KERATOCONUS AUSTRALIA

Annual General Meeting 2006

Victorian College of Optometry
30 November 2006

PRESIDENT'S REPORT

Good evening everybody and welcome to the Association's Annual General Meeting for 2006.

On behalf of the committee of management of Keratoconus Australia, I would like to present an outline of the Association's activities during the year ending June 30, 2006 and some more recent developments.

During that time, the keratoconus community has seen some exciting advances in Australia and the Association has played a key role in their evolution.

SUPPORT

As in previous years, the Association's principal activity in 2005-06 was providing support to people with keratoconus and their families. Most questions and requests for assistance continue to be directed to us via the online forum page of our website and by telephone. They cover a range of issues relating to keratoconus and its impact on people's lives. Support work is done with the assistance of a handful of committed optometrists and ophthalmologists who provide technical and medical advice in response to members' queries.

The actual number of people contacting Keratoconus Australia with support questions stabilized in 2005-06 at around the 200 mark (compared to around 190 in 2005-04).

That figure included around 50 people who contacted us in April and May 2006 with specific questions about the corneal collagen crosslinking trial starting at the Royal Victorian Eye and Ear Hospital (RVEEH), which received widespread national publicity over the Easter weekend. The Association's involvement in all aspects of the corneal collagen crosslinking trial is discussed in more detail later.

Most questions directed to the Association concern specific problems being experienced by people with keratoconus. The Association is unable to deal with the detail of a keratoconus-related medical problem and therefore many of these people are referred back to eye-carers. In some cases, these problems arise because the eye-carers treating these people have little experience with the condition. The Association's main contribution to resolving these problems is to direct patients to optometrists and ophthalmologists with extensive experience in treating this condition.

During the past year, requests for support fell into a few main categories:

- By far the most common request is for assistance in finding eye-carers who specialize in keratoconus, and especially contact lenses for keratoconus.
- Advice and reassurance for people who have just been diagnosed with keratoconus. In particular, the Association receives many requests for information and support from the parents of adolescents who have just been diagnosed with the condition but have received little information about the likely prognosis.
- Information about keratoconus, its likely evolution and corneal transplants
- Advice and information about contact lenses

- Information about the cost of contact lenses and corneal transplants, and the possibilities for rebates or low cost options.
- Non-traditional ways of slowing or halting the progression of keratoconus (vitamins, herbal medicines etc).

As mentioned above, there has been growing interest in the new surgical procedures becoming available in trial or treatment form such corneal collagen crosslinking and in particular, intacs.

This latter technique, which involves the insertion of small plastic rings into the cornea to flatten it, has received a lot of attention recently and many people have contacted the Association for further information and the names of surgeons offering this treatment. While the Association is pleased to provide this information, we are also concerned that many people with keratoconus see intacs as a quick solution to their keratoconus-related problems. Based on advice from corneal surgeons working in this area, it would appear that the interest in intacs is being generated largely by marketing campaigns conducted by the manufacturers and doctors promoting their use rather than the outcomes being achieved for keratoconus patients. In fact, it would seem that intacs might be suitable only for a small number of contact lens intolerant patients with mild to moderate keratoconus. Problems have also appeared after an apparently successful outcome, raising doubts about their efficacy as a long term solution.

The federal minister of health rejected an application by the Australian distributor of intacs for public funding of this procedure in November 2005.

Advice by the Medical Services Advisory Committee (MSAC) indicated that there was insufficient evidence of their long-term benefit to patients or their cost effectiveness. (Details of this decision can be found on the website of the MSAC).

However recently, trials have begun into the effectiveness of combining intacs with corneal collagen crosslinking for patients with advanced keratoconus as an alternative to a corneal transplant.

The Association will continue to monitor new treatments for keratoconus and will try to provide updates on research into their effectiveness whenever possible. But we will continue to caution people seeking miracle cures for their keratoconus-related vision problems.

RESEARCH

Perhaps the most significant development for the Association in the 2005-06 financial year related to its involvement in two keratoconus research projects.

Intergenerational Genetics Study

In early 2005, we were approached to support a study into the **genetic origins of keratoconus**. This study aims to identify keratoconus across at least three generations of family members in order to obtain a better understanding of the genetic component of keratoconus. The Association used its database of members to assist the researchers in recruiting families to participate in the Victorian-based intergenerational study. The research team headed by Dr Michael Loughnan conducted scans of family members for signs of keratoconus in late 2005 and early 2006 and is currently analyzing the results of this work.

