



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

# **WHY KERATOCONUS PATIENTS NEED HIGHER OPTOMETRIC BENEFITS**

**Ancillary Committee Meeting**

**MBF**

**Level 18**

**50 Bridge Street**

**Sydney**

**8 December 2004**



## What is Keratoconus?

Keratoconus comes from Greek and literally means **conical cornea**. It is a **degenerative** disease that leads to a **progressive thinning of the cornea and causes asymmetric astigmatism**. Keratoconus is almost always bilateral, although it usually progresses at different rates in each eye. **Its causes are largely unknown and it is incurable. All treatments are therefore directed at countering vision loss caused by the disease.**

**Keratoconus is generally diagnosed in teenagers and young adults.** It arises when the middle of the cornea thins and gradually bulges outward, forming a rounded cone shape. This abnormal curvature changes the cornea's refractive power, producing moderate to severe distortion (astigmatism) and blurriness (nearsightedness) of vision. Keratoconus may also cause swelling and a sight-impairing scarring of the tissue.

**At first, people can correct their vision with spectacles.** But **as the astigmatism worsens, they must rely on specially fitted contact lenses** (usually rigid gas permeable lenses) to reduce the distortion and provide better vision. Finding a comfortable contact lens can be an extremely frustrating and difficult process. But it is crucial because a poorly fitting lens can further damage the cornea and make wearing a contact lens intolerable. **Advanced keratoconus can result in severe vision loss and legal blindness.**

**Keratoconus generally advances from the teen years to the mid-thirties, sometimes extremely rapidly. In about 10 to 20 percent of cases, the cornea will eventually become too scarred or too steep to tolerate a contact lens. If either of these problems occurs, a corneal transplant may be needed.** This operation is successful in more than 90 percent of those with advanced keratoconus. Several studies have also reported that 80 percent or more of these patients have 6/12 vision or better after the operation. But **the majority of transplant patients still require glasses or contact lenses for best vision.**

Studies indicate that keratoconus stems from one of several possible causes:

- An inherited corneal abnormality. About 7 to 10 percent of those with the condition have a family history of keratoconus.
- An eye injury, i.e., excessive eye rubbing or wearing hard contact lenses for many years.
- Certain eye diseases, such as retinitis pigmentosa, retinopathy of prematurity, and vernal keratoconjunctivitis.
- Systemic diseases, such as Leber's congenital amaurosis, Ehlers-Danlos syndrome, Down syndrome, and osteogenesis imperfecta.

**Keratoconus** is the most common corneal dystrophy and **is estimated to affect one in every 2000 Australians.** This indicates some 10,000 people could have keratoconus. However, that figure depends heavily on the diagnostic criteria used; the rate of keratoconus in the population is also being revised upwards as better detection techniques indicate that many more people could have a "forme fruste" or very mild keratoconus that hardly affects their vision. Some medical sources believe that when these cases are included, up to 40,000 Australians may have some form of keratoconus.



## Who is Keratoconus Australia?

**Keratoconus Australia is a not-for-profit charitable association** formed and operated by people with the eye disease keratoconus. It was incorporated in April 2000 with the expressed aim of providing assistance in all forms to people with keratoconus and their families. **It is run by volunteers and is entirely self-funded** from donations and sales of its products. **KA's committee of management is comprised only of people with keratoconus or the parents of children with keratoconus.** The Association currently has **500 full members around Australia.**

## OUR AIMS

The purposes of Keratoconus Australia Inc are to prevent and control visual impairment caused by keratoconus or caused by incorrect diagnosis or treatment of keratoconus by, without limitation:

1. raising the awareness and understanding in the medical and general community of keratoconus, its early signs and its effects;
2. promoting research into the causes, prevention and control of keratoconus; and
3. as incidental activities, acting as a representative body on behalf of sufferers of keratoconus and providing, where necessary, counselling, support and referrals to the sufferers of keratoconus and their families.

## OUR WORK

### Support

Keratoconus Australia is doing **extensive work in the area of supporting people with keratoconus** and their families. Over the past year, the Association has fielded more than **180 requests for support** of different kinds.

A **breakdown** of the type of support provided shows that assistance fell broadly into the following categories

1. Referrals to experienced eye-carers: after initial diagnosis and for second opinions (45%)
2. Surgery related issues (15%)
3. Support from other keratoconus patients (15%)
- 4. Responding to complaints about high cost of contact lenses and other treatments (15%)**
5. Answering general questions about keratoconus, contact lenses and related subjects (10%)

### Raising community awareness about keratoconus

Keratoconus Australia also:

- maintains a **website** at **[www.keratoconus.asn.au](http://www.keratoconus.asn.au)** that plays a key role in enabling people to source information about keratoconus and the Association, and to ask questions and seek support.
- publishes a regular **electronic newsletter** for distribution to members, supporters and eye-carers
- holds regular **information seminars** open to anyone with keratoconus, eye-carers and the general public. Keynote speakers are generally recruited from eye-carer ranks to explain a particular issue relating to keratoconus.



