

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

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FROM THE PRESIDENT

Keratoconus Australia experienced a mixed year in 2011-12 as the Association grappled with the personnel changes announced at its previous Annual General Meeting. The loss of several key members of the Committee of Management in November 2011 was compounded by the unexpected retirement of our new-old Vice President, Matt Vaughan, in August 2012. Personal and professional commitments restricted the contributions of our other volunteer committee members, including myself throughout most of 2012.

Against that often difficult background, the Association focused its efforts on its primary *raison d'être*: supporting people with keratoconus and their families. We dealt with some 300 individuals and families and hopefully assisted many in resolving issues with contact lenses and easing concerns about surgical treatments, in particular corneal collagen crosslinking.

That latter procedure remains the focus of our ongoing interest. Despite its rapid spread within Australia, crosslinking remains at the “investigative” phase. There is no agreed protocol for its use and ophthalmologists are still debating many aspects of its implementation. That is normal for a new medical procedure. We will continue to liaise with ophthalmologists over crosslinking and try to keep you informed about new developments in this important procedure.

Apart from support, one of our greatest achievements in the past year was the formalisation of our agreement with the University of Melbourne’s Eyecare Clinic to provide a 50% discount on contact lenses for keratoconus in exchange for members participating in the keratoconus training clinic for optometry students. This has provided a model for other optometrist teaching colleges and we hope to extend it to other states in the future.

The Association continues to act as an advocate for the keratoconus community on a range of issues. We worked closely with Vision 2020 Australia and other eye health groups in submitting our views on the National Disability Insurance Scheme to government and continued to work towards lowering the cost of contact lenses.

What we really need now is your help. Our Summer 2012 newsletter listed the areas requiring experienced, self-motivated volunteers. Outcomes for the coming year will depend on your involvement.

Larry Kornhauser
November 29, 2012

Support for people with keratoconus and their families remained the primary focus of Keratoconus Australia's activities in 2011-12. The Association logged almost 700 contacts with around 300 individuals and families in Australia and overseas over the 12 month period.

Email remains the primary interface between the Association and people seeking support. Depending on the complexity of the request or support required, the Association will then follow up by telephone or arrange a meeting to discuss the issues involved.

Most people seek out assistance at three stages of their keratoconus: 1) at diagnosis, 2) when glasses fail to provide adequate vision and 3) when they encounter problems with their contact lenses. Progression through these stages also raises questions for patients about the need to consider corneal collagen crosslinking, the new procedure designed to halt the degeneration in their vision.

As in past years, most support requests ultimately related to the need for patients to **find eye-carers** who were more experienced in treating and managing keratoconus than their existing practitioner. The Association continues to seek out optometrists and corneal surgeons who specialise in keratoconus to enable these patients to find experienced keratoconus eye-carers in their local area if possible. Most of the keratoconus-related issues reported to us by patients – especially problems with contact lenses - can generally be resolved by a second opinion from an eye-carer who specialises in this field. (But as in any field of medicine, the more complex cases can provide challenges even for the most experienced practitioner.)

Consequently, almost 40% of support logged by the Association last year related to assisting patients and their families find specialist eye-carers for keratoconus. In many cases when the person lived outside the capital cities where most of the specialists work, the Association also provided patients with information about state-based medical travel assistance subsidies to reduce the financial burden of travelling to consult these eye-carers.

Many of the inquiries relating to surgical procedures - like corneal collagen crosslinking, intra-corneal rings and corneal transplantation - and contact lenses also resulted in patients eventually being counselled to seek a second opinion. Hence, support related to finding a new eye-carer probably amounted to over 75% of the interactions between the Association and keratoconus patients and their families.

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.

Questions about **contact lenses** and **corneal collagen crosslinking** also dominated support issues last year.

Poor fitting contact lenses account for a large proportion of all problems experienced by people with keratoconus. Many think that they are contact lens “intolerant” – a condition that actually afflicts very few people. Almost all are suffering the effects of incorrectly fitted lenses – either because of progression in their keratoconus or a less-than-optimal fit performed by their optometrist (or both in some cases). In these instances, a review by a specialist contact lens fitter for keratoconus and a lens refit – often using a more complex lens design – can resolve the issue. Patients should always consider a review of their lenses before considering a surgical option like intra-corneal rings or a corneal transplant.

There has never been a wider range of specialised contact lenses available for keratoconus than today. New designs in new materials have broadened the spectrum of people suitable for contact lenses – although most lenses remain of the rigid gas permeable type. These now include mini-sclerals, which have a larger diameter than traditional designs and provide new options for post-corneal graft patients. Others like Synergeyes hybrid lenses offer comfort and fit possibilities never before available to those with advanced keratoconus – albeit at a high cost.

