



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

ANNUAL REPORT 2008

KERATOCONUS AUSTRALIA INC A00395 46H ABN 80 683 325 208
PO Box 8188 Camberwell North Victoria 3124 Australia
PHONE 0409 644 811 EMAIL info@keratoconus.asn.au
WEB www.keratoconus.asn.au

CONTENTS

INTRODUCTION 3

SUPPORT 3

RESEARCH 6

ACTION ON CONTACT LENS REBATES 6

OPTOMETRIST TRAINING 7

DATABASE 8

WEBSITE 8

MEMBERSHIP 9

EVENTS 10

STATE SUPPORT GROUPS 10

COMMUNITY RELATIONS 10

INTERNATIONAL RELATIONS 11

THE COMMITTEE 12

Annual General Meeting 2008

Madame Mango Cafe
29 November 2008

INTRODUCTION

Good morning everybody and welcome to the Association's Annual General Meeting for 2008.

This morning I will present a report on the activities of Keratoconus Australia in the year ending June 30, 2008 and discuss some of the Association's recent activities.

Unfortunately, as predicted at the last AGM the inability of the Association to replace committee members has led to a cutback in our activities and hampered the development of new projects. A number of initiatives foreshadowed in the 2007 report have not been implemented – but have not been forgotten either. We are doing our best and still offering a range of services and support for people with keratoconus and their families.

SUPPORT

While we have been forced to reduce our efforts in some areas because of a lack of regular volunteers, we have strived to maintain support to members, their families and other people with keratoconus who require assistance. Support is the reason Keratoconus Australia was formed and we will continue to do everything possible to assist those who are experiencing difficulties because of their keratoconus.

As previously discussed, the Internet and email have greatly enhanced our ability to reach out to people with keratoconus around Australia and the world. Today email is the primary form of initial contact between the Association and those looking for support in some form. When information can be offered in a printed format, it is generally sent by email. If more direct contact is required, we are always pleased to speak to people and discuss their issues and concerns for as long as necessary.

We would like to do more follow-up on support to ensure that people are actually benefiting from the advice and information we offer. However once again, we simply do not have sufficient volunteers to perform as much follow-up work as we would like. Fortunately we do also receive feedback from people who are grateful for the help and advice they have received from the Association.

We have discussed in previous annual reports the guidelines we use when dealing with requests for support. But briefly:

- We provide general information about all aspects of keratoconus, including emerging treatments
- We do not offer opinions or comment on the specific medical problems experienced by patients. Nor do we consider any medical data such as corneal topographies or information about the state of a patient's cornea.
- We may refer some specific requests about a patient's medical condition on to our consulting ophthalmologists or optometrists. But they will generally

provide no more than a general comment about the possible causes of an issue and how to treat it.

- We are pleased to discuss our experiences as a guide to others in coping with their own situations while recognizing that each person will find their own unique solution to the issues arising from their keratoconus and associated vision loss.

In all cases, patients are told that a full examination of their eyes by a practitioner experienced in keratoconus is required before a diagnosis can be made and specific treatment options offered.

Support takes many forms:

- The majority of requests for support essentially boil down to the need to find eye-carers who understand the condition and can provide information and proper treatments.
- Contact lenses create problems for many people as they are often fitted incorrectly by optometrists with little experience in this field. Most of these problems can be resolved by an experienced contact lens fitter. The Association uses its resources to find such practitioners for people around Australia.
- The prospect of surgery can be daunting for a patient and many contact us for information about these procedures. We distribute free of charge to members an excellent booklet on corneal transplants compiled by the National Keratoconus Foundation in the United States.
- Many patients like to know more about their prospective surgery and recovery period; we try to put them in contact with others who have already had similar procedures. This is always beneficial. We are very grateful to the many members who offer their time to perform this invaluable and much appreciated outreach service.
- The initial diagnosis of keratoconus is a scary moment for any person, and especially for a parent whose child has just been diagnosed with the condition. After the initial shock, it becomes hard to absorb any further information during the consultation – and often not much is provided anyway. Keratoconus Australia plays an important role in putting a perspective on the vast amounts of information encountered by patients who then seek to understand their condition by searching the internet.

