

ANNUAL REPORT 2009

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EXECUTIVE SUMMARY

SUPPORT

Keratoconus Australia recorded just over 130 separate requests for support last year from members or other people who contacted the Association. This was down slightly from about 160 (revised) for the 2007-08 year.

In 2008-09, over 90% of all support contacts were initiated or conducted via the Internet.

During 2008-09, over 30% of all support inquires related to CXL alone. Issues with contact lenses also accounted for around 30% of support. Support requests relating to surgery (apart from corneal collagen crosslinking) accounted for over a third of the total last year. About 8% of support was directed towards patients or the parents of adolescents who had just been diagnosed.

RESEARCH

The Association has continued its collaboration with the world's first large scale randomized clinical 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).

Keratoconus Australia received a request from the Flinders University Department of Ophthalmology to make a joint application to the Australian Government's National Health and Medical Research Council (NHMRC - Australia's peak body for supporting health and medical research) for a partnership grant to fund three keratoconus research projects. Unfortunately, our joint proposal was not among those awarded grants by the NHMRC in October 2009.

OPTOMETRIST TRAINING

The third annual round of teaching clinics and lectures for final year optometry students at Melbourne University's Department of Optometry and Vision Sciences was held during September and October 2008.

ACTION ON CONTACT LENS REBATES

KA attended the July 2, 2009 meeting of Vision2020 Australia's Low Vision & Rehabilitation Working Group which endorsed the KA initiative to secure subsidized contact lenses and authorized Vision2020 to provide ongoing support to KA. Since then, Belinda and Larry have had talks with various representatives of optometrist groups in a bid to advance this issue.

DATABASE

The Keratoconus Australia database is in need of an overhaul. Anyone with experience in developing in Filemaker Pro 9 or 10 and who has time to work on this project should contact Larry Kornhauser at the Association.

INTERNET, WEBSITE & SOCIAL NETWORKING

The website visit statistics continued to improve last year rising to slightly above 100 hits a week (c.f. just below 100 in 2007-08) with a return rate averaging about 34%.

The Association is planning to upgrade and overhaul the website in 2010 to include:

- further free audio podcasts of some of our recent seminars
- separate pages relating to resources for study and work
- additional podcasts from seminars in early 2010
- a special page on corneal collagen crosslinking

MEMBERSHIP

Membership of Keratoconus Australia continues to expand rapidly. On June 30, 2009, the Association had a total of 1,354 members, or 14% more than one year earlier (1,189). Membership currently stands at 1,425.

EVENTS

The Association held one Demystifying Keratoconus seminar during 2008-09 on the topics of contact lenses and corneal collagen crosslinking. The seminar was self-funded with door donations of \$282.35 and DVD sales of \$325 to date.

THE COMMITTEE

Time constraints caused by our paid employment and family obligations restricted our ability to achieve some of our objectives in 2008-09. The committee has responded to this ongoing situation in a number of ways. Our new administrative assistant, Mary Veal, will be taking on a number of tasks such as database management and contact with the membership. We hope we can provide better follow up on support too. Mary has launched a review of the Association's rules and our accounting systems. We hope she can work with volunteers on specific projects to ensure that tasks are allocated and completed in a timely manner.

Heidi Littleford has joined the committee and will concentrate on assisting members with issues concerning work and education.

FINANCIAL REPORT 2008-09

Keratoconus Australia earned a net profit for the year 2008-09 of \$10,396, which was more than 6 times the net profit earned in 2007-08 (\$1,652). The higher result came thanks mainly to a large donation made through the Myer Family Office.

Overall net income totalled \$12,984 last year (up about 300% cf. to \$4,254 in 2007-08), while expenses remained almost steady at \$2,588 (cf. \$2,602 in 2007-08). The Keratoconus Australia balance sheet remains strong given our current funding requirements. At the end of the 2008-09 financial year, the Association held net assets of \$51,308, or 25% higher than on June 30, 2008 (\$40,912).

ANNUAL REPORT 2009

INTRODUCTION

Good morning all and thank you for joining us today at the Keratoconus Australia Annual General Meeting for 2009.

This is a very exciting time for the keratoconus community as we continue to search for treatments that could halt progression in the condition (or even reverse it one day), and to expand the range of new procedures and contact lenses to manage vision loss caused by keratoconus. The Association has tried to play an active role in these changes, by counselling members and keeping them informed of their options, helping them find specialists, supporting research, advocating for patient rights and generally trying to improve the lives of people with keratoconus and their families.

In trying to assess the Association's performance over the past year, members need to take into account the continued shortage of volunteers to participate on the committee and assist with the various plans, which the committee would like to implement. This has been a recurring theme in past annual reports. Despite numerous appeals over recent years for a more participatory membership, the response has generally been limited to one-off events such as organization of meetings, participation in optometrist teaching clinics and research projects.