Not surprisingly, many patients are confused by the myriad of options available and increasing numbers are seeking our advice on which ones to choose.

As a result support regarding contact lenses continues to rise and last year reached about 15% of total inquiries.

While we can suggest ways to find contact lens fitters who can improve wearing outcomes, it is impossible to say which design is best suited to a particular patient. That is a matter to be determined in conjunction with your contact lens fitter.

In 2011-12, about 16% of all support was for patients interested in corneal collagen crosslinking. Corneal crosslinking has now become a standard procedure in Australia for anyone with progressive keratoconus. It is also being offered routinely to patients – especially teenagers – soon after diagnosis and even before significant progression has occurred. Most corneal surgeons would agree that although widespread, crosslinking is still in the investigative phase – in other words, there is no long term proof of its safety and effectiveness. Still the results are impressive to date and many patients have seen a halt in the progression and even an improvement in their vision in the months and years following crosslinking.

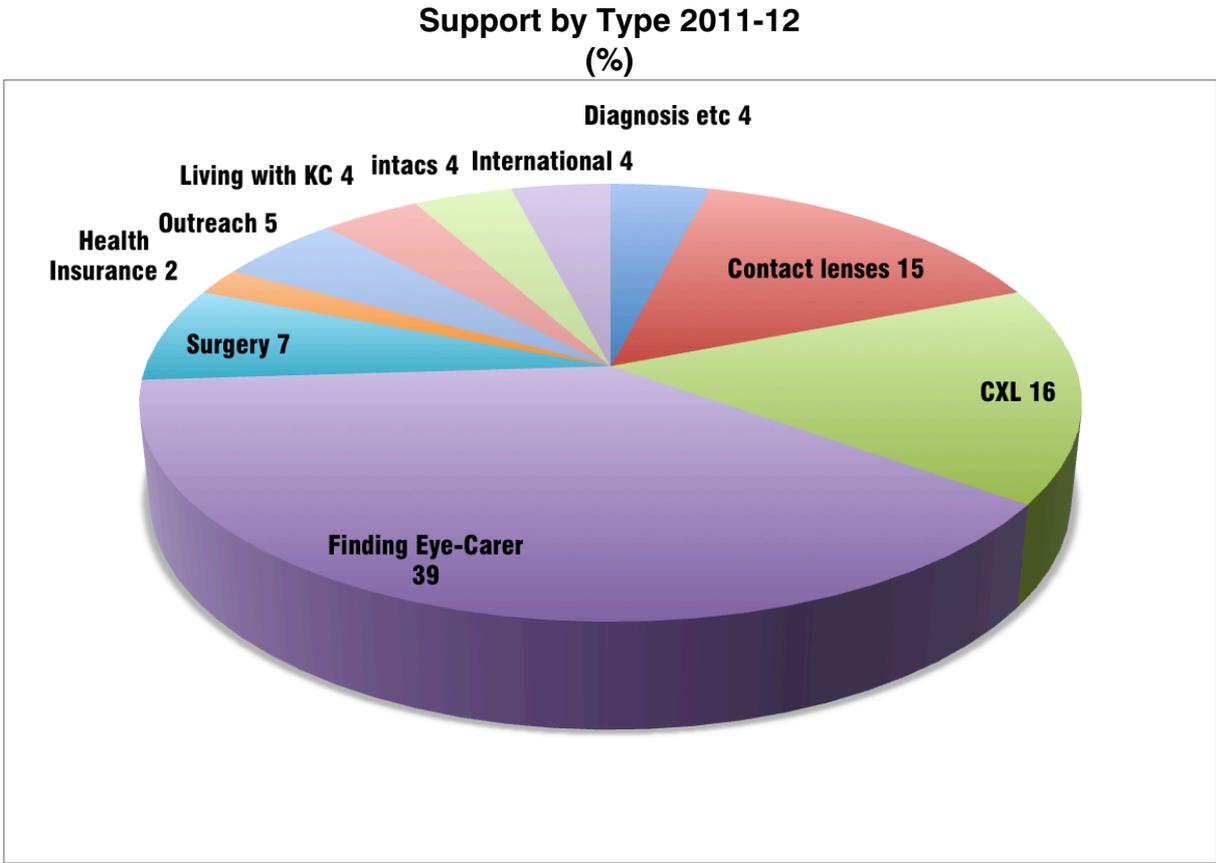
However others have not – and sadly, these are often young patients with the most aggressive forms of keratoconus. There is still a lot to learn about crosslinking and the protocols for its application are under constant revision.

Keratoconus Australia tries to help families with the complex decisions around crosslinking. But like so much associated with the treatment and management of keratoconus, there are no clear answers for everyone. The failure of corneal surgeons to agree on a common protocol for crosslinking only further complicates the decision facing patients and their families.

