

**Annual General Meeting
Thursday 30th November, 2006
6:00pm, Victorian College of Optometry
Secretary report**

It is very hard to believe that another year has flown by!

In my report, I will echo much of what Larry has already covered while focusing on some of the Association's significant achievements. Phone support continues to be an important feature of our work, though admittedly it's gradually decreasing as people increasingly opt for email. By and large, people with keratoconus – across Australia – who phone the Association generally request information about eye-carers experienced in fitting contact lenses. Phone support provides an invaluable opportunity for people to have their concerns about their condition heard, and often anxieties put to rest. It's rare that a phone call lasts less than half an hour! On a few occasions in the past year, I have met up with keratoconus patients from interstate who have come to Melbourne and had never spoken to – let alone met – someone with the condition. Numerous people have requested information about the new trial, corneal collagen cross linking treatment (C3-r) being conducted in Melbourne, which Larry has discussed in detail. I'm pleased to present a progress report on the study on behalf of Dr Christine Wittig, the lead researcher.

Progress Report: Corneal Collagen Cross-linking (C3-R) for keratoconus

Dr Christine Wittig

Introduction:

Between March and September 2006, I have been (and still am) working as a research fellow at the Royal Victorian Eye and Ear Hospital (RVEEH) in Melbourne conducting a randomised controlled clinical trial on the effectiveness and safety of Collagen Cross-Linking in treating patients with keratoconus. Keratoconus is a degenerative disease which leads to a thinning and cone-like protrusion of the inferior and central part of the cornea and can therefore lead to severe vision loss. It is the most common reason for a corneal transplant in young patients.

If the new treatment for Keratoconus proves effective it promises to be a simple, cost effective and minimally invasive way of stopping the progression of the condition and therefore may prevent many of these people from needing a corneal

transplant. Fewer transplants needed for keratoconus patients at the same time mean that more corneal donor tissue is available for patients with other debilitating eye conditions.

Outcomes of the program of research

My research at RVEEH is the first of its kind in Australia and to our knowledge, the first randomised controlled trial of this technique carried out anywhere in the world. It is expected that this study will confirm and prove the promising results from several case studies in Europe and lead to a deeper understanding and wider availability of the treatment.

As of the end of Sept 2006, I had, supported by her supervisors, fully established the research project and enrolled 30 participants, despite the very strict recruitment and enrolment criteria which are necessary to make the trial scientifically meaningful. Of the 30 recruited participants 13 were randomised into the treatment group, 11 of which have already undergone the Cross-Linking procedure. One month follow-up examinations have been performed on 10, and three month follow-up on 5 participants. Preliminary results show very encouraging trends with all treated participants showing stabilisation of their keratoconus, some have experienced measurable improvement in their condition. Current plans are to enrol another 70 participants over the next 1 year and follow them up for at least 5 years to evaluate the long-term outcomes.

The research project has attracted high interest in the general population, another sign of how common and important the condition is, and the research project has received national media coverage. In the meantime, the study has now become a multi-centre trial involving researchers at the Queensland Eye Institute. Also, eye centres in Tasmania and Western Australia have expressed interest in becoming part of the trial. However, the cooperation of these sites has not been finalised yet.

Over the next six months, I also plan to conduct several in-vitro trials, including the evaluation of enzyme resistance of cross-linked versus untreated normal and keratoconic human corneal buttons.

Proposed follow-up action in Australia and your country

It is intended that the project will continue to run until the end of 2011 in Australia. Research into the treatment continues to take place in many countries around the world and, in particular, in Dresden, Germany, where the procedure was first developed and where the results of this randomised trial are awaited with great anticipation. Therefore, this project will ensure that the RVEEH makes a considerable contribution to German as well as international research in this area.

