



## **Annual General Meeting 2005**

**3 December 2005**

La Colussi Café

### **COMMITTEE REPORT**

Good morning everyone and welcome to the Keratoconus Australia Annual General Meeting for 2005.

On behalf of the committee of management, I would like to present a brief summary of the Association's activities in the 2004-05 year and some recent developments.

### **SUPPORT**

The Association continues to give primary importance to providing support for people with keratoconus and their families. Most people seeking support from the Association do so via our website and via email, with additional support being provided by telephone. On certain occasions, we have also met up with members and their families to discuss particular issues. As much as we would like to provide more face-to-face support, the widespread nature of our membership base generally makes this difficult.

Support offered continued to climb in 2004-05 and the Association logged more than 190 separate requests for assistance in the past financial year. That represented an increase of some 20% over the previous year.

Requests for support fall into a few main categories:

- By far the most common request is for assistance in finding eye-carers who specialize in keratoconus, and in particular contact lenses for keratoconus.
- Advice for people and their families after a family member has been diagnosed with keratoconus
- distribution of information about keratoconus and corneal transplants
- advice about contact lenses
- information about new surgical procedures such as intacs and research into the new C3-R treatment
- information about the cost of contact lenses and corneal transplants, and the possibilities for rebates or low cost options.

Support work is done with the kind assistance of a group of optometrists and ophthalmologists who provide technical and medical advice in response to members' queries.

Support requests also provide pointers to the Association about the need for further action. An example this year was a problem encountered by a SA member over contact lens warranties. The Association has since started campaigning for an improved deal in these warranties, which can significantly affect the cost to patients of new lenses and the type of lenses used by contact lens fitters.

### **EVENTS**

Keratoconus Australia held three information seminars in 2004-05 – all at the Victorian College of Optometry in Melbourne. An average of around 60 people attended these seminars including a significant proportion of optometrists and ophthalmologists. The

Victorian Optometrists Association now recognizes these information seminars and optometrists attending can receive continuing education points.

**In August 2004**, we held a forum on Living with Keratoconus which was addressed by eye-carers and KA members who discussed their experiences with keratoconus.

**In November 2004**, Dr Alex Poon, a Melbourne corneal surgeon, addressed the Association on the topic of *Corneal Transplants: getting informed before giving consent*. Dr Poon gave a detailed presentation of the issues facing a patient before and after a corneal transplant, and discussed the pros and cons of the deep lamellar type of graft versus the full penetrating graft usually practiced on patients.

**In May 2005**, Mark Roth, a Melbourne clinical optometrist, presented on the topic of *Contact Lenses: good eye days, bad eye days* and reviewed some of the reasons why patients have "bad eye days" including common complaints related to dry eyes, allergies and general eye redness. Mr Roth provided a detailed analysis of the causes of these conditions and outlined a range of options for their management and ways of improving the ocular surface. Mr Roth also discussed some of new contact lens cleaning agents which can greatly facilitate lens care and comfort.

Two more seminars were held in October 2005, including **KA's first-ever Sydney event**. The committee has plans for some exciting seminars in 2006 and hopes the Sydney group will support further events.

All seminars are filmed and videos are sold to members around Australia who are unable to attend. The cost of these videos is now being covered by entry donations and sales income.

With demand for videos in DVD format now rising, the Association has cut the price of these DVDs to \$25 – the same as for videos in VHS cassette format.

Finally, following requests from members unable to drive at night, we are planning to hold at least one daytime seminar on a weekend in 2006.

## **STATE SUPPORT GROUPS**

Progress was made last year in developing support groups outside of the Association's main area of metropolitan Melbourne.

Keratoconus Australia member Pam Mayne is working on behalf of KA to disseminate information about the Association and keratoconus in the Kerang area, in northern Victoria while Pam Close is doing similar work in the Finlay area of southern NSW.

As already mentioned, KA held an information seminar in Sydney in October and we are hoping that this could provide the spark for the formation of a Sydney-based group in the near future.

Finally, the Sorrell Lions Club in Hobart has launched a project with the assistance of Keratoconus Australia to publish a pamphlet on keratoconus for distribution around Tasmania.

## **ORGAN DONATION**

In February 2005, Keratoconus Australia again threw its support behind efforts to increase organ donation in Australia during National Organ Donation Awareness Week. In particular, the committee worked closely with the Melbourne Corneal Donation Service and the Centre for Eye Research of Australia (CERA) to publicize the need for higher donation rates. As a result of this collaboration, CERA was able to organize interviews with a number of our members who have benefited from corneal transplants. These appeared on television and in newspapers during National Organ Donation Awareness Week.

Keratoconus Australia is continuing to include brochures on organ and corneal donations in its new member kits to encourage members to discuss the issue with family and friends.