Outreach involving contact between people with keratoconus and their families and discussions with our work-study expert Heidi Littleford accounted for about 10% of support activities last year. These sorts of informal discussions can be conducted online or by telephone or in person. They have proved extremely useful in reassuring patients facing difficult decisions about how best to treat their keratoconus.

The decision to have irreversible **surgery**, and especially a corneal transplant, can be challenging too and not to be taken lightly. Keratoconus Australia has an excellent booklet on corneal transplantation available from the US National Keratoconus Foundation. It is free so contact us to obtain a copy.

Below is a percentage breakdown of support provided in 2011-12 by type





International Support

In 2011-12, 4% of support requests came from patients living outside of Australia. Although the Association is limited in what support it can provide to these people, we do our best to assist and/or refer them on to their local support groups if possible.

Last year, support requests were received from Germany, Iran, Lebanon, Malaysia, Nepal, New Zealand, Pakistan and the United Kingdom. Topics canvassed ranged from the effectiveness of crosslinking, where to find a contact lens fitter in the Himalayas, how to obtain a visa to come from Iran to Australia for crosslinking treatment (we found the person a clinic in Iran to perform the operation) to information on corneal transplants.

We thank Cathy Warren at the US National Keratoconus Foundation (NKCF) for assisting us in dealing with these requests for international support. The NKCF also provides Keratoconus Australia with their exceptional booklets on keratoconus and corneal transplantation at nominal cost.

One of the key purposes of Keratoconus Australia is to promote research into the causes, prevention and control of keratoconus. While the Association does not conduct research itself, it does provide support for research projects in various ways including funding, collection of information and assistance in the recruitment of participants.

Centre for Eye Research Australia, Melbourne

Genes and Keratoconus trial

In mid-2011, the Association was asked to assist with a project to recruit people with keratoconus for a *Genes In Keratoconus and Myopia Study* being conducted by Associate Professor Paul Baird and Ms Srujana Sahebjada of the Centre for Eye Research (CERA). This study complements the study being conducted by Flinders University into identifying the gene(s) that cause keratoconus.

The CERA study differs from the Flinders University study in that the CERA researchers are looking for similarity in genes between short sightedness and keratoconus based on clinical eye measurements or other factors that may influence the development of keratoconus. The study is also looking at the impact of keratoconus on quality of life. Due to the similarity in these two studies, the researchers are collaborating with each other: blood samples and clinical data of participants in both studies is being shared.

CERA researchers are hoping that data generated from their study will allow determination of how specific hereditary components influence the development of myopia and keratoconus in individuals and in families and will assist in the development of a diagnostic gene test to complement existing management strategies. "This will then allow us to explore the aetiology of both the conditions and thus identify ways of either preventing or slowing their progression," they say.

Keratoconus Australia mailed Victorian members about joining the study in late 2011 and again in mid-2012 after receiving a further request from Ms Sahebjada. Ms Sahebjada presented her early results to scientific conferences during the course of 2012. More information about the study can be found on the CERA website.

Corneal collagen crosslinking trial

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.



We received a brief update on the project in mid-2012, which indicated that three-year follow up visits have been completed for all participants and data is now being analysed.

At that time, the CERA trial was only one of two randomized trials into the safety and effectiveness of crosslinking to publish results and is the longest running randomized trial in the world. It expects to complete its research in early 2015.

The trial has engaged two new researchers to assist Associate Professor Grant Snibson and Dr Christine Wittig-Silva.

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

Department of Ophthalmology at Flinders University, Adelaide

Lack of funding and changes in personnel at both the Association and Flinders with the retirement of Professor Doug Coster as head of the Department of Ophthalmology and the departure of KA's Belinda Cerritelli have slowed our cooperation over a number of planned research projects.

We hope to revitalise these projects in 2013 and will keep members informed of developments. Anyone experienced in medical research and who would be interested in working with the Association on these projects should contact us.

Mater Hospital, Brisbane

It came to our attention in November 2011 that Keratoconus Australia 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" is being conducted under the auspices of the Mater Hospital by Dr Jim McAlister, formerly of the Queensland Eye Institute.

The Association would therefore like to advise members that we are not associated with this trial.

Keratoconus Australia's standard practice is to support a research project only after having conducted a full review of the medical protocol submitted to and approved by the research institute's Human Research Ethics Committee.

University of Melbourne DOVS Optometrist training clinics

Keratoconus Australia in collaboration with the University of Melbourne's Department of Optometry and Vision Sciences (DOVS) and Associate Professor Richard Vojlay, conducted the 6th annual keratoconus teaching clinics and lecture for final year optometry students in September and October 2011.

