: 0039546H

Balance Sheet

As of June 2011

Assets

Current Assets

Cash On Hand

Westpac DGF Account \$8,541.84

Westpac Max-iDirect \$54,240.90

Total Cash On Hand \$62,782.74

Trade Debtors \$15.00

Total Current Assets \$62,797.74

Property & Equipment

Software Development

Website \$3,100.00

Total Software Development \$3,100.00

Total Property & Equipment \$3,100.00

Total Assets \$65,897.74

Liabilities

Current Liabilities

GST Liabilities

GST Collected \$250.80

GST Paid (\$81.77)

Total GST Liabilities \$169.03

Total Current Liabilities \$169.03

Total Liabilities \$169.03

Net Assets \$65,728.71

Equity

Retained Earnings \$57,921.56

Current Year Earnings \$7,807.15

Total Equity \$65,728.71




ACKNOWLEDGEMENTS

Keratoconus Australia would like to acknowledge the special contributions of the following people and organizations during 2010-11.

Associate Professor Richard Vojlay

Audio Visual Solutions

Centre for Eye Research Australia

Flinders University Department of Ophthalmology

GMK Partners

Minuteman Press

Optometrist Association of Australia

The Australian College of Optometry

The Department of Optometry and Vision Sciences, University of Melbourne

The Eye Foundation

Viewgrow Capital Pty Ltd




ANNEXES

Randomized controlled trial of corneal collagen cross-linking - 2011 update

Now in its fifth year, researchers at the Centre for Eye Research Australia (CERA) and the Royal Victorian Eye and Ear Hospital, are continuing their work with the world's first randomized controlled trial of a treatment for Keratoconus known as corneal collagen cross-linking (CXL). This novel treatment aims to stop the progression of keratoconus by increasing the rigidity of the cornea. A combination of topical Riboflavin (vitamin B2) and a defined dose of ultra violet light (UVA) irradiation are applied to the eye which triggers a photo-chemical reaction in the cornea and strengthens the corneal tissue.

One-hundred participants between 16 and 42 years of age (average age 26 years) have been randomly allocated to either the treatment group (50 patients) or control group (50 patients). Patients from both groups are followed according to the same schedule which includes subjective tests (i.e. vision testing) and more objective measurements such as corneal curvature and cell density.

Interim results:

Data analysis including up to 4 year findings were presented at the 6th International Congress of Collagen Cross Linking in Milan in January 2011.

At the time of the last interim analysis, nine treated patients and ten patients from the control group had completed their four year follow-up. While there are considerable individual differences in the initial post-operative period, follow-up at the 4 year mark indicates that patients who receive CXL remain stable or show a slight improvement in either vision, corneal steepness, or both.

Participants in the control group on average experienced a slight worsening of their condition. In cases where marked progression was noted, patients in the control group were offered the treatment on compassionate grounds. To date, 13 patients have received CXL for this reason.

It should be emphasized that this trial only involves patients with progressive keratoconus who are 16 years or older. While there is increasing interest in CXL for younger patients, there is currently only limited research data available to support this. Therefore any decision to treat a patient under 16 years of age with CXL would need to be carefully considered and can only be made on an individual basis.

The conference highlighted the high level of interest internationally of the Australian trial. During the congress, two major variations of the current recommended protocol were the subject of lively discussion. These were: 1) the potential to achieve effective CXL treatment without removing the corneal epithelium (outer skin of the cornea) and 2) variations in the treatment parameters intended to achieve comparable results with shorter treatment times.

While these amendments would be equally appealing to both people undergoing the treatment and clinicians performing CXL, doubts were expressed about the efficacy of the currently trialed 'epithelium on' options. Although the concept of a shorter treatment time might hold great future potential, the majority of Congress delegates agreed that there is a need for thorough scientific evaluation of any treatment variation and that a formally structured protocol should be developed.

Update on local Pilot studies

Two pilot studies, one involving keratoconus patients with a cornea thinner than 400µm ('thin cornea' study) and one including patients who have developed Keratectasia after laser surgery (a complication with symptoms similar to those of keratoconus) are currently underway and still recruiting participants. See below for further details.