Members' support on these occasions has been tremendous and proof of a desire to promote the work of the Association, to assist others with keratoconus and further the quest for knowledge about this condition and for safe and effective treatments.

The Association acknowledges and values this assistance, which has enabled us to achieve some important successes. But the committee believes we could do so much more if we had a few additional members willing to make a longer-term commitment to completing some projects already underway and the development and initiation of new ideas.

This report will try to identify some of our successes in the past year, and what we hope to achieve in 2010. It will also discuss some of the changes happening at the Association that should improve services offered to members and others with keratoconus.

SUPPORT

The key purpose of Keratoconus Australia is to provide support for people with keratoconus and their families. That is why the Association was created in 2000 and that remains our priority. We aim to minimize the impact of our small numbers on this vital service.

The Internet and email are critical in enabling us to maintain this service. In 2008-09, over 90% of all support contacts were initiated or conducted via the Internet. In many cases, follow-up contacts took place by telephone, SMS or in face-to-face meetings.

Support is generally offered in accordance with certain broad guidelines. These include:

- Providing general information about keratoconus and treatments.
- Responding to patient and family questions about specific situations and keratoconus issues. In most cases, medical and optical related questions are referred on to our team of consulting ophthalmologists and optometrists for their expert opinions.

(However due to the limitations on providing patient-specific health information via the internet and without a full patient examination, these experts can provide only general comments and information about keratoconus-related questions.)

- Counselling patients and their families about the likely impact of keratoconus on their daily lives based on the experiences of members, and other keratoconus patients.

Due emphasis is always given to the need for individual patients and their families to seek opinions (and second opinions) from keratoconus specialists, and to find and adopt solutions best suited to their own personal circumstances.

- Keratoconus Australia does NOT give opinions or comment on specific medical issues or problems being experienced by patients. Nor do we consider any medical information provided by patients such as corneal topographies, or other data on a patient's cornea or eye condition in general.

Please remember we are simply people with keratoconus like you, and are not qualified to provide any sort of medical opinions, recommendations or referrals.

Keratoconus Australia recorded just over 130 separate requests for support last year from members or other people who contacted the Association. This was down slightly from about 160 (revised) for the 2007-08 year. It does not include the many anonymous requests we receive every year from Australians and international patients with keratoconus.

An analysis of these requests for support reveal some broad trends in the type of support people are seeking from the Association.

- **Finding Eye-Carers**

As in previous years, the vast majority of requests for support – no matter what the particular issue triggering the call for help – result in patients requesting guidance in finding eye-carers appropriately qualified and experienced to assist in resolving their problem. Keratoconus Australia does its utmost to help patients

find ophthalmologists and optometrists who specialize in keratoconus in their local or nearby area.

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.

- **Corneal Collagen Crosslinking**

Over the past 18 months, corneal collagen crosslinking (CXL) has switched from being an experimental procedure available in only a few centres around Australia to a mainstream treatment being offered by a range of ophthalmologists around the country.

As many of you would know already, CXL - originally developed in Germany - attempts to stiffen the cornea by first irrigating it with riboflavin and then irradiating it with ultra-violet light. Clinical trials in Melbourne and elsewhere are showing its potential to halt progression in keratoconus and even slightly reverse it in some patients. Little is known about the long term effects of this treatment and different ophthalmologists are now performing the procedure in different ways, e.g. leaving the epithelium (or outer layer of the cornea) on, although most studies and clinical observations indicate that the treatment is most effective when the epithelium is first scraped off.

Confusion about the procedure, when it should be performed (at diagnosis of keratoconus or only when there are clear signs of progression), which method should be employed, who is a suitable candidate etc. all have led to an upsurge in questions from patients and especially concerned parents.

During 2008-09, over 30% of all support inquires related to CXL alone. Keratoconus Australia has held a number of patient seminars over recent years to follow the progress of the debate over corneal collagen crosslinking and in particular to track the results of the world' first randomized clinical trial of the procedure being conducted by the Centre for Eye Research Australia in Melbourne. The Association's guidance to patients on this issue remains heavily based on the outcomes from the Melbourne trial and the views of the principal researchers, Associate Professor Grant Snibson and Dr Christine Wittig-Silva. Assoc. Prof. Snibson and Dr Wittig-Silva presented their latest results and conclusions at a seminar held in August 2009. We strongly recommend that anyone considering the procedure view the video of this seminar before proceeding. An audio podcast of the seminar will also be posted to the Keratoconus Australia website in early January 2010. (See **Research** for more on corneal collagen crosslinking).

