



I-C



Newsletter of Retina Australia (ACT) Inc

June 2016

When a Stranger Leaves You \$125 Million

One morning last year, when Bryan Bashin (pictured on right) sat down to check his email, a short note caught his attention. "A businessman has passed away. I think you might want to talk to us," it read.

Bashin directs a non-profit organisation in San Francisco called the LightHouse for the Blind and Visually Impaired, so he gets a lot of email about donations. But this one felt different.

It came from a group of lawyers handling the estate of a Seattle businessman who had died, Donald Sirkin (pictured below).

When Bashin and the LightHouse's Director of Development, Jennifer Sachs, checked the LightHouse's donor database, they found no record of him. Sirkin had never donated to the LightHouse for the Blind and Visually Impaired before, or used its services. And yet, in his Will, Sirkin had left

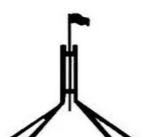
almost his entire estate to the LightHouse, with no explanation.



The gift totalled over \$125 million, more than 15 times the LightHouse's annual budget. Bashin believes it's the largest single gift ever given to a blindness organisation.

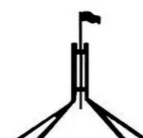


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PRESIDENT'S REPORT



Welcome to the first newsletter of the year, which we, your committee, naturally hope you find interesting.

We have a new member on the committee: Barbara Burton's son Noel, who is something of a 'whiz' when it comes to IT, including the design and formatting of newsletters. I'm sure you will agree with me that Noel has ensured a great improvement.

We have tried, as usual, to provide an eclectic mix of 'General' and 'Research' news. It's also good to see a 'canine contribution' from Lindy Hou's new best friend, Comet.

Best wishes to all...

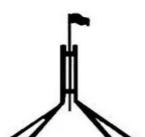
ROBIN POKE AM

President

Retina Australia (ACT)

MISSION STATEMENT

To provide information and support to people and families affected by inherited retinal dystrophies, and, with the support of the Australian community, to raise funds to finance scientific research into the causes, prevention and cure of retinitis pigmentosa.



THOROUGHBRED PARK CANBERRA

As most members of Retina Australia (ACT) know, when not supporting members and their families affected by inherited retinal diseases or providing information about them, we are looking for every opportunity to raise funds for research into a cure for the diseases. With this in mind I recently attended a meeting of our major supporters, "Women In Racing", who were aghast when they heard that, for a variety of reasons, we might not be able to hold a fundraiser at Thoroughbred Park this year.

But Fear not! Solutions have been found and ideas exchanged, and we're now looking at Sunday 13th November as the date for what will be our tenth such gathering.

Double figures! It seems only yesterday...

I'll have more information in the next edition of I-C.

POTENTIAL BIG BOOST FROM THE GREEN SHED

Our delightful Minutes Secretary Lyn Barlow emailed the committee with some good news recently: Retina Australia (ACT) has been selected by the Green Shed at Mitchell to be the recipient of the takings at their next Charity Day. The generous folk at The Green Shed, notably Elaine Stanford, hold a charity day on the last Wednesday of each month - and on 29 June it's our turn!

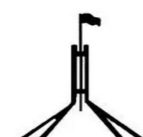
It's a massive opportunity for us, because the profits of the day generate close to \$10,000! Members are therefore encouraged to help those who help us by donating as much of their unwanted 'stuff' to The Green Shed - and at the same time help themselves by having a good old clear out! Win-Win!

All the best...

JAN JAMES

Secretary

Retina Australia (ACT)



NEW TACTILE BANKNOTES

Congratulations to campaigner and Vision Australia client Connor McLeod on jointly winning the Emerging Leader in Disability Awareness category of the National Disability Awards.

Vision Australia has lobbied the Reserve Bank of Australia over many years to introduce tactile banknotes so that people who are blind or have low vision can identify different banknotes.



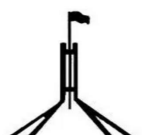
GOOD2GIVE

A new avenue is open to those wishing to make donations to Retina ACT through the Good2Give workplace giving program.

The Good2Give scheme makes it easy for businesses and donors to give low-cost donations to charitable organisations they care about.

