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Newsletter for Retina Australia (ACT) Inc

EDITION 1-2011

March 2011

Message from our President

Welcome to the first Retina Australia (ACT) newsletter for 2011. We trust the year will be all that you want it to be.

With new year resolution in mind your committee has embarked on a planning program that we hope will help us raise more funds for research into inherited retinal diseases this year than ever before. As you will see below, our major 2010 function was a great success, but we want, if we can, to expand the fundraising program and raise just that little bit more every year. Any fundraising ideas members might have would be most welcome. Every little helps as we bid to find that elusive cure.

We are also keen to expand our membership. We know for sure that there are many more people in the ACT with an inherited retinal disease than there are members of Retina Australia (ACT) and we will again be raising awareness of our role and function through the media and whatever other means might become available. Again, input from members would be greatly valued.

This first edition contains the usual mix of news and research information. We hope you find it valuable.

ROBIN POKE

MEMBERS' "MONTHLY LUNCH DATE"

Where: West Belconnen Leagues Club

Hardwick Crescent
Holt ACT 2615
0419 201 815

Date: 1st Monday of the Month

Location: West Belconnen Leagues Club, part of the Canberra Raiders Sports Club Group is located in the heart of West Belconnen, close to bus stops and Kippax Shopping Centre, and has ample on-site parking.

In February nine members enjoyed a lovely lunch at this friendly club. Lunch time specials are very reasonable priced and the quality of the food was high.

Please let me know if you have a problem with transport and I will try to arrange for someone to pick you up.

Jan James

Secretary

Ph 6258 4823

NEWS ANNUAL FUNDRAISER

What a lovely afternoon at the Races!!!!!!!!!!



David and Rachel drawing the raffle



Yes it was full house in the Rich Rewards Room

What a wonderful afternoon at the races!!!!!!!!!! There were 14 tables and over 130 very happy guests at our annual Thoroughbred Park fundraiser. We again broke our attendance record, with more than 130 people enjoying the lovely lunch and helping us raise over \$4000. So thank you all for your generosity and friendship. All monies raised will go towards research into the prevention and cure of Retinitis Pigmentosa.

Guests from Women in Racing, Canberra Blind Society, Bungendore Carriage Driving Club, Bungendore CWA and Women in Racing again supported the event and we would like to say a big "thank you" to them all for their continued support.

The day would not have been such a success without the generous support of a number of local companies. MYER Tuggeranong donated wonderful gift baskets full of cosmetics for both the guys and the gals, Wai Wurri Furniture provided stacks of cushions, and Helms, Shaw's and Doonkuna wineries donated some of the regions' best wines. So be sure when next out shopping to support these warm-hearted corporate partners of ours. Murrumbateman Motel Hotel was also very generous, so if you want to treat yourselves to a luscious lunch or a lovely dinner in a great atmosphere just take a leisurely drive down the scenic Barton Highway, and a special thank you, too, to Last Stop Ambledown, Jennie and David Kilby's fabulous B&B.

The afternoon kicked off with a complimentary glass of bubbly followed by roast ham, turkey and vegetables and a selection of yummy desserts. Our wonderful Patron and great friend David Kilby entertained us as he always does and kept the afternoon rolling along with lots of laughter. There was the betting competition, which was won by the table hosted by Rachel Wallace, and a fun Fashions of the Field, Best Dressed Couple and Best Hat competition with all who took part looking stunning in their elegant racing clothes.

I would also like to take the opportunity to thank Bob Barlow and his staff at Elders Belconnen Real Estate, who so generously printed all the programs for the fundraiser. They also donate throughout the year their board room/meeting room for our committee meetings and AGM, and print our newsletters, too.

To top off a wonderful occasion, so many people came up to me as they departed and told me what a wonderful afternoon it had been, how much they had enjoyed themselves and that they looked forward to attending next year.

Thanks everyone!

Jan James
Committee

Website preparation

Retina Australia (ACT) will soon have its own, 'stand alone' website. The site, the URL of which is <http://www.raact.org.au/wordpress>, is being built by Chris Martin, the son of our immediate past president Faye Martin. Take a look: we think you'll be impressed. Ideas for additional information are naturally welcome.