- **Contact Lenses**



Issues with contact lenses also accounted for around 30% of support offered by the Association in 2008-09. This is hardly surprising as rigid gas permeable (RGPS) contact lenses are the primary means for correcting vision loss caused by keratoconus and are worn by the majority of patients with moderate to advanced keratoconus. But they can be tricky to fit and there are very few experienced contact lens fitters for keratoconus in Australia, and almost none outside of the major capital cities.

Many of the people contacting Keratoconus Australia claim they can no longer wear contact lenses and are seeking surgical solutions like corneal transplantation or intacs etc. But most problems are related to fit (either poorly-fitted lens or progression or both). The Association has assisted many patients find an experienced contact lens fitter for keratoconus in their area and in the majority of cases, new contact lenses can resolve the problem without surgery.

Since the arrival in Australia (finally!) of a new hybrid lens called Synergeyes from the US in late 2008, patients – especially those with advanced keratoconus - have a new possibility of a non-surgical solution to resolve their vision loss. These lenses are being made available to a growing number of contact lens fitters around the country and the Association would be pleased to help you find an optometrist with access to them. Please note, however, they are quite expensive and need to be replaced every 6-12 months.

Other new designs and materials for RGP lenses are appearing on the market regularly and many of the larger lenses, like the mini-sclerals, offer new hope to many patients who have given up on contact lenses in the past. So if your lenses are causing you grief, it is worth seeing a contact lens fitter for keratoconus to try some new options.

The Association held a seminar on new contact lenses for keratoconus in July 2008; a video of the seminar is available and a free audio podcast can be found on the video page of our website.

- **Surgery**

Support requests relating to surgery (apart from corneal collagen crosslinking) accounted for over a third of the total last year. The majority of these were from people considering a corneal transplant in the near future. Any surgery is scary and corneal transplantation – although a highly successful operation for keratoconus – is no less so. Patients contact Keratoconus Australia for information about the operation... and just reassurance.

The Association sends prospective grantees a free booklet on corneal transplants published by the US-based National Keratoconus Foundation, which explains the operation, aftercare and includes a comprehensive list of questions for your corneal surgeon. We also suggest that patients who are unsure about the operation or their need for it consult another corneal surgeon for a second

opinion. Where necessary, we assist patients in finding other specialists. Once again, we have a series of videos on surgery for keratoconus and how to decide when is the right time.

We also offer to put patients in contact with members who have had transplants recently and who can explain the procedure and what to expect in the months and years following the operation. We receive very positive feedback from those who take advantage of this outreach service and owe a very big Thank You to those members who so kindly offer their time to perform this invaluable task.

As discussed last year, intacs remain a point of contention. Some 12% of all support requests last year related to these curved plastic inserts, which are widely advertised on the Internet as a solution to keratoconus. People with problematic contact lenses believe intacs are a better alternative and are often determined to find a surgeon who will insert them. They are also increasingly offered as an adjunct to corneal collagen crosslinking.

However corneal surgeons have repeatedly told Keratoconus Australia that intacs have proved little more than a short term measure for most patients to whom they have been fitted. Most have them removed for a variety of reasons within about two to three years. Intacs are very expensive, they tend to make contact lens fits much more difficult, they can damage and compromise a cornea which may need a corneal transplant later on – and there are very few keratoconus patients who can benefit from them. They are unnecessary for a good outcome to corneal collagen crosslinking and may even be counter-productive if their removal causes damage to an otherwise stable cornea. In short, Keratoconus Australia tries to give patients seeking quick fixes like intacs a wider perspective on these new surgeries of often dubious value.

- **Diagnosis**

A diagnosis of keratoconus is a difficult time for anyone, and especially the parents of young children with keratoconus. Most eye-carers know little about the disease and the likely prognosis, and offer little information even if they do. Most patients have never heard of keratoconus and find it difficult to absorb much information anyway after the initial diagnosis. This often leads to patients becoming overly anxious and fearful about their vision and their ability to function normally in the longer term. Searches for information on the Internet may provide some comfort – but can also worsen the situation by raising the spectre of severe vision loss, corneal transplants, or other surgery.

Keratoconus Australia plays an important role in giving patients and their families an opportunity to discuss their concerns with people who actually have been living with the condition for many years – some of us since we were barely teenagers.



Last year, about 8% of all support was directed towards patients or the parents of adolescents who had just been diagnosed. The Association pays special attention to these requests for assistance and tries to do everything possible to reassure people about their prospects, explain the treatments and direct them to specialists who can ensure they receive the very best treatments available in their area.

We also offer to connect these people with others in a similar situation to enable them to gain a better understanding of how keratoconus may affect their own or child's education, employment options, social and sporting activities.