Keratoconus patients are provided with an opportunity to discuss their own experiences through the Patient's Story segment. Those attending are given ample time to question the speakers and mingle over coffee and cake afterwards.

**Topics** already covered at these information seminars include

- Beyond diagnosis of keratoconus
- Parenting and keratoconus
- Contact lenses – how they work and their management
- Various aspects of corneal transplants
- Corneal donations and eye banking
- Intacs and other new surgical techniques
- The history of corneal transplants and keratoconus treatments

**Videos** of the seminars are available for sale and provide a useful resource for people living interstate and in country areas.

- distributes **booklets** published by the US National Keratoconus Foundation on keratoconus and corneal transplants.
- supports efforts to increase **organ donation** rates and distributes material on behalf of the Australian Organ Donor Register
- is developing a **national registry and database** on Australians with keratoconus designed to assist in networking individuals and groups within Australia, and to form a basis for future research work.

The Association maintains informal **links** with Vision Australia, Vision 2020, the Optometrists Association of Australia and the Victorian College of Optometry. We also **cooperate with overseas groups** like the US National Keratoconus Foundation, the UK Keratoconus Support group and the French L'Assoc Kératocône.

## **Keratoconus Australia contacts**

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## Keratoconus and private health funds

### Why keratoconus patients need special treatment

- **Unlike most common and serious eye diseases** (cataracts, glaucoma age-related macular degeneration) **keratoconus is generally diagnosed in adolescence.**
- Its causes remain unknown and **it is incurable.** This means people with keratoconus face **a lifetime of optometric and medical treatment for vision loss** caused by the disease and at least **annual optometric reviews.**
- The disease generally **advances – sometimes very rapidly - for at least 20 years** before often stabilizing. However studies show that further deterioration occurs in people after 50 years of age. This means **patients are required to change their optical prescriptions regularly** – sometimes several times within a year.
- **Glasses are useful only in the very early stages** of keratoconus; thereafter **contact lenses (usually rigid) are the only means of maintaining functional vision.**
- Because of the early onset on keratoconus and its often rapid advance during these early years, **keratoconus can impact heavily on a patient's ability to study and complete education qualifications, choose and start a career, maintain a job, cope with the demands of raising a young family and in extreme cases, even perform basic self-care functions.**
- Because of the sensitivity of a keratoconic cornea, **most patients wearing rigid contact lenses have a limited wearing time.** This generally ranges from 8-14 hours a day. As a result, **they often require glasses too,** in order to maintain some, if poorer quality, vision at other times.

For all of these reasons, **contact lenses used to correct vision loss caused by keratoconus must be considered as an essential medical device** that in many cases allows the wearer to maintain functional vision. Without them many keratoconus patients would be **effectively disabled. About 60% of our members wear contact lenses.** Extrapolated to total keratoconus figures, that implies **a population of some 6000 keratoconic contact lens wearers in Australia.**

The **high cost and low rebates on complex contact lenses** for keratoconus, **can lead to a number of perverse outcomes** for the patient and the community:

1. **Because of their high cost, people often seek to buy them at the lowest price rather than from higher-priced experienced contact lens fitters.** Consequently they go to the chain optometrist stores where optometrists have little experience in fitting lenses for keratoconus and spend little time on the fitting process. These optometrists generally charge less per lens but often don't get a very good fit.
2. **If the contact lenses do not fit correctly, they can cause ulcers, and eventually lead to scarring that can necessitate a premature corneal transplant** (at considerable cost to patient, health funds and the community). Most people still require glasses or contact lenses after a corneal transplant anyway.
3. **Ill-fitting lenses can discourage people from wearing them and make them believe there is no solution to their vision problem.** They can then fail to complete their education, find it difficult to obtain or maintain employment etc, become depressed and eventually dependent on public aid and disability pensions etc.



