

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

# **ANNUAL REPORT 2010**

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## TEN YEARS ALREADY

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Keratoconus Australia celebrated its tenth anniversary in 2010 and it is perhaps worth reflecting on the Association's origins and achievements over that time.

The idea for a support group for people with keratoconus first came from Melbourne optometrist, now Associate Professor Richard Vojlay, who believed that keratoconus patients were not receiving the quality of care they deserved and that a patient support group could offer the type of first-hand advice and assistance that eye-carers were unable to provide. Professor Vojlay asked a few of his patients if they would like to meet over coffee one evening to discuss the idea and see what could be done. Robyn Gillis was the driving force behind the formation of the group, ringing around to patients and urging them to become involved.

The initial meeting was held at the Grocery Café in Burke Rd Camberwell in late 1999. About 25 people attended. Some of us were a bit sceptical about the need for such a support group. But after listening to many of the harrowing stories recounted that night, we all left convinced it was time to change the way people with keratoconus were treated – both metaphorically and literally.

As in many small groups of well-intentioned people striving to achieve lofty goals, the early momentum was impressive. The committee meetings were well attended, the projects were never lacking and the enthusiasm was infectious. Slowly, we built the Association from the ground up. There were plenty of mistakes made. None of us had much experience in this sort of thing, all of us had full time jobs elsewhere.

Yet once the mission statement was drawn up and the Association was registered, we knew we had a structure and plan. Implementation of that plan has been slower than we might have imagined back then. Many of the founding members have stepped back for various professional and personal reasons. But the desire to maintain a support group for keratoconus has not waned. Nor has the need.

So what has been achieved over the past ten years? Quite a lot of what is set out in the original mission statement, actually.

## RAISING AWARENESS

- Raised awareness of keratoconus in the medical, patient and general community through a range of initiatives. These include
  - the distribution of information about keratoconus – notably booklets on keratoconus and corneal transplantation, which we source from the National Keratoconus Foundation in the US. All members receive these free of charge.

- Public Demystifying Keratoconus seminars addressed by both keratoconus specialists and patients. These are attended by patients, their families and ophthalmologists and optometrists seeking to learn more about keratoconus, its treatments and how they affect patients.

The Association has held 20 of these public seminars since 2000.

- Videos of these seminars have been sold to patients and eye-carers unable to attend in person.
- A website for Keratoconus Australia was created to post information about keratoconus, as a means for communicating with members and to allow people with keratoconus to ask questions and receive responses from other patients and eye-carers.

This is now the primary point for contact for people seeking information about Keratoconus Australia and keratoconus.

- Participation in medical conferences and advocacy groups to raise the profile of keratoconus and its implications for patients.
- The distribution of pamphlets about the Association and its services to eye-carers to make available to their keratoconus patients.

## RESEARCH

- The Association has also largely fulfilled its objective of promoting research into the causes, prevention and control of keratoconus by:
  - Supporting a number of research projects conducted in Melbourne, Adelaide and Brisbane. These included:
    - The inheritance of keratoconus in families genetic study conducted by the Centre for Eye Research Australia and the Melbourne Excimer Laser Group;
    - A study into Intraocular pressure and corneal shape conducted by the QUT Institute of Health and Biomedical Innovation;
    - The world's first randomized clinical study of corneal collagen crosslinking being conducted by the Centre for Eye Research Australia;
    - Research by Flinders University into Understanding the Genetic Causes of Corneal Disease
    - An evidential review of keratoconus surgery also being conducted by Flinders University



- The Association has also been involved in two joint applications with Flinders Ophthalmology Department at Flinders University to obtain funding for research projects via the National Health & Medical Research Council Partnership grant scheme. Both have been refused. However the Association will continue to examine ways for funding what could be ground-breaking research.
- The development of a members database with basic information about members' experiences with keratoconus has proved invaluable in assisting researchers quickly identify and contact large numbers of potential candidates for these studies. All personal information is provided only on an anonymous basis or with the consent of the person involved.

## ADVOCACY

- The Association has also developed into an effective advocacy group for people with keratoconus and their families. Although small in size, we have attempted to make our voices heard in the halls of government and private industry and in medical circles in an effort to improve treatments, benefits and rebates for keratoconus.

Our efforts in this regard include a campaign to reduce the costs to patients of specialised contact lenses for keratoconus. These can be prohibitively expensive for some people – especially those showing rapid progression and who require regular changes in contact lens prescriptions.

This campaign has involved representations to the private health fund industry, the federal government, the peak eye care bodies including Vision 2020 and the Optometrist Association of Australia. But this is a complex issue and the Association has achieved only moderate success to date. (see below for the latest on this campaign).

Keratoconus Australia is now a name recognized in this field of eye care and there is a general respect in the community for our role in representing the interests of people with keratoconus and their families and advocating for their rights.

The fact that Keratoconus Australia has remained totally independent of funding by government or private corporations and is controlled entirely by a committee of management comprising only people with keratoconus has enhanced our credibility to speak on behalf of the keratoconus community.

## ORGAN DONATION

- The Association is also participating in efforts to increase organ donations and thereby reduce waiting times for corneal grafts. We have been involved in a

number of national campaigns to this end over the years. We include organ donation information pamphlets in our new member kits for people to show to and discuss with their families and friends.

## SUPPORT

- Vision is arguably the most valued of all our senses and surveys have shown that Australians' fear of losing their sight is second only to that of cancer. Low vision has been correlated with a range of negative outcomes including lower employment opportunities, higher rates of morbidity, mortality and depression, lower productivity and generally poorer health outcomes.

While most vision impairment or loss occurs in later life due to diseases like glaucoma, age-related macular degeneration and cataracts, keratoconus generally begins early in a person's life – with the most severe cases often starting in early adolescence. This means that a person will have to deal with keratoconus-related vision impairment throughout their life. If not properly corrected, that can impact on their education, employment, family and social activities.

The good news is that keratoconus doesn't lead to blindness and although it can result in severe vision loss, in most cases this can be corrected to enable people to live full and active lives. The problem is often finding the specialists who can achieve best-corrected vision for patients.