- **Members helping Members**

The essential ingredient of support is connecting people with others who have already had a similar experience. Everyone who works with Keratoconus Australia has keratoconus or is the parent of a child with keratoconus. As discussed above, if you have just been diagnosed or are having problems with contact lenses or are considering surgery, we can help you find and talk to someone who knows what you are facing. Hearing how they dealt with these issues can assist you in coping with your own situation.

We greatly appreciate those members who have participated in the support program and the many thank you letters we receive are a testimony to the value of their work.

If you have had surgery or have a child with and are prepared to discuss your experiences, please drop us a line and we can include you on our list of support contacts.

- **International**

Keratoconus Australia receives many support requests from outside Australia via the Internet. While it is not our primary role to assist non-Australian residents, we do our best to respond these appeals for help. They usually lead to a fascinating exchange of information on how keratoconus impacts on people in other (often developing) countries and the various treatments available to them.

Last year, we communicated with a young woman from Swaziland and helped her find other correspondents via the NKCF kc-link, a global email list for keratoconus. We also had an enlightening dialogue with a young Jordanian man living in Algeria and seeking advice about whether his fiancée, who also has eye problems (but not keratoconus) would make a suitable marriage partner for a person with keratoconus through the family.

Other contacts were made with a social worker in New Zealand seeking assistance for a person severely disabled by her keratoconus, and an Australian in the Canary Islands looking for an experienced contact lens fitter for keratoconus.

Although support requests were down in 2009, the current year is shaping up to be a record. Already over 115 requests have been handled to date. Once again, most relate to contact lenses and finding contact lens fitters, and corneal collagen crosslinking.

RESEARCH

Keratoconus Australia has participated in a range of keratoconus-related research projects over recent years and will make whatever contribution it can in the future. But much of this research requires major funding beyond the capacity of the Association.

Members are therefore urged to contact the Association if they are able to make contributions towards financing these projects or would like to assist in applying for grants and other funding options.

Corneal Collagen Crosslinking

Support for keratoconus-related research is a key component of Keratoconus Australia's strategy to help control and prevent keratoconus within the community.

Since 2006, the Association has been involved in the world's first large scale randomized clinical 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). Keratoconus Australia has provided funding for the project in the belief that all keratoconus patients will benefit from proper scientific evidence showing whether or not this procedure is both safe and effective. The trial has generated tremendous interest both in Australia and overseas and ophthalmologists and patients around the world are following it closely. Details of the trial can be found on the Keratoconus Australia website.

So far, all the reports and updates from the CERA trial indicate a very positive outcome for the patients treated with corneal collagen crosslinking.

An update on the trial sent to Keratoconus Australia in mid-2009 indicated that the key findings to date were:

- Although results varied in the first 3-6 months, after 12 months all patients who received the crosslinking treatment showed stabilization in their keratoconus at their pre-treatment level.
- Some patients even experienced a mild flattening in their cornea.

CERA is also conducting a pilot study of crosslinking for patients with corneas with a thickness of less than 400 microns. Members who are interested in participating in the 'thin cornea' pilot study or in being assessed for a placement on the waiting list are

advised to contact their eye care specialist or Trial Coordinator Tony Ngo on 03 9929 8618 or via email at tonyn@unimelb.edu.au

Funding is urgently required for both the current and future studies. Please contact either Keratoconus Australia or Tony Ngo (details above) if you can assist.

Flinders University Department of Ophthalmology Research Proposal

As foreshadowed in the 2008 Annual Report, Keratoconus Australia received a request from the Flinders University Department of Ophthalmology to make a joint application to the Australian Government's National Health and Medical Research Council (NHMRC - Australia's peak body for supporting health and medical research) for a partnership grant to fund three keratoconus research projects. The Flinders University proposal was:

- 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.

Keratoconus Australia and Flinders University submitted the application to the NHMRC in December 2008. Unfortunately, our joint proposal was not among those awarded grants by the NHMRC in October 2009.

The Committee still believes this research would be extremely beneficial for keratoconus patients and we intend pursuing other avenues for launching these projects with Flinders University in 2010. Significant funding would be required to complete all three projects and any Keratoconus Australia members who would be interested in providing financial assistance should contact the Association directly.

Resources for Students with Keratoconus project

In March 2009, Heidi Littleford –a teacher with Vision Australia and Keratoconus Australia member - contacted the Association about doing her Masters of Special Education on resources for students with keratoconus. The Association put her in touch with other members interested in this subject and gave her access to background material about keratoconus. Heidi submitted the project in May and has since made it available to us to use as a resource.

The Association will post the information on resources for keratoconus students on its website soon. We will let members know when it is available for viewing.

The other happy outcome of this collaboration is that Heidi has agreed to join the committee and continue her work on compiling resources to meet the special needs of people with keratoconus.