Through the program, donors can make ongoing donations direct from their pay to Retina ACT.

An advantage of making regular donations in this way is that tax deduction is received immediately, thereby eliminating the need to collect and store receipts. It is also easy to start, stop or change your donations at any time. Further information can be found at: www.good2give.ngo



UPCOMING EVENTS

RETINA INTERNATIONAL WORLD CONGRESS

Theme: Foresight - When East Meets West

Taipei International Convention Centre Taiwan 8 – 10 July 2016



RIWC 2016
T A I P E I

The 19th International World Congress is being organised by Retinitis Pigmentosa Taipei assisted by long-time Retina International member Retina Hong Kong.

The program is still being developed but will include presentations from world renowned scientists currently undertaking research into all forms of inherited retinal diseases.

Sessions on Traditional Chinese Medicine as it is applied to retinal degenerative diseases may also be a unique inclusion at the Congress.

The official language of the Congress is English, with translation into Mandarin. Registration is still open. Further information and the online booking form is available at <http://riwc2016.org>

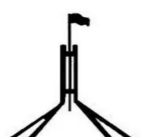
RETINA INTERNATIONAL YOUTH MEETING



A Retina International Youth meeting is being organised by the hosts of the Retina International World. The meeting is open to young people up to 35 years old. Accommodation will

be arranged for the youth participants at Taiwan University, and it will be possible for them to participate in the scientific program at the Retina International Congress as well as the social program.

Anyone wishing to participate in the planning of the meeting can join the Facebook group Retina International Youth.



When a Stranger Leaves You \$125 Million

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"It's one of those experiences where time stands still, where you know that every little bit of what you're experiencing will be engraved in your memory,"

Bashin said. "This is the moment that everything is going to change."

He's 60 years old, tall and almost always smiling. His eyes are cloudy; he walks with a cane. He gives the impression of being an entirely functional, confident blind person. But this Bryan Bashin is a relatively recent incarnation, because for a long time, Bashin didn't identify as blind at all. "I didn't say the "B" word," Bashin says.



"Instead I used euphemisms if I had to. I used the lingo of the day: 'visual impairment,' 'low vision,' 'visual challenge' ... that kind of thing."

Bashin's vision began to falter when he was in his teens, and gradually got worse. By his 20s, he was legally blind. Today, he says, he sees the world "as if through wax paper." He can make out some light and color, but not faces or words. Yet through his 20s and most of his 30s, Bashin squeezed by on the little vision he had, relying on magnifiers and special lamps to read what he could. He memorised the map of his daily route so as to not get lost. He only went out during daylight, to avoid the confusion of navigating in complete darkness. Bashin says that a lot of blind Americans use work-arounds like these.

"Most never use a cane, or a dog, or Braille or any of the things that identify the blind," he says. "In the blind community we say we're 'in the closet', and it is just like being in the closet in the gay community. You try to be somebody you're not."



But as Bashin's vision declined, these work-arounds became harder to pull off. They were time-consuming and exhausting. Finally, when Bashin was 38, with his vision at about 10 percent of normal, he realised he couldn't hide anymore. He decided to learn to be a blind person in public.

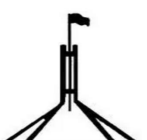
A friend took Bashin to a local blindness agency that Bashin found dishearteningly shabby. Stuffing was coming out of the chairs. The air conditioners buzzed. The office hadn't been painted in decades.

For Bashin all of this was symbolic. The place lacked dignity. "None of that period made me feel like I could be a cool blind person and do stuff in the future," Bashin said. "I felt ashamed. I felt confirmed in my suspicion that blindness would be a diminishment of my potential." But he did get something out of it. He learned how to navigate with a cane. He started learning the technologies that make life vastly simpler for blind people than it had been a generation ago: the smart phone, text readers and pocket recorders. And suddenly, everything got easier. For example, using text-to-speech was "vastly quicker" than trying to make out giant letters on a screen.

Since then, Bashin has made it his life's mission to help other blind people make the leap he did. He got a job at the agency with the ripped up couches. And in 2010, he became the Executive Director of the LightHouse for the Blind and Visually Impaired in San Francisco. Bashin says that with the right tools and training, blindness can be reduced to the level of inconvenience. "Don't just hide," he says. "This is not a tragedy or shame. This is not some kind of deep loss. This is just another side of being human."