We try to assist parents in talking to other parents about the likely course of their child's condition and the possible impact on education, jobs and social and sporting activities. Where possible, it is useful to put adolescents in direct contact with each other to allow an exchange of information about coping strategies.

- Many people simply want to discuss their experiences with keratoconus but are unable because no-one around them has the condition. We are always delighted to have a chat and show people that they are not alone in facing the often complex issues that arise from keratoconus. Our seminars also provide a forum for this sort of interaction.

- As discussed in the past, many people search the internet to find solutions for their problems with contact lenses and often seem to come up with intacs. However most contact lens-related problems can be resolved by a refit done by an experienced contact lens fitter for keratoconus. Despite the risks associated with almost all eye surgery, people seem convinced that intacs in particular are the treatment of choice for just about any problem with contact lenses. Surgeons in Australia have repeatedly told Keratoconus Australia that in fact few people with keratoconus are suitable for intacs implants and the results from these operations can be less than satisfactory in the long term. The Association tries to offer a wider perspective on these sorts of new treatments to patients looking for the quick fix to what is a lifelong condition.

In 2007-08, Keratoconus Australia handled around 132 requests for support of various types from Australian residents. This was a down on previous years (187 in 2006-07 and about 200 in 2005-06). These requests cover a range of issues but in particular problems relating to contact lenses and requests for more information about corneal collagen crosslinking (CXL), the new surgical procedure which shows promise for halting the progression of keratoconus.

Corneal collagen crosslinking, which involves using ultra-violet light and riboflavin to strengthen the corneal collagen, is now being offered by a handful of corneal surgeons in a number of states around Australia. More are planning to adopt the procedure as positive results from the clinical trials in Melbourne and Brisbane continue to filter through.

If proved safe and effective, this treatment could significantly reduce the impact of keratoconus on young patients (and their families) and newly-diagnosed patients with only mild keratoconus. It could lead to a reduction in corneal transplants for keratoconus, which in turn would free up precious donor corneas for the most urgent cases.

However, discussions with some corneal surgeons indicate that uncertainty about the long-term impact of this treatment could restrict its application for the time being to patients showing rapid progression in their keratoconus rather than as a prophylactic available for all patients diagnosed with keratoconus.

The transitional state of knowledge about corneal collagen crosslinking has made it more complex to discuss this procedure with patients seeking advice and we generally counsel patients to have a full ophthalmic examination to evaluate their suitability for the procedure (not everyone can have it) and to discuss it with their eye-carers.

Our support effort includes the information seminars we hold regularly in Melbourne to keep members informed about the latest developments in keratoconus treatments. Because of the widespread interest in intacs and corneal collagen crosslinking, we organized a seminar on new surgical options for keratoconus in November 2007 during which Drs Michael Loughnan and Terry Ong provided a review of these and other treatments (see below).

RESEARCH

Keratoconus Australia remains committed to supporting research into keratoconus. As noted in past reports, we have assisted research into genetic studies of keratoconus and the world's first large scale 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) since mid-2006.

Early results from the RVEEH study indicate that the corneal collagen crosslinking procedure can be both safe and effective. But these results are not final and more follow-up on patients will be required. The Association still considers this procedure to be experimental. However corneal surgeons in a number of states have already begun offering corneal collagen crosslinking as treatment based on the early positive results from the CERA study. These results were reported to Keratoconus Australia by Dr Michael Loughnan at our November 2007 seminar in Melbourne.

The Association will monitor the ongoing results from the CERA study (and other overseas studies) and hopefully provide an update report on our website in early 2009. We are also trying to organize a presentation on the latest results from the CERA study in early 2009. Members will be notified when this seminar is confirmed.

During 2007-08, Keratoconus Australia provided support to a research project into Intraocular pressure and corneal shape conducted by Dr Scott Read, a Post-doctoral research fellow with the School of Optometry at the Queensland University of Technology in Brisbane. Dr Read's study was designed to assess the influence of the eye's internal pressure on the optics and biometrics of the human eye, particularly the cornea (the eye's front surface). Data collected from this study are expected to improve knowledge of factors influencing corneal shape, and may aid in the understanding of the causes of corneal disorders such as Keratoconus.