Without question, the major achievement of the Association over the past decade has been in the area of support for the keratoconus community. That was our primary objective back in 1999 and it remains our focus today. Since 2000, Keratoconus Australia has communicated with thousands of people and families affected by keratoconus. Many of them come to us distraught and concerned for their future or that of their young children. Many have seen optometrists or ophthalmologists without finding a solution to their vision impairment.

Keratoconus Australia has endeavoured to help these people find the specialists who can assist in improving their vision – no matter where they live. While there are usually a handful of contact lens fitters and corneal surgeon specialising in keratoconus in the capital cities, they are extremely rare in country and outback areas. We have had requests for help from the Kimberleys to the Gulf of Carpentaria, Alice Springs, the Great Australian Bight, the tropics of Queensland and the mining towns of the Pilbara. Yet strangely, some of the worst cases have involved people living only a few suburbs away from the eye-carers who could assist them.

Thanks to the support of a small network of eye-carers around Australia and the power of the internet, we have directed most of these people to eye-carers who have been able to restore their vision and allow them to resume their lives.



We have also spent time communicating with people about their issues, helping them understand how they can live with keratoconus, explaining strategies for coping at school and work, finding resources to assist with specific problems.

We have also created outreach services for patients and their families confronting the often difficult question of whether to have surgery. We now have a small and dedicated group of members willing to discuss their experiences with corneal transplantation or more recently, corneal collagen crosslinking. Anyone considering surgery can today find out what to expect – not just during the operation, but in the days, weeks and months during the recovery period and thereafter. Feedback we receive from people who take advantage of this service indicates that it can be of immense assistance prior to surgery.

In Annex 1 to this report; we have included extracts from some of the letters we receive from members who have received support from Keratoconus Australia over the past ten years.

***We think they provide ample evidence of why we need a support group – and why it is worthwhile becoming involved with the Association.***

## **OPTOMETRIST TRAINING**

- As most people with keratoconus know, finding the right pair of contact lens – usually rigid gas permeable lenses – can be the key to restoring normal vision and resuming a more normal life. That generally means finding a specialist contact lens fitter for keratoconus. As already noted, there are not many around and they can be hard to find. Worse, none of them are getting any younger and some are near the age of retirement.

So Keratoconus Australia decided some time ago that we needed to do something to increase the pool of experienced contact lens fitters for keratoconus. This led to a proposal to inject specialized contact lens fitting for keratoconus into the optometrist training curriculum. As a result, the Association, in conjunction with Professor Vojlay and Melbourne University's Department of Optometry and Visual Science, have been conducting contact lens fitting clinics for keratoconus over the past 4 years. Keratoconus Australia members have played a major role in offering their time and eyes to allow final year students an opportunity to have first hand experience in fitting RGP lenses onto keratoconic corneas and post-graft patients. The clinics are supplemented by a special lecture on keratoconus, addressed by officers of the Association.

This initiative is unique in Australia and the only known instance of a support group participating directly in the training of eye-carers. Already a few students from each year are moving into the specialized keratoconus practices in Melbourne – a tremendous result for both current and future keratoconus patients. The Association is now looking for other ways to encourage further

post-graduate work in this field and to spread the initiative to other optometrist training course around Australia.

These are just some of the Association's achievements over the past ten years. We can do more – but only with your assistance.

## ACTIVITIES IN 2009-10

### SUPPORT

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The Association's top priority remains to provide support for keratoconus patients and their families. The Association attempts to offer this support in a timely manner, regardless of the restrictions imposed on our other activities by our limited personnel and availability constraints.

The primary point of contact between the Association and its members remains the internet. Almost 95% of all requests for support in 2009-10 were initiated via the internet. This was slightly up on last year and reflects the continuing trend for people to search online for ways to deal with health issues.

Many of these requests are handled by email exchanges. However whenever necessary, the Association makes direct contact with members to discuss their issues and ways of resolving them.

As discussed in previous annual reports, the Association has broad guidelines to help us deal with requests for supports. These include:

- Providing general information about keratoconus and treatments.
- Handling 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.

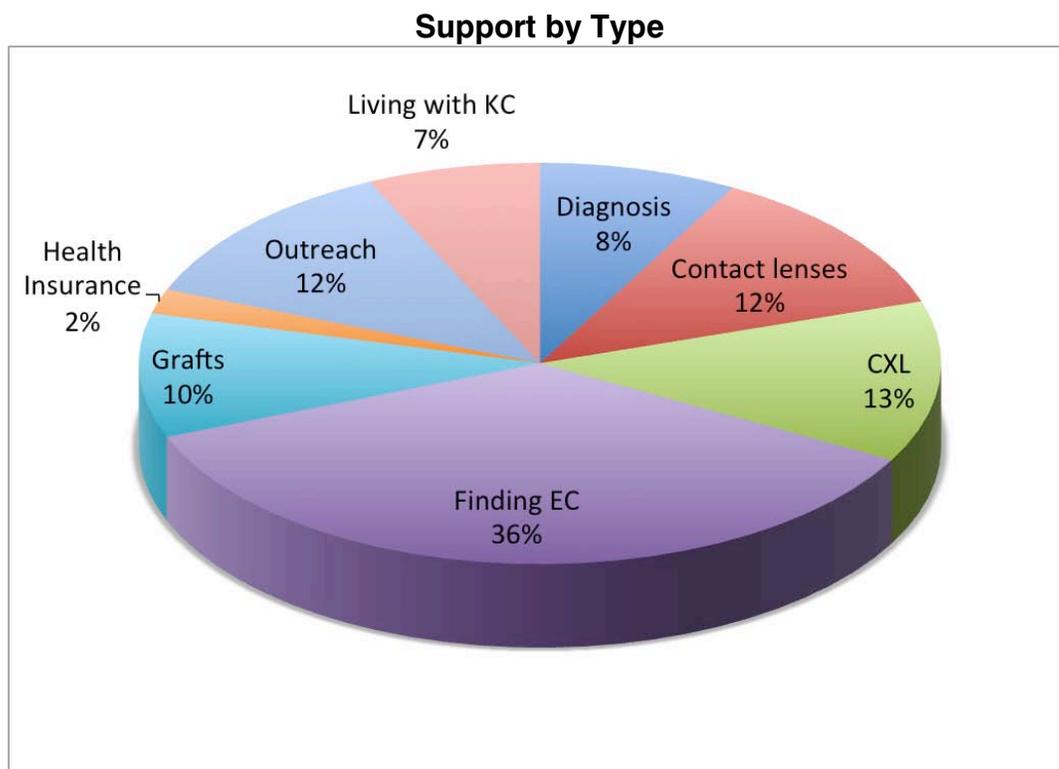
Due emphasis is always given to the need for individual patients and their families to seek opinions (and second opinions) from keratoconus specialists, and to find and adopt solutions best suited to their own personal circumstances.