Other Research

- A number of members contacted the Association in May about the University of NSW's use of stem cells on contact lenses to restore sight to people suffering from corneal damage. In particular, members asked if this procedure could be used to halt progression in keratoconus or reverse damage from the condition.

The simple answer is "no" at this stage. The NSW procedure affects only the very outer layer of the cornea (the epithelium) and not the stroma, which is weakened by keratoconus. The researchers told Keratoconus Australia they are looking at ways to use the procedure to repair and strengthen the stroma - but clinical trials could be "still years away."

Dr Stephanie Watson, a member of the UNSW team, said this about the procedure and keratoconus: *Our treatment only replenishes the very first layer of the cornea, the epithelium. This layer is like the skin of the eye. In keratoconus it is the middle section of the cornea, the stroma that is abnormal. A different set of stem cells looks after this part of the cornea so it is these cells that need to be replenished not the surface layer. Our lab is investigating these cells but our findings are not ready for clinical application yet.*

- The Association has also received a request from the School of Optometry and Vision Science at the University of New South Wales to help fund post graduate research into whether there are changes to the tears of people who have keratoconus, and whether these changes can be used to get a better understanding of the condition, and perhaps to monitor its progression.

The Association is currently trying to determine details of the project and what level of assistance is required. Once again, any members who would be interested in providing funding to support this project should contact Keratoconus Australia directly.

OPTOMETRIST TRAINING

The third annual round of teaching clinics and lectures for final year optometry students at Melbourne University's Department of Optometry and Vision Sciences was held during September and October 2008. The program was expanded last year to include 4 clinics for keratoconus and two special post-graft clinics to allow students an opportunity to fit contact lenses on patients with corneal transplants.

Keratoconus Australia's Victorian members proved very supportive of this unique initiative which is aimed at teaching optometry students more about keratoconus, the

concerns of patients and in particular, how best to fit contact lenses on keratoconic eyes and corneal transplants. Members again kindly volunteered their time to allow students to examine their corneas and attempt contact lens fits under the supervision of Associate Professor Richard Vojlay.

A special lecture on keratoconus presented by Associate Professor Vojlay, KA President Larry Kornhauser, and Secretary Belinda Cerritelli in early October 2008 was very well attended by students and led to a discussion on various aspects of contact lens fitting for keratoconus and the particular problems facing optometrists treating keratoconus patients and working with their families. The lecture concluded with a lively Q&A session, which tested the students' ability to deal with real life situations.

Following the success of the expanded training clinic format last year, the Department of Optometry and Vision Sciences adopted a similar format in 2009. Associate Professor Richard Vojlay conducted the clinics with the assistance of Dr Laura Downie, who has extensive experience in fitting lenses for keratoconus and works in Associate Professor Vojlay's practice.

The Association is delighted to be able to report that the clinics would appear to be having the desired effect: Optometry graduates are now moving into the larger keratoconus practices in Melbourne to develop the skills necessary to achieve optimum contact lens fits on keratoconus patients.

We would like to thank Richard Vojlay, Laura Downie, the Department of Optometry and Vision Sciences and all of the Keratoconus Australia members who have made the clinics and lectures such a success over the past four years. They will unquestionably benefit all keratoconus patients in the future and we hope that optometry colleges in other states will soon instigate similar teaching clinics for their students.

ACTION ON CONTACT LENS REBATES

Keratoconus Australia continues to press for action to lower the cost of specialized contact lenses for keratoconus. (Details of recent and past efforts in this regard can be found on our Action on Contact Lenses page on our website.)

But that could take time. So in the meantime, we suggest 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%20Insurance%20letter.pdf>.

Latest initiatives

KA attended the July 2 meeting of Vision2020 Australia's Low Vision & Rehabilitation Working Group to secure backing from affiliated members for our campaign to lower the cost of contact lenses for keratoconus. A vote taken at the meeting endorsed the KA initiative and authorized Vision2020 to provide ongoing support to KA. Since then, Belinda and Larry have had talks with various representatives of optometrist groups in a bid to advance this issue. We will report back as developments occur.

DATABASE

The Keratoconus Australia database is in need of an overhaul. It is a patchwork of various modifications made since first developed in 2000. But it functions well and the addition of a log function in recent years has made reporting on the Association's activities more streamlined. Anyone with experience in developing in Filemaker Pro 9 or 10 and who has time to work on this project should contact Larry Kornhauser at the Association.

In the meantime, the Association will continue to update members' details – please let us know if you change your email as this is the easiest and most cost-efficient (and environmentally friendly) means for us to communicate with you.

Our new administrative assistant, Mary Veal, who started at the Association in October 2009, will be in touch occasionally if we lose track of you. Please assist her in keeping our records up to date.

