



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

# **ANNUAL REPORT 2007**

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## **Annual General Meeting 2007**

Victorian College of Optometry  
21 November 2007

### **INTRODUCTION**

Good evening everybody and welcome to the Association's Annual General Meeting for 2007.

Tonight I would like to present a report on the activities of Keratoconus Australia in year ending June 30, 2007 and some of the Association's more recent activities.

And for the first time ever, we able to report on some interesting developments in treatments for keratoconus, which hold hope for the future. These are also issues that will be discussed later in more depth by our guest speakers tonight.

On the bleaker side, resignations from the committee have reduced the Association's ability to operate as we would like and the coming year will be difficult without further hands-on involvement by members.

### **SUPPORT**

Without question, the principal function of Keratoconus Australia remains providing support to people with keratoconus and their families. Ideally, this would be done through face-to-face contact. But this is simply impractical and would limit the reach of our support service. Instead most of the support work is done via the internet (email) or telephone. Email has become our primary form of initial contact and has enabled us to assist people all over Australia - in some of the remotest parts of the country - and overseas.

The Association has strict guidelines governing the way it handles requests for support. Many people send very detailed requests for opinions on their specific medical conditions or problems – sometimes accompanied by medical data including corneal topographies. While the internet has facilitated the transmission of this information, we are not qualified medical practitioners and we do not give opinions on this information. We may refer some of these specific requests 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. In all cases, patients are told that a proper examination of their eyes by an experienced practitioner is required before a diagnosis can be made and specific treatment options offered.

What we will do is provide general information about all aspects of keratoconus, including emerging treatments.

Support takes many forms:

- One of the most confronting moments for a new patient is the initial diagnosis. Perhaps even worse, is when parents learn their child has this

mysterious eye 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.

- Many facing surgery would like to discuss their upcoming operation with someone who has already gone through that experience. We try to put them in contact with people who have recently had the same type of surgery and can explain what it actually feels like and what to expect in the post-operative period. This service has proved especially useful for patients preparing for a corneal transplant.

A big thanks to all those members who agreed to talk about their experiences with others over the past year. You provide an invaluable service to the Association and it is greatly appreciated by all of us.

- Many people simply want to share their experiences with keratoconus but cannot 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
- By the far, the majority of requests for assistance come from those looking for eye-carers experienced in treating different aspects of keratoconus. Contact lenses are a particular source of problems for many people as they are often fitted incorrectly by optometrists with little experience in this field. We try to find experienced contact lens fitters for these people whenever possible.
- As discussed last year, there are increasing numbers of people trawling the internet to find solutions for their issues with contact lenses and the main one they seem to come up with is 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 2006-07, Keratoconus Australia handled another 187 requests for support of various types. This was a similar level to previous years (200 in 2005-06 and about 190 in 2004-05). Regardless of their initial reason for contacting the Association, most requests result in the patient being offered the names of an experienced eye practitioner to provide additional care.

A majority of these types of requests concern ongoing problems with contact lenses. The new development since the last AGM is the emerging evidence that corneal collagen crosslinking could provide a means for halting the progression of keratoconus. An Australian clinical trial of this procedure – which uses ultra-violet light and riboflavin to strengthen the corneal collagen – is confirming results from

Europe that the procedure appears to stabilize progression in keratoconus without any significant side-effects.

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.

Corneal collagen crosslinking could also lead to important changes in the type of support required by keratoconus patients and their families. It is still too early to understand fully the impact of these developments. But many people with existing moderate to advanced keratoconus will still require support for the myriad of problems they may still experience even if the corneal collagen crosslinking treatment offered the promise of no further progression.

Part of this support effort includes the information seminars we hold regularly in Melbourne to keep members informed about the latest developments in keratoconus treatments. These provide a rare opportunity for patients to question specialists about different aspects of keratoconus and the scientific basis of the treatments offered to them.