Three clinics for contact lens fits on keratoconus patients were held along with two post-graft contact lens fitting clinics.

As in the past, many of our Melbourne-based members agreed to offer their time to attend these clinics so that the students could attempt fits on a wide range of keratoconus and corneal transplants.

A/Prof Vojlay organised a special lecture for the final year students on keratoconus just prior to the end of final term. Larry and Belinda presented information about keratoconus and the Association's activities at this lecture and discussed their own experience with keratoconus, the importance of contact lenses to patients and what optometrists can do to improve care for keratoconus patients in general. Feedback from the students was excellent. Since then, the Association has been contacted by one of the graduate students who is interested in working in the field of keratoconus in 2013.

With the opening of the keratoconus clinic at the University of Melbourne's EyeCare Clinic in Carlton, these training clinics may be cut back in future as students are able to access a greater pool of keratoconus patients. In the meantime, we once again thank everyone who volunteered to attend the clinics. Hopefully your time and effort will help ensure all keratoconus patients receive better care in the future.

Australian College of Optometry

Keratoconus Australia has had a long association with the Australian College of Optometry (ACO – formerly known as the Victorian College of Optometry). The college provides us with free access to their Amies Theatre for our seminars and has supported our efforts to train optometry students in the intricacies of fitting contact lenses on keratoconus.

In July 2011, we received a request from the College asking us to help recruit keratoconus patients to participate in a contact lens refresher course for practising optometrists. The course was designed for skills development of the participating optometrists and not to provide treatment. As such, it was very similar to the contact lens fitting clinics for optometry students that the Association runs in conjunction with Melbourne University.



Mary Wilson, General Manager Professional Development at ACO, wrote later to thank us for the attendance of our members, which ensured the success of the course.

Following a recent reshuffle at the top of the ACO, KA President Larry Kornhauser and Vice President, Matt Vaughan, arranged to meet the new CEO Professor Sarah Hosking and the new Head Of Clinical Services, Professor Jonathon Jackson in March 2012. We discussed a range of topics relating to the delivery of optimum services to the keratoconus community including the prospects for regular clinics in country and remote areas around Australia. The ACO understands that better care for keratoconus patients demands more from the optometrist community than has been offered in the past.

Professor Jackson also agreed to give a presentation on contact lenses to our members; that seminar was held in June 2012 (see Events).

Ophthalmologists

Feedback from members indicates that there is concern among some patients that ophthalmologists are not spending enough time explaining issues surrounding the treatment of keratoconus.

The Committee has noted this and plans to raise the matter with corneal surgeons in coming months to see if it would be possible for the Association to become involved in the training of ophthalmologists in the same way it has for optometrists in Melbourne.

Other eye-carer matters

Keratoconus Australia is extremely grateful to the many eye-carers who assist the Association in providing up-to-date information to our members. These eye-carers are generous with their time and advice and counsel about a wide range of matters of interest to the keratoconus community. As we are not eye-carers ourselves, just simple patients, we rely on these experts to help us provide support to others.

We also use our experience and discussions with other people with keratoconus to provide feedback from the patient group and their families to help eye-carers improve their service and treatments. This two-way flow of information has been – we believe –of benefit to all concerned.

As noted last year, we are providing increasing numbers of eye-carer practices with information resources for their patients. The Association supplies this material to eye-carers at a nominal cost to cover our expenses.

However requests to become involved in marketing or endorsing individual practitioners or products and treatments for keratoconus are declined.

UME Keratoconus Teaching Clinic

Keratoconus Australia and the University of Melbourne (UM) were delighted to announce an agreement in March 2012 to enable members to access cheaper contact lenses at the University's new keratoconus teaching clinic.

In its previous Annual Report, the Association explained that the University of Melbourne's Department of Optometrist and Vision Sciences (DOVS) had accepted our submission in April 2011 seeking an expanded keratoconus service as part of the redevelopment of the University's Melbourne EyeCare Clinic.

The submission to the DOVS 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.



The keratoconus clinic, located at the University's newly expanded Melbourne Eyecare practice in Swanston St, Carlton, started seeing patients in late 2011. However it only began operating on a regular basis at the start of the 2012 academic year.

In March 2012, the Association negotiated an agreement with DOVS over the terms of access for Keratoconus Australia members. As a result, members are eligible for a 50% discount off normal prices for all contact lenses fitted at the teaching clinics. This discount is usually available only to UM teaching staff and their families.

The clinic offers a full range of specialized contact lenses for keratoconus.

Due to the limited number of appointments available at the clinic, the Association has asked that only members experiencing serious financial difficulties seek to access this service. We do not recommend this option to patients requiring urgent eye care or modifications to their contact lenses.