Interested in becoming a study participant?

Patients who are interested in participating in the 'thin cornea' pilot study, keratectasia pilot, or in being involved in future trials are advised to contact their eye care specialist or Tony Wu (Trial Coordinator) on 03 9929 8618 or tonyn@unimelb.edu.au.

Funding to continue these important trials is still required. If you would like to donate, please contact Jessica Boccamazzo (CERA Fundraising Administrator) on 03 9929 8426 or jboc@unimelb.edu.au.



K E R A T O C O N U S AUSTRALIA

IMPROVING CONTACT LENS OUTCOMES FOR KERATOCONUS

April 2011

KERATOCONUS AUSTRALIA INC A00395 46H ABN 80 683 325 208
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INITIATIVE TO PROMOTE THE TRAINING OF OPTOMETRISTS IN FITTING CONTACT LENSES FOR KERATOCONUS

BACKGROUND

Keratoconus Australia Inc is a support group for people with the eye condition keratoconus. Based on past research, about 1 in 2000 people have keratoconus, implying a population of around 10,000 in Australia. However better diagnostic tools now indicate that figure could be much higher.

While there is no cure at present for keratoconus, vision loss caused by this condition can generally be corrected with glasses and then contact lenses, usually rigid gas permeable (RGPs). Only about 15-20% of people with keratoconus ever require a corneal transplant, and many of these require additional correction for best post-graft vision.

Corneal collagen crosslinking, which appears to halt (but not reverse) the progression of keratoconus offers the hope that even fewer keratoconus patients will require corneal transplantation in the future. It may also reduce the number of new patients requiring highly specialized contact lenses for advanced keratoconus.

Although this surgical option may impact on the requirement for contact lenses in the long term, finding an optometrist experienced in treating this condition and able to fit complex contact lenses on moderate to advanced keratoconus and corneal transplants will remain an imperative in the successful management of vision loss caused by this condition for the foreseeable future.

KERATOCONUS AUSTRALIA'S ROLE

One the key elements of our mission statement is

"to assist people in finding optometrists and ophthalmologists/corneal surgeons experienced in treating keratoconus."

In the ten years since the Association was incorporated, the overwhelming majority of requests for support from people with keratoconus and their families related to issues that could have been resolved by an optometrist experienced in fitting rigid gas permeable or similar contact lenses on a keratoconic eye.

The problems encountered by these people could be classified essentially into seven groups:

1. Incorrect diagnosis by the initial treating optometrist
2. Insufficient information about keratoconus provided on diagnosis leading to unnecessary anxiety and stress in the patient and their family
3. Inability of treating optometrist to fit complex contact lenses as keratoconus advances
4. Improper use and maintenance of contact lenses by patients, leading to unnecessary issues that may compromise the patient's ability to wear contact lenses long term and resulting in a premature corneal transplant
5. Lack of information on how and where to find optometrists experienced in fitting complex contact lenses on advancing keratoconus
6. The high and sometimes prohibitive cost of contact lenses for keratoconus – especially for people whose progressive keratoconus requires regular refits of contact lenses.
7. Perhaps the worst of all, is the premature referral of a patient for a corneal transplant because of the optometrist's inability to fit an appropriate lens on a keratoconic patient

The lack of access to optometrists experienced in managing keratoconus has other pernicious side-effects.

- Patients who cannot find a means of improving their vision become anxious and depressed, creating new and unnecessary medical problems that can affect their studies, relationships, activities and ability to work and earn an income.
- Greater than necessary recourse to surgical options including corneal transplants, and a search for experimental treatments and other solutions which are often short term and less useful than properly fitted contact lenses.

Keratoconus Australia has numerous letters and emails from members who have resolved seemingly insurmountable problems with their vision thanks to the help provided to them by the Association in finding an optometrist experienced in keratoconus. **We believe that many more people with keratoconus could achieve better visual outcomes if they had access to such experienced optometrists, and contact lenses at a reasonable cost.**

ACTION

Keratoconus Australia believes that a number of initiatives should be taken by the optometric community to help alleviate the serious shortage of optometrists with experience in managing keratoconus.