- Keratoconus Australia does NOT give opinions or comment on specific medical issues or problems being experienced by patients. Nor do we evaluate 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. We are not qualified to provide any sort of medical opinions, recommendations or referrals.*

In 2009-10, Keratoconus Australia logged almost 230 separate requests for support from members and others who were in contact with the Association. This was a record number and significantly higher than in recent years. It does not include the many anonymous requests we receive every year from Australians and international patients with keratoconus.

Below is a percentage breakdown of support provided in 2009-10 by type



- **Help in Finding Eye-Carers**

The vast majority of requests for support generally result in patients being directed to eye-carers appropriately qualified and experienced in solving their particular problem. Wherever possible, the Association uses its contacts in the keratoconus community to try to find specialist ophthalmologists and optometrists in a patient's local area or region. This is desirable because of the regular and ongoing nature of treatments for keratoconus.



(The chart above indicates that some 36% of all support was attributable directly to requests for an eye-carer. However up to 80% of all support may have resulted in information about keratoconus specialists being provided to the patient or family.)

*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.*

- **Diagnosis**

A keratoconus diagnosis is a stressful experience and can create anxiety and concern about the future. Most eye-carers know little about the disease and often the patient comes away from a consultation with little information about their likely prognosis. Most people have never heard of keratoconus and are too stressed during a consultation to absorb much of the information they might be receiving from the eye-carer. 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.

We receive many requests for further information about keratoconus after an initial diagnosis. Most people have not been given any written information that they can read in their own time. Which is why all new members of the Association receive a booklet on keratoconus from the US National Keratoconus Foundation.

Keratoconus Australia also plays an important role in discussing keratoconus with parents of newly-diagnosed children. It vital to reassure parents about the prospects for their child, explain the treatments and management strategies and to direct the families to specialists to ensure the child is receiving the best possible care.

Last year, about 10% of all support inquiries were from newly diagnosed people or the parents of children just diagnosed with keratoconus.

- **Contact Lenses**

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. Not surprisingly then, many of the requests for support related in some way to issues with contact lenses. In many cases, people were seeking information about surgery because they had given

up hope on successful contact lens wearing or had been told by their eye-carer that they could no longer wear contact lenses.

Yet many of these so-called problems are related to fit rather than a patient's suitability to continue with lenses. Bad fits can arise from the optometrist's lack of knowledge or progression in keratoconus, or both. The Association generally urges patients to seek a second opinion from an experienced contact lens fitter for keratoconus before giving up on lenses. Usually – although not always – this results in a new prescription and the patient can often delay surgery indefinitely.

The introduction of new, advanced types of contact lenses for keratoconus is enabling many patients who previously were unable to manage with contact lenses to wear them again successfully. Amongst these are the Synergeyes® and mini-sclerals, which are available only from a handful of contact lens fitters around Australia. Although these can often be expensive, they can be preferable (and cheaper) than surgery. Please contact us if you require more information. 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 & Corneal Transplantation**

Surgery for keratoconus is major step for anyone as it generally involves a corneal transplant. Although only about 15% of people with keratoconus will ever contemplate a corneal transplant, when the time comes it is generally at the end of a long road of visits to contact lens fitters and innumerable changes of contact lenses. Patients can be frustrated by the process and scared by the future.

Corneal transplants must be considered carefully as they can involve significant life style changes with some restrictions on activities, notably those involving contact sports. It can also take up to two years before the visual outcome is known and rejection always remains a possibility. Statistics also show that most people will require either glasses or contact lenses after the graft and that the average life of corneal transplant is about 20 years. In short, this is a major step that may not lead to a permanent resolution of a person's vision impairment.

It is no wonder then that patients appreciate having another avenue to more information than they might receive from a time-poor corneal surgeon with a busy practice. Last year, about 10% of support given by Keratoconus Australia related to graft surgery.

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 an outreach service for corneal transplant patients (see below).

Last year we noted the trend towards questions about intra-corneal rings such as intacs and kera-rings. The Association has remained wary of these rings being used as a substitute for contact lenses – except in rare cases of contact lens intolerance and mild keratoconus. Unfortunately many people having trouble with contact lenses and who trawl the internet seeking solutions read marketing material that suggests intacs will resolve their issues. But in most cases, they are suffering from incorrect fits, and refits by an experienced contact lens fitter for keratoconus can overcome the problem without recourse to surgery.

Most intra-corneal rings are removed for a variety of reasons within about two to three years. They 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 suitability for the majority of keratoconus patients.

- **Corneal Collagen Crosslinking**

Last year about 12% of support was concerned with corneal collagen crosslinking (CXL), which remains the hottest topic in the keratoconus community today. All around the world, ophthalmologists and patients are hoping that this may just be the treatment that could halt keratoconus in its tracks and prevent most patients ever suffering anything more than mild vision loss from keratoconus.

CXL was originally developed in Dresden, Germany and attempts to stiffen the cornea by first irrigating it with riboflavin (to protect the inner part of the eye) and then irradiating it with ultra-violet light to create new, stronger links between collagen in the stroma layer of the cornea. Clinical trials being conducted by the Centre for Eye Research Australia (CERA) 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. So far, the trial is showing no harmful effects and there has been no reported progression in patients treated under the trial protocol.

However, there is no clinical trial studying the effects on children under the age of 16 – yet the procedure is now being commonly offered to and performed on

children as young as nine years old. Not always with the desired results, according to discussions between the Association and parents of a few of these children. Amongst adults, there are also reports of cases involving damage to the inner eye from UV exposure and corneal infections, leading to further complications.

The difficulty is that different ophthalmologists are now performing the procedure in different ways, e.g. leaving on the epithelium (or outer layer of the cornea), although most studies and clinical observations indicate that the treatment is most effective when the epithelium is first scraped off. Trials using substitutes for riboflavin are also underway. There is also no standard for the UV light source used in the procedure and different devices can expose the cornea to varying concentrations of UV exposure.

