

# AGM 2004

## Annual General Meeting 2004

10 NOVEMBER 2004

### President's Report

Good evening everybody. I'm Larry Kornhauser, President of Keratoconus Australia and I would like to welcome you all to the Association's AGM for 2004.

On behalf of the Association's committee of management, I will present a summary of the Association's activities over the past twelve months to bring you all up to date with what we have been doing since we last met.

### E-news

I'll keep it fairly brief because hopefully you are aware of much of what's been happening thanks to one of our key achievements in 2004 the launch of an electronic newsletter. Long promised but finally a reality, the first KA e-news was sent in June while another update went out last month. We expect to continue these at regular intervals to ensure that members can keep informed of what the committee and the association are doing.

In fact, the past year has seen the Association make significant progress in achieving several of our other core objectives.

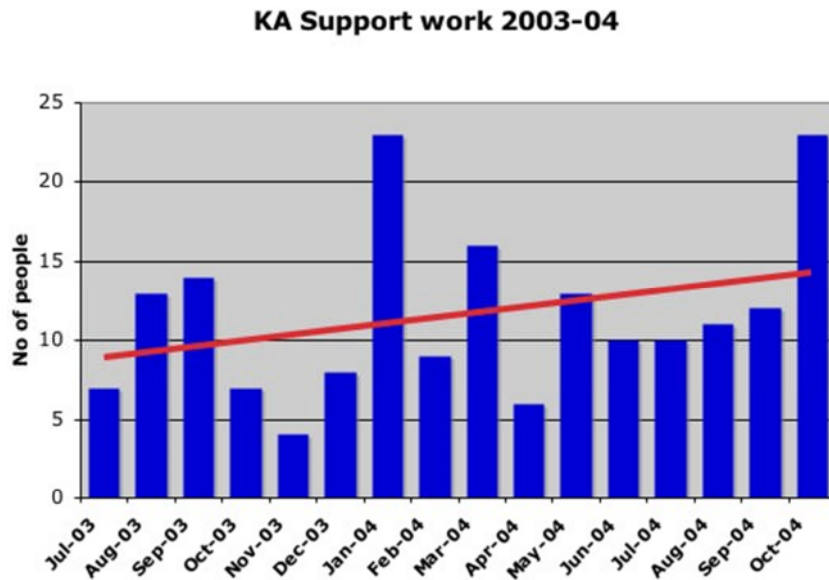
### Support

KA's primary activity remains providing support to people with keratoconus and their families. The Association's activities in that area continued to grow in the past year and we provided assistance to almost 160 people around Australia up from about 120 the previous year.

This support has taken various forms including:

- assistance in finding eye-carers experienced in fitting contact lenses for keratoconus and performing corneal transplants
- counselling for people before and after corneal transplants

- distribution of information about keratoconus and corneal transplants
- providing advice about contact lenses
- providing information about intacs and other surgical procedures



## Eye-carers

The committee has acted on a number of fronts to boost KA's image and credibility amongst eye-carers in the past year. By in large we believe these initiatives have been successful and KA is now recognized Australia-wide as the representative body for people with keratoconus.

In particular, Matt Vaughan and I addressed a conference of corneal surgeons in Melbourne in March at which we outlined the Association's work and how it could assist in helping patients reach informed consent prior to a corneal transplant. This was a major step in raising the Association's profile amongst surgeons and establishing our credibility as a serious support group that could act as a partner for corneal surgeons.

Other actions taken include

- sending videos, brochures and registration forms to eye-carers in SA, NSW WA and Qld
- Providing brochures to members in western and northern Victoria and NT for distribution to eye-carers.
- Arranging for the distribution of our brochures at the Victorian Eye & Ear Hospital

- Publicizing our seminars through the contact lens society of Victoria that has led to good attendances of optometrists.
- Making contact with Professor Doug Coster of the Corneal Graft registry in Adelaide, who would like to give a presentation next year.

### **Website**

The website has been upgraded to improve clarity and ease of use. Pages have been added covering the latest research, news, topics of interest and videos of previous seminars.