## **FUNDRAISING**

Our mid-year fundraiser was another major success and as can be seen from the Treasurer's report, donations almost doubled to around \$12,000. Seminar videos are proving popular and generous donations by people attending these events are helping to cover the costs of these information evenings

Keratoconus Australia remains independently funded by members and other supporters and receives no government funding or corporate sponsorship at this stage. The committee of management believes that this is preferable to guarantee the Association's freedom of action in favor of people with keratoconus.

## **ACTION ON CONTACT LENSES**

Keratoconus Australia kicked off its campaign for higher rebates for gas permeable contact lenses at a meeting with the private health funds late last year. KA president Larry Kornhauser and secretary, Belinda Cerritelli, presented a submission in support of its case to the Ancillary Committee meeting of the major health funds held on December 8, 2004 in Sydney.

**A key point made to the funds was that a survey of our members shows some 92% of are dissatisfied with current rebates on RGPs.**

A full report on that meeting can be found on our new Action on contact lenses page. There is also a pdf version of the submission put to the health funds and articles by KA and Brisbane optometrist John Mountford on the subject that appeared in the December issue of the Optometrists Association of Australia newsletter. Another article by John Mountford on the problems of inexperienced optometrists fitting contact lenses for keratoconus appeared in the May issue of OAA newsletter.

Mr Mountford is a strong supporter of the Association's position on rebates and is also assisting the Association in improving warranties for rigid gas permeable lens for keratoconus. An article on that latter issue appeared in the November issue of *Australian Optometrist*.

However it seems unlikely the health funds will provide higher benefits on contact lenses unless the optometrists find a means of identifying qualified contact lens fitters for keratoconus. Even then, the association believes the longer term solution lies in a new business/subsidy model for the delivery of rigid contact lenses to keratoconus patients. The Association now plans to study the New Zealand model of subsidized lenses for keratoconus in the hope of finding new solutions applicable to the Australian market.

**Once again, any volunteers to assist with this effort would be greatly appreciated.**

## **RESEARCH**

Keratoconus Australia remains committed to supporting research aimed at treating and curing keratoconus. Earlier this year, we were approached to support a study into the **genetic origins of keratoconus**. The Association assisted the researchers by contacting all of our Victorian members to ask if they would participate in the intergenerational study. The research team headed by Dr Michael Loughnan received a very positive response and is currently undertaking the scans that form the basis of this research.

Team member, Dr Tim Steele presented an outline of the study to our October 25, 2005 seminar and has agreed to do another presentation in 2006 on the results of this research.

The Association was also asked to support a trial in Australia of the new German-developed **C3-R collagen crosslinking treatment** which stiffens the corneal stroma and offers hope of slowing the progression of keratoconus. If the trial goes ahead, the committee will consider what – if any – participation the Association should have.

**Feedback** from members on this issue would be appreciated.

Finally at our recent Melbourne seminar, Prof Doug Coster from Flinders University asked the group what research we would like to see done. The committee has sent a proposal for collaboration on a number of projects including a revamp of our member questionnaire to ensure we maximize the usefulness of responses and to assist in analysis. **We urge members to send us other suggestions so that we can use our own funding to launch some small but potentially important projects.**

## **WEBSITE**

The Keratoconus Australia website remains the key contact point for the Association with the general community and in particular with people looking for information about keratoconus. The site's online forum page, which allows people to send us questions about keratoconus, is a vital element in our support structure.

In the year ending June 30, 2005, the site recorded over 2,600 hits or an average of some 50 a week. This represents an increase of some 25% compared to the 2003-04 financial year.

The site is being regularly updated with new information about keratoconus, the Association's activities and other information relevant to members. Please keep coming back to see the latest news.

## **NEWSLETTER**

Keratoconus Australia achieved another milestone in May 2005 with publication of its first print edition newsletter dubbed **KA Contact**. The print edition was sent to all members without email and a number of eye-carers working in the field of keratoconus. Feedback was generally positive to this initiative. However due to lack of time and volunteers, we have been unable to publish another newsletter in the second half of 2005 to date.

Electronic newsletters were sent to members on email in October 2004 and April 2005.

The committee will endeavor to publish regular updates on the Association's activities. But these will remain ad hoc until we receive greater backing from members to reduce our workload in other areas.

## **EYE-CARERS**

Keratoconus Australia believes that collaboration with eye-carers is an integral part of our work to prevent and control the eye disease, keratoconus, and visual impairment caused by keratoconus. The Association has played a major role in advocating the rights of keratoconus patients and ensuring that patients receive the best possible care. It is now recognized as a legitimate player in the field of keratoconus. Evidence of this is the increasing interest of eye-carers in the Association and in ways of working together to improve outcomes for keratoconus patients.

As already mentioned, the Association is fielding more requests from eye-carers and researchers to participate in studies and research.