The keratoconus clinic has been operating throughout 2012 under the following conditions:

- 
- All contact lenses are fitted by groups of four student optometrists under the supervision of a teaching specialist with extensive experience in managing keratoconus
 - Patients should anticipate spending two hours for a first consultation and the need for multiple visits over several months to achieve the best possible outcome for their vision correction. There may be long waiting times for the initial appointment, depending on demand
 - The keratoconus clinic operated on Tuesday afternoons (weekly) and Wednesday mornings (fortnightly)
 - Eye tests done in the Keratoconus clinic are covered by Medicare.
 - Contact lenses dispensed by the UM Eyecare practice include a 6 month warranty

These are extremely favourable terms for contact lenses and the Association has received very positive feedback from members who have availed themselves of the service.

KA members requiring contact lenses for keratoconus can contact the UME practice on 03 9349 1714 or email: uni-eyecare@unimelb.edu.au to make an appointment. Please note the service is not open to new patients over the 2012-13 Holiday period and will reopen in February 2013.

The service is also providing optometry students with a better opportunity to deepen their keratoconus skills as they now have a chance to pursue a contact lens fit to its conclusion. A win-win for everybody involved.

Vision 2020 Australia

Keratoconus Australia has been a member of Vision 2020 Australia for some years as part of its effort to act as the leading advocate for people with keratoconus and their families.

In December 2011, the Association received a request from Vision 2020 to participate in a survey of eye health organisations being conducted by the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) to assist in the design and structure of the National Disability Insurance Scheme (NDIS). We provided FaHCSIA with the information being sought and have continued to be involved in the processes surrounding the National Disability Insurance Scheme.

Committee members also participated in Vision 2020 Australia's Low Vision and Rehabilitation committee and its newly-formed Prevention and Early Intervention Committee during the year.

Action on Contact Lens Rebates

Keratoconus Australia continues to examine ways of lowering the cost of contact lenses for keratoconus. The Melbourne EyeCare clinic provides a model for other states to adopt as one means for providing cheaper lenses to financially disadvantaged persons. But it does not offer a global solution to the problem.

During 2011-12, we have held ongoing discussions with Vision 2020 Australia about the issue, the Australian College of Optometry, representatives of private health funds and leading members of the optometry community.

One issue raised was the fact that keratoconus is not recognised as a condition under the Medicare regime. Until this gross injustice is rectified, it is hard to see how people with keratoconus will get a fairer deal from either Medicare or the private health funds.

Matt Vaughan also held discussions with the Macular Degeneration Foundation about their similar campaign for a low vision assistive subsidy scheme.

Meanwhile optometrists are lobbying for the government cap on fees for optometric services to be lifted. Should they succeed, it would open the way for higher charges for contact lens consultations. Unless optometrists responded by implementing significant cuts in their contact lens pricing, patients could be even worse off.

These are matters the Association will continue to monitor.

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 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.

Corneal collagen crosslinking

Keratoconus Australia notes the proliferation of protocols for performing corneal collagen crosslinking in Australia and the lack of clear, reliable information for patients about the many and varied methodologies used by ophthalmologists.

In view of reports from patients around the country about how crosslinking is being performed and the variation in costs associated with this procedure, the Committee has held discussions with a number of corneal surgeons about clarifying this situation for patients. We intend pursuing this with the Royal Australian and New Zealand College of Ophthalmologists (RANZCO).

Keratoconus Australia held one Demystifying Keratoconus event during 2011-12 in Melbourne.

Contact lenses - a challenge for optometrist and patient

held on Tuesday June 5, 2012

Speaker Professor Jonathan Jackson, Head of Clinical Services at the Australian College of Optometry

In his presentation, Professor Jackson explained what keratoconus is and the challenge it poses for both optometrist and patient. He reviewed the symptoms and signs associated with the condition and discussed the relative importance of a range of techniques used to both detect and quantify the severity of the condition.

Professor Jackson also examined the merits of providing various types of optical correction including both spectacles and contact lenses and the need for proper aftercare. Finally, he reviewed his clinical experiences in Northern Ireland working with a variety of keratoconus patients.

The presentation was followed by a lively Q & A session, which raised some interesting issues about the role of contact lenses in the treatment of keratoconus.

Professor Jackson is a renowned optometrist from Ireland who, until recently, was Head of Optometry at the Royal Victoria Hospital Belfast, Assistant Director of Integrated Care (Optometry) NI Health & Social Services Board and Policy Advisor (Optometry) at the Northern Ireland Department of Health & Social Services. He has been awarded Fellowship of the British Contact Lens Association (FBCLA, 2006) and the American Academy of Optometry (FAAOptom, 2008).