Inherited Retinal Diseases Register Update

Dr John De Roach, Principal Medical Physicist at the Sir Charles Gairdner Hospital in Western Australia, has reported that the IRDR website now contains a document indicating the number of DNA samples stored, their origin, and any genes containing disease causing mutations that they believe they have identified.

The document can be viewed online at:
www.scgh.health.wa.gov.au/Research/InheritedRetinal.html

There are now more than 1300 DNA samples in the bank. More than 35 per cent of these originate from beyond Western Australia. The research team believe they are on track for

3000 samples by the end of the funding period, and they still have many expressions of interest to work through.

The DNA analysed has not shown a significant jump in this update, but the researchers are working on about ten different diagnoses in parallel using whatever strategies are appropriate for each diagnosis. It is expected that the numbers of disease-causing mutations identified will jump sharply for the next one or two updates of the website. These are carried out around every three months.

With the assistance of Retina Australia and Retina Australia (ACT) Dr De Roach has recently submitted to the National Health and Medical Research Council a request for funding of the IRDR and DNA Bank from 2012 to 2015.

Anyone for Grange?

Retina Australia (ACT)'s president Robin Poke noted with great interest an item in the 18 February edition of the *Canberra Times*. The report indicated that the Governor-General, Ms Quentin Bryce AC, was generously donating 100 autographed bottles of Grange Hermitage for charitable purposes.

Robin has therefore written to Government House requesting that our organisation be considered for receipt of a bottle. Grange Hermitage is regarded as the best and certainly most prestigious of Australia's red wines, and a bottle could net a healthy fundraising sum.

Robin also pointed out in his letter, just in case there was a surplus once all requests had been met, that our national organisation is made up of six other state or territory chapters, all of which, he was sure, would also welcome the Governor-General's generosity!

If you don't ask...

Audiovisual opportunities

On 11 October 2010 the *Health Report* on ABC Radio National featured a special item about eye problems. The presenter, Dr Norman Swan, visited one of the world's leading eye research centres at University College London and spoke to researchers about their latest work in the areas of glaucoma, macular degeneration and inherited retinal problems. There is an audio and transcript on the following link that you should find very interesting.

<http://www.abc.net.au/rn/healthreport/stories/2010/3030140.htm>

Four days later, on 15 October 2010, Canadian poet, journalist and essayist Ryan Knighton spoke with Margaret Throsby on ABC Classic FM. Knighton's recently published book, *Cockeyed*, reviewed in the last edition of this Newsletter, describes his life with RP and in particular the strategies he developed for 'getting by'. This engaging and sometimes funny interview can be heard on the following link:

http://mpegmedia.abc.net.au/classic/podcast/current/audioonly/mti_20101015.mp3

An Australian who has written a book about dealing with RP is Paul Funnell. Paul's book, *In Spite of My Eyes*, released by Antelope Publishing, is a valuable insight into how Paul, like Ryan Knighton, came to terms with his condition and developed strategies to deal with it. The book is available on request from Retina Australia (ACT) for a nominal donation.

We also have available for viewing a DVD, *Living With RP*, produced by RP Fighting Blindness in the United Kingdom.

Are You Game?

RP Fighting Blindness UK is arranging what is probably a unique fundraising event. On September 10th 2011 a 'mass' parachute jump will be held at Hinton in Oxfordshire. The jump is tandem and suits both sighted and visually impaired/blind people. Participants will be jumping with other RP Fighting Blindness supporters and experiencing the thrill of free fall before being safely landed by their tandem instructor.

Top Ten Foods for Eye Health

(Courtesy of the Retina New Zealand Newsletter)

A number of recent studies on nutrients and eye health have indicated that diet can benefit your long-term eye health.