On going discussions with Brisbane keratoconus specialist optometrist, John Mountford, resulted in a series of articles on keratoconus appearing in the

Optometrists Association of Australia (OAA) newsletter **Australian Optometrist** written by KA's officers and Mr Mountford, urging optometrists to support a better deal on contact lenses for keratoconus patients. Mr Mountford also warned of the dangers to patients of optometrists "dabbling" in fitting contact lenses for keratoconus and asked his colleagues to support the Association.

A meeting in December 2004, with Jim Kokkinakis, a leading Sydney contact lens fitter for keratoconus, culminated in the organization of the Association's Sydney information seminar in October. Mr Kokkinakis has also been speaking to optometrist groups around NSW about the dangers of dabbling in keratoconus and the need to refer-on difficult keratoconus contact lens fits to more experienced contact lens fitters.

As a result of this action, we have received reports that increasing numbers of optometrists are referring their keratoconus patients to more experienced practitioners. The Association has also enjoyed a massive increase of optometrist referrals of keratoconus patients – as evidenced by the jump in membership and inquiries since December 2004.

Both the optometrist's and the ophthalmologist's professional associations have been very supportive of Keratoconus Australia's efforts and have provided us with free access to their facilities for our information seminars. The OAA has also continued to publish regular updates on our activities, views and events.

Other actions taken include

- sending videos, brochures and registration forms to eye-carers in VIC, SA, NSW WA and Qld
- individual contacts and meetings with optometrists and ophthalmologists Australia-wide to inform them of the Association's activities and services
- ongoing collaboration with eye-carers to provide up-to-date information on developments in keratoconus to members

KA has also held preliminary discussions with Vision 2020 Australia and hopes to create closer ties with the general eye care community in 2006 through this umbrella group.

## **COMMUNITY RELATIONS**

Keratoconus Australia believes that it has a role to play in publicizing keratoconus and its effects within the wider community. The Association has developed a number of resources to assist in the process, primarily its website, videos of information seminars, the provision of booklets on keratoconus and corneal transplants edited by the US National Keratoconus Foundation, brochures and pamphlets.

During the past year, the Association has fielded a number of requests from eye-carers for patient information, assisted other medical practitioners in obtaining information about keratoconus and helped organize media interviews on keratoconus-related topics. The Association has also provided resources to members and other interested people to distribute in their local areas and via their local media.

**Internationally**, the Association's work was publicized by former KA vice president Matt Vaughan who gave two presentations to the UK Keratoconus support group in 2004-05.

Keratoconus Australia has also created links with eye-carers in Italy and Greece and continues to work closely with Cathy Warren of the US keratoconus support group.

The Association has offered support to people in countries as diverse as the UK, Iran, Pakistan, India, Spain, the US, Mexico, Singapore and New Zealand.

## **MEMBERSHIP**

Greater eye-carer backing for Keratoconus Australia led to a dramatic increase in the Association's membership in 2004-05. Total adjusted membership on June 30, 2005 stood at 613 Australia-wide, a 47% increase compared to one year earlier (417). The Association has continued to grow rapidly since then and currently has around 680 members.

The most dramatic increases came in Queensland and South Australia where strong support from local optometrists boosted numbers by 72% and 123% respectively. NSW membership increased by 61% last year and now totals 129, accounting for 21% of total membership. We hope that following our recent Sydney seminar, NSW will play an increasing role in the Association's activities.

Finally, our Victorian base also continued to grow (+23% in 2004-05) and we now have 261 members in that state. However the importance of the Victorian membership continues to fall as the Association expands into other states; it now accounts for only 43% of total membership (cf. 51% in 2004).

## **COMMITTEE**

The committee is still laboring under a shortage of volunteers to assist in the planning and execution of its activities. We remind members that the committee operates on a volunteer basis and most of its members have other part or full time occupations.

We urgently require new committee members to help spread the workload and initiate new projects. Until we do receive further assistance, the Association will do its best to carry out its primary functions of support and dissemination of information about keratoconus. However, progress on other ventures is likely to remain slow and unpredictable. So if you want to the Association to achieve more, please find the time to do more.

On behalf of the committee I would like to thank all of those who did offer to assist the Association in the past year. Particular thanks goes to all the ophthalmologists and optometrists who help in our support work. Special thanks also to the Victorian College of Optometry and the Royal Australian and New Zealand College of Ophthalmologists for providing us free access to their facilities for our information seminars.

Finally, once again we are so grateful to our secretary, Belinda Cerritelli for allowing the committee to use her kitchen for its meetings.

Before concluding, I would like to announce the association's new officeholders. As only one nomination for each position was received by November 27, 2005, the following persons were elected unopposed.

Secretary - Belinda Cerritelli

Treasurer – Elizabeth Bray

President – Larry Kornhauser

No nomination was received for vice president and that position remains vacant.

Thank you for attending the 2005 AGM

Larry Kornhauser  
President