



The Hon Tony Abbott MP
Minister for Health and Ageing
House of Representatives
Parliament House
Canberra ACT 2600

30 April 2007

Dear Minister Abbott,

Following our brief exchange at the Vision 2020 Australia Members' Forum on March 27 in Canberra, I am writing to bring to your attention anomalies in the current health care system which limit the ability of people to obtain adequate treatment for vision loss caused by keratoconus, a serious, incurable and potentially disabling corneal disease. Thank you for the invitation to consider investigating this important issue.

Specialised contact lenses are the primary remedy for keratoconus-related vision loss and Australia is a world leader in many aspects of their development. Yet ironically, many patients are unable to access either affordable contact lenses for keratoconus or eye health practitioners experienced in this field.

This contrasts to the situation in other countries, for example New Zealand and the United Kingdom, where keratoconus is recognised at government level as a serious eye condition meriting special attention. Both countries have schemes in place to subsidise the cost of contact lenses to patients – many of whom need to change their contact lenses several times a year if their condition progresses rapidly.

Australian Government support for Australians with keratoconus would also seem appropriate. Unlike many common and debilitating eye diseases (cataracts, glaucoma, age-related macular degeneration) keratoconus is generally diagnosed in early adolescence. This means people with keratoconus face a lifetime of optometric and ophthalmologic treatment for vision loss caused by the disease.

Keratoconus and treatments

Keratoconus (or "conical cornea") is a degenerative disease of unknown origin that leads to a progressive thinning and bulging of the cornea. It is typically bilateral, although it usually advances at different rates in each eye. It is estimated to affect at least 10,000 people in Australia – but ophthalmologists say that figure could be as high as 40,000.

Keratoconus is characterised by asymmetric astigmatism and spectacles cannot correct the resulting severe vision distortion, except in the very early stages. Specialised contact lenses, usually rigid gas permeables (RGPs), can achieve remarkable results in restoring functional sight to people who would otherwise be effectively disabled by keratoconus. About 15-20% of patients with severe keratoconus and who cannot wear contact lenses for other reasons will require a corneal transplant, which is usually successful in restoring at least useable vision. Keratoconus patients comprise the single largest group of corneal graft recipients.

The early onset of keratoconus and its often rapid advance during these first years means keratoconus can impact heavily on a person's ability to study and complete secondary or tertiary education, enter the workforce or maintain employment, cope with the demands of raising a family and in extreme cases, even to perform basic self-care functions.

Keratoconus Australia Inc

Keratoconus Australia Inc (KA) is a not-for-profit association created to prevent and control the eye disease, keratoconus, and visual impairment caused by keratoconus. KA is a self-funded national body operated entirely by volunteers. KA provides support for people with keratoconus and their families through public information seminars, individual phone and email support. We promote research into the causes, prevention and control of keratoconus and act as a representative body on behalf of people with keratoconus. We currently have 980 members Australia-wide. (Further information at: www.keratoconus.asn.au).

The issue

The complex, customised contact lenses used to correct for keratoconus are not recognised in Australia as a medical device. Nor are optometrists apparently compensated adequately under the current Medicare scheme for the time they spend ensuring RGPs are fitted correctly to avoid further damaging an already fragile cornea weakened by keratoconus. So when prescribed by a contact lens fitter highly experienced in this field, RGPs designed for keratoconus patients are very expensive, ranging from \$250 to over \$1,000 *each*, depending on their design. Even when patients are prepared to pay this cost out of necessity, they often have difficulty finding a contact lens fitter experienced enough to prescribe the lens correctly.

KA believes that the high cost of these lenses, linked to the shortage of optometrists experienced in fitting them, is creating severe and unnecessary hardship for many people with keratoconus in Australia. We also believe that this situation is probably resulting in unnecessary corneal transplantation for keratoconus in a context of an acute shortage of donor tissue. This problem is exacerbated for people living outside of the major capital cities.

Implications (summarised)

- People often try to buy RGPs at the lowest price rather than from experienced contact lens fitters who generally charge more to compensate for the time needed to achieve a correct fit. Optometrists inexperienced in fitting specialised RGPs often do not spend the necessary time on the fitting process. These optometrists generally charge less per lens but often do not get an appropriate fit. It is a time consuming process and there are simply no short cuts.
- Badly fitted lenses can cause ulcers, and eventually lead to scarring that can necessitate a premature corneal transplant at considerable cost to patient, health funds and/or the community. (Most people still require glasses or contact lenses to achieve best vision after a corneal transplant anyway.)
- Poorly fitted lenses discourage people from wearing them and incorrectly persuade them there is no non-surgical solution to their vision problem. This has been shown to result in some people failing to complete their education or to obtain/maintain employment, and then becoming depressed and eventually dependent on public aid and disability pensions etc.

KA acknowledges that subsidised RGPs are available at the state level from some eye hospitals and optometry teaching colleges. However, these lenses are often fitted by eye health practitioners with limited experience with keratoconus and can result in the negative outcomes described above. People outside the major capital cities have virtually no access to either subsidised lenses or experienced contact lens fitters for keratoconus in their areas.

Private health funds do not recognise the medical status of RGPs for keratoconus and treat contact lenses as cosmetic alternatives to spectacles, offering lower rebates on them than for spectacles or off-the-shelf contact lenses. A survey of our members found that in these circumstances there is little or no incentive for people with keratoconus to take out ancillaries private health insurance cover.

Requested action

KA appreciates the complexity of this matter. However, we believe that the Australian Government is ideally placed to coordinate efforts required to address this significant issue, which are likely to include **reclassifying contact lenses as medical devices for people with keratoconus**. Key objectives of any scheme would include providing:

- specialised contact lenses for keratoconus at affordable prices
- best-fit lenses by contact lens fitters experienced in keratoconus
- greater access to quality care for people outside of the major capital cities
- greater incentives for optometrists to specialise in this field
- funding to allow the appropriate skilling of optometrists in cooperation with optometrists representative bodies
- measures to prevent inexperienced optometrists from dabbling in contact lens fitting for keratoconus at the expense of patient welfare
- a review of Medicare rebates for contact lens fitters specialising in keratoconus to end unrecovered costs being passed on to patients in the form of higher costs for RGP lenses.

Anticipated outcomes

There are many immediate and obvious benefits for both the community and individuals suffering real disadvantage from a lack of access to affordable vision correction and optometrists experienced in fitting RGPs to keratoconus patients.

We believe that a relatively small investment in lowering the cost of contact lenses for keratoconus and upskilling optometrists in the management of keratoconus could have significant social and economic benefits such as:

- better visual outcomes for a large proportion of people diagnosed with keratoconus. That would also result in a significant reduction in the number of those despondent about their chances of obtaining high quality and affordable non-surgical treatment options
- better educational outcomes for adolescents (and others) with keratoconus
- greater potential for people to obtain and maintain regular employment. This should reduce welfare payments and increase income tax revenue
- lower workforce absentee costs by reducing the number of people who have recurring issues with their vision caused by inappropriate contact lenses or less than optimal outcomes from corneal transplants
- a reduction in the number of corneal transplants performed which may help induce a fall in long waiting lists for those in need of corneal surgery

We would welcome the opportunity to provide additional supporting information for these proposals, or to discuss these issues in person. Keratoconus Australia is committed to improving outcomes for people with keratoconus and their families. We hope other stakeholders, including the Australian Government, will join us in the search for better treatment, management and support options for this potentially disabling eye condition. Our contact details can be found below.

We look forward to your reply.

Yours sincerely

Ms Belinda Cerritelli
Secretary

Mr Larry Kornhauser
President

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