## **RESEARCH**

As reported at the Association's last AGM, Keratoconus Australia supported two important research projects in the past 18 months.

The first - the Keratoconus Inheritance Study - on the genetic origins of keratoconus, was completed in 2006. The study results were presented by team member Dr Tim Steele at a seminar held by the Association in May 2007. The study of members of eight families (recruited with the aid of Keratoconus Australia) including relatives with keratoconus showed that there was a higher incidence of corneal abnormalities in families in which one member had keratoconus than in a control group. The study researchers concluded that based on their results, "caution should be taken when evaluating refractive surgery candidates with a family history of keratoconus." An article on the results of the study was submitted to the American Journal of Ophthalmology in October 2007. The abstract of the article will be posted to the Keratoconus Australia website soon.

The other research being supported by Keratoconus Australia relates to the corneal collagen crosslinking treatment developed in Europe and now being introduced to Australia. A clinical trial of the 3C-R technique began in mid-2006 at the Centre of Eye Research Australia (CERA) at the Royal Victorian Eye and Ear Hospital (RVEEH) in Melbourne. As reported last year, the trial team led by Dr Grant Snibson and Dr Christine Wittig (a member of the German team which developed the treatment) presented an outline of the treatment at a public meeting organized by Keratoconus Australia in May 2006. The Association then wrote up a list of frequently asked questions and responses for prospective trial candidates that was posted to the Keratoconus Australia website. It was subsequently printed and distributed by the CERA to people seeking more information about the trial.

The widespread interest in the trial – which is believed to be the first and largest of its type in the world – resulted in its extension to Brisbane in October 2006 where

Professor Lawrence Hirst is also treating patients under the CERA trial protocol. Although initially limited to patients with a corneal thickness of 400 microns, the trial protocol was modified in February 2007 by the RVEEH Human Research Ethics Committee to allow eyes with a corneal thickness of at least 330 microns to be enrolled in the trial.

As reported last year, Keratoconus Australia approved a \$5000 grant to purchase equipment for the RVEEH trial in September 2006. It is hoped this equipment will be used to provide ongoing 3C-R treatment for patients in the future. The Association was also instrumental in arranging additional private funding for the trial.

In May 2007, Dr Wittig presented the preliminary results from the trial, which showed that all patients treated with the corneal collagen crosslinking had stabilized with no long-term side effects. Although it is still very early days, these results were encouraging and we hope to receive further updates on the interim results in the near future.

As noted previously, the challenge for the Association will be to ensure that this surgery, which is now being offered as treatment by other ophthalmologists under non-trial conditions, is implemented with proper protocols and inclusion and exclusion criteria.

We will obviously need the cooperation of the medical community to monitor the situation and ensure patient's rights and welfare are respected as these and other new surgeries for keratoconus are introduced.

## **ACTION ON CONTACT LENS REBATES**

Corneal collagen crosslinking may prove effective for limiting the progression and severity of keratoconus in the future and reducing the need for other surgeries and especially corneal transplants. In the meantime, we think that spectacles and then contact lenses still remain the primary means for correcting vision loss resulting from keratoconus. But more needs to be done to improve the delivery of contact lenses for keratoconus patients.

In our 2006 report we identified two key deficiencies in that respect:

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

We noted then the connection between the two and the need to act on both fronts to improve the situation.

We also said that the refusal by private health funds to improve rebates on contact lenses for keratoconus meant we had decided to change tack and approach the Australian government in the hope of implementing a government contact lens scheme similar to those operating in New Zealand and the United Kingdom.

We subsequently obtained background information on the New Zealand scheme through contacts passed on to us by Melbourne optometrist Russell Lowe. We then worked with Vision 2020, the umbrella organization for all vision related groups in Australia, to prepare a submission to the government on these two issues.

In March 2007, our secretary Belinda Cerritelli, attended a Vision 2020 parliamentary group meeting addressed by Federal Health Minister, Tony Abbott. She was able to raise the cost of contact lenses for keratoconus with Minister Abbott during question time. He responded positively and asked for a short outline of the problem to be sent to his department.