Videos

Videos of the Jackson presentation and all past events can be purchased from the Association.

COMMUNITY RELATIONS

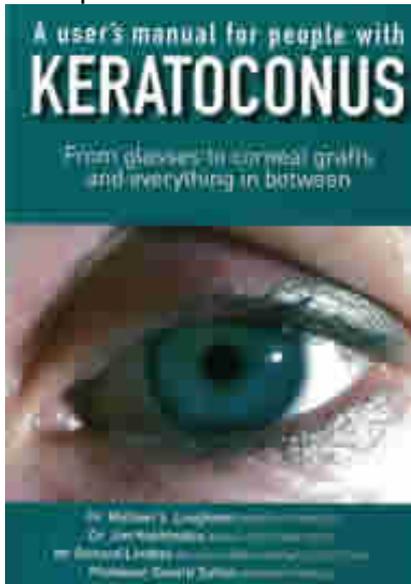
One of Keratoconus Australia's key missions is to publicize keratoconus and its effects on individuals and families in the wider community.

Vision 2020 Australia

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. This partnership with Vision 2020 was strengthened considerably in 2012 when our former secretary Belinda Cerritelli joined that organisation as its National Advocacy Adviser. Belinda continues to be a valuable link between the keratoconus community and other eye health groups and we thank her for this ongoing contribution to the Association's work.

Australian Keratoconus Book

The long-awaited book by four leading Australian eye specialists aimed at explaining all aspects of keratoconus and its treatments to patients and their families was finally published in early 2012.



The authors - Dr Michael Loughnan, Dr Jim Kokkinakis, Richard Lindsay, and Prof Gerard Sutton - all have extensive experience in treating patients with keratoconus. Their book is a welcome contribution to the understanding of keratoconus within the community.

Keratoconus Australia worked with the authors on the early drafts and congratulates them on publishing a fine resource for the keratoconus community. The Association has also helped publicize the book to its members (Note: we have no financial interest in this publication).

Users manual for people with keratoconus: from glasses to corneal grafts and everything in between is available online from [Wilkinson Publishing](#), select bookstores or from the authors' practices. RRP \$19.95.

RANZCO's JuIEYE 2011

As discussed in last year's Annual Report, the committee decided in 2010 that rather than try to hold a Keratoconus Day, we would try to join up with other eye health



promotions run by other larger organisations like those run by Vision 2020 Australia and the annual JulEYE campaign organised by The Eye Foundation.

As a result of contacts made with The Eye Foundation in early 2011, Keratoconus was featured during the JulEYE 2011 campaign and can be seen at <http://www.eyefoundation.org.au/news-a-events/news/257-1-juleye-2011>.

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). JulEYE is The Eye Foundation's eye health awareness month that takes place during July each year.

Keratoconus was promoted again in the JulEYE 2012 campaign and we will continue to participate in this worthwhile promotion of eye health.

Optometrist Association of Australia

Keratoconus Australia has maintained a long standing relationship with the Optometrist Association of Australia, which continued in 2011-12. The Association provides the OAA with information about its activities and occasional articles about keratoconus appear in the OAA newsletter,