INTERNET, WEBSITE & SOCIAL NETWORKING

Keratoconus Australia owes its ability to function and stay in touch with our membership largely to the Internet. The Association's website is our window to the world and the main avenue for members and other people with keratoconus to easily and quickly obtain information about different aspects of keratoconus and the Association's activities. But like the database, it is overloaded with information and needs a remake to provide easier access to important information.

The Association has taken a number of initiatives since the last Annual General Meeting to improve the site and will continue to do so in 2010. We have identified a web designer/developer who we believe can review the site and offer solutions at a reasonable price. We plan to start exploring some options in early 2010 with the expectation that a revamp could be completed by the end of the 2010 financial year.

We have also renegotiated our domain hosting contract with Netspace Online which will provide us with more space on their servers for the same cost. Initially, we intend to add

further free audio podcasts of some of our recent seminars. Later we plan to post some video clips of some of our seminar “highlights”.

However we do not anticipate posting full videos of the seminars at this stage given their length (100 minutes on average) and the bandwidth required to up and download them. We will consider these options, however, as hosting and download plans continue to evolve and broadband speeds increase.

The Association remains cognisant of the growth in social networking via Facebook, Twitter etc. We would like to enter this space too. But we have been limited in our ability to offer Australian chat sites and other options because of the need for close moderation to avoid misinformation and consideration of privacy and security issues. In the absence of qualified volunteers to oversee and operate these types of networks, we remain reticent about offering these services. However we will include consideration of a Facebook site in our review of our web presence.

The Association has a number of members who work in web design and development and we would certainly appreciate any comments on the current site and suggestions to improve it. All members should feel free to contact us with any suggestions or ideas about what they would like to see on the site and the other options for social networking.

In the meantime, we will continue to update the site regularly with news about keratoconus, its treatments and the Association’s activities. We are constantly adding to our resources pages and recently posted a Spring 09 news update. Topics included

- Seminar - Corneal crosslinking: how safe and effective is it really?
- Keratoconus and allergies
- Update on CERA corneal crosslinking trial
- Latest seminar videos
- Volunteers flock to Melbourne optometrist training clinics
- Organ Donation Awareness
- Action on contact lenses
- Support work
- Useful Australian eye health and other health-related sites
- Association news
- Articles on the Net with a focus on corneal collagen crosslinking
- Research - NSW stem cell breakthrough & keratoconus

As already noted, we plan to add separate pages relating to resources for study and work and additional podcasts from seminars in early 2010. We also want to break out a special page on corneal collagen crosslinking, which is fast becoming the topic of greatest interest to many patients, especially those newly diagnosed. We are still hoping to one day to start a page of patient stories of different experiences in managing

vision loss caused by keratoconus, living and working with the condition and coping with corneal transplants, corneal collagen crosslinking etc.

The website visit statistics continued to improve last year rising to slightly above 100 hits a week (c.f. just below 100 in 2007-08) with a return rate averaging about 34%. We hope that the regular addition of new material including podcasts will ensure steady growth.

Below is a table highlighting the source of visitors to the Keratoconus Australia website over the past year.

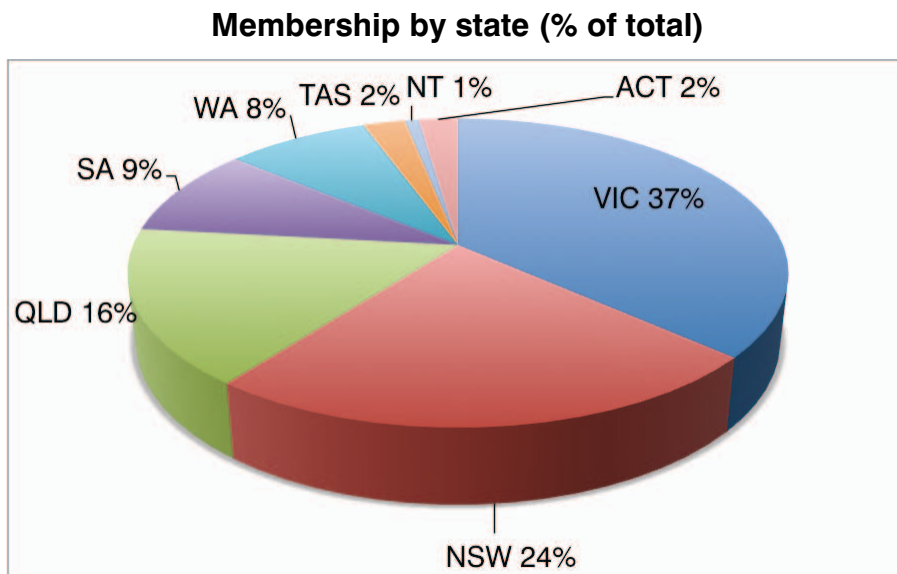
**Website Hits Top Ten by country of origin
since November 2008**