There is no consensus either among corneal surgeons about when this treatment should be offered: at diagnosis of even sub-clinical keratoconus or only when a patient is showing clear progression in their keratoconus? At the recent Queensland seminar held by Queensland Eye Institute (QEI) and Keratoconus Australia, QEI director of corneal surgery, Dr Jim McAlister, said that he believed the time had come to offer it immediately to all keratoconus patients. Yet he also acknowledged that no studies had been done on the crosslinking effect on the under-16 age group – the ones in which the most aggressive cases of keratoconus are generally found. Surgeons in Melbourne involved in the CERA trial still take a more conservative view and prefer to see clear progression before offering the procedure.

Not surprisingly, patients and their families have mixed views about CXL. Some want it at any price and will travel overseas if refused in Australia. Others are torn between the risks of having it and the possibility of further sight impairment if they don't.

The Association cannot resolve these dilemmas for members. What we can do is offer the information we have on the procedure and put people in touch with others who have had CXL to hear about their experiences. Like all surgery, patients are required to give "informed consent" prior to the operation and it is important that they understand both the benefits and the risks before agreeing to surgery. Especially when they are making that decision on behalf of their children.

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 CERA's Melbourne trial, which was the world's first randomized clinical of the procedure.

The Association's guidance to patients on this issue remains heavily based on the outcomes from the Melbourne trial and the conservative views of the principal researchers, Associate Professor Grant Snibson and Dr Christine Wittig-



Silva. Professor Snibson and Dr Wittig-Silva presented their latest results and conclusions at a seminar held in August 2009. At our September 2010 seminar, Professor Snibson affirmed that none of the trial participants had suffered either progression or adverse side effects since then. We strongly recommend that anyone considering the procedure view the videos of the August 2009 and September 2010 seminars before proceeding.

We are still waiting for full updates on the CERA trial results and hope to have them available soon after the international corneal crosslinking congress being held in January 2011.

- **Outreach services**

The Association's primary function is to offer support for people with keratoconus and their families. Providing information about an issue is always a good start. But even better is to talk with people about their experiences. Each person has a different story to tell about his or her life with keratoconus – and while they may resemble, we all have something to learn from others.

Last year, about 12% of support involved outreach. In the past, this has mainly concerned corneal transplant patients wishing to speak to others about the operation and post-operation care and recovery. Many parents of adolescents want to speak to other parents to see how they have handled this difficult time and to find out more information about how their child has coped with school, sport and social activities after having a transplant. Many adults too want to know how things will be after a graft and how it can affect employment and family life.

A number of families have been wonderful in helping with this outreach over many years now and we thank them for their ongoing involvement. We also have a growing band of people with grafts who are regularly assisting others about to receive a corneal transplant.

Over the past 12 months, the Association has been fielding more calls from people considering corneal collagen crosslinking and who want to know more about the procedure and whether it has been working for others. Again, members have been quick to respond to our calls for assistance to those people and to recount their own experiences.

The outreach work done by Keratoconus Australia members is greatly appreciated by the Association and those they assist – as evidenced by the many thank you letters we receive saying what a difference it made to them.

- **Living With Keratoconus**

Although most people contacting the Association are seeking professional help to resolve their problems, some simply want advice on living with keratoconus.

About 7% of support calls last year related to issues concerning work, education, sport and other things affecting their daily activities.

Our new committee member Heidi Littleford, an educator for sight-impaired students, has taken on much of the support work in this area. Heidi has used her extensive knowledge of the education system to counsel many families trying to deal with the special problems encountered by children struggling with their education because of sight impairment. Some are recovering from corneal transplants and need advice on how to obtain special consideration for examinations and other assessments.

She is also well versed in dealing with vision-related issues in the workplace and can provide advice to members on a range of issues and strategies for dealing with vision impairment at work. Heidi can be contacted at [livingwith@keratoconus.asn.au](mailto:livingwith@keratoconus.asn.au).

- **International**

Keratoconus Australia receives many requests for support from outside of Australia via our online forum page. Although it is often impossible to assist people who have specific issues and need to consult a local eye-carer, we do our best. One such case last year involved a man from Lebanon who had advanced keratoconus and a large white spot in front of his vision. We sent him some general advice from our consulting ophthalmologist and instructed him to see his ophthalmologist immediately. We also referred a woman in the US who was suffering severe vision impairment from keratoconus to the National Keratoconus Foundation for financial and medical assistance.

The Association also responded to a query from the Legislative Library of Ontario, Canada concerning the rebates available in Australia for corneal collagen crosslinking.

We receive a number of requests for support from New Zealand, where there is no keratoconus support group. Over the years, we have compiled a short list of eye-carers who work with keratoconus and generally try to assist these people in finding the help they require.

## **RESEARCH**

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Keratoconus Australia continues to fulfil its primary mission to help control and prevent keratoconus within the community by supporting and participating in research projects around Australia.

### ***CERA clinical study into Corneal Collagen Crosslinking***

The world's first large scale randomized clinical trial of the corneal collagen crosslinking procedure is being conducted by the Centre for Eye Research Australia (CERA) at the Royal Victorian Eye and Ear Hospital (RVEEH). The Association has been directly involved in this project since its inception in 2006. We have 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. Members should understand this does not mean we endorse or recommend corneal collagen crosslinking as a treatment at this early stage.

There is little news on this trial to report since our last annual general meeting. As noted above, we are awaiting another update from the trial convenors, which we hope to receive early in 2011. We also hope to hold a seminar to update progress on the trial before mid-2011.

Informal reports back from trial researcher Dr Christine Wittig-Silva and trial convenor Associate Professor Grant Snibson confirm that all patients who received the crosslinking treatment have showed stabilization in their keratoconus at their pre-treatment level. Some patients even experienced a mild flattening in their cornea. Moreover this flattening effect seems to be continuing even some years after the treatment was done.

CERA is still recruiting for its 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](mailto: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.

### ***Department of Ophthalmology at Flinders University, Adelaide***

Keratoconus Australia is continuing to work closely with the Department of Ophthalmology at Flinders University in Adelaide on a range of keratoconus-related projects. Professor Doug Coster, who created the world's first corneal graft registry, is an enthusiastic supporter of research into keratoconus and the work being done by the Association.