- Load up on vitamins, minerals and antioxidants
- Eat very little saturated fat and vegetable oils (including margarine)
- Look for foods with vitamins A, C and E, zinc, and omega-3 fatty acids. Pick and mix to suit your budget, general health profile and personal tastes
- Choose leafy green dark vegetables like silver beet, spinach, dark salad greens
- Berries of all kinds: black, blue and red
- Orange, yellow and red vegetables: pumpkin, carrots, sweetcorn
- Orange, yellow and red fruit: citrus fruits, apricots, persimmon, papaya, plums, rockmelon, watermelon and tomato
- Cruciferous vegetables: broccoli, cabbage, bok choy and brussel sprouts
- Fish, particularly shellfish, and fatty fish like tuna, salmon and sardines
- Nuts: raw or dry roasted, walnuts, almonds, brazil and pine-nuts
- Beans
- Lean meat
- Olive oil: use to make dressings and for cooking

Green Tea May Ward Off Eye Disease

Substances found in green tea work their way into the tissues of the eye and could protect against common eye diseases like glaucoma, researchers say. The findings, published in a recent issue of the *Journal of Agricultural and Food Chemistry*, suggest that the substances, known as catechins, are absorbed by the lens, retina and other parts of the eye. Catechins are antioxidants thought to protect the body against damage from oxygen.

"Our results indicate that green tea consumption could benefit the eye against oxidative stress," the authors said.

Source: American Chemical Society, News Release, February 2010

Vitamin A Plus Lutein Can Slow Vision Decline in RP

Vitamin A and its precursor, beta-carotene, have long been known to have eye-related health

benefits, hence the saying that carrots are good for the eyes. In a new study conducted at the Harvard Medical School in Boston, researchers have found that daily lutein supplements in addition to Vitamin A can help slow progressive vision loss in non-smoking patients with retinitis pigmentosa (RP). Eliot L. Berson MD and colleagues studied a group of 225 non-smoking patients with RP. The participants, divided into two groups, were given 15,000 IU per day of vitamin A palmitate plus 12 milligrams of lutein or the vitamin A plus placebo. The groups were evaluated to disease progression over a study period of four years.

Those given lutein had a slower loss of vision in the mid-peripheral visual field. The researchers estimated that visual sensitivity could be preserved for an additional three to ten years with lutein supplementation. Lutein is a carotenoid found in dark green leafy vegetables such as kale and spinach, and in egg yolks. In addition to RP, lutein has also been studied in the eye disease macular degeneration (AMD) because the compound is highly concentrated in the macula of the eye. The average American consumes only 1 to 2 milligrams of lutein per day, less than the 6 to 10 milligrams thought to have the most nutritional and health benefits.

Coping

How To Avoid Falls

A fall can occur at any age, but unfortunately the older you get the more often they can happen. When people develop a vision impairment, falls are an ever-present worry, whatever a person's age. They can happen as the result of a simple trip, loss of balance, medication usage and weakness in the leg muscles. It is very important to discuss any falls you may have with your general practitioner and ophthalmologist. Your GP can assess your balance and muscle strength along with your overall health, and then offer you recommendations.

Having a fall shakes you up and makes you very wary about having another fall. It can reduce your confidence, leave you feeling very uncertain, and reluctant to get out and about as you once did. Often falls can be prevented by taking relatively minor steps such as changing your medication dosage, altering your glasses, or taking some exercise. Reducing risks in your home will help too.

Falls are often prevented by undertaking a regular form of exercise that improves muscle strength, balance and fitness. Discuss with your doctor if the exercise you are already taking, or are about to start, will prevent falls. Ask the doctor what type of exercise program is right for you.

At home there are several steps you can take to reduce the risk of a fall.

- Remove or secure mats and rugs
- Tape loose cords out of the way or use a multi-plug system
- Keep busy traffic areas in your house free of clutter
- Try non-slip mats or vinyl in wet areas such as the bathroom
- Install grab rails to help you in the shower or toilet
- Wear non-slip well-fitting shoes
- Store items you use regularly between eye and hip level
- Ensure you have plenty of lighting to help you see your way
- Have a telephone that is easy to reach if you should have a fall