Country of Origin	No. of hits	% of total
Australia	2894	74.95%
United States	232	6.01%
Poland	98	2.54%
United Kingdom	90	2.33%
New Zealand	61	1.58%
Ireland	45	1.17%
Germany	28	0.73%
India	27	0.70%
Canada	27	0.70%
Japan	23	0.60%

MEMBERSHIP

Membership of Keratoconus Australia continues to expand rapidly. On June 30, 2009, the Association had a total of 1,354 members, or 14% more than one year earlier (1,189). Membership currently stands at 1,425.

Victoria remains the centre of the Association's membership base with just under 500 members at June 30, 2009. NSW and Queensland also grew strongly last year reaching 323 and 221 members respectively at end 2008-09. Western Australia continued to show strong growth reaching 113 members.



EVENTS

The Association held one Demystifying Keratoconus seminar during 2008-09 on the topics of contact lenses and corneal collagen crosslinking.

Melbourne optometrist & contact lens fitter Richard Lindsay has a large keratoconus practice in Melbourne and addressed some of the misconceptions surrounding contact lenses. Many patients (and optometrists too!) are unaware of the progress made in the area of contact lenses for keratoconus, while others believe that wearing contact lenses will just be too hard. Richard explained why contact lenses are so effective in managing this condition and why they should be explored fully before considering surgical options, such as intacs and corneal transplants. He also described the latest developments in contact lenses for keratoconus, including soft lenses, different rigid lens designs (small lenses, large diameter lenses, decentred optic zones, mini-sclerals), hybrid lenses (SynergEyes and SoftPerm) and piggyback systems (rigid on soft).

Following Richard's presentation, Ainslie Fitzsimons, nurse and participant in the CERA corneal collagen crosslinking trial presented *A Patient's Story* about her experience in having corneal collagen crosslinking done as part of the Melbourne trial. Her vivid description of the procedure and the post-operation recovery period was appreciated by the audience, many of whom were considering the operation for themselves or their family members. Attendees were able to question both speakers at length and discuss the various issues during an informal gathering over coffee and tea afterwards.

The seminar was self-funded with door donations of \$282.35 and DVD sales of \$325 to date.

The Association also held its Annual General Meeting for 2007-08 on November 29, 2008 at the Madame Mango Café in Melbourne.

COMMUNITY RELATIONS

An important part of Keratoconus Australia's mission is to help inform the wider community of keratoconus and its effect on those with the condition and their families.

Our website is a primary resource for anybody seeking information about keratoconus and has many links to other sites which deal with specific issues relating to the condition.

The Association also has booklets on keratoconus that we source from the US National Keratoconus Foundation (NKCF). These are sent out as part of the welcome pack provided to new members and are available on request, free of charge. The NKCF also provides us with their excellent booklet on corneal transplants which is distributed free to anyone seeking more information on this procedure.

All of our Demystifying Keratoconus seminars are videoed and DVDs can be purchased from the Association for \$25 each. A full list of the videos can be found on the Video page of our website. As discussed earlier, audio podcasts of the seminars are being posted to the Association's website and can be downloaded free.

The Association maintains close contacts with ophthalmologists and optometrists around Australia in order to assist patients obtain the best possible treatment, to discuss the concerns of members and to keep up to date on the latest developments. For example, last year, we were able to compile a list of contact lens fitters around Australia who now have access to synergeyes hybrid lenses and make that available to patients seeking alternatives to their current lenses. We also were able to assist optometrists in finding corneal surgeons who are now performing corneal collagen crosslinking in their area.

We also act as a conduit for various media and medical groups to make contact with people with keratoconus and again thank all those members who so kindly respond to

requests to participate in the various public events, which relate to keratoconus from time to time.

THE COMMITTEE

The committee continues to work hard to fulfil the Association's mission statement with the limited resources available to it. We are all volunteers, we all have keratoconus and we would love to be able to spend more time on Association business. But once again, time constraints caused by our paid employment and family obligations restricted our ability to achieve some of our objectives in 2008-09. Yet we remain committed to maintaining support services for members and their families and to providing information about keratoconus as best we can. We also consider that optometrist training and research into keratoconus should be high priorities for the Association. The quest for cheaper contact lenses for keratoconus patients is also a priority – but one proving far more complex because of the bureaucratic maze we need to traverse and the lack of time to do so.

The committee has responded to this ongoing situation in a number of ways and recent changes should help us provide a better service in 2010. Our new administrative assistant, Mary Veal, will be taking on a number of tasks that have been neglected over recent times, such as database management and contact with the membership. We hope that with her assistance we can provide better follow up on support too.