The Association assisted Dr Read in identifying and recruiting patients in the Brisbane area for the study. We will report on results received from Dr Read's study in due course.

Finally, the Association recently received new requests from researchers in NSW and South Australia for assistance and participation in research projects into the genetics of keratoconus, the effectiveness of keratoconus treatments and patients' responses and attitudes to their condition. We hope to have more information on these projects in early 2009.

ACTION ON CONTACT LENS REBATES

Since our last report on this issue at the 2007 Annual General Meeting, there has been little change in the situation concerning rebates on contact lenses for keratoconus. As reported then, our attempts to persuade the previous government to take action on the cost of contact lenses came to naught. Our submission to the former Minister for Health, Tony Abbott and the response from the Medical Benefits Division of his department have been posted to our website under Action on Contact Lens Rebates.

We have also posted a letter from Keratoconus Australia (written with the assistance of the US National Keratoconus Foundation) requesting that private insurance companies pay higher benefits on contact lenses for keratoconus. We urge members

dissatisfied with their current rebates to send this letter along with their claims for rebates on contact lenses for keratoconus.

We are also compiling information from our health surveys sent to all new members in an effort to make a renewed bid for higher benefits on the new contact lenses being marketed for keratoconus. Assistance with this submission would be appreciated.

The arrival in Australia of Synergeyes hybrid lenses from the US earlier this year has made this effort more urgent. These lenses are proving useful for many patients who could not previously tolerate rigid gas permeable contact lenses, thereby offering the prospect of delayed corneal transplants. But they are expensive (\$450+ each) and currently available only from two optometrists in Australia. Keratoconus Australia is working towards having these lenses distributed more widely around Australia and we hope that planned training courses will lead to about 20 contact lens fitters gaining access to these Synergeyes lenses in 2009.

OPTOMETRIST TRAINING

In 2006, Keratoconus Australia, Melbourne optometrist Richard Vojlay and Melbourne University's Department of Optometry and Vision Sciences launched special keratoconus clinics and lectures for final year optometry students. These clinics were structured to teach students more about keratoconus, the concerns of their patients and in particular, how best to fit contact lenses on keratoconic eyes and corneal transplants. The Association believes this initiative is vital to the future of all keratoconus patients as there is a serious shortage of optometrists Australia-wide who are experienced in fitting the complex lenses often required for keratoconus patients.

The first clinics and lectures were extremely successful and greatly appreciated by the students and the Department of Optometry and Vision Sciences. The Association has heard that a handful of graduates who attended the 2006 clinics have taken a special interest in keratoconus thanks to these seminars. In particular, we were delighted to learn recently that one former attendee is now working in Melbourne's largest keratoconus practice.

Keratoconus Australia remains greatly concerned by the lack of experienced contact lens fitters for keratoconus and is supporting the Department of Optometry and Vision Sciences in organizing these clinics and lectures on a more permanent basis.

In 2007, the Department of Optometry and Vision Sciences conducted another four special keratoconus clinics in July and August and a lecture with the assistance of Keratoconus Australia. The Association was instrumental in finding sufficient keratoconus patients to ensure that the students had an opportunity to fit lenses during the clinics. Secretary Belinda Cerritelli and President Larry Kornhauser participated in the lecture presented by Richard Vojlay, explaining the concerns of keratoconus patients and answering students' questions. As noted in last year's report, the 2007 lecture was particularly animated and reflected the interest of the students in learning more about keratoconus.

In 2008, the program was further expanded to include 4 clinics for keratoconus patients and two clinics on post-graft contact lens fitting. The lecture, held in early

October, was extremely well attended – an indication of the interest shown by the students in this valuable initiative.

Unfortunately we have been unable to finalize a version of the lecture notes as foreshadowed in the previous annual report. But we hope to do so in conjunction with Mr Vojlay in 2009. When completed, this information will be posted to the website and made available to all members.

We would like to take this opportunity to thank Richard Vojlay for the enormous effort he has put into organizing these clinics, and all the Keratoconus Australia members who have responded to our calls for volunteers to attend the clinics. We have also received many apologies from members unable to participate because of work commitments but who support this program. The Association greatly appreciates your feedback and hopes this support will continue into the future so this training opportunity - unique in Australia - can be sustained.

