# RETINA AUSTRALIA (ACT)
# MEDIA RELEASE

### BLIND CANBERRA CYCLIST TO RIDE FROM THE GOLD COAST TO SYDNEY

Blind Canberra cyclist Lindy Hou will set out from the Gold Coast next Sunday (18 September) on a week-long tandem ride to Sydney in a bid to raise funds for research into the as yet incurable inherited retinal disease, Retinitis Pigmentosa (RP).

Lindy, who has won a total of six Paralympic cycling medals, including a gold at the Athens Paralympic Games in 2004, will be accompanied by her Canberra 'pilot', Rosemary Robinson.

The pair will be joined in their 800-kilometre ride by Matt Formston, from Sydney, and John Domandl of Newcastle. Matt suffers macular degeneration while John, like Lindy, has RP. Both will also be assisted by 'pilot' cyclists.

Five other riders and a support group will accompany the three teams, who aim to finish their 'Ride4Retina' in Sydney on 24 September – World Retina Day.

Lindy, Matt, John and their sighted companions are seeking to raise awareness of and funds for Retina Australia, the national advocacy organization for people afflicted by genetic eye conditions, which has as its motto 'Fighting Blindness'. Retina Australia is targeting in particular a cure for blindness in children.

Lindy began losing her sight in the mid 1980s and has been legally blind since 1996. Unless a cure can be found, she will one day become totally blind.

The money she and her companions raise will goes towards research into and support for the estimated eight thousand Australians suffering genetic eye conditions. Retinitis Pigmentosa, Macular Degeneration, Stargardt Disease and Usher Syndrome are some of the many such conditions that afflict those Retina Australia supports.

Lindy is a member of and advocate for the Canberra cycling group Females in Training, FIT.

The Gold Coast to Sydney ride will be her fourth charity challenge. In 1999 and 2000 she cycled from Sydney to Leeton via Canberra and the Snowy Mountain to raise awareness for Retina Australia, then in 2009 she cycled from Cairns to Melbourne.

A full profile of Lindy is attached.

Those wishing to support Lindy and her team can make a tax deducible donation via the www.ride4retina.com website.

**Lindy and her pilot, Rosemary Robinson, will be available for interview and picture opportunities at 8.30 a.m. on Wednesday, 14 September, at 30 Morriset Street, Queanbeyan.**

**Note to electronic media: A 30-second radio Community Service Announcement promoting the**

**Ride4Retina is available for your use on request, as is a generic television CSA about children with Retinitis Pigmentosa.**

*Lindy Hou can be contacted on 0402 113 836*

*Issued by Robin Poke, President, Retina Australia (ACT), 0431 970 850*

**RETINA AUSTRALIA (ACT) Inc**
**FACT SHEET**

Retina Australia (ACT) Inc. is a member of the national body, Retina Australia (RA). Other members of RA are Retina Australia (NSW), Retina Australia (VIC) – which incorporates activities in Tasmania – Retina Australia (QLD), Retina Australia (WA) and Retina Australia (SA), which incorporates a newly-formed group in the Northern Territory.

Our role, and that of our fellow organisations, is to provide information and support to people and families affected by Retinitis Pigmentosa and other retinal dystrophies. We also raise funds for scientific research into the causes and prevention of these dystrophies.

Retina Australia is a member of Retina International, which has members and affiliates in more than 50 countries. It is estimated that more than 20 million people worldwide are affected by some form of retinal dystrophy.

Retinal Dystrophy is the term used to cover all inherited degenerative eye conditions affecting the light sensitive area of the eye known as the retina. The time of onset and the severity of these conditions vary, but all lead to significant vision loss or blindness. Some dystrophies also involve deafness and metabolic disturbances.

We in RA (ACT) are devoted to helping people in Canberra and the region manage the effects of loss of vision so that they can continue to lead fulfilling and productive lives. We are, essentially, a volunteer-based self-help group concerned with two main tasks:

- Ensuring that individuals and their families receive information that provides them with support and referral to specialist organisations so as to learn ways of managing the changing circumstances that will inevitably affect every aspect of their lives, and

- Raising funds for research into treatments and cures for Retinitis Pigmentosa and a range of other retinal dystrophies.

New members are referred to us by ophthalmologists, optometrists, doctors and specialist blindness agencies.

We provide new members with information and telephone contact. We also produce a regular newsletter that provides information on local events, research updates and other items likely to be of interest to members.

We have regular social meetings aimed at helping members stay in touch and new members to learn from existing members' experiences. Some people with failing vision are initially reluctant to seek the services and assistance they need. Our social events are designed to introduce them to others who have

been in their situation and can pass on the advice they need.

Research is intensifying throughout the world in an effort to halt the progress of retinal dystrophies and find a treatment or cure. In recent years more than 100 mutant genes have been identified as responsible for inherited degenerative loss of vision. Clinical trials have been conducted recently using drugs that inhibit the death of cells in the eye. There have also been gene therapy trials. A Melbourne-based consortium is making marked progress with research into a bionic eye, while a national Inherited Retinal Diseases Register and DNA Bank has been established aimed at identifying specific rogue genes. Stem cell research has also come into the retinal dystrophies equation. Scientists believe, based on the pace of current research, that a number of treatments will be available within three to five years.

RA (ACT) therefore wants to ensure that current and potential members do not have to experience a lifetime of anxiety and loss but, rather, that their lives will be brightened by new treatments and perhaps a cure for their condition.

Each piece of research on a particular form of retinal dystrophy has the potential to reveal more information about allied conditions. Scientists around the world meet regularly to discuss and reorient trends in research in their ongoing attempts to ameliorate blindness. To encourage research – and the funding of that research – is to promote a better future for all people with a retinal dystrophy

Genetic blindness is by far the major cause of blindness in young people, is second only to diabetic retinopathy as the cause of blindness in the working age population and as macular degeneration is responsible for virtually all blindness in the aged population. Other important groups are USHERS where loss of hearing is also involved and STARGARDTS where loss of vision starts in the centre of the retina and expands outwards.