Team member Dr Tim Steele gave a presentation on the research to a meeting organized by Keratoconus Australia in October 2005 and will provide an update on the study outcomes and conclusions in early 2007.

Corneal Collagen Crosslinking Study

As foreshadowed in the previous annual report, Keratoconus Australia also received a request in mid-2005 to support an Australian trial of the new German-developed corneal collagen crosslinking treatment (C3-R), which stiffens the corneal stroma and offers hope of slowing or halting the progression of keratoconus.

After a number of false starts, the trial leader Dr Grant Snibson secured both ethics approval for a randomized control study of the C3-R treatment and the services of Dr Christine Wittig, a member of the German team that developed the procedure, to conduct the trial at Melbourne's Royal Victorian Eye and Ear Hospital (RVEEH).

The clinical trial of 100 patients aims to evaluate the effectiveness and safety of C3-R in treating keratoconus.

If the new treatment for Keratoconus proves effective and safe, it promises to be a simple, cost effective and minimally invasive way of stopping the progression of the condition. It may therefore avoid many people with advancing keratoconus ever requiring a corneal transplant. This could reduce waiting lists for corneal transplants required by those already with advanced keratoconus and also make more corneal donor tissue for patients with other debilitating corneal conditions.

The C3-R treatment potentially offers immense benefits to people being diagnosed with early keratoconus, and especially adolescents, and those with mild and moderate keratoconus. The committee of management therefore decided to accept requests from the trial organizers for both funding and logistical support for the study. Critical to our decision to assist in funding was that the trial is being conducted in a public hospital under the auspices of the Centre for Eye Research Australia (CERA), a research arm of the University of Melbourne. Results of the study will be published in peer-reviewed ophthalmologic journals and presented at conferences.

The Association subsequently donated $5000 to the study, which is being used to purchase equipment required for the study. The committee expects that this equipment will be used for future ongoing treatment of patients, if the procedure is proved safe and effective.

As previously mentioned, news of the proposed C3-R trial was splashed across the national media over Easter.

The unprecedented interest in the corneal collagen crosslinking study and the lack of coherent information about the procedure, the trial and eligible candidates resulted in the Association being flooded with misinformed questions about C3-R which were impossible to answer on an individual basis. The committee therefore decided to collaborate with the trial organizers in preparing a Frequently Asked Questions sheet about the procedure and trial that was put up on the Association's website. A print copy was also made available to members unable to access the internet. In order to meet the overwhelming demand for information directed to the trial organizers, we subsequently made the FAQ sheet available for distribution by the RVEEH and CERA.

Finally, the committee also decided to meet demand for detailed information about the trial by organizing a public meeting on May 30, 2006, which was addressed by trial organizers Dr Grant Snibson and Dr Christine Wittig.

The meeting was held at the RVEEH and attracted some 110 members and their families from around Australia. It was the biggest information meeting ever held by the Association and was videoed to give people unable to attend access to proceedings. Apart from providing detailed information about the corneal collagen crosslinking procedure, the meeting provided a public forum for potential participants and their families to quiz the trial organizers about the procedure detail, trial methodology, its risks and the likely outcomes.

Since then, the Association has been informed that similar trials have started or are being started in NSW at the Sydney Eye Hospital and Brisbane. Results from all three trials are expected to be compiled to provide a comprehensive picture of the effectiveness of the C3-R procedure in halting the progression of keratoconus before it is offered for general treatment. Eye centres in Tasmania and Western Australia have expressed interest in becoming part of the trial too.

Finally, the Association understands that a trial of a modified form of the C3-R technique in conjunction with intacs started in May 2006 at the Eye Institute, a private eye clinic in Sydney.

We hope to post updates on all of these trials onto our website in early 2007 and as we receive further information.

EYE-CARERS

Keratoconus Australia continues to gain recognition for its work in the eye carer community. Apart from its involvement with medical researchers, the Association has cemented and expanded its relationships with both optometrists and ophthalmologists specializing in the treatment of keratoconus.

In mid-2005, we were contacted by Rene Maligre, manager of the Adelaide Eye Care optometry group, seeking information about Keratoconus Australia. We provided his practice, one of the largest for keratoconus in Australia, with registration forms and patient information brochures. Following the release of details of the Melbourne C3-R trial we also sent his group information about the procedure and trial. We hope to cooperate in the future on developing additional patient resource material.