In March, we were fortunate to become a supporting member of Vision 2020. Vision 2020 Australia is an umbrella group for eye health-related organisations in Australia. It was established in 2000 and is part of a worldwide initiative of the World Health Organisation. Vision 2020's aim is to prevent avoidable blindness and to improve vision care throughout Australia. It is part of a national partnership of over forty Australian based organisations involved in local and global eye care service delivery, health promotion, education and development, low vision support, vision rehabilitation, eye research, professional assistance and community support. This partnership has been, and will continue to be, fundamental in assisting Keratoconus Australia in awareness raising, advocacy efforts and provides a direct link to other vision organisations.

Earlier this year Marisa and myself, attended Vision 2020's second Member Forum in Adelaide attended by the South Australian Minister for Health, the Hon John Hill MP. The focus of the Forum was on the implementation of the National Framework for Action aimed to promote eye health and prevention of avoidable blindness.

The first part of the forum included a workshop on how to create effective advocacy campaigns. The message here was simple: have a clearly articulated issue, understand who is involved and be diligent about how you deliver your point. This is particularly relevant to Keratoconus Australia with regards to pushing for better rebates on contact lenses and urging optometrists who have less experience in treating keratoconus to refer their patients on to more skilled optometrists in this area.

Following from this was the inaugural meeting of the National Advocacy Network where the group met face to face for the first time and were given the opportunity to clarify the purpose of the network, identify collaborative advocacy initiatives and establish network communications. The remainder of the afternoon was spent discussing the National Framework for Action to promote eye health and prevention of avoidable blindness. This framework is a document to help coordinate action by governments, health professionals, non-government organisations, industry and individuals to work in partnership to improve eye care. It was a most insightful session where KA advocacy-novices we were given the opportunity to work and interact with experts in eye-care.

It was an invaluable networking occasion to meet people from many other vision organisations including, Seeing Eye Dogs Australia, Retina Australia, Vision Australia, Optometrists Association Australia, Centre for Eye Research Australia and the Institute for Eye Research. This Forum opened up avenues for Keratoconus Australia to conduct information seminars in SA and has enabled us to better understand how other organisations function that will assist KA to expand its operations.

Also present at this meeting was Joe Shakman, Executive Officer of the Optometrists' Association of Australia. Joe was pleased to hear of the work of Keratoconus Australia and was interested to further discuss our concerns around appropriate fitting of specialised contact lens for keratoconus and the associated costs. At this stage a preliminary meeting has been held where we were able to inform Joe of our key concerns and he has agreed to further investigate this.

Most recently, Vision 2020 have forwarded information compiled by us on contact lens subsidy to a contact at Department of Health in Canberra. We understand that the CEO met last week at the Department and we are awaiting feedback and the avenues we will need to follow to pursue this issue.

Other important relationships include:

1. Colin Clements, optometrist who has agreed to provide monthly updates on the latest research in keratoconus.

2. Gill Cochran, PhD research student is developing a model for support services for children with low vision. Gill informed us of the Statewide Vision Resource Centre who provide advice and equipment to schools. Useful reference for us to be aware of and to refer members to.
3. Charity Jenkins, database developer for the keratoconus survey data entry and analyses. As Larry eluded to, this will be instrumental in securing higher rebates and reducing costs for contact lenses as no other data of this kind exist in Australia.

There's a snapshot of some of our achievements of 2005/06.

Official Committee Meetings were held on (other meetings in between)

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|---------------------------------|-----------------------------|
| 15 th August 2005 | 1 st March 2006 |
| 12 th September 2005 | 11 th March 2006 |
| 17 th October 2005 | 5 th April 2006 |
| 3 rd December 2005 | 20 th May 2006 |

I too would like to extend a very warm thank you to the Committee of Management. Our working relationship is tight knit. We all work on borrowed time and there's no doubt that if any one of us are unable to continue our involvement with Keratoconus Australia there's every good chance that it would have detrimental effects to the Association's longevity. We wish everyone well in 2007.

Thank you.

Belinda Cerritelli
Secretary