DATABASE

The Association continues to develop its database to provide better and more easily accessible information to users. Data entry from our health surveys sent out with new member kits has now been completed and we hope to soon provide a summary of this information on the website.

Once again we urge members to provide us with their new email addresses when they change them. Email remains the most cost-effective and environmentally responsible means of communicating with our expanding membership base.

WEBSITE

Keratoconus Australia remains heavily dependent on the internet and in particular its website to remain in contact with members and for the dissemination of information about keratoconus. The online resources pages offer easy access to information about keratoconus, treatments and coping strategies for people in Australia and overseas.

Our FAQ pages on the corneal collagen crosslinking trials being conducted in Melbourne and Brisbane have proved an invaluable source of information on their nature, entry criteria and progress. We hope to update these pages again soon. Updates on intacs and some of the other treatments available for keratoconus are also required and we hope to add these progressively to the website in 2009. When finalized, the notes used for Melbourne University training clinics will form the basis for a new FAQ section on all aspects of keratoconus.

The website's continued popularity is evidenced by another substantial increase in hits last year. After rising from an average in 2005 and 2006 of around 60 a week to almost a 100 per week in 2006-07, total hits averaged more than 160 a week in 2007-08. Return visits are steadily climbing too: from around 30% in 2006-07 to over 35% last year. This figure will continue to improve if we can achieve our aim of providing news pages and current research pages that are updated in a more timely manner than at present. All contributions in terms of articles, information, research etc are all welcome. Please email us if you are interested in assisting. (Contact us too

if you find any dead links.)

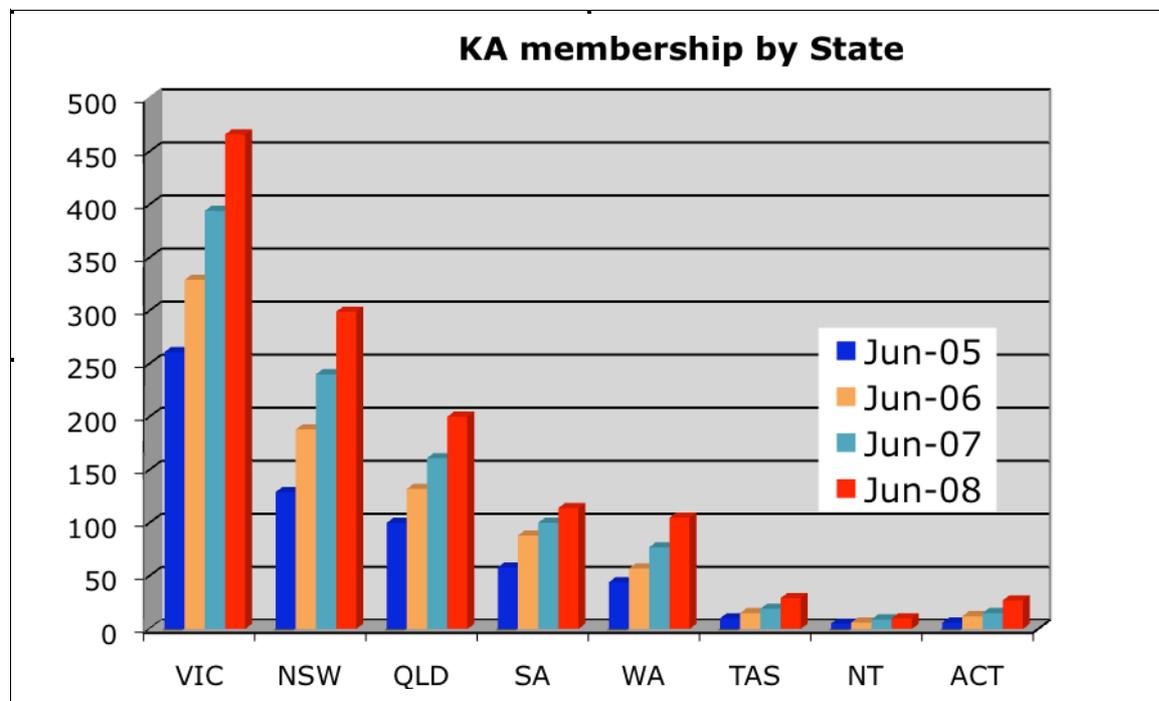
The online forum is still the main conduit for people seeking to ask questions about keratoconus, to find eye-carers and to obtain support in general. Although we cannot provide medical comment on a patient's condition, we do refer specific medical questions on to our team of consulting ophthalmologists and contact lens fitters for general comment.