Despite enormous technological gains that have made life vastly easier for blind people in the last decade, there are still significant obstacles to independence. The unemployment rate among working-age blind people is

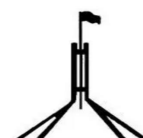


50 percent — ten times the national average. Job training is expensive, and learning to live independently as a blind person takes time and resources. It's often easier to get disability checks than to find and pay for necessary training. To really master walking around using a white cane, Bashin says, requires 200 to 400 hours of training with somebody who is being paid to work with you. Learning to use a computer requires that same kind of training.

Through constant fundraising, Bashin's organisation has the resources to provide basic services to their clients. But what Bashin wants is bigger than that: a change in how blindness is perceived. He wants to encourage more blind people to come "out of the closet," to embrace and celebrate blindness as a difference, and get the skills they need to pursue their ambitions. Now, suddenly, thanks to this mysterious businessman in Seattle, Bashin and the LightHouse are looking at a different scale of ambition. "When you get right down to it, the Sirkin bequest is about ... feeling like we can dream and have options and be proud of who we are," Bashin says.

LightHouse for the Blind and Visually Impaired is just beginning its strategic planning process, to decide how to spend the Sirkin money, but Bashin has some ideas. One major project — which had begun well before the Sirkin grant — is a new headquarters in San Francisco. The building will have expanded facilities, including a dormitory where blind people can stay while they receive training in blind tech, cane navigation, and other necessary skills. There's also the idea of an award for blind people who do extraordinary things, such as travel around the world independently, or invent some kind of game-changing tool for blind accessibility.

To Bryan Bashin, Sirkin is a black box, a mystery. Estranged from his family, reclusive, even to those who worked with him. A guy who also made this dramatic, final gesture — this extravagant gift — to people he had never met. What Bashin found in Sirkin's home reminded him of his own difficulty in "coming out" as blind. Sirkin couldn't make the leap Bashin did. Instead, he hid. But he also did something else.



He left his entire inheritance to a group of people who could have helped him, but didn't get the chance.



Source: Amy Standen, 23 November 2015, www.npr.org.

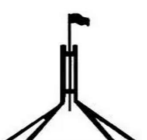
To hear more about the donor you can listen to the podcast on <http://ww2.kqed.org/news/2015/11/03/episode-3-when-a-stranger-gives-you-125-million>

Donations Appeal

We have reached that time of year when annual donations are welcomed. As you are all aware, Retina ACT relies to a great extent on your generosity to ensure that we can maintain our services to members.

Your donations are used to cover the costs of our newsletter, telephone-based peer support, and the printing and posting of information pamphlets and kits.

Thank you very much.



LINDY HAS A NEW COMPANION

Many readers of the Retina Australia (ACT) Newsletter would have followed the fortunes of Harper, Lindy Hou's iconic guide dog, through his regular 'column', and mourned when the old fellow passed on. For some time there was a void in our lives, but now Lindy has found another companion – and guess what! He's also a columnist! Here's what Comet has to say for himself...



"I have been busy learning to read and write over the last two months. I've been real nervous about publishing my first ever newsletter. I know I can never be exactly like Harper, but hope that his followers will bear with me while I learn the trade."

"For those of you who can't see my photo, I am a white Labrador: some might even describe me as 'white as a polar bear'. I am a little bit taller than Harper and a bit longer in the body. Fortunately, I can still fit under the dashboard in front of Lindy when we travel in a car. Harper and I share the same Chinese horoscope and star sign, with our birthdays being 12 years and one day apart. I celebrated my second birthday on the 22nd of March."

"More news on my progress will appear in future newsletters."



CHRIS LOOKS TO THE FUTURE WITH HIS ESIGHT EYEWEAR

By Christopher Burton

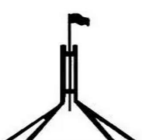
In the middle of 2015 my family and friends raised enough money for a pair of very special glasses which I hoped would change my life.

The glasses were called “Esight eyewear” and they have made an immeasurable difference to all my day to day tasks.