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

THE ASSOCIATION

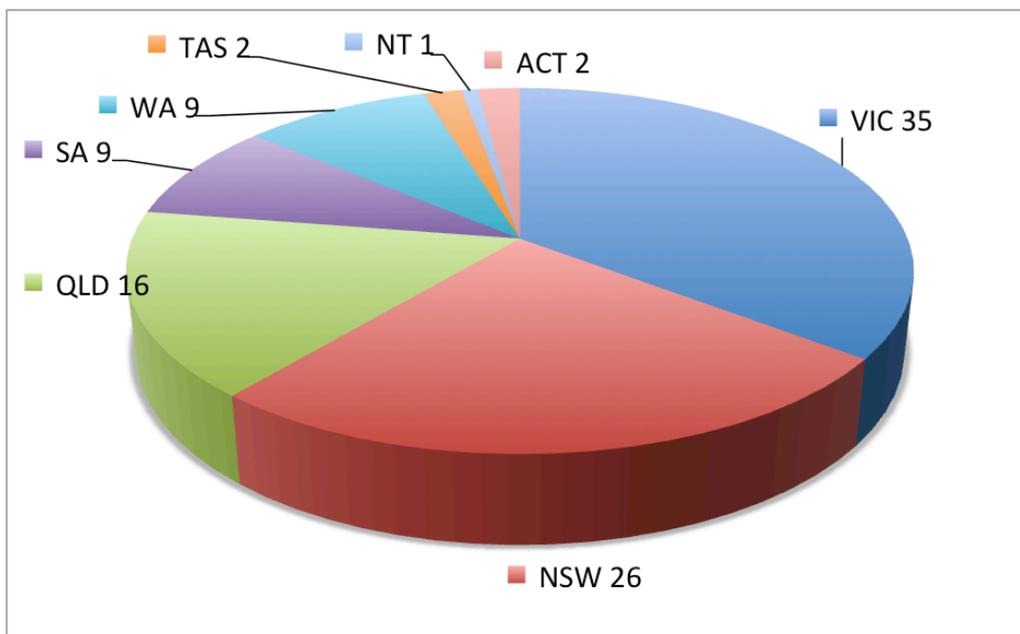
Membership

At 30 June 2012, Keratoconus Australia had 1,763 registered members. This represented an increase of 4.4% above the 1,688 members registered one year earlier.

Victoria (624 members, +1.8%) continues to account for more than one-third (35.4% at June 30, 2012) of the Association's total membership base. Rising membership in NSW continues to erode Victoria's share: NSW members now number 453, an increase of 8.6% over the previous year. The NSW share in total membership was almost 26% at the end of the 2011-12 year. The growing importance of NSW within the Association emphasises the need for members located in the Sydney area to form a local support group there. With 289 members, Queensland is the third largest state in the Association's membership base (16.4% of the total), although numbers grew more slowly there last year (+1.8%).

Membership continued to grow strongly in South Australia and Western Australia (+6.2% and +13.5% respectively), while Tasmania and the ACT comprise about 2% each.

Membership by state (% of total)



(Please note that constant updating of information in the KA database means that membership data is not directly comparable from one year to the next.)

Supporters

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 2011-12, notably GMK (accounting), The Australian College of Optometry (seminar venue) and Viewgrow Capital Pty Ltd (meeting venue and administrative support services). As discussed elsewhere, the University of Melbourne has strongly backed Keratoconus Australia's efforts to improve access to cheap, well-fitted contact lenses for keratoconus patients.

Fundraising and Grants

The Association would again like to acknowledge the long standing and generous support of the Ray and Margaret Wilson Foundation. We received a very kind letter from the Wilson family during the year and would simply like to say that we could not continue our work without the support of wonderful people like the Wilsons.

We also would like to thank a number of other donors who made significant contributions during 2011-12.

No grants were sought or received during the year.

Website

The Association's website averaged about 1,500 hits a month in 2011-12 – a similar level to 2010-11. Apart from the home page, the most popular pages on the site were FAQs on keratoconus, our resources and events pages, the 2011 Annual Report 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.

Work on the website redevelopment is continuing and we hope to have the new site operating in 2013. In the meantime, the site can still be found at www.keratoconus.asn.au.

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 2011-12, the committee met eight times and held informal discussions on other occasions.

The committee last year comprised:

Larry Kornhauser, President
Belinda Cerritelli and Jennifer Toom, Secretary
Heidi Littleford,
Marisa Cerritelli
Matt Vaughan

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



As noted last year, Belinda Cerritelli stepped down from her position as Secretary and from the Committee at the AGM 2011 after a decade of service to the Association. Belinda made a wonderful contribution to the Association and the keratoconus community in general during her time with us. We miss her and her many talents, which she is now employing in commerce and at Vision 2020 Australia. Jennifer Toom replaced Belinda as secretary and is managing new volunteers and a range of other areas including social media policy.

Marisa Cerritelli also retired from the committee in November 2011.

Matt Vaughan, a past vice president of the Association, rejoined the committee in late 2011 and took over some of Belinda's work in advocacy.

However, Matt was forced to resign from the committee in August 2012 due to a transfer overseas. Heidi Littleford, who handles work and study issues, was also obliged to reduce her involvement with the Committee.

New volunteers

As a result of the recent changes in the committee, the Association now is in desperate need of new committee members and volunteers to ensure it can function properly in the future.

The Association urgently requires *highly skilled* people 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:

- | | |
|---------------------|--|
| 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 organisations• 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• event management |
| Treasurer | <ul style="list-style-type: none">• 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 material for distribution
- Volunteers**
- coordinate volunteers and project management

The Association will be winding down its activities by early December for the summer break. However, you can email us over the holiday period if you would be interested in contributing in 2013 in any of the above areas.

We have a long list of tasks and projects we would like to perform. But the existing committee is simply unable to do everything because of time constraints and a lack of expertise in certain areas. We really do need talented and enthusiastic people to join us in developing the Association and its activities.

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.

State Support Groups

We have long encouraged members to consider setting up a local or state level support operating under auspices of Keratoconus Australia. We can provide resources, advice and encouragement to anyone who is prepared to organize small meetings in their locality on a regular basis.