We continue to collaborate with Queensland's largest keratoconus optometry practice headed by John Mountford and maintain links with eye-carers specializing in keratoconus in the Sydney area.

We are in discussions with Professor Doug Coster from Flinders University in Adelaide about the possibility of pooling our resources to conduct research into keratoconus in the future.

Early in 2006, we met with Vision 2020 about the possibility of utilizing their resources in the eye-care community to further our activities and we subsequently joined their network as a corresponding member. As part of our involvement with Vision 2020, we participated in a member forum in Adelaide last July and in activities organized by Vision 2020 around World Sight Day in October.

Contacts made by our secretary Belinda Cerritelli through Vision 2020 have also led to discussions with the Optometrists Association of Australia (OAA) over our campaign to obtain higher rebates for contact lenses for keratoconus.

Belinda will discuss the Vision 2020 partnership and its fruits in more detail in her report.

The Association's officers continue to hold ad hoc meetings with eye-carers working in the field of keratoconus to discuss a range of issues affecting members.

Finally, the Association continues to work closely with the OAA's newsletter, Australian Optometry. We have been able to publicize our activities, seminars and views on a range of keratoconus-related topics thanks to the kind support of the newsletter's editors.

ACTION ON CONTACT LENSES

Despite the publicity surrounding new experimental procedures like corneal collagen crosslinking, contact lenses remain the primary treatment for vision loss resulting from keratoconus. The Association has identified two key deficiencies in the delivery of contact lenses to keratoconus patients

1. The **cost of specialized contact lenses and poor warranty conditions** offered on these lenses compared to contact lenses for other conditions
2. The **shortage of experienced contact lens fitters** in Australia to ensure these lenses are properly fitted for keratoconus patients

As there appears to be a link between the high cost / poor warranty conditions for keratoconus contact lenses and the shortage of optometrists to fit these lenses, Keratoconus Australia has been working on both fronts in the past year to try to improve the situation.

Contact lens costs

Following our unsuccessful efforts to obtain higher rebates for contact lenses from the private health funds (although these have coincidentally been raised over the past two years), the Association decided to turn its efforts towards the implementation of a government-funded contact lens rebate scheme based on those operating in New Zealand and the United Kingdom. In both countries, the government provides subsidies to cover the costs of contact lenses for people unable to wear spectacles – which is the case for most of us with anything but very mild keratoconus.

Thanks to the efforts of Melbourne optometrist Russell Lowe, we have been able to obtain considerable information on the New Zealand contact lens subsidy scheme over recent months. This will now be analyzed and included in a submission we are planning to put to the Federal Government in 2007 on the issue of contact lenses costs for keratoconus patients.

One of the primary functions of Vision 2020 is to act as an advocate to government on behalf of the eye-care sector. The Association is now working closely with Vision 2020 to take advantage of their extensive contacts and experience in preparing a submission on the contact lens rebate issue. We hope to provide reports in the new year on progress on this project.

Optometrist training

A key argument put to us by the private health funds in refusing to raise benefits for specialized rigid gas permeable contact lenses for keratoconus was that it would simply encourage more inexperienced optometrists to try to fit these complex lenses – leading to higher costs for the funds and potentially poor outcomes for patients.

Contact lenses laboratories cite similar concerns when explaining why they provide the worst warranties (generally measured as the number of free refits allowed by an optometrist on a new lens) on the best contact lenses for keratoconus to discourage all but the most experienced lens fitters from trying to fit their complex keratoconus designs on the most difficult cases. Optometrists tell us this leads to the perverse outcome that they are often wary of using these "best" option (but worst warranty) contact lenses for complex fits for fear of not succeeding to obtain a "best fit" within the limited the warranty conditions offered by the laboratories. Instead they use other lenses in the hope they can achieve a good fit for the patient under the less stringent warranties on offer with these lenses.

Keratoconus Australia intends to pursue the issue of warranties with the laboratories in the future.

In the meantime, we decided that the lack of experienced contact lens fitters for keratoconus, especially outside of the major capital cities, needed to be addressed urgently. We therefore discussed with Melbourne optometrist Richard Vojlay the possibility of holding special training clinics at the University of Melbourne's College of Optometry (VCO). In April 2006, we sent a submission to the School of Optometry arguing for these special clinics to provide an opportunity for final year students to examine keratoconus patients and practice lenses fitting before graduating. The submission, entitled ***Improving Contact Lens Outcomes For Keratoconus*** *wi*ll be posted to our website soon for members.