In December 2008, Flinders University and Keratoconus Australia submitted 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 this application was not successful. We submitted a modified application in April 2010 to the NHMRC, which was again unsuccessful.

However, we are now seeking ways to fund this research, as we believe it is important. The Flinders team has already recruited a post-graduate student 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. We hope to have preliminary results available from that review in 2011.

As noted last year, Flinders University would also like to assist Keratoconus Australia to develop a national registry of Australians with keratoconus, using the University's experience with the Australian Corneal Graft Registry. We are now considering how this could be integrated into an overhaul of the Association's website so that it could operate online.

### **Genetic study of Corneal Disease**

We did manage to assist in the launch of one research project with Flinders University in 2009-10. In June 2010, all members received a letter sent via Keratoconus Australia from the Flinders Medical Centre asking them to participate in a study of the genetic causes of keratoconus. This study, which requires participants to send a blood sample for analysis, will try to determine what factors may be important in keratoconus and other corneal dystrophies. Thanks to the involvement of Keratoconus Australia members, the response received by the researchers was overwhelming and ensured that the Flinders project will have sufficient participants. We will provide updates to members on this project as soon as possible.

*Significant funding is required to complete all of these research projects and any Keratoconus Australia members who would be interested in providing financial assistance should contact the Association directly.*

## **OPTOMETRIST TRAINING**

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In September and October 2009, Keratoconus Australia participated in the fourth annual teaching clinics and lecture for final year optometry students at Melbourne University's Department of Optometry and Vision Sciences. The clinics followed the format adopted in 2008: four keratoconus teaching clinics and two post-graft clinics.

As in previous years, Keratoconus Australia's Victorian members responded to the call for volunteers to participate in this vital initiative, 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. Associate Professor Richard Vojlay and Melbourne optometrist, Dr Laura Downie, supervised the contact lens fitting clinics. Keratoconus Australia president, Larry Kornhauser and secretary Belinda Cerritelli again presented information about keratoconus and the Association's work at the annual keratoconus lecture organized for the final year students by Professor Vojlay.

The success of this joint initiative is becoming apparent now with a handful of students from each year taking an interest in furthering their knowledge of contact lens fitting for keratoconus. The Association is currently in discussions to see if there are ways of expanding this unique project to other states and to offer further incentives for optometrists to specialize in this field.

It would be the ultimate irony if we failed to train enough optometrists to fit the complex rigid gas permeable and hybrid lenses finally arriving on the Australian market which offer an unparalleled level of comfort and vision.

The Association thanks Richard Vojlay, Laura Downie, Melbourne University's Department of Optometry and Vision Sciences and all of the Keratoconus Australia members who continue to support these clinics and make them such a success.

## **ADVOCACY**

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### ***Action on Contact Lens Rebates***

The Association continues to do what it can to lower the cost of specialized contact lenses for keratoconus. But as we have said previously, this is a complex area involving a range of parties including Medicare, the optometrists, the private health funds and the contact lens manufacturers.

We reported last year on talks held with Vision 2020 Low Vision & Rehabilitation Committee meeting in July 2009, which voted to support action in favour of the Keratoconus Australia initiative. But no further significant action has occurred since - apart from a meeting with Optometrist Association of Australia officials in April 2010. A

suggestion from that meeting to examine precedents set with other optical devices has not been followed up by Vision 2020.

In the absence of progress in this matter, we repeat our suggestion that members put pressure on their private health funds to recognize the special nature of contact lenses for keratoconus and to provide higher rebates on claims for these specialized and indispensable lenses. With the assistance of the US Keratoconus Foundation, we have prepared a letter, which members can download, and print to send along with their contact lens claims to their private health fund. Please send this letter to your health fund EVERY TIME you submit a claim for a rebate on your new contact lenses. The letter to request a higher rebate from your health fund can be downloaded off our website at [http://www.keratoconus.asn.au/Resources-F/KA\\_Insurance\\_letter.pdf](http://www.keratoconus.asn.au/Resources-F/KA_Insurance_letter.pdf).

We have spoken to a number of members who have received higher rebates on contact lenses than those initially offered by using this letter and ringing their funds directly to complain about the level of rebates. One member also noted that PeopleCare health fund has for some years reimbursed the cost of a lens up to the full level of the available benefit. Most funds reimburse either a fixed dollar amount or only a percentage of the cost of the lens.

### **Corneal Collagen Crosslinking**

The Association received a request from Professor Grant Snibson in mid-2010 asking that Keratoconus Australia support an application to the Federal government for Medicare rebates on corneal collagen crosslinking performed in public hospitals. There has been no further contact concerning this issue. However the committee will consider the matter in due course when a formal request and submission is presented to the Association.

## **DATABASE**

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Our new administrative assistant Mary Veal has been working hard to keep the database up to date. If you are changing your contact details or email address, please send Mary an email at [admin@keratoconus.asn.au](mailto:admin@keratoconus.asn.au). Email is the easiest and most cost-efficient (and environmentally friendly) means for us to communicate with you.

No further development work was done on the database in 2009-10 as we are now reviewing our current setup as part of the web site redevelopment project.

## **THE WEBSITE**

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The Keratoconus Australia website at [www.keratoconus.asn.au](http://www.keratoconus.asn.au) is our principal tool for communicating information to members. First developed in 2000, it is showing its age and while it still works fine, it no longer conforms to the latest internet standards.

Last year, we hoped to complete a revamp of the site in 2010. While we have made some progress, other commitments have prevented us from advancing as far as we had anticipated. As discussed in the Research section, the process was also slowed by the possibility of integrating a patient registry into the design. We are now examining how this registry needs to be developed and how it can be programmed into the site to facilitate data entry. These things take time and we need to get them right. Other changes foreshadowed in last year's report have also been delayed until we have a better idea of what the new site will look like.

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. Members were asked in the November 2010 email update 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, the site is being updated regularly with news about keratoconus and the Association's activities.

The Association renegotiated its domain hosting contract with Netspace Online in March 2010 and despite some initial teething problems, we now have more space available. We will continue to add audio podcasts of our seminars to the site.