That could mean organizing a fundraiser or an information seminar. There is certainly a need in areas like Sydney, Brisbane and Adelaide while members on the Gold Coast have also expressed an interest in meeting locally. Ultimately we should have a contact person for the Association in each city and town around Australia so that people with keratoconus can discuss and share their experiences with others in their area. Please contact us if you are prepared to be involved.

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 2013.

Larry Kornhauser,
President

29 November 2012




FINANCIAL REPORTS

The Association reported a **net profit** in 2011-12 of \$6,403. This was down 18% on the previous year's net profit of \$7,807.

The lower result largely reflected a new depreciation charge of \$1,376 and a slight fall in donations in 2011-12 to \$9,023 (down 8% compared to \$9,785 in 2010-11). Seminar entrance fees and video sales plummeted as only one seminar was held last year. Bank interest remained flat at \$2,430, reflecting the steady fall in interest rates over the period. Total income for the year was \$11,966 (\$13,358 in 2010-11).

Although expenses associated with organizing only one Demystifying Keratoconus seminar last year were lower, timing of invoice payments meant that some expenses from 2010-11 were carried over into the 2011-12 financial year. Video recording costs was the main expense affected, rising from \$364 in 2010-11 to \$802 last year.

Despite the various changes in expenses, overall expenses remained almost steady at \$5,563 compared to \$5,551 in 2010-11.

The **balance sheet** for 2011-12 showed net assets of \$72,131 on June 30, 2012, or 9.7% higher than one year earlier (\$65,729). End-year assets totalled \$72,317 (\$64,898 on June 30, 2011), held mostly in cash (\$68,143). Around \$57,000 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.




ACKNOWLEDGEMENTS

Keratoconus Australia would like to acknowledge the special contributions of the following people and organizations during 2011-12.

Associate Professor Richard Vojlay

Audio Visual Solutions

Centre for Eye Research Australia

Dr Michael Loughnan

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

Vision 2020 Australia


**ANNEXES**

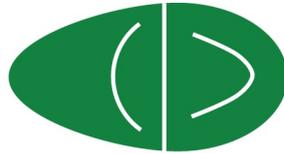


K E R A T O C O N U S AUSTRALIA

Profit & Loss

July 2011 through June 2012

	2012	2011
Income		
Donations	\$9,023	\$9,785
Seminar Entrance Fees	\$84	\$488
Video Sales	\$150	\$609
Booklet sales	\$114	\$14
Reimbursement Research Expense	\$165	\$0
Miscellaneous Income	\$0	\$3
Bank Interest	\$2,430	\$2,459
Total Income	\$11,966	\$13,358
Expenses		
Advertising	\$0	\$177
Domain Name Registration	\$107	\$36
Bank Charges	\$18	\$14
Catering	\$164	\$167
Stationery	\$293	\$381
Depreciation	\$1,376	\$0
Dues & Subscriptions	\$238	\$254
Late Fees Paid	\$45	\$0
License Fees	\$0	\$219
Vision 2020	\$211	\$0
Postage	\$956	\$1,184
Printing	\$170	\$605
Photocopying	\$124	\$0
Booklets	\$151	\$0
Seminar Expenses Melbourne	\$142	\$758
Seminar Expenses - Brisbane	\$0	\$304
PO Box Rental	\$357	\$276
Video Recording	\$802	\$364
Website Hosting	\$325	\$245
Telephone and Internet	\$82	\$112
Travel	\$0	\$455
Total Expenses	\$5,563	\$5,551
Net Profit / (Loss)	\$6,403	\$7,807



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

Balance Sheet at June 30. 2012

	2012	2011
Assets		
Current Assets		
Cash On Hand		
Westpac DGF Account	\$11,490	\$7,542
Westpac Max-iDirect	\$56,653	\$54,241
Total Cash On Hand	\$68,143	\$61,783
Trade Debtors	\$0	\$15
Total Current Assets	\$68,143	\$61,798
Property & Equipment		
Clubhouse		
Website	\$5,550	\$3,100
Less: Accumulated	(\$1,376)	\$0
Depreciation		
Total Clubhouse	\$4,174	\$3,100
Total Property & Equipment	\$4,174	\$3,100
Total Assets	\$72,317	\$64,898
Liabilities		
Current Liabilities		
MasterCard	\$0	-\$1,000
GST Liabilities		
GST Collected	\$272	\$251
GST Paid	(\$86)	-\$82
Total GST Liabilities	\$186	\$169
Total Current Liabilities	\$186	-\$831
Total Liabilities	\$186	-\$831
Net Assets	\$72,131	\$65,729
Equity		
Retained Earnings	\$65,729	\$57,922
Current Year Earnings	\$6,403	\$7,807
Total Equity	\$72,131	\$65,729

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