The Association collaborated with Vision 2020 to produce a four-page submission to Minister Abbott outlining what we considered to be the key issues facing people with keratoconus and their families and the actions we would like implemented to improve deficiencies in care for keratoconus patients. The letter was sent in early May 2007 to the minister's office. (That letter will be posted soon to the Keratoconus Australia website on the Action on Contact Lenses page.)

The reply received in early July from the Medical Benefits Division of the Department of Health and Ageing was disappointing to say the least. In it, the Acting Director of that division, Veronica Davidson, confined her remarks to the cost of contact lenses only and failed, to address our concerns on the availability of cheap lenses and qualified practitioners to fit them. She also ignored our criticisms of the existing private health fund schemes and rebates for contact lenses for keratoconus.

We have summarized Ms Davidson's response below.

- Medicare does not and was never intended to provide direct assistance with the costs incurred in the purchase of optical appliances. These are a state government responsibility and each state has schemes to address the issue.
- If further funding for keratoconus is required under Medicare beyond the existing rebates for contact lens consultations, then either the Royal Australian and New Zealand College of Ophthalmologists or Optometrists Association of Australia need to apply through their respective Medicare consultative committees.
- Indirect Australian Government assistance towards the cost of optical appliances is already provided via the 30% rebate on private health insurance cover. These private health insurance policies offer ancillary cover for optical services including contact lenses – but benefits are decided by individual private health funds.
- Patients dissatisfied with the current rebates for contact lenses for keratoconus should research alternatives to find more suitable cover from another health fund.
- Further indirect assistance is provided via the Australia Government's Net Medical Expenses Tax Offset scheme administered by the Australian Tax Office. Under that scheme, taxpayers can claim medical expenses over \$1500 not reimbursed by Medicare or private health insurance to receive a tax offset of 20% (in 2006-07).

### **What now?**

The response of the Australian Government is all the more exasperating for the fact the Department of Health simply ignored our reference to the inadequate rebates offered by private health funds and that keratoconus patients have no incentive to take out private health ancillary cover for optical services. Moreover, the funds have already told the Association they cannot consider raising benefits for keratoconus contact lenses without a list of accredited contact lens fitters for keratoconus. The

Optometrists Association of Australia has so far failed to act on our requests to create such an accreditation.

Faced with this Catch-22 situation, the Association is now considering a short to medium term strategy of putting more pressure on the private health funds to raise their rebates on contact lenses for keratoconus while seeking a long term solution supported by the medical associations working in this field.

We are finalizing a letter for patients to send to their health funds explaining the nature of keratoconus and why rebates for these contact lenses should be higher than currently offered. Hopefully, this sort of letter campaign will force the funds to reconsider their policies on these specialized contact lenses. A draft letter has already been written with the assistance of the US National Keratoconus Foundation and will be posted on the Keratoconus Australia website early in the new year.

We urge all members to download the letter and modify it to their requirements and send it to their health funds. Obviously this does not help those without private health insurance. We will try to compile a list of state-based assistance available for keratoconus patients in 2008. Volunteers to help with this task in their own state would be welcomed.

The situation is all the more vexing as new contact lens designs are appearing for keratoconus that offer the hope of greater comfort and long wearing times – but they are unlikely to be cheap.

## **OPTOMETRIST TRAINING**

In our 2006 report, we explained the link between poor rebates and warranties on contact lenses and the dearth of expert contact lens fitters for keratoconus. While the issue of warranties still requires more attention, the Association has launched an initiative to assist in the training of optometrists in fitting contact lenses on keratoconus patients.

Last year Keratoconus Australia, Melbourne optometrist Richard Vojlay and the Melbourne University, Department of Optometry and Vision Sciences, organized special clinics for final year (fifth year) optometry students to teach them more about keratoconus and how to best fit contact lenses on keratoconic eyes. And in a first for the Department of Optometry and Vision Sciences, the Association was invited to attend and present at a special lecture on keratoconus held in October 2006 following the contact lens clinics.