Despite several requests, we are not planning to post full free seminar videos in the foreseeable future. Our sales of DVDs help defray the considerable cost of videoing our seminars and are a convenient means of distributing these videos around the country. Many members, especially in regional and country areas, don't have access to sufficient high speed bandwidth to download reasonable quality video of these seminars, which run for up to two hours. We will keep the question of online video under review and may include the option of paid video downloads as part of the new web design.

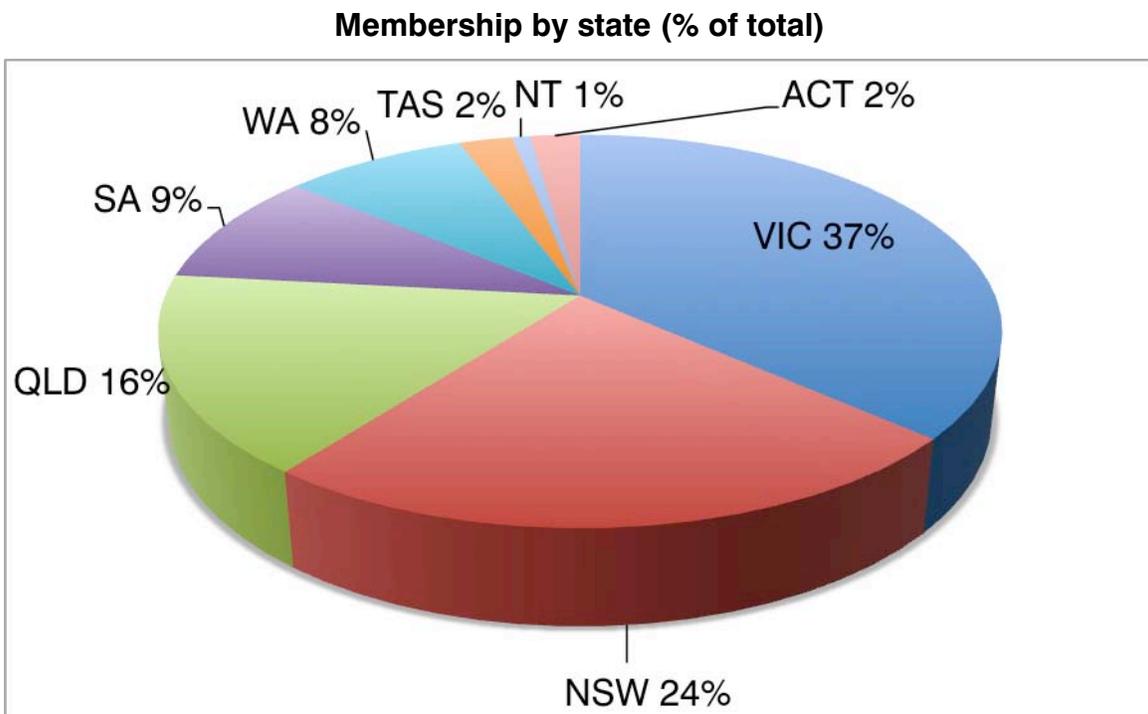
There has been a change in our website visit statistics since the switch to the new domain host plan. According to the new statistics for the whole site (not just the home page as previously), we are averaging about 3,500 visits a month.

## MEMBERSHIP

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The Association's membership stood at 1,510 on June 30, 2010. This was 11.5% higher than one year earlier ((1,354 members).

Over a third of the Association's membership is located in Victoria (556 members at June 30, 2010 or 12.3% more than last year), while 24% are in NSW (363; +12.4%). Queensland accounts for some 16% of members (244; +10.4%), followed by South Australia (134) and WA (128).



## EVENTS

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The Association held one Demystifying Keratoconus seminar during 2009-10 in Melbourne on the subject of corneal collagen crosslinking.

The seminar was held in August 2009 at the Australian College of Optometry and was addressed by Associate Professor Grant Snibson and Dr Christine Wittig-Silva, principal investigators on the CXL trial at CERA. Professor Snibson and Dr Wittig-Silva presented the most recent results from the trial and explained what these mean for patients considering this treatment. They also discussed plans for future research, which will hopefully extend the pool of keratoconus patients who may be able to benefit from CXL.

Professor Snibson dealt with the most common questions raised about crosslinking in a clear and succinct presentation.

Both speakers answered many questions from attendees about their research and the implications of this work for the development of treatments for keratoconus in the future.

Joanne Brooks, Australia's first trial participant, provided a colourful account of her personal experience leading up to and since the treatment.

The Association also held its Annual General Meeting for 2008-09 on December 5, 2009 at the Madame Mango Café in Melbourne.

We regularly receive requests from members asking why events are always held in Melbourne. The simple answer is that Keratoconus Australia is based in Melbourne and the committee finds it easiest to organize events in its home town.

Events have been held in other cities (Sydney, Perth, Brisbane). But these have required the active involvement of members in those cities. We will provide logistical backing for any member who wants to organize an event in their locality, and find a suitable venue. Please contact us at [info@keratoconus.asn.au](mailto:info@keratoconus.asn.au) if you would like further information on how to get started.

## **COMMUNITY RELATIONS**

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The Association maintains relationships within the vision and general communities as part of its commitment to inform the wider community about keratoconus and its effect on those with the condition and their families.

The Association has used its ongoing relationship with Vision 2020 to promote our causes and to educate other vision groups about our existence and our activities. Secretary Belinda Cerritelli attends the regular Vision 2020 member forums and uses these forums as an opportunity to network with other organizations – both professional and patient support groups. Her work has been instrumental in raising the profile of Keratoconus Australia in the vision community.

Keratoconus Australia maintains close relationships with ophthalmologists and optometrists working in the field of keratoconus to keep up with the latest treatments and research. The Association's committee of management has regular informal discussions and correspondence with these eye-carers to exchange views about patient care and concerns and how these can be addressed.

The Optometrist Association of Australia kindly includes regular articles in its monthly newsletter about the Association's activities.

In July 2009, the Queensland Vision Initiative Inc. (QVI), an alliance of health care professionals working together with the aim of improving eye health in Queensland, contacted the Association about participating in its new website. The Association sent QVI information about keratoconus, which can be accessed at <http://www.qvi.org.au/eye-conditions.html>.