Training

For the past four years, Keratoconus Australia, Associate Professor Richard Vojlay and the Melbourne University's Department of Optometry and Visual Science have cooperated to conduct a special clinic to provide final year students with experience in fitting contact lenses on keratoconic and post-graft corneae. Associate Professor Vojlay and Keratoconus Australia have also presented a special keratoconus lecture to these students to raise awareness of the special vision issues facing people with keratoconus and their families.

These clinics and lectures have been well received by students and should be continued.

However there is a need for further consideration of how optometry students throughout Australia can be made more aware of keratoconus and its consequences, and encouraged to spend more time practicing how to fit contact lenses on keratoconus patients.

Initiatives are also required to up-skill optometrists, especially in non-metropolitan areas, in the diagnosis and management of keratoconus, and in prescribing contact lenses for this condition. Emphasis needs to be given to referrals of more advanced cases to specialist contact lens fitters for keratoconus.

Optometrists Registry

Keratoconus Australia believes that the optometric community needs to consider creating a registry of optometrists experienced in fitting RGPs on keratoconus patients. Criteria for admission to this registry need to be agreed. A minimum requirement for the number of lenses for keratoconus fitted per annum should be considered. Information from Medicare would assist in this. **Patients seeking experienced practitioners would find such a registry of immense benefit.**

We note that in recent times, the Cornea and Contact Lens Society of Australia has created an online database of its members, which could serve as a starting point for this type of a more specialized keratoconus registry.

Higher rebates – better warranties

Based on discussions already held with the private health funds, Keratoconus Australia believes that existence of such a registry would also assist in securing **higher benefits** from the private funds.

However in the longer term, Keratoconus Australia believes that contact lenses for keratoconus above a certain power should be treated as **medical devices** and reimbursed by Medicare.

Medicare **rebates** for optometrist visits should also be raised to encourage optometrists to work in this field, which can often be very time-consuming and therefore costly to practitioners. Keratoconus Australia believes current rebates are a major disincentive to optometrists specializing in this field.

Finally, **warranties** on contact lenses for keratoconus need to be improved to allow experienced optometrists the opportunity to make the necessary adjustments in new lenses to achieve optimal fitting outcomes.

Keratoconus Australia's proposal to the University of Melbourne's Department of Optometry and Visual Science

As noted above, Keratoconus Australia is already cooperating with Melbourne University's Department of Optometry and Visual Science (DOVS) in the training of final students to provide them with greater exposure to keratoconus patients, their problems, needs and involvement in the development of solutions.

However we believe that more can be done. We propose that DOVS should:

- Maintain the existing annual student contact lens fitting clinics for keratoconus and special lecture as part of the 5th year curriculum.

- Work with Vision 2020 and the Optometrist Association of Australia to promote greater funding for upskilling and training of optometrists in the community with particular focus on non-metropolitan areas.
- Offer a prize or postgraduate scholarship to optometry students for excellence in the field of fitting contact lenses for keratoconus. Keratoconus Australia would help fund the ongoing cost of this prize and would hope that additional funding for this initiative would also come from other stakeholders in the field of keratoconus.

University of Melbourne Eyecare Practice

Keratoconus Australia believes that the University of Melbourne Eyecare Practice offers an opportunity for both optometry students and patients.

- The Association would like to be able to refer more low income patients to the practice who could benefit from access to low cost treatments – notably bulk billed consultations and subsidized contact lenses.
- Although the annual 5th year student contact lens fitting clinics referred to above provide an introduction to fitting lenses on keratoconic and post-graft corneae, very few (if any) students perform a complete fitting within that environment.
- Keratoconus clinics at the Eyecare Practice would provide optometry students a far greater and ongoing opportunity to fit contact lenses to keratoconus and post corneal graft patients.