Patients wishing to chat with other people with keratoconus are being referred to the kc-link, an international chat list created by the US NKCF and moderated by both the foundation's executive director, Cathy Warren and a team of consulting ophthalmologists and optometrists who specialize in keratoconus. We acknowledge that debate on this site sometimes tends to be a little US-centric, but in the absence of a means to create a properly monitored Australian chat forum, we believe it is the next best alternative.

Last year we again raised the issue of adding patient stories to the website to allow others to benefit from your experiences with keratoconus. Still no responses. But we would like to put up at least some accounts of patient experiences in the corneal collagen crosslinking so that people considering this new treatment will know what to expect. Please contact us if you would like to share your keratoconus story.

MEMBERSHIP

Keratoconus Australia's membership base continues to expand. On June 30, 2008 the Association had a total of 1,197 members, an increase of 18% over the previous year total of 1,016. Membership currently stands at just over 1,250.



Membership numbers grew strongly in Western Australia again (+36%) and we now have over 100 members there. Queensland rose by 24% to 200 members, as did NSW (299 members). Victoria remains the centre of the Association's membership base (466 members, +18% on 2007) – but its share in the overall membership base slipped again to 39% of the total.

EVENTS

The Association organized one seminar in the 2007-08 financial year – a review of new surgery for keratoconus, held in November 2007. The seminar focused on three new types of surgery currently on offer to keratoconus patients: corneal collagen crosslinking, intacs, deep lamellar transplants. Dr Michael Loughnan presented a review of corneal collagen crosslinking, and concluded this was a promising treatment that should be offered to people showing progression in their keratoconus. Dr Terry Ong presented an overview of intacs, which indicated that these corneal inserts had not lived up to their promise and were generally removed again within the first two years after surgery. Both ophthalmologists said they would not perform the intacs operation based on current medical evidence regarding the effectiveness of this procedure. Dr Ong also explained the deep lamellar transplant surgery, what results had been achieved and when it was appropriate as a substitute for full thickness corneal transplantation.

As always, attendees had plenty of time to ask questions and to meet after the event over coffee and refreshments.

The seminar was again self-funding with \$361 collected in door donations and another \$375 earned from video sales.

The Association's Annual General Meeting for 2007 preceded the seminar.

STATE SUPPORT GROUPS

The Association is still keen to support any local or regional groups who would like to set up a small keratoconus support centre – please contact us if you are interested in such a project. We will provide whatever resources we can.

COMMUNITY RELATIONS

An important part of Keratoconus Australia's work is to increase the understanding of keratoconus and its impact on patients and their families in the medical and general community.

Patients seeking information about keratoconus can now access a wide range of resources including booklets and brochures on keratoconus and corneal transplants, videos of all the seminars held by the Association since 2001 on a range of topics, and an expanding list of articles and links to information on our website. Much of this material is included free in an information kit provided to all new members and anyone contacting the Association.

Free audio podcasts of our seminars will be put on the website regularly and are available from the Association on request. Members with ideas on how past videos could be distributed via the internet should contact us.

As mentioned previously, we are hoping to finalize a revised version of the lecture notes from the optometrist training clinics and make them available in both printed and electronic form.

The Association also has maintained contacts with contact lens fitters around Australia to discuss issues of concern to keratoconus patients, to update our information on specialists in the field and to learn about new developments in contact lenses for keratoconus.

The Association has been contacted by ophthalmologists regarding a book on keratoconus currently being written by some of Australia's leading experts in contact lens fitting for keratoconus and corneal surgery. This would provide another detailed resource for patients and their families, doctors and the general public to improve their understanding of keratoconus and available treatments. The Association will offer whatever assistance possible to this worthwhile effort. We hope to provide a further update on the book's likely publication date in 2009.