The clinics and lecture were extremely successful and greatly appreciated by the students and the head of the Department of Optometry and Vision Sciences, Professor Neville McBrien. Hopefully some of the students will go on to specialize in contact lenses and will take a particular interest in keratoconus. This would be welcome as there is a serious shortage of optometrists experienced in fitting the often complex lenses required for keratoconus patients.

Keratoconus Australia remains greatly concerned by the situation and agreed to support the Department of Optometry and Vision Sciences in organizing another series of clinics and a special lecture in 2007.

Four clinics were held at the Department of Optometry and Vision Sciences in August 2007 for the final year optometry students. To ensure the success of these clinics,



the Association organized for volunteers with keratoconus to attend as patients.

A lecture on the practical aspects of treating keratoconus patients was again held in October 2007. Belinda and myself from Keratoconus Australia assisted Mr Vojlay with the presentation, which proved a lively and interactive affair and much appreciated by the students.

As foreshadowed in last year's report, the lecture notes on all aspects of keratoconus and its treatments prepared by Mr Vojlay for these clinics are now being compiled into a format useable by patients. We hope to make these available both on our website and in printed format in 2008.

Hopefully optometry schools in other states will also consider conducting specialized clinics on keratoconus for students.

## **DATABASE**

The Association continues to develop its database to provide better and more easily accessible information to users. We have now entered most of the data from our health surveys sent out with new member kits and will be using that data to further support our case for higher benefits for contact lenses.

Our new logging function is facilitating data entry and assisting with member tracking. This enables us to provide more timely support, which is essential at present given the small number of volunteers available to assist with Association work.

Given our reliance on email as a means of communication, we do appreciate if members provide us with their new email addresses when they change them.

## **WEBSITE**

The Keratoconus Australia website remains the primary contact point for most people seeking assistance with their keratoconus issues. The online resources are a handy means for people from Australia and around the world to find information about different aspects of keratoconus and its treatment. 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.

The website is becoming increasingly popular as shown by the significant rise in hits over the past year. These have grown from about 60 a week over recent years to almost a 100 per week in 2006-07. Return visits were also up from about 25% of hits to close to 30%. 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 timelier manner than at present.

The online forum provides members and others with a means of asking questions, which we can quickly respond to or pass on to medical practitioners for comment. We have received a number of requests for a more interactive form of chat list to enable members to contact each other directly. Although the web services now available have made this type of forum easier to set up, the real issue remains monitoring the exchanges. Keratoconus Australia simply does not have the resources to monitor adequately this sort of chat site. We therefore advise people wishing to