- Keep up-to-date emergency numbers by the phone or stored in the phone memory
- Be aware of pets that could get in your way (this includes guide dogs!)
- When you are outside be wary of uneven or cracked pathways
- Take note of changes between concrete, cobbled or tiled areas outside
- Keep all pathways and outside areas tidy
- If you are in real danger of having a debilitating fall consider getting a personal alarm
- Install extra outside lighting, particularly if you go out in the evening frequently
- Use light globes that are brighter. Energy saver globes may be too dull
- Leave nightlights on in passageways
- Keep a torch near your bed
- Highlight the edges of steps
- Sprinkle sand or other such material on patios and steps to prevent slipping.
- Fine wire nailed to steps and patios can also prevent slipping

Exercise

- Physical activity, even household chores, can be beneficial
- Join a walking or swimming group
- Try line dancing, Tai Chi or seated exercises
- Gardening, relaxation exercises or yoga can be helpful
- Take part in family or community activities
- Daily exercise does not have to be strenuous, just beneficial
- Keeping physically active and eating healthy foods will help you maintain a healthy weight, which can help prevent a fall
- Wear comfortable, non-slip shoes when exercising

Falls can be prevented if you avoid taking unnecessary risks.

Cooking

When you have a vision impairment the kitchen can seem rather daunting. But don't give up! By adapting how you work in the kitchen and using special equipment a great deal can be achieved. The following suggestions may help you if you want to get back into the kitchen with confidence or provide you with some new tips if you are already trying to adapt to cooking with a sight loss.

Shopping and Labelling

When shopping for food do not be afraid to ask for help. Many of the staff in the supermarket will understand your difficulties and be very happy to help you. If possible, shop early in the day when the supermarket is not busy; this makes it easier for you to stand close to the shelves and choose what you require, and the staff have more opportunity to support you.

Once you arrive home, labelling your food can be difficult. Having someone to help you can be useful, although there are several ways of marking tins and boxes so you know what the contents are. You can put a magnetic plastic letter (available from toy shops) on the tops of the tins, or write the contents of the tins on a large label with a thick black marker and place it on the top of the tins.

Lighting

Make sure that your kitchen lighting helps you use the sight you have. Good strong central lighting is important, as well as lights under wall cupboards which shine onto worktops. A clip on spotlight that can be used as needed is very useful, and matt rather than shiny surfaces help avoid glare.

Colour and Contrast

These can make things much easier to see. You can find light coloured food like potatoes on a dark chopping board, cake mixes show up better in a dark bowl (unless it is chocolate cake!), and dark handles on light kitchen fittings are easier to find. If you are pouring a drink it is easier to see how full the cup is if it is a contrasting colour. Alternatively, place it in the sink rather than trying to pour it on the bench where the cup may be difficult to see. Plugs and sockets are easier to find if they are a different colour to the wall.

Peeling and Chopping

Using knives can be worrying for people with poor sight. Sharp sturdy knives are safer than blunt ones, and you are less likely to have an accident when using them. Always keep your knives in the same place with the handle foremost to avoid any accidents when reaching for them. Some people may prefer a peeler to a knife for fruit and vegetables.

Cooking

The choice of a gas or electric cooker is usually a personal preference but there are some helpful tips for using either. Use the back elements rather than the front ones to avoid accidentally disturbing the pots. Put the pot on the element before turning it on and keep the handles pointed away from the front of the stove. Become familiar with the distance between your workbench and the top of the stove. Always keep your work surfaces clear of clutter: this will provide you with plenty of space when you wish to take something out of the oven.

RESEARCH REPORTS

INTERNATIONAL CONGRESS, STRESA, ITALY

Extracted from a report by Leighton and Rosemary Boyd of RA Victoria

We were very fortunate to attend the 16th Retina International World Congress with its associated General Assembly and Continuous Education Program. These activities were held in the small town of Stresa, which lies alongside Lake Maggiore in northern Italy. The Australian representation included the President of Retina Australia, Graeme Banks, and his wife Lynette.

There were more than 500 people in attendance during each of the two days of the Congress, the theme of which was "Change our Vision: Bridging the gap from the lab to the patients". Although many participants were members of Retina Italy, there were a significant number of people who had travelled a long way to attend the Congress. In all, 28 countries were represented there.