The Association continues to assist with requests from other medical and media groups seeking contact with keratoconus patients. We again thank all those members who have kindly offered their time to these efforts to broaden the understanding of keratoconus within the community.

Finally, members have brought to our attention occasional programs on TV referring to keratoconus and "cures". In early 2008, the Association was contacted about a program on the Royal Flying Doctor service, which apparently showed a woman having an intacs operation. Repeated attempts to find more information about this program and the operation from Channel 9 and the Royal Flying Doctor Service failed to yield results – despite promises from both organizations to provide a video of the program. We regret we were unable to assist members find out more about this issue and the circumstances surrounding it being shown on TV. We hope to receive better cooperation from organizations promoting treatments for keratoconus in the future.

INTERNATIONAL RELATIONS

Keratoconus Australia continues to work closely with the US National Keratoconus Foundation (NKCF). The NKCF is still sending us booklets on keratoconus and corneal transplants, which we offer free to members. The NKCF also publicizes our events on their international chat list, *kc-link*. The US foundation has allowed us to offer members a modified version of their letter to insurance companies for higher rebates on contact lenses (see above). As always, we thank Cathy Warren, NKCF Executive Director, for her invaluable assistance over the past 12 months.

As indicated in last year's report, we were unable to attend the first European conference on keratoconus (EuroKeratocône 2007) held in Toulouse in November 2007. The conference was attended by almost 600 ophthalmologists, optometrists and a handful of representatives of European keratoconus patient groups.

The president of the French association, Anne de Fonvillars, was provided the rare opportunity of addressing this prestigious international medical conference on behalf of the patients' groups to explain their work and the common concerns of their members. Anne kindly included reference to Keratoconus Australia and the work we are doing. A second European conference on keratoconus is planned for November 2009 and the Association will be represented if possible.

During 2007-08, the Association also provided support to people with keratoconus in a number of countries including New Zealand, Vietnam, Pakistan, Ghana, Britain and

Ireland. We have also received a number of unusual requests including one to provide corneal tissue to an ophthalmologist in Pakistan.

In August 2007, the Association also received a terse letter from Marie Hogan, Administrator of the Boxer Wachler Vision Institute, threatening Keratoconus Australia with legal action unless we removed all references to the trademarked term *C3-R* on our website or indicated the term was trademarked to the BW Institute. After several exchanges with Ms Hogan, whose Los Angeles-based institute is an aggressive marketer of the use of intacs with epithelium-on corneal collagen crosslinking, we changed all references to the term *C3-R* to *3C-R*. Following the recent adoption of the acronym *CXL* to denote corneal collagen crosslinking, the Association will use this abbreviation in future to avoid further trademark or copyright disputes.

(We also note that Ms Hogan's spirited public defence of her institute's trademarked "product" in correspondence to a number of the international keratoconus sites contrasted to the low profile she adopted when posting to the NKCF's kc-link chat group: Ms Hogan repeatedly wrote posts touting the benefits of *C3-R* and intacs without ever revealing she was from the Boxer Wachler Institute and had a vested interest in that "product". She suddenly disappeared from the chat group when her connections were unmasked.)

THE COMMITTEE

As noted earlier, 2007-08 was a difficult year for the committee due to resignations and the limited support from volunteers. The remaining committee members have struggled to find time to devote to the Association because of full time work, family and other obligations. However we are committed to providing support to everybody who contacts the Association and continue to give top priority to meeting that objective. We also believe our efforts in promoting optometrist training and research remain critical long-term priorities.

But as noted in this report, there are other activities we would like to do or could do much better with the assistance of others. These include better communication with members through more regular website updates and news bulletins, more information seminars – especially outside of Melbourne, better advocacy on behalf of keratoconus patients through regular contact with eye-carers and health officials, submissions to government and the development of resources for keratoconus patients and their families.

Once 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 this type of work in not-for profits would be useful. We would love to hear from you even if you have some experience in any of the fields discussed above and would like to participate on just a one-off, project basis.

Finally, I would like to close the meeting by thanking our secretary Belinda Cerritelli for keeping things afloat and to Marisa Cerritelli, our other committee member.

Thank you for attending the Annual General Meeting for 2008.

Larry Kornhauser
President