The site continues to provide the key point of contact with keratoconus patients Australia-wide as indicated by site statistics. These show an average 40 new hits a week and over 2,000 hits in the past twelve months.

### **Events**

This is second seminar held in 2004, and the third in the past 12 months. Russell Lowe gave an excellent talk in October 2003 on managing contact lenses, while last August we held a forum on Living with Keratoconus addressed by both eye-carers and KA members. All three were very successful and happily these seminars are now paying their way in door donations and video sales.

We will continue to hold these information seminars and hope to have more interesting topics and speakers in 2005.

Our Annual Picnic/BBQ was held in February at the delightful Alexandra Gardens in Kew. Members enjoyed a pleasant lunch and discussed their concerns, suggestions and ideas with committee members.

### **State support groups**

We continue to move slowly towards creating groups outside of the Melbourne area.

NSW remains our main target area and we are gradually creating contacts in Sydney in the hope of starting seminars and regular meetings in the near future. Dr Colin Clement, a member who is providing material for our research pages, is assisting in that effort. I will be holding discussions with eye-carers in Sydney next month in the hope of galvanizing support for the creation of a local group there.

But all efforts so far have been halted by the lack of enough willing volunteers to take on the workload involved in organizing seminars and events.

Pam Mayne, who is a speaker at tonight's seminar, has agreed to try to form a small group in northern Victoria and raise our profile amongst local eye-carers.

We also have a new committee member in Qld who is hoping to start a group in the Brisbane area in 2005 Belinda will talk about that in her report.

Finally, we have received interest from Tasmanian members too about starting a small group - although it is not yet clear what form that might take.

### **Fundraising**

Keratoconus Australia has enjoyed a successful year financially too as can be seen from the financial report. Our June fundraising drive raised almost \$7000 which was a fantastic first effort.

Earlier this year, we also applied for a small community support grant but were unsuccessful. We intend applying for similar grants in the future.

### **Organ Donation**

Last February we took our commitment to supporting campaigns to lift organ donation rates a few steps further by actively participating in National Organ Donation Week.

- KA issued a press release to national media outlets in support of Organ Donation Week
- Members were encouraged to contact the media about their own experiences with corneal transplants and support events organized by their local eye banks.
- In Melbourne, the committee distributed information on organ donation at the Eye and Ear Hospital.
- Brochures on organ and corneal donations have now been included in the membership kits so that all new members can raise the issue with their family and friends.
- A page with Eye Bank information has also been added to the website.

## **Contact lens rebates**

KA has pursued its efforts to improve rebates for contact lenses; notably rigid gas permeables. Retiring vice president Matt Vaughan has arranged for an article arguing the KA case for higher private health fund rebates for contact lenses to appear in the Optometry Association of Australia newsletter next month. An article from Brisbane optometrist John Mountford, who strongly supports KA's position, will also be published in the same issue.

.John, who develops contact lenses for keratoconus, is urging all optometrists to lobby the health funds over the issue and to promote membership of KA amongst their patients to help strengthen our role as advocates on this issue. These articles will be posted on the website after publication.

Belinda and I are meeting with the private health funds next month in Sydney to argue the case for treating contact lenses for keratoconus as a medical device and for raising rebates from their currently unacceptable level. We'll keep you informed on progress but don't hold your breath at this stage.

## **Publicity**

The committee has been actively pursuing a series of initiatives to raise the profile of KA amongst eye-carers and within the general community.

Perhaps the most noteworthy initiative recently was the contact made with the producers of Channel 9 RPA series, which showed a corneal transplant last month. This led to RPA putting a link to our website on their website. We subsequently received a flood of inquiries about keratoconus and the Association from RPA viewers.