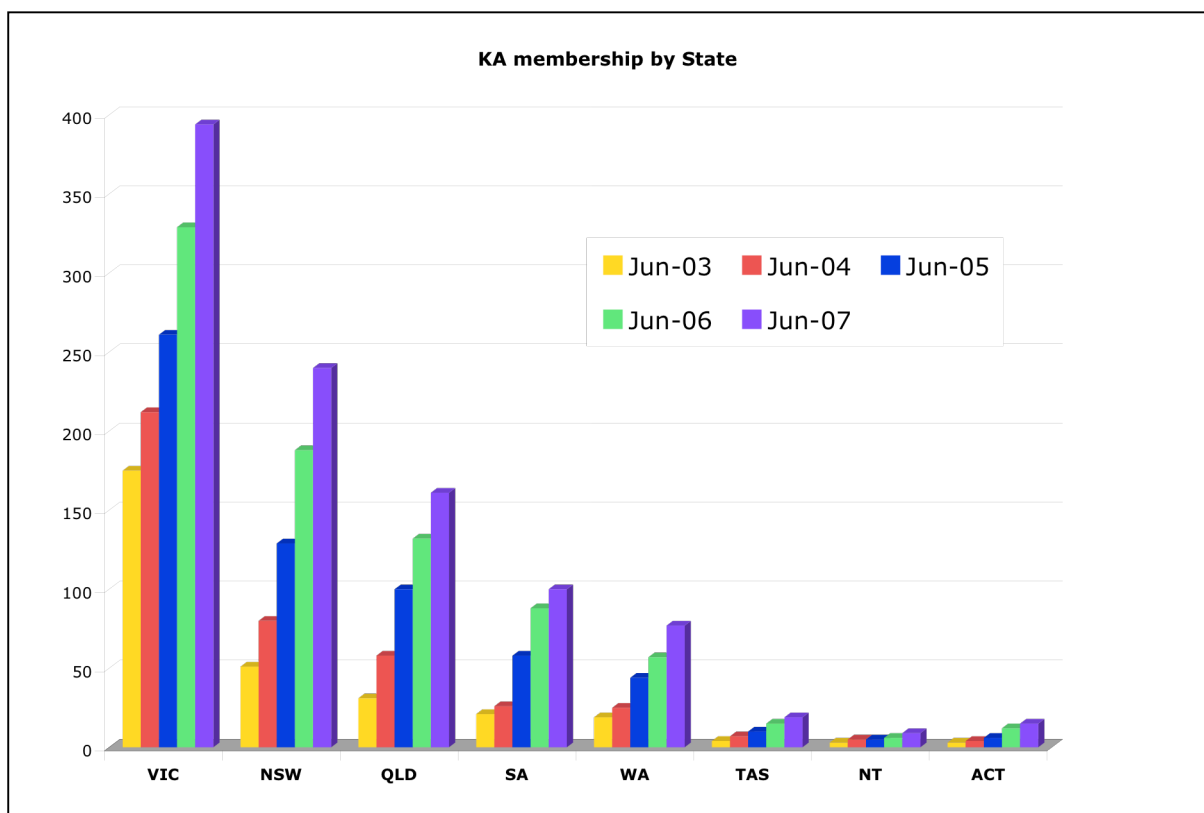
have direct contact with others with keratoconus to join the kc-link, an international chat list created by the US NKCF and moderated by both the foundation’s executive director, Cathy Warren and a team of consulting ophthalmologists and optometrists who specialize in keratoconus.

Unfortunately these chat lists can be infiltrated by people seeking to disrupt the general flow of information and exchange of ideas as we all discovered recently. There is also an issue of marketing material being posted disguised as “information from patients”. Finally, many participants fail to consider the privacy implications of participating in such open forums which deal with sensitive personal medical information.

Last year we raised the issue of adding patient stories to the website to allow others to benefit from your experiences with keratoconus. We received no response to this call. We are still hoping to launch a section on the website devoted to patient stories and experiences – written anonymously if necessary – which we believe could benefit others. Let us know if you would like to participate.

## MEMBERSHIP

Keratoconus Australia membership continued to grow in 2006-07, albeit more slowly than the previous year. On June 30, 2007 the Association had a total of 1016 members registered or an increase of 23% above the total one year earlier of 827.



Victoria remains the centre of the Association’s membership base with some 394 members located in that state or 39% of the total. But the rate of increase in Victorian members declined to just under 20% last year compared to almost 28% in NSW. NSW now accounts for 24% of Keratoconus Australia membership followed by

Queensland (16%), SA (10%) and WA (7.6%).

## **EVENTS**

The Association organized only one seminar in the 2006-07 financial year – an update on the two research projects mentioned previously which was held in May 2007. The seminar was again well attended and gave an opportunity to both patients and eye-carers to hear more about progress in the corneal collagen crosslinking trial and the outcome of the keratoconus inheritance study. 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 \$256 collected in door donations and another \$577 earned from video sales.

For the first time, the Association also made the seminar available in audio podcast form on our internet site – enabling people to either listen to the video soundtrack through their web browser or download the audio file to their MP3 player. We will continue to make these audio podcasts available soon after seminar videos are completed.