The head of the school, Professor Neville McBrien, a long time supporter of the Association, agreed to allow Richard Vojlay to conduct four clinics and a lecture in conjunction with Keratoconus Australia. We understand that this is the first time in Australia that a patient support group has been directly involved in optometrist training in this way.

Keratoconus Australia undertook to organize for keratoconus patients to attend the clinics. As they have done previously when asked to assist, Victorian members responded magnificently in offering their time and corneas for examination by the optometry students. The four clinics were held between July and September 2006 and proved invaluable for the students by allowing them hands-on experience with keratoconus and corneal transplant patients. Richard Vojlay, Belinda and myself presented the lecture in early October. Feedback indicated an excellent response to both the clinics and lecture from the students and Professor McBrien. Hopefully we can repeat the experience again in 2007.

Apart from the exposure to keratoconus patients offered to the optometry students, these clinics will also assist the Association in providing a model for future optometrist training which we hope will be taken up by other optometry schools around Australia.

DATABASE

As part of the effort to secure higher benefits for contact lenses, the Association distributes a health survey to all new members to obtain information about what type of visual correction (spectacles, contact lenses, etc) they use, the cost of these optometry services and their opinions on current rebates for contact lenses and the cost of private health insurance. This information has been used to support our claim for higher rebates on contact lenses for keratoconus.

Until now, the results of these surveys have been compiled manually. In early 2006, the committee obtained the services of a database developer, Charity Jenkins, who is currently developing a database which will facilitate the entry of this information onto computer, and the automatic analysis and formatting of these survey results for use in our submissions. We hope to complete this database development work in early 2007.

The members database has also been redeveloped to provide better log facilities and easier data entry. We would like to thank Marisa Cerritelli and Bettie Kornhauser for assisting us in keeping the membership details up-to-date.

WEBSITE

The website and the Internet remain the Association's windows to the world. We disseminate information about keratoconus via the website, while people wishing to contact us for support do so either via the online forum page or by email. The online form facilitates registration and information about the Association's activities can be easily found online.

Visits to the website have gradually increased from 50 a week last year to about 60 in 2006. However the value of the website as a low cost source of information was proved last April when visits rose by a factor of six as people swamped the site searching for reliable information about the corneal collagen crosslinking trial publicized in the national media over Easter. Revisits to the site are also rising and currently stand at about 25%. We hope to increase that figure even further in 2007.

That will require a better performance on website updates. In the past 12 months we have tried to ensure that essential information is posted to the site in a timely manner. But time constraints have meant that we have not always succeeded. While event information is being regularly updated to ensure members can find out about the Association's activities, we have not always been able to keep the news section current.

A rethink of the site layout is also proposed for 2007 to enable easier navigation and to group certain resources and information better than under the current design, which was developed originally with a much smaller site in mind.

Dr Colin Clement has resumed his ***Eye on Research*** page after a 12-month break due to study commitments and we hope to have quarterly updates on current research into keratoconus available.

Our FAQ page on the corneal collagen crosslinking trial has been extremely popular and we will continue to provide updates on the trials around Australia as they become available.

We also urge members to check out our Resources page, which contains valuable information about contact lenses and their care, and corneal transplants. Anybody contemplating a corneal transplant in the near future would benefit from reading *The 20 Questions For Your Surgeon* page.