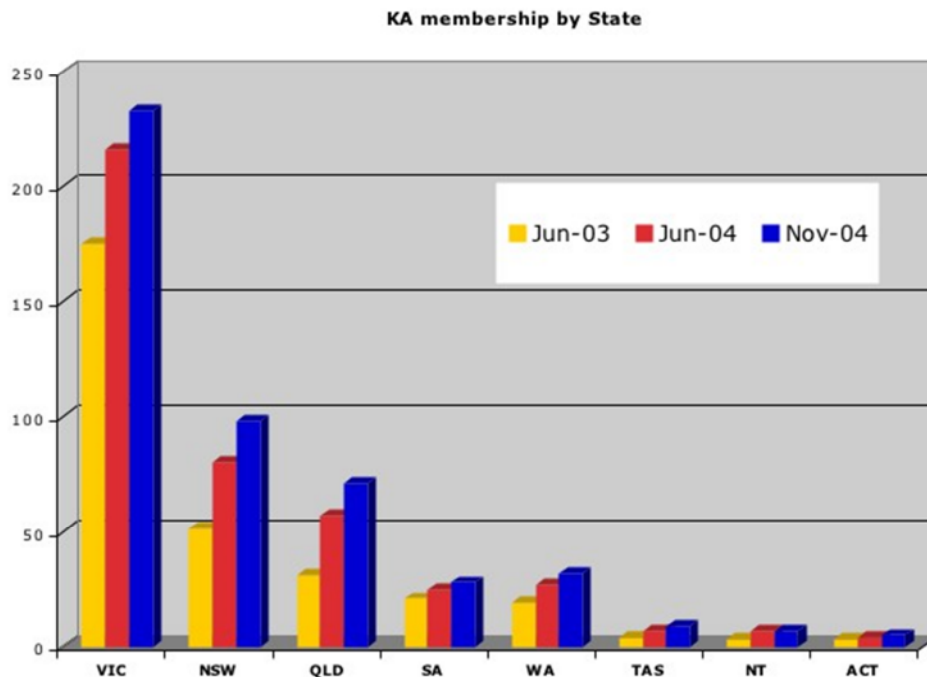
The committee will continue to take advantage of all such opportunities to promote the Association and its activities.

## **Membership**

Membership has continued to grow rapidly. The number of full members rose from 307 in June 2003 to 423 in June 2004 and currently stands at 483 Australia-wide an increase of 57% in the past 16 months.

Membership in NSW has almost doubled in that same period from 51 in June 2003 to 98 today. Thanks to the efforts of John Mountford, Queensland membership has jumped 130% to 71 members while Western Australian membership has climbed to 32.

Although Victoria remains the centre of our activities with 233 members, growth in NSW and Queensland has reduced the Victorian share in total membership to just under 50% for the first time.



## Committee

Finally, I would like to extend a vote of thanks to retiring vice president Matt Vaughan who has gone overseas to pursue new career paths. Matt was a founding member of KA and its committee. Often in these volunteer-run organizations, people tend to arrive with great enthusiasm but over time lose interest or fail to maintain their involvement because of other activities. Not Matt. He was a dynamic, reliable and hard-working member of the group and both initiated and participated in many of the association's actions. He continued his work for the Association while completing a university degree and despite the problems and hardship he suffered as a result of losing useable vision in one eye. He then required a corneal transplant, which was followed by a lengthy recovery period. Rather than simply disengage from the Association at that time to concentrate on his own personal situation, Matt decided to draw on his experience to assist others to confront and overcome the many complications caused by

this eye disease.

In particular, he gave presentations on his experiences with keratoconus and his corneal transplant at information seminars organized by the association. Amongst his other achievements, he launched an inquiry into health insurance rebates for keratoconus in an effort to assist financially disadvantaged patients. He also provided counselling to members of the association as part of its support work.

Matt will be sorely missed by the committee and we wish him all the very best in his future activities and with his keratoconus. We also wish he would start using traditional wetting and cleaning solutions for his contact lenses.

The Association would also like to thank the College of Optometry for its support during the year and for kindly allowing us to use its facilities to hold our seminars and meetings. Special thanks also to the optometrists and ophthalmologists who support our work and assist us by providing technical answers to the many issues raised by members. Finally, many thanks to our hard-working committee for their efforts during the year and in particular to Belinda for allowing us to hold our meetings at her place.

Thank you again for coming along tonight and supporting the association.

Before concluding, I would like to announce the association's new officeholders. As only one nomination for each position was received by November 3, 2003, 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.

I would also like to welcome Helen Rizvi to the committee. Helen will soon be based in Brisbane and hopes to be able to organize a support group there in 2005.