The Association has also sent material on keratoconus to optometrists who require information for newly-diagnosed patients. We have also provided optometrists with information on corneal collagen crosslinking and where they can find corneal surgeons able to perform the procedure.

The Association also distributes booklets on keratoconus that we source from the US National Keratoconus Foundation. These are sent out as part of the welcome pack provided to all 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.

Finally, the Association began collaboration with a group of ophthalmologists and optometrists who are currently preparing a new book on keratoconus for patients. It is hoped this will be published in 2011 and will provide an additional resource for patients and their families.

## **ADMINISTRATION**

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The Committee of Management meets regularly to discuss the Association's activities, projects and to review its finances and procedures.

In 2009-10, the Committee held 8 meetings and a number of informal meetings amongst committee members when a quorum was not present.

The Association's current administration is:

### **Committee**

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

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

All committee members are volunteers and have keratoconus. While we would love to spend more time on the Association's affairs, we have full time jobs and a variety of family commitments. We therefore give top priority to maintaining support services and ensuring that people receive the information about keratoconus they need. Training optometrists in contact lens fitting and research are our other main focus at present.

Mary Veal has taken over a number of administrative tasks, freeing Belinda and Larry to do more work in other areas. This made a huge difference to our internal operations in 2010. We hope the results will become more evident to members in 2011, with more seminars, faster response times for support, a new website, greater involvement in research and other projects with eye-carers and hopefully an expanded optometrist training initiative.

Members are also receiving more timely updates by email of the Association's activities and welcome packs and other requested information are being sent sooner to new members. Mary will also contact you as required to keep your details up to date on our database.

As part of our compliance procedures, Mary completed a review of the Association's rules with Freehills in 2010. These were ticked off as compliant with current legislation. Mary is also working closely with GMK Partners, who provide us with accounting services on a pro bono basis.

Heidi Littleford's involvement has already been highly rewarding for the Association. Heidi's experience in education for sight impaired students has brought a new skill set to Keratoconus Australia and given us the ability to offer additional services to members and their families.

The arrival of Heidi and Mary has freed up our secretary Belinda Cerritelli, to take on a greater role in advocacy and research. Belinda has developed an online survey for members which may be integrated into the new website in 2011. But information already compiled from member questionnaires may also be merged into a larger dataset as part of a research project with Flinders University. The Association will provide members with more information on these survey projects as they develop.

Belinda is also working closely with Vision 2020, and the CERA and Flinders University research teams.

### ***Donations and Fundraising***

The Association did not hold a fundraiser in 2009-10. However, in view of a number of projects scheduled for 2010-11 relating to the new website, research and optometrist training in particular, we anticipate holding a fundraising event in the next 12 months.

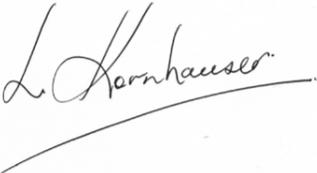
In the meantime, generous donations were received from long time supporters The Ray & Margaret Wilson Foundation and George Ferteklis.

## Volunteers

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 meantime, we are tending to rely on volunteers to offer assistance on specific projects.

Finally, a big THANK YOU to everyone who has assisted the Association over the past decade. I can assure you, the existence of Keratoconus Australia has made an enormous difference to the lives of many people with keratoconus and their families.

A handwritten signature in black ink that reads "L. Kornhauser". The signature is written in a cursive style and is underlined with a single horizontal stroke.

Larry Kornhauser  
President

25 November 2010

## **FINANCIAL REPORT 2009-10**

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The Association made a net profit in 2009-10 of \$6,613.93. This compared to net profit of \$10,396 in the previous financial year.

The net result was down 36% as a result of a combination of lower income (donations) and higher expenses. Donations totalled \$8,770 (\$10,817.40 in 2009-10), while our other prime source of income – bank interest – was down slightly to \$1,124, reflecting lower interest rates.

Expenses amounted to \$6,614, up from \$2,588 in 2009-10. A number of factors contributed to this increase. Travel and entertainment expenses rose sharply to \$974 (\$220 in 2009-10), mainly due to the inclusion of committee meeting expenses. These meetings were previously held in the evening at committee members' residences. But due to work commitments, they are now being held at lunchtime at outside locations. These expenses will be separated out in next year's accounts. Seminar expenses were also higher at \$468, partly due to a need to cover speakers' travel and accommodation costs. Dues and subscriptions were also higher because of a timing issue relating to payment of our associate member dues to Vision 2020. Finally, sundry expenses rose to \$288 to cover purchase of database upgrade software.

The balance sheet for 2009-10 showed net assets of \$57,921.56, up from \$51,307.63 in 2009. Total assets totaled \$58,108.34, held entirely in cash. Around \$50,000 of this is being held in a high interest deposit account. We are currently reviewing our accounts to see if we can reinvest these funds in a term deposit at higher interest rates.

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.

## **ANNEXES**

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Financial Reports 2009-10

Extracts from Letters received by the Association since 2000.



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

## Profit & Loss Statement

July 2009 through June 2010

### **Income**

Donations	\$8,769.90	
Seminar Entrance Fees	\$212.00	
Video Sales	\$581.82	
Bank Interest	\$1,124.43	
<b>Total Income</b>		<u>\$10,688.15</u>

Cost of Sales

**Gross Profit** \$10,688.15

### **Expenses**

Bank Charges	\$8.50	
Stationery	\$75.93	
Dues & Subscriptions	\$568.18	
Postage	\$524.71	
Printing	\$395.55	
Seminar Expenses Melbourne	\$468.20	
PO Box Rental	\$182.73	
Video Recording	\$363.64	
Website Hosting	\$153.49	
Telephone and Internet	\$70.63	
Travel & Entertainment	\$974.54	
Sundry expenses	\$288.12	
<b>Total Expenses</b>		<u>\$4,074.22</u>