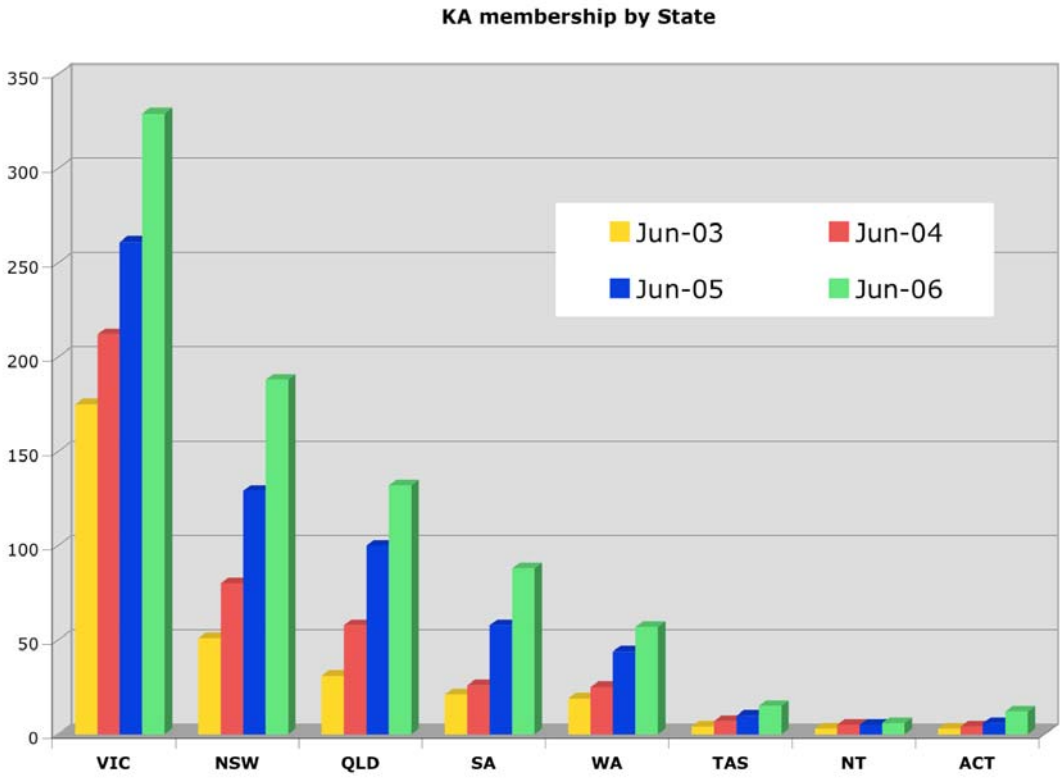
Finally, we would like to expand our resources into new areas. In particular we would like to launch a page with suggestions from members on coping with keratoconus, strategies for using contact lenses, pre and post corneal transplant experiences. We would also be interested in publishing people's experiences in dealing with their own diagnosis of keratoconus or that of their child.

MEMBERSHIP

Keratoconus Australia membership continued to climb in 2005-06 and stood at 827 members Australia-wide on June 30, 2006. That represented an increase of 35% over the previous year. Membership grew strongly again in NSW (+46% to 188 members), South Australia (+52% to 88) and Queensland (+32% to 132). This largely reflected the growing publicity about the Association's activities and the referrals from optometrists who are working with the Association in those states.

The bulk of the membership is still located in Victoria where membership grew 26% to 321. But Victorian members now account for less than 40% of the total, compared to NSW (23%), Queensland (16%) and South Australia (11%).

(See table below)



EVENTS

Keratoconus Australia organized three information seminars during 2005-06 as part of its ongoing Demystifying Keratoconus series. All three proved to be groundbreaking for different reasons and were well attended.

In **October 2005**, the Association held its first-ever event in NSW. This was a major development for the Association as we had received many requests for a Sydney seminar over the years but were unable to garner sufficient logistical support to make it happen. The seminar was addressed by **Dr Anthony Maloof,** ophthalmologist and corneal surgeon, who gave an interactive presentation describing newer approaches to surgical intervention for keratoconus. Dr Maloof gave particular attention to Deep Lamellar Keratoplasty as a way of eliminating endothelial rejection after transplantation, the most common cause of transplant failure. Indications for surgical management were discussed. A brief overview of the principles of surgical correction of the cornea for Keratoconus was also presented. **Jim Kokkinakis,** clinical optometrist, discussed the latest advances in non-surgical options for keratoconus patients.

We hope to organize another Sydney seminar in 2007. Please offer to assist if you would like it to happen.

Then later that same month, we were honored to have a presentation to our Victorian members by **Professor Doug Coster**, the head of ophthalmology at Flinders University, founder of the Australian graft registry and an internationally-acclaimed researcher in the field of keratoconus. In his presentation, Prof Coster attempted to clarify the reasons for the increase in frequency of keratoconus, looked at the genetics of the condition, and reviewed the available treatments. He outlined a decision tree for the treatment of keratoconus that would be a valuable resource for anybody confronting the formidable task of choosing the right option for dealing with their keratoconus.

Finally, as mentioned earlier, in **May 2006** we held an information seminar on the corneal collagen crosslinking procedure and trial starting at the RVEEH. That seminar,

addressed by Dr Grant Snibson and Dr Christine Wittig, was the biggest ever organized by Association.