The program for the Congress included keynote speakers and themed parallel sessions, at which the presenters spoke about their research progress, the results so far and their aims for future investigations. There were more than fifty presenters, representing countries such as Italy, the United Kingdom, USA, Switzerland, Sweden, Germany, Ireland, France and the Netherlands. As many of the sessions were concurrent, Congress participants could choose

which of the sessions they were interested in then go to the allocated venue at the appointed time. All of the presentations made in English were translated into Italian and vice versa.

The first keynote lecture was presented by Professor Alan Bird, who gave one of the main lectures at the 5th Retina International World Congress held in Melbourne in 1988. He spoke about the developments, and the lessons learned, from research during the past forty years. Alan mentioned the significant work conducted into retinal diseases by Doctors Nettleship, Jay, Kemp, Ernst, Battacharya and Ali. He also stated that the work of these researchers has given us knowledge of genes, and of cells expressing genes and disease mechanisms, and that this has led to successful treatment in animal models and subsequently to human trials. He completed his lecture by stating that recent work is very successful and bodes well for the future. He said he believed that in the next few years great things will come from the current research.

Professor Gerald Chader presented his perspectives of inherited retinal degeneration research by summarising two decades of progress as the move from "scientific darkness to the light of clinical trials". He commented that in 1990 no gene mutations for Retinitis Pigmentosa (RP) were known and there was very little idea about mechanisms that could slow down the degeneration. Nowadays, however, about half of the RP mutations are known, while much is known too about the mechanism of cell death and how to inhibit it. Professor Chader also spoke about the clinical trials currently in progress for Neuroprotection, Gene Therapy, Antioxidant therapy and Electronic implants. In summing up, Professor Chader stated that:

- (i) we can now treat and, in some cases, virtually cure photoreceptor diseases in many animal models of RP;
- (ii) we will soon be able to effectively treat some of the human Retinal Dystrophy conditions; and
- (iii) the next few years will be very exciting and productive times for both researchers and patients.

The last researcher to speak was Professor Joe Hollyfield, whose main interest is in Age-related Macular Degeneration (AMD). He also spoke positively of the speed at which research has developed during the previous twenty years. He mentioned how informed researchers were nowadays about the causes of both forms of the disease, and that although some drugs have been discovered to treat dry AMD, many more treatments are being investigated and he is hopeful that in the not too distant future treatments will also be available for Wet AMD.

It was interesting to note how many of the presenters spoke about how important it was that people with an inherited retinal disease should ensure that they register their name with an IRD registry and have their DNA tested, so that when a cure or treatment is available they will find out about it. This information was extremely encouraging because it confirmed that Retina Australia's decision to commit research funds to assist with the establishment of such a registry in Perth, at the Sir Charles Gairdner Hospital, was a good one. The statements were also supportive of the fact that we have encouraged members to register with this IRDR and DNA bank.

Another factor mentioned by numerous researchers was the need for people with inherited retinal diseases to be cautious in using Vitamin A supplements. It was apparent that for some forms of retinal disease, Vitamin A supplements have slowed down the degeneration of the

disease. However, for Stargardts disease in particular, and some other RP related diseases, the taking of Vitamin A supplements not only assists with the degeneration of the disease, it can cause other side effects. Consequently the recommendation by researchers was that no one should take Vitamin A unless specifically recommended by their ophthalmologist.

RECENT DEVELOPMENTS IN RETINAL DEGENERATION PREVENTION

By A/Prof Erica Fletcher and Dr Ursula Greferath from the University of Melbourne.

There have been considerable advances in our knowledge of the pathogenesis of inherited retinal degenerations over the last five years that have led to the development of some very promising treatments. We have summarised below some of our own findings examining new animal models of inherited retinal degeneration, ways to slow photoreceptor death and also novel ways of replacing lost photoreceptors.