Tasks that have really been difficult in the past such as catching a bus, crossing a street, reading menus, labels, price tags and signs are all now second nature.



I’m studying civil engineering at TAFE at the moment and before I got the Esight glasses, I struggled to keep up with my fellow students in lectures where reading textbooks, writing notes or solving complex maths is essential.





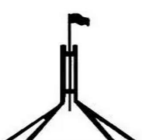
Now I am able to visually follow what the lecturer writes on the board while taking notes.

The Esight eyewear has also helped me socially. I went out with a few friends recently and it was amazing how much more seeing people's faces and reading facial expressions helped me to follow conversations while relaxing and having a good time.

I really feel that the Esight eyewear has truly changed my life for the better. I'm able to do so many things I hadn't been able to do since I was a child. This kind of technology has the potential to change many lives and to create a brighter and clearer future for those using them.

I am starting a vlog (Video Blog) to share my experiences with the Esight eyewear and will provide links once it is set up

For further details on Esight eyewear go to <http://www.esighteyewear.com>
To see a video on how they work go to <https://youtu.be/-E2dcekXzts>



STUDY FINDS THAT EXPLAINING BLINDNESS IS A STRUGGLE

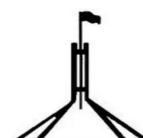
A new study shows that explaining their blindness to others is the biggest difficulty faced by people with Retinitis Pigmentosa. The research, carried out by academics at Anglia Ruskin University and published in the journal PLOS ONE, involved 166 people living with the inherited condition, which is the most common form of blindness among people of working age in the UK.

The researchers asked the participants about how they deal with misunderstandings resulting from their visual impairment and how easily they are able to explain to others what they can and cannot see. These tasks were rated as 'impossible' or 'very difficult' by 39 per cent of respondents, with a further 27 per cent rating them as 'moderately difficult'.

Dr Keziah Latham, Reader in the Department of Vision and Hearing Sciences at Anglia Ruskin University, said: "We know a great deal about how visual impairment affects people carrying out everyday tasks, but less research has been carried out into the emotional impact. Until this study we knew even less about RP, which affects a much younger group of people than does other forms of blindness. We found that the biggest emotional problem faced by people with RP is



communicating their vision loss to others. This is partly because explaining blindness is very difficult, but it is also made more difficult if other people do not have a good understanding of vision loss, perhaps thinking that 'blind' means unable to see anything at all, or that only central vision is affected."



The research was supported by the charity RP Fighting Blindness, which helped with the recruitment of volunteers. Tina Houlihan, Chief Executive at RP Fighting Blindness, said: “We welcome these findings as the emotional aspects of living with a condition such as RP are often overlooked. We are aware that many members of the public have misconceptions about visual impairment and do not realise RP does not necessarily equate to full blindness. We have heard about the frustration felt by some members of our patient group due to the lack of knowledge the general public has about such matters.”

Source: <http://www.anglia.ac.uk> , 12 January 2016.

USHER KIDS

Emily Shepard and Hollie Feller, the co-founders of UsherKids Australia, have advised that the support website for families with children diagnosed with Usher syndrome in Australia is now LIVE.



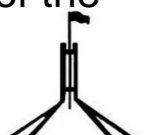
This website can be found at www.usherkidsaustralia.com.

Usher syndrome is a rare genetic condition characterised by hearing loss or deafness, the progressive loss of vision and in some cases, vestibular dysfunction. Until now there has been no support network in Australia dedicated to children. As parents of recently diagnosed young children, Emily and Hollie have set up the website as a resource and contact point for all families of children with Usher syndrome in Australia. They also hope it will be a valuable tool for clinicians and support services in contact with children with Usher syndrome nationally.