**Operating Profit** \$6,613.93

Other Expenses

**Net Profit / (Loss)** \$6,613.93

PO Box 8188  
Camberwell North  
Vic 3124



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

## Balance Sheet

As of June 2010

### Assets

Current Assets

Cash On Hand

Westpac DGF Account \$8,207.27

Westpac Max-iDirect \$49,901.07

Total Cash On Hand \$58,108.34

Total Current Assets \$58,108.34

Property & Equipment

Clubhouse

Total Property & Equipment \$0.00

**Total Assets**

**\$58,108.34**

### Liabilities

Current Liabilities

GST Liabilities

GST Collected \$428.60

GST Paid **(\$1,643.82)**

GST Refund \$1,402.00

Total GST Liabilities \$186.78

Total Current Liabilities \$186.78

**Total Liabilities**

**\$186.78**

**Net Assets**

**\$57,921.56**

### Equity

Retained Earnings

\$51,307.63

Current Year Earnings

\$6,613.93

**Total Equity**

**\$57,921.56**



**EXTRACTS FROM LETTERS RECEIVED BY THE ASSOCIATION SINCE 2000.**

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**Caroline, VIC**

*Thanks for the email. Yes I did see XXX. He was very helpful and I did sort out my problems. I now wear glasses and am very happy with them. I feel like a different person. I still don't really want to know about my kc but I'm sure in time I will come to terms with the condition. Thanks for your concern.*

**Melanie, NSW**

*Thanks for all of your help. I know that Emily has felt better knowing that she is not alone in this, after all the information we have been able to gather for her this week. I wish we had found you sooner. It's great for her peace of mind to know that she can call and talk to you all.*

**Kim, VIC**

*I just wanted to take the time to say a big Thank You to you for all your help !! In the last few days I have in the first time in 4 weeks had some ease in pain in my eyes making life much better for me and my poor hubby (he's been so worried about me ). My panic attacks are much less and I'm sleeping better. Still finding the world's way to bright for me but that will get better. I have been so stressed with worry but now things are looking up...*

*I do have hydrops and i have got a couple of weeks to go with it... Your telephone call to take time from your busy day to call me and give the gentle nudge (which i so needed) to seek medical treatment has helped so much, after talking to you and having someone to chat with that understands made making the next step not so hard. Once again thank you*

**Lawrence**

*I have recently undergone my second corneal graft (i have now had both eyes done.) I recently was made aware of this site and after looking at it i have found it to be a very informative site about keratoconus as we do need to make public circles aware of this disease, so again congratulations on the site and good luck with future prospects.*

**Karen, NSW**

*Good news, Colby has had contact with various health offices and will need and have her corneal transplant in the new year, at no charge. Colby is so grateful for all your assistance as am I. Thank you from the bottom of my heart.*

**Bronwynn, NSW**

*Thank you so much for this fantastic - and extremely prompt - reply. I am pleased to say that my friend has been to see his optometrist (who is apparently one of the best in Sydney and all is looking good at this stage. (HmMMM it seems nagging does work!).*

*I am much relieved and thanks to you now have a much better understanding of keratoconus. Thanks again, I will not hesitate to come back to you should I need further guidance or information.*

**Margaret, VIC**

*Thanks for the information regarding health funds and the best cover for kc. I realise it is quite a complex issue but am thankful for your time in giving me the info. It's great to have the association 'at our fingertips' when we have any queries, keep up the good work.*

**Scott, VIC**

*I really appreciate the time you have spent replying to my query and think it is great that there is a website for Australian's who suffer from keratoconus.*

**Dallas, QLD**

*I would like to thank everyone involved with this foundation, especially for the information that was sent to me prior to the transplant surgery. The information booklets I received were very helpful and instrumental for me to be able to come to terms with the entire situation I am currently facing. I feel without this information and help it would have been a lot harder then it was/is to accept and live with my current circumstances. Once again thank you very much for your support and help, it has really been appreciated. When I return to work and start earning a wage again I will definitely be making a donation to the foundation, and I will definitely be making it an annual donation!*

**David, QLD**

*I very much appreciate the advice given to me by you several years ago and the referral to XXX. My vision and comfort using his recommended large single contact lens is great and seems slightly improved now even when I do not wear it. A much better solution than the risky and expensive surgery options being recommended to me up until that point. I am so grateful that you had a website and a contact number and were so willing to help, and I hope that you can continue to be there for others in the same predicament.*

**Tatiana, NSW**

*I would like to thank you for the help you provided for us with regards to finding the right specialist for my son's problem. He has a new lens fitted, which he can tolerate for the whole day. His sufferings with the old lens are over. I wish I'd learned about your organization and your work earlier.*

**Steve**

*Just a quick note to thank you very much for your detailed reply. It certainly has cleared quite a few things up and I happily forwarded it onto my sister to check out. It's not often you send one of these emails out and even expect to get an answer, so yours was much appreciated.*

**Nick, VIC**

*Thanks heaps for that information, it's been great to be a part of the support group and to obtain some useful experience from other people with this condition.*



**Christine, VIC**

*It's good to have the support of your association, and your own...I don't think many people really appreciate how debilitating this condition can be when the lenses aren't working properly.*

**Sanjay, QLD**

*I would also just like to compliment you guys on providing such a wonderful service, it's very inspiring.*

**Stirling, VIC**

*I am unable to get to the seminar, however I thought I would write to let you know that I really do appreciate the work that Keratoconus Australia does do and that I will be looking forward to seeing the podcast. It seems like it will contain expert advice addressing some questions that I have been having difficulty getting answered to my satisfaction. Fantastic!*

**Shah, Dubai**

*I thank you very much from the bottom of my heart. May god bless your organization.*

**Tracey, WA**

*Thanks heaps for the great information. It is so refreshing to know that there is support out there.*

**Gabrielle, UK**

*Many thanks for all your kind information and time. I shall make sure that she is well prepared. Kind regards from an extremely hot England.*

**Cheryl, SA**

*Thank you for sending me the names of some optometrists and for our chat the other day. It was so good to get some positive news about keratoconus (like it doesn't lead to blindness and is likely to begin slowing down now due to my age). This was very relieving information to receive! And it is so good to know that I am not alone with this condition. It's been a lonely, frustrating and scary journey these past 20 years.*

*Thanks for helping lift all these awful feelings, with simply a bit of information, and a kind word and some of your time. With much appreciation*

**Renee, NSW**

*Hi. The conversation we had the other day was more than just assisting, it was invaluable! I really thank you for taking the time to talk to me about my options and give me the concerning advice you gave. It means a lot to have someone to talk to who understands!*