The seminars are now self-funding from door donations, which totaled $1181 in 2005-06. All seminars are videoed and last year, video sales earned a further $782.

STATE SUPPORT GROUPS

The long-standing project by the Lions Club of Sorrells to produce a brochure on keratoconus and the Association's activities moved towards completion in 2005-06. The text for the brochure entitled *Looking at Keratoconus* was completed some months ago and we recently agreed on a final version. The first copies of what we believe is to be a 15,000 print run arrived at the Association only this week. We would like to thank and congratulate the Lions Club of Sorrell for funding this brochure and all the people locally who have contributed to its publication.

COMMUNITY RELATIONS

As part of its charter, Keratoconus Australia has undertaken to publicize keratoconus and its impact within the community. The Association is continuing to develop an array of resources to achieve that goal.

Following the presentation by Professor Coster in October 2005, we have discussed how we could develop his decision making tree as a resource to make available to all people diagnosed with keratoconus and their families. We hope to advance that project further in 2007.

We are also looking at ways to exploit material prepared for the VCO lecture held in October. Although this material was prepared for delivery to optometry students, it could be modified to provide the basis for our own source of information on keratoconus. Initially, this could be included on our website and later made available in printed form for wider distribution within the community to specific groups such as optometrists, schools, employers and other groups who may have direct contact with people with keratoconus.

In the meantime, we continue to distribute information about keratoconus to all new members of the Association. We also have videos of our information seminars, booklets on keratoconus and corneal transplants edited by the US National Keratoconus Foundation, brochures and pamphlets.

During 2005-06, we have provided information to the Australian air force about intacs, assisted a university career counselor deal with a student having difficulties because of keratoconus, provided a briefing to a Member of Parliament seeking information about keratoconus for one his constituents and assisted ophthalmologists and optometrists in supporting patients experiencing problems relating to keratoconus. We also dealt with multiple requests for information about the corneal collagen crosslinking trial, in particular from a group of Monash university students who were analyzing media coverage of trial.

We have also added to our website links to other organizations working in the field of vision disability to provide access to other resources. In particular, we have added links to the Federal Government's new *Eye Health* webpage and resources for children and students with a vision disability provided by the Victorian Statewide Vision Resource Centre.

Internationally, the Association continues its collaboration with the US keratoconus support group and has also been in contact with other keratoconus support groups forming around the world. We have also maintained links with optometrists and ophthalmologists overseas who are working in the field of keratoconus or interested in

our activities. The Association has offered support to people in countries as diverse as the UK, Dubai, Pakistan, India, Canada, Singapore and New Zealand.

COMMITTEE

As the above review indicates, the 2005-06 year proved a mixed bag for the Association. The committee made some significant progress in some areas, launched projects in new areas such as optometrist training, steered the Association into direct participation in some important advances in keratoconus research and treatments and expanded our capacity for advocacy on behalf of keratoconus patients. We have done all of that while maintaining other key functions such support and information dissemination. Perhaps our greatest weakness in 2005-06 has been in the area of feedback to members about the Association's work and achievements.

Committee members all remain on a volunteer basis and perform their functions while trying to maintain full time jobs and other activities. Unfortunately during the past year, all of us have been distracted by personal issues that have further limited our time available to deal with Association business.

Once again, we implore members to consider making a direct contribution to the Association in some way. Our secretary Belinda Cerritelli would be delighted to hear from you and discuss what options are available to help the committee of management.

I would like to thank all of our committee for their great efforts during the year and their commitment to continuing these in 2007. I would also like to welcome Laura Towers to the committee and thank her for her work already for the Association. Special thanks goes to all the ophthalmologists and optometrists who help in our support and advocacy work. Thanks also to the Victorian College of Optometry and the Royal Victorian Eye and Ear Hospital for providing us free access to their facilities for our information seminars. We greatly appreciated the support from Professor McBrien at the VCO also in promoting keratoconus amongst his students this year. We would also like to acknowledge the efforts of Jennifer Thompson at Vision 2020 for her assistance with our advocacy work.

Finally many thanks to Belinda and Marisa for allowing us to use their kitchen for committee meetings and the wonderful, nourishing food and drinks provided to keep us working late into the night on Association business.

Before concluding, I would like to announce the association's new officeholders. As only one nomination for each position was received by November 24, 2006, 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.

Laura Towers and Marisa Cerritelli remain on the committee.

Thank you for attending the 2006 AGM

Larry Kornhauser

President