New animal models: Most research into the mechanisms of photoreceptor death have utilised animal models that carry mutations in rod associated proteins (e.g. rhodopsin). While this work has been very important, it has little relevance to some of the rarer forms of retinal degeneration such as Leber Congenital Amaurosis. Recently, we have identified a novel mouse that replicates many of the features of one form of Leber Congenital Amaurosis. This mouse, called the Histidine decarboxylase null mouse, develops severe changes in the outer retina because the support cells of the retina lack proteins that maintain the correct position of the rods and cones. We will use these mice to study some of the rarer forms of retinal degeneration.

Slowing photoreceptor death: Much of our work over the last few years has been directed at examining whether dying rods release a toxic factor that effects neighbouring photoreceptors. Our work has shown that the energy molecule, ATP, is released in large amounts from dying rods and accelerates the death of neighbouring cells. We have tested two drugs known to block the action of ATP, and shown them to slow photoreceptor death in a mouse model of retinal degeneration. In addition, we have found that the rate of photoreceptor death is slowed in transgenic mice that lack the expression of the receptor to ATP. Agents that block the action of ATP are under development by large pharmaceutical companies because of their potential role in controlling some forms of pain. We hope our work expands the possible uses of these compounds into the ophthalmic area.

Novel ways of replacing lost photoreceptors: The two most exciting developments to restore vision in those who have few photoreceptors remaining are the development of electronic implants, and the use of gene therapy to target visual pigments to the remaining neurons of the inner retina. There are currently two large groups in Australia developing electronic implants to restore vision. One group is designing retinal implants: a wide-field device that sits underneath the retina, and another high visual acuity device that is designed to target the output neurons of the retina. It is hoped that trials for the wide view device in patients will begin in the next year. The high visual acuity device is currently undergoing preclinical testing. A second group, based at Monash University, is designing an implant to be inserted into the visual area of the brain. This device is intended to restore vision in those who have no remaining ganglion cells or an intact optic nerve. Currently this device is undergoing extensive preclinical development.

Gene therapy has been used to target visual pigment to inner retinal neurons. The inner retina of those with inherited retinal degeneration is usually intact. By using gene therapy,

inner retinal neurons can become light sensitive, performing the duties of photoreceptors. These studies are very exciting because the technology can be used in most patients with inherited retinal degeneration, irrespective of the specific genetic cause of the disease.

In summary, over the last few years our knowledge of inherited retinal degeneration has increased dramatically, to the point where treatments are now being tested in patients and with exciting results.

Treating colour blindness with gene therapy shifts long held beliefs.

Recent research has demonstrated that colour blindness may be treated by a simple sub-retinal injection of the genetic sequence for the missing photopigment. A research team based at the University of Washington has comprehensively shown that animals previously documented to be colour-blind are capable of colour discrimination within 20 weeks of treatment. The research not only adds optimism to the field of gene therapy for many other retinal disorders but also suggests an encouraging level of plasticity in how the brain manages new information.

The research, led by Professors Jay and Maureen Neitz, was aimed not so much at developing a gene-based therapy for the treatment of human colour blindness but rather to demonstrate the principle of gene therapy for correcting a genetic fault in the retina. While the technology could be developed further and used to treat the condition in humans it is likely that regulatory authorities would prefer to observe the use of gene therapy for more severe ocular disorders before approving such technology for use in an otherwise healthy retina.

The observations, reported in the journal *Nature* (Vol. 461, pp784-788), provide encouragement that gene delivery to the eye in the context of adult onset diseases may have a real prospect of success.

Bionic Vision Australia (BVA) website

BVA is currently completing preliminary research looking at the relationship between retinal structure and vision, in order to develop the best possible bionic eye implant and testing procedure. The Bionic Vision Australia website has been updated. It is at www.bionicvision.org.au

Part of the latest news release from Advanced Cell Technology, Marlborough, Maryland, USA.

Advanced Cell Technology Receives FDA Clearance For the First Clinical Trial Using Embryonic Stem Cells to Treat Macular Degeneration

Advanced Cell Technology, Inc. announced today that the US Food and Drug Administration (FDA) has cleared the Company's Investigational New Drug (IND) application to immediately initiate a Phase One/Two multicenter clinical trial using retinal cells derived from human embryonic stem cells (hESCs) to treat patients with Stargardt's Macular Dystrophy (SMD), one of the most common forms of juvenile macular degeneration in the world. The decision removes the clinical hold that the FDA had placed on the trial.