The key requirement for this proposal would be a guarantee that all contact lens fits were done under the strict supervision of an experienced contact lens fitter for keratoconus. This may require the creation of a regular (e.g. fortnightly) keratoconus clinic to ensure the availability of an experienced contact lens fitter for keratoconus.

It would also require that the University of Melbourne Eyecare Practice was able to source a range of complex contact lenses for keratoconus and supply them to patients at heavily reduced prices.

We also suggest that students be required to complete contact lens fits and deliver lenses as part of training procedure.

OUTCOMES

There are many immediate and obvious benefits for both the community and individuals suffering real disadvantage from a lack of affordable access to optometrists competent in fitting RGPs to keratoconus patients.

We believe that studies would show that a small investment in upskilling optometrists in the management of keratoconus would have significant economic and social benefits in

- **Providing the community with a larger pool of better qualified optometrists**, able to work with keratoconus patients competently,
- **Better educational outcomes** for adolescents affected by keratoconus,
- **Lower workforce absentee costs** for people who have recurring issues with their vision caused by inappropriate contact lenses
- **Reduced welfare payments and higher income tax receipts** by enabling people to return to regular employment

Keratoconus Australia also believes that by achieving better outcomes with contact lenses, it would be possible to **reduce the number of corneal transplants** performed sufficiently to induce a significant reduction in long waiting lists for those in need of surgery. This alone would be a very important outcome in the context of Australia's low organ donation rates.

Response to Productivity Commission draft report into Disability Care and Support – Keratoconus Australia, April 2011

The revision of the current disability services to support all Australians presents an opportunity for consideration and inclusion of Keratoconus, a serious, incurable and potentially disabling corneal disease, which is not adequately recognized by the present disability support system.

Keratoconus and its treatments

Keratoconus is a degenerative corneal disease whose onset (usually in adolescence) can result in severe, lifetime vision impairment. Based on research, up to 40,000 Australians could suffer from this disease. While most people suffer vision impairment or loss in later life due to diseases like glaucoma, age-related macular degeneration and cataracts, Keratoconus generally begins early in a person's life – with the most severe cases often starting in early adolescence. This means that a person will often have to deal with keratoconus-related vision impairment throughout their life. If not properly corrected, that can impact heavily on a person's ability to study, enter the workforce or maintain employment, their social activities, to cope with the demands of raising a family and in extreme cases, even to perform basic self-care functions.

Keratoconus is characterised by asymmetric astigmatism & spectacles cannot correct the resulting severe vision distortion, except in the very early stages. While approximately 10-15% of people with Keratoconus will require a corneal transplant, post-graft vision correction can often be required. Keratoconus only rarely leads to blindness. Although it can result in severe vision loss, in most cases this can be corrected with the use of specialized contact lenses, usually rigid gas permeables. These lenses can be used to achieve remarkable results in restoring functional sight to people who would otherwise be effectively disabled by keratoconus.

Keratoconus Australia Inc

Keratoconus Australia Inc (KA) is a not-for-profit association created to provide support, advocacy & research services for people with keratoconus. KA was formed in 2000 & is a self-funded Victorian registered body operated entirely by volunteers. We provide direct support to people with kc & their families & by email & phone. We have an outreach service to support & network keratoconus patients. We disseminate information on the disease via seminars, a website, videos, booklets & brochures. We also promote research into the prevention & treatment of keratoconus, engage in advocacy to achieve better outcomes for patients, provide information on kc for eye-carers & participate in the training of optometrists. We currently have 1650 members.

The issue

Keratoconus is not recognised as a disability in Australia. Further, the complex, customised contact lenses used to correct for keratoconus are not recognised in Australia as a medical device. In other countries, for example New Zealand and the United Kingdom, keratoconus is recognised at government level as a serious eye condition meriting special attention which is currently not the case in Australia. Both countries have schemes in place to subsidise the cost of contact lenses to patients – many of whom need to change their contact lenses several times a year if their condition progresses rapidly. Unlike many common and debilitating eye diseases (cataracts, glaucoma, age-related macular degeneration) Keratoconus is generally diagnosed in early adolescence. This means people with keratoconus face a lifetime of optometric and ophthalmologic treatment for vision loss caused by the disease.