Mary has also launched a review of the Association's rules to ensure they conform with recent changes in legislation relating to not-for profit organizations. Freehills, who assisted in amending the rules for the Association in 2002, will conduct the review which will also included what changes may be needed to the Association's registration in the light of its expanded activities and any other compliance issues it considers relevant.

Mary will review our accounting systems and coordinate with our accountants too. (All legal and accounting work is performed for the Association on a pro bono basis at no cost to members). We also hope that she can work with volunteers on specific projects to ensure that tasks are allocated and completed in a timely manner.

Heidi Littleford has joined the committee and we would like to welcome her and thank her for making the commitment to the Association. Heidi will concentrate on assisting members with issues concerning work and education. With her help, we hope to offer more access to resources to aid students with their studies and to help educational institutions better understand the needs of their students. Heidi will also be able to assist members with vision-related issues in the workplace.

Again, we ask that if you have time to work for the Association on a regular basis and would like to join the committee of management, please contact us. Experience in working for not-for profits would be useful. The Association desperately needs dynamic

people with new ideas to take it in new directions. And as anyone who has worked for a not-for-profit can testify, it is an extremely enriching experience – especially when you are helping others with whom you have something in common.

In the absence of these long term volunteers for the committee, we plan to send out requests for assistance on specific projects in future. Hopefully, those with particular expertise will be able to take on these tasks or help us find people who can.

Finally, I would like to thank our secretary Belinda Cerritelli for all her hard work again this year despite her own personal difficulties. We wish her and Marisa Cerritelli, also on our committee all the very best for the future.

Thank you for attending the Annual General Meeting for 2009.

Larry Kornhauser
President

05 December 2009

FINANCIAL REPORT 2008-09

Keratoconus Australia remained largely unaffected by the economic crisis in the wider community in 2008-09. The Association earned a net profit for the year 2008-09 of \$10,396, which was more than 6 times the net profit earned in 2007-08 (\$1,652). The higher result came thanks mainly to a large donation made through the Myer Family Office on behalf of one of our major supporters. We thank the family for their generosity.

Overall net income totalled \$12,984 last year (up about 300% cf. to \$4,254 in 2007-08), while expenses remained almost steady at \$2,588 (cf. \$2,602 in 2007-08). The Association's ability to hold expenses steady in the face of a rapidly growing membership base reflected our ability to conduct most of our business online and thereby minimize printing and postage costs. Members understanding in allowing us to communicate via the internet whenever possible is much appreciated.

Bank interest on our online deposit account also contributed \$1,612 last year. The Association continues to monitor its funding requirements to ensure that we maintain an optimal spread of funds between our current account and interest bearing deposit account.

The Keratoconus Australia balance sheet remains strong given our current funding requirements. At the end of the 2008-09 financial year, the Association held net assets of \$51,308, or 25% higher than on June 30, 2008 (\$40,912).

See Appendix 1 below for full details of profit Statement and Balance Sheet for the year ending 30 June 2009.

APPENDIX 1

FINANCIAL STATEMENTS 2009
Balance Sheet

As at 30 June 2009

ASSETS

Current Assets

Cash On Hand

Westpac DGF Account \$10,257.78

Westpac Max-iDirect \$41,261.08

Total Cash On Hand \$51,518.86

Total Current Assets \$51,518.86

Property & Equipment

Clubhouse

Total Property & Equipment \$0.00

Total Assets \$51,518.86

LIABILITIES

Current Liabilities

GST Liabilities

GST Collected \$255.42

GST Paid (\$1,431.19)

GST Refund \$1,387.00

Total GST Liabilities \$211.23

Total Current Liabilities \$211.23

Total Liabilities \$211.23

NET ASSETS \$51,307.63

EQUITY

Retained Earnings \$40,911.75

Current Year Earnings \$10,395.88

Total Equity \$51,307.63

Profit & Loss Statement

July 2008 through June 2009

INCOME

Donations	\$10,817.40	
Seminar Entrance Fees	\$282.35	
Video Sales	\$272.76	
Bank Interest	\$1,611.78	
Total Income		\$12,984.29

Gross Profit **\$12,984.29**

EXPENSES

Bank Charges	\$4.00
Catering	\$75.18
Dues & Subscriptions	\$190.91
Postage	\$411.04
Printing	\$322.92
Booklets	\$195.33
Seminar Expenses Melbourne	\$496.19
Telephone and Internet	\$494.89
Travel & Entertainment	\$220.09
Sundry expenses	\$177.86

Total Expenses **\$2,588.41**

Operating Profit **\$10,395.88**

Other Income	0.00
Other Expenses	0.00

Net Profit / (Loss) **\$10,395.88**