Stargardt's Macular Dystrophy causes progressive vision loss, usually starting in children between 10 to 20 years of age. Eventually, blindness results from photoreceptor loss associated with degeneration in the pigmented layer of the retina, called the retinal pigment epithelium (RPE).

"There is currently no treatment for Stargardt's disease," said Dr. Robert Lanza, ACT's Chief Scientific Officer.

"Using stem cells, we can generate a virtually unlimited supply of healthy RPE cells, which are the first cells to die off in SMD and other forms of macular degeneration. We've tested these cells in animal models of eye disease. In rats, we've seen 100 per cent improvement in visual performance over untreated animals without any adverse effects. Our studies showed that the cells were capable of extensive rescue of photoreceptors in animals that otherwise would have gone blind. Near-normal function was also achieved in a mouse model of Stargardt's disease. We hope to see a similar benefit in patients with various forms of macular degeneration."

The Phase One/Two trial will be a prospective, open-label study that is designed to determine the safety and tolerability of the RPE cells following sub-retinal transplantation to patients with advanced SMD. A total of twelve patients will be enrolled in the study at multiple clinical sites.

Stem Cells and Cell Therapy: a recent lecture by Robin Ali, Professor, Institute of Ophthalmology, London

Robin Ali commenced his talk by saying that although his laboratory was primarily interested in gene replacement, he realised that other treatments could work together with gene replacement to give a better outcome for patients. To this end he is working with stem cells alongside his other work.

He said that retinal repair by cell transplantation might provide generitreatment for retinal degeneration but it is early days yet. Prerequisites are identification of appropriate donor cells and successful incorporation of transplanted cells into the retina.

Retinal repair is an evolutionarily limited phenomenon, he noted. In amphibians and fish the retina changes throughout life and can regenerate completely after damage, but in humans this is not the case.

Just a few of the points Professor Ali mentioned in reference to stem cells were:

- * It is possible to transplant photoreceptors into adult mouse retinas provided they are at a very specific stage of development
- * We have clear evidence that cell transplantation is capable of improving vision in a mouse
- * Transplanted retinal stem cells are able to differentiate but not integrate
- * To restore vision we need to improve the quality of the transplant process, altering the recipient retina and stimulating the migration

* Current challenges include presence of the outer limiting membrane , or Gliosis

Robin concluded by stating that his team hopes to show proof of concept within the next year and then move forward with their experimentation after that. He said that he, and others, had made huge progress in the past ten years and he expected things to happen even more quickly in the future.

ABOUT US

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 (SA) and Retina Australia (WA). There is also 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.

MEMBERSHIP DONATIONS

Dear fellow members of Retina Australia (ACT)

As you all know, once you became a member of our organisation you are a member for life and are not required to pay annual renewal fees or subscriptions. We do, however, ask that you consider making an annual tax-deductible donation. Usually we make such requests a couple of months before the end of the financial year.

Retina Australia (ACT) receives neither government nor any other form of funding. The organisation therefore relies on your donations so that we can maintain our services to you, our members. Among these services are the provision of telephone-based peer support, the printing and distribution of the "I-C" newsletter and information kits, the organising of social events, and the raising of funds for research into the causes of retinal diseases. A percentage of the monies raised through your donations are also channeled into Australian research. Currently, our major project is to support the Australian Inherited Retinal Disease Register and DNA Bank. It is pleasing to note a significant number of our members have already registered their interest in participating personally in this project. Sundry other administrative tasks such as printing, photocopying and postage must also be paid for.

It should also be noted that executive members of Retina Australia (ACT) are all volunteers, giving their time in a bid to ensure a brighter future for family, friends and fellow citizens who are facing the onset of blindness.

Please therefore return the completed form below, along with your donation, to Doris Wallace, Treasurer, Retina Australia (ACT), 40 McKillop Circuit, Kambah, ACT 2902 as soon as possible.

Thank you for your continued membership and support.

Yours sincerely

ROBIN POKE
President

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