Based on current rebates for rigid contact lenses, **we currently see no reason for people with keratoconus to take out ancillaries health insurance.** In fact our survey results confirm that virtually all respondents already believe **private health insurance is poor value for money.**

## Results of Keratoconus Australia health rebate survey

Keratoconus Australia recently conducted a survey of a random sample of 170 members. Key results included:

### Sample demographics

- >75% rely on contact lens for visual correction
- only 25% wear glasses to correct for keratoconus
- >60% specifically require rigid gas permeable (RGP) lenses

### Amount spent for adequate vision (average per year):

- contact lenses = \$272
- cleaning, disinfecting and wetting solutions = \$285
- 94% of participants must spend this to gain “useable” vision

### Private health insurance (PHI):

- 72% have PHI
- Of those who don't, 53% feel it is poor value for money and 47% believe it is simply too expensive for the rebates offered
- Average cost of PHI each year = \$1,338 (either hospital and/or ancillary cover)
- Average limit on benefits for optometric items = ~ \$180
- Average rebate per RGP lens = \$50-\$60

**At a cost of \$272 per lens, a person with keratoconus would need to spend around \$900 per annum on contact lenses to receive the full \$180 benefit.** Private health insurance funds generally refund more for a pair of simple reading glasses than for a pair of RGP lenses for keratoconus. **Not surprisingly, 92% of respondents are not satisfied with the current PHI rebates on lenses for keratoconus.**

**The responses to the question “Are you satisfied with the rebates offered to you for contact lenses (and glasses) by these insurers?” fall into four categories:**

#### 1. I don't wear contact lenses for “cosmetic” reasons, I need them to see!

*“No. I have to wear contacts or glasses to function. I am a camera person; sight is vital to me. I am not wearing contacts for the look. Need then to be able to see. I need contacts the same way someone needs an artificial limb to walk – It should be a medical rebate.”*

*“No. For people who can only have good vision through contact lenses there should be a 100% rebate because it is not ‘cosmetic’. 100% rebate is available for spectacles – but if you cannot get good vision from them, then you should be able to get 100% rebate for contact lenses.”*

*“No. The rebate provided is the same as someone who has contacts for aesthetic reasons or for less life changing reasons, where I need them to maintain any sight for a normal life. It is not because I can't read the paper up close but rather so I can see at all if I don't have them.”*



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*“No. As an essential item to function in a normal life – I believe the rebate should be more. My lenses are valuable to me, as an artificial limb to a man without an arm or a leg.”*



## 2. Given the nature of keratoconus, I need to change my contact lenses fairly frequently:

*“No. I had to experiment with several types of lenses in the last 3 yrs. I have extra cover but as I wear both soft and hard lenses for my right eye only, I am personally outlaying over \$1000 per yr on contact lenses. My coverage per year is only approx. \$130”*

*“... I don't understand how my insurance can cover me if I jump off a roof and break my arm, and yet not cover the difficulties experienced with constantly changing vision needs, that leave me legally blind if I don't buy new lenses, are not covered.”*

## 3. Private health insurance does not cover the cost of solutions

*“No. I'm offended every time I have to provide a script for a lens replacement. Rebate is poor and IT'S THE COST OF SOLUTIONS, WHICH IS A KILLER!! (No rebate) I HAVE TO WEAR LENSES TO SEE – I HAVE TO CLEAN THEM PROPERLY!!”*

## 4. Extras cover is poor value

*“No!! I'm furious!! I'm seriously considering dropping Extra's as it is poor value. Last Oct. 2002 I paid \$380 for 2 hard contact lenses and I received \$120 back from XXX. They have set limits 1 hard contact lens each.”*

*“No. 6 months into the year we are already \$500 out of pocket. We have no choice but to pay it so our son can see. (He is visually impaired without them)”*

*“No. I don't bother because the premiums would cost me more than the required rebates”*

## Recent focus groups with KA members about this issue indicated:

- Many only have PHI for optometric rebates and claim far less on other benefits
- Given inadequate rebates, a large proportion are seriously considering dropping out of ancillary cover and a smaller proportion are thinking about dropping out of PHI altogether
- If there is better recognition of the needs of keratoconus patients, members would be much more likely to stay with PHI
- If one fund were to offer increased optometric benefits for keratoconus patients, they would definitely change funds irrespective of other rebates offered





## What we would like from the private health funds

### 1. Rigid contact lenses defined as a medical device

We believe that private health funds should recognize the medical importance of rigid contact lenses for keratoconus. These lenses need to be reclassified as **medical devices** such as hearing aids or other medical prostheses.

### 2. Higher benefits for contact lenses and higher optometric limits

**Keratoconus Australia would like to see higher rebates for contact lenses** prescribed to keratoconic patients and **higher limits on claims**.

### 3. Benefits for contact lens solutions

We also believe **rebates should apply to contact lens solutions** too, as they are essential for the care, maintenance and comfortable wearing of contact lenses.

Current rebates for rigid contact lenses are lower than for reading spectacles in most cases. Limits on optometric claims are also about half those for so-called complementary treatments of unproven value like naturopathic and other remedies or so-called living well programs (weight loss, yoga etc). Some funds even provide rebates on sporting equipment items that may never be used after purchase.

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