If you have any comments or feedback you get in contact with Emily or Hollie directly at info@usherkidsaustralia.com

AUSTRALIAN INHERITED RETINAL DISEASES REGISTER AND DNA BANK (AIRDR)

The board of Retina Australia, along with all state/territory retina organisations, believe it is essential that we continue our support of the

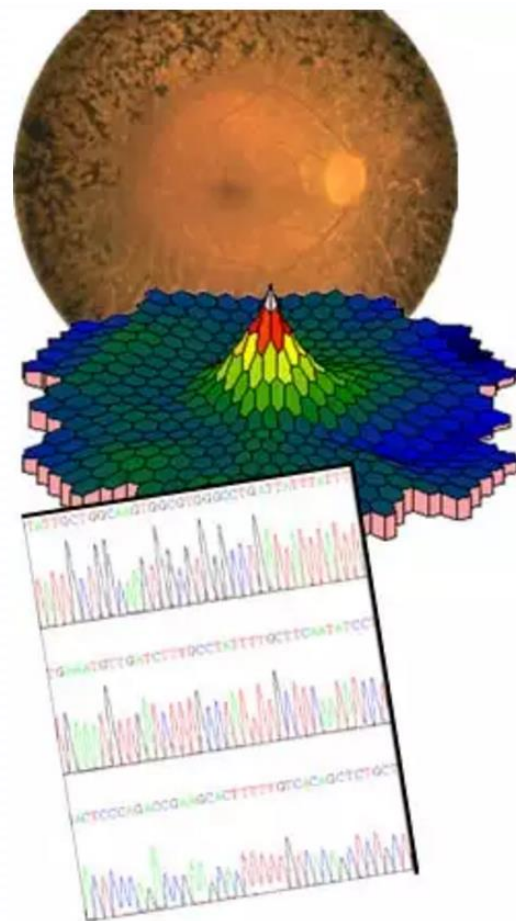


AIRDR, as this will keep alive the most viable current pathway to a cure or treatment for family, friends or fellow Australians with an inherited retinal disease. National president Leighton Boyd has asked that we continue to make these donations so that this work can be maintained and one day lead to the provision of a treatment or cure for inherited retinal disease.

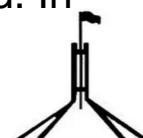
During 2015, Retina Australia agreed to continue its support of the AIRDR by pledging an amount of \$110,000 towards the research being undertaken in 2016. This means that by the end of 2016, the total amount contributed by Retina Australia since 2009 will be over \$1.2 million dollars.

As a result of these donations from members and friends of Retina organisations across Australia, the work of the AIRDR has been advanced thus:

- There are more than 6700 persons in the register
- DNA has been collected from over 5100 Australians who have, or have a family member with, an inherited retinal disease
- More than one third of the DNA collected to date has been analysed and the probable disease-causing variant has been identified in 60% of these analyses.
- Analysis of a further 25% is currently underway or committed, and when this DNA analysis has been completed, 60% of affected and carrier participants held in the DNA bank will have been analysed
- Disease-causing variants have been found in 102 different genes in the Australian population, and
- More than 280 participants have been provided with detailed genetic analysis reports regarding their own condition.



Significant progress has been made during the past 12 months with regard to identifying potential candidates for current or anticipated clinical trials which are being conducted in various laboratories throughout the world. In



particular, the AIRDR team identified two participants who are genetically suitable for an RPE65 gene specific clinical trial for Leber Congenital

Amaurosis, and 18 participants were identified who are genetically suitable for a CHM gene-specific clinical trial for Choroideremia.

Many participants have also been identified as possible candidates for anticipated gene-specific trials. These include participants with mutations established in the genes AIPL1 (Leber Congenital Amaurosis), MYO7A (Usher syndrome), ABCA4 (Stargardt disease), RPGR (x-linked retinitis pigmentosa), and RS1 (Retinoschisis).

The AIRDR staff continue to work towards having participants accepted into existing clinical trials in a variety of countries, and, in conjunction with the Lions Eye Institute in Perth, towards attracting gene-specific clinical trials to Australia.

RETINA INTERNATIONAL PRESS RELEASE:

Spark therapeutics treatment for form of LCA on course to become the first gene therapy to be approved in the USA

The initial results from a pivotal late stage clinical trial for a form of inherited retinal degeneration have been announced, after many years of ground-breaking retinal research by the University of Pennsylvania.