## **STATE SUPPORT GROUPS**

As mentioned last year, the Lions Club of Sorrells (Hobart) finalized their keratoconus brochure in November 2006 and provided us with a large print run for distribution. We are very grateful for the efforts of all concerned and have been distributing the brochures to patients and eye-carers on request.

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**

A key plank in the Keratoconus Australia mission statement 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. Free audio podcasts of our seminars will be put on the website regularly and are available from the Association on request.

Much of this material is included free in an information kit provided to all new members and anyone contacting the Association.

Lecture notes from the optometrist training clinics mentioned earlier will also be made available soon in pdf and printed form.

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.

## **INTERNATIONAL RELATIONS**

The Association continues to work with overseas support groups as part of its efforts to ensure that Australian patients maintain a voice in the global keratoconus community.

In 2006-07, the Association made contact with the Italian keratoconus support group and agreed to include links to each other's websites.

We also continued our close collaboration with the US NKCF which kindly supplies us with their patients booklets on keratoconus and corneal transplants at nominal cost. These are distributed free to our members.

The NKCF has also assisted in our contact lens campaign by allowing us to use parts of their letter to insurance companies for our own rebate campaign.

Finally, I met with the French keratoconus group in July 2007 in Paris and held wide ranging discussions about support work and how the international groups can cooperate. One suggestion we hope to implement soon is to create an international website which would provide information for travelers such as where to find assistance with keratoconus-related problems while overseas and the names of the most commonly-used contact lens products (e.g. cleaning and soaking solutions) in the local languages.

These contacts are already bearing fruit as we are now using our foreign language skills to assist patients coming to Australia from overseas. We have already provided contact names to people from France in recent months who were referred to us by the French keratoconus group.

We have also provided support to people in Switzerland, the UK, Egypt, Pakistan, Kenya, New Zealand, Mexico, Belgium, Papua New Guinea, Malaysia, Northern Ireland and Vietnam.

Finally I had hoped to attend the first European Keratoconus Conference in Toulouse on November 29 in particular to meet up with representatives of other European support groups from Britain, Germany Italy etc who will be attending. But this proved impossible due to work commitments. Perhaps next year.

## **THE COMMITTEE**

The 2006-07 year proved difficult for the committee with all members being restricted in their volunteer work for the Association by increasing paid work and family commitments. Committee members have tried their best to provide the level of support that we believe keratoconus patients deserve. We have also tried to act as an effective advocate on behalf of the rights and interests of keratoconus patients and their families. We believe that in spite of a serious lack of resources, we have still managed to make some significant progress in the past year.

But we desperately need more input from members prepared to work hard on the committee and our projects. We feel like we are now battling to keep the Association going.

If you do have time to work for the Association on a regular basis and would like to join the committee of management, please contact us. But we now need more than ideas and a helping hand. We need people prepared to make a significant time investment in launching new projects and maintaining the existing structures.

I would like to conclude by thanking all our committee members for their contributions throughout the year and the hard work they have done – often under severe pressures of work and family.

A very special thank you to Liz Bray, who resigned at the end of the 2006-07 year as Treasurer after almost four years in the position. Liz initially agreed to take up the position on a temporary basis until we found someone to replace her. She worked tirelessly to reorganize our accounts and set in place reporting systems that have ensured the sound financial basis of the Association going forward. As you can see from our financial report for 2006-07, she leaves the Association in a very healthy financial state. But Liz also made many other fine contributions to the committee and the Association and her insights, intelligence and good humour will be sorely missed by all of us. Thank you Liz and all the very best to you and your family for the future.

I would also like to thank our secretary Belinda Cerritelli for her efforts to keep the Association operational and to our committee members Marisa Cerritelli and Laura Towers who have provided invaluable support to the Association throughout the year.

Thank you for attending the 2007 AGM

Larry Kornhauser

President