Keratoconus Australia provides support to people with Keratoconus across Australia and their families. Our experience indicates that patients who cannot find a means of improving their vision become anxious and depressed, creating new and unnecessary medical problems that can affect their studies, relationships, activities and ability to work and earn an income.

Keratoconus Australia's response

Points have been taken from the "Key features of the proposed scheme" document

1. *Who would be covered? "... Support packages would be people targeted at all people with a significant disability ... anyone with, or affected by, a disability could approach the scheme for information and referrals"*

Based on this definition, people with Keratoconus appear to be eligible, at least for information and referral. **Suitable eligibility criteria** would need to be developed to ensure that **Keratoconus patients will be eligible** for support packages.

2. *What would it provide? "... Reasonable and necessary supports across a full range of long-term disability supports currently provided by specialist providers."*

In addition to the traditional equipment and aids required for people who have reduced vision or who are blind, "reasonable and necessary supports" in the case of Keratoconus would need to include specialized contact lenses as they are the primary remedy for keratoconus-related vision loss. In New Zealand, a subsidy is available for people who cannot wear spectacles for medical reasons and need to wear contact lenses for vision correction. An Australian system should also reflect this.

3. *"People would be able to choose their provider or providers. They could choose to have a disability support organisation manage their packages or to act in other ways on their behalf"*

It is imperative that "specialist providers" for the fitting of the specialized contact lenses are optometrists experienced in the care of people with Keratoconus. Our experience indicates that numerous problems are encountered by patients who do not have access to experienced eye-carers, including:

- ◆ Insufficient information about keratoconus provided on diagnosis leading to unnecessary anxiety and stress in the patient and their family
- ◆ Inability of treating optometrist to fit complex contact lenses as keratoconus advances
- ◆ Improper use and maintenance of contact lenses leading to unnecessary issues that may compromise the patient's ability to wear contact lenses long term and resulting in a premature corneal transplant
- ◆ Perhaps the worst of all, is the premature referral of a patient for a corneal transplant because of the optometrist's inability to fit an appropriate lens on a keratoconic patient

Disability support agencies engaged to act on behalf of people with Keratoconus would need to be aware of the issues surrounding treating keratoconus and the correct fitting of contact lenses. For this to be successful, engaging professional bodies such as the Optometrists Association of Australia and Keratoconus Australia would be necessary.

4. *"The scheme would have many safeguards to ensure costs did not get out of control ... Benchmarking against schemes overseas and between the NIIS & NDIS"*

In the case of Keratoconus, it would be suitable to benchmark against the New Zealand Ministry of Health, Publicly Funded Health and Disability Services, which covers people who, for medical reasons, cannot wear glasses.

We would welcome the opportunity to provide additional supporting information regarding the issues facing people with Keratoconus, or to discuss these issues in person. Keratoconus Australia is committed to improving outcomes for people with keratoconus and their families. We hope other stakeholders, including the Australian Government, will assist in our efforts for better treatment, management and support options for this potentially disabling eye condition.

Kind regards

Belinda Cerritelli
Secretary

Suggested references:

1. Contact Lens Subsidy, Publicly Funded Health & Disability Services, New Zealand Ministry of Health: <http://www.moh.govt.nz/moh.nsf/indexmh/sectorservices-claims-contactlens>
2. Equipment for people who are blind or have reduced vision, New Zealand: <http://www.moh.govt.nz/moh.nsf/indexmh/disability-fundedservices-equipmentforvisualimpairment>
3. Queensland Government Spectacle Supply Scheme: <http://www.health.qld.gov.au/mass/resourcesss.asp>
4. Government of South Australia Spectacle Scheme: <http://www.dfc.sa.gov.au/pub/tabId/209/itemId/350/moduleId/795/Spectacles-scheme.aspx>
5. Keratoconus Australia Inc: <http://www.keratoconus.asn.au/>