Spark Therapeutics have developed a potential gene therapy for a rare form of blindness known as Leber Congenital Amaurosis (LCA). This therapy is for a particular form of LCA known as LCA2, as it is caused by mutations in the RPE65 gene. Individuals with this condition experience night blindness as one of the earliest symptoms and this can deteriorate to severe vision impairment. There is currently no approved therapy for LCA. Spark's therapy, known as SPK-RPE65, replaces the defective gene by using viruses to deliver a working copy of the RPE65 gene directly to the patient's eye.

In a study of 31 people with LCA2, 21 received the therapy, and 10 people were in the control group. After treatment, two thirds of individuals in the



therapy group were able to successfully navigate a specially designed mobility course under very low light conditions, indicating a restoration in their vision.

There were no serious events during the trial related to the therapy: it is safe and well tolerated. The trial also showed that participants who received the treatment also out-performed those in the control group on two secondary goals: improving light sensitivity of the eye and change in mobility test score for the first eye treated. The third endpoint, which is the ability to read further on the standard eye chart, did not achieve a statistically significant result.

Only individuals with this form of LCA will benefit from this therapy as it replaces the defective RPE65 gene, responsible for subtype 2 of the disease. Spark will now look to engage with the US drug regulators, the FDA, in order to file for approval of the therapy next year.

“Retina International will report on developments as they arise to ensure our membership is kept fully informed,” said Christina Fasser, President of Retina International.

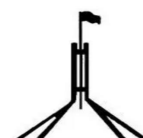
**ReNeuron announces first patient treated in US Phase I/II clinical trial
in blindness-causing disease, retinitis pigmentosa
Marks initiation of ReNeuron’s clinical development activities in the
US**

ReNeuron Group plc, a leading UK-based stem cell therapy development company, is pleased to announce a first-in-human US clinical trial in which the patient received the

company’s cell therapy candidate for treating the blindness-causing disease retinitis pigmentosa (RP). The procedure involved a single injection of hRPC cells under the retina. It was conducted at Massachusetts Eye and Ear in Boston, a teaching affiliate of Harvard Medical School (HMS) and a world-renowned clinical and research centre for the treatment of eye disease, including retinal degeneration. The patient was discharged from hospital on the same day.

ReNeuron

ReNeuron has demonstrated that its Human Retinal Progenitor Cells (hRPCs) improve visual acuity in pre-clinical models of retinal degeneration.

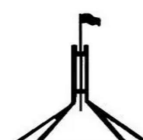


Uniquely, the cells appear to both protect the host retina from further degeneration as well as to engraft into the retina itself and differentiate into the photoreceptor cell types that are lost as a result of the disease. These putative mechanisms of action suggest that ReNeuron's cell therapy candidate could potentially treat any of the specific genetic variants of RP rather than, as is the case with gene therapy approaches, being restricted to the targeting of one particular genetic cause of disease.

The Phase I/II clinical trial is an open-label, dose escalation study to evaluate the safety, tolerability and preliminary efficacy of ReNeuron's hRPC cell therapy candidate in 15 patients with advanced RP. Importantly, the study marks the company's initiation of clinical trial activities in the US.

The FDA has granted Fast Track designation to ReNeuron's hRPC program targeting RP. This, together with the program's Orphan Drug Designation in both the US and Europe, provides accelerated clinical development and marketing authorisation review processes for the RP therapeutic candidate, as well as the potential for a significant period of market exclusivity once approved in these major territories. Further patients have been identified for recruitment into the study, and initial short-term safety and tolerability data from the Phase I part of the study are expected towards the end of 2016, with preliminary efficacy read-outs in the first half of 2017. Subject to the outcome of the Phase I/II study, the company expects to be able to file an application in the second half of 2017 to commence a pivotal Phase II/III clinical trial with its cell therapy candidate for RP. A positive outcome from this pivotal study is expected to form the basis for subsequent marketing authorisation filings in both the US and Europe.

Eric Pierce, MD, PhD, Director of the Ocular Genomics Institute and Berman Gund Laboratory for Study of Retinal Degenerations at Mass. Eye and Ear and HMS and Principal Investigator for the clinical trial, commented: "We are delighted to have treated the first patient in this important Phase I/II clinical trial. The human Retinal Progenitor Cells being tested in the study are promising, since they can make photoreceptors. The implanted cells may not only prevent degeneration of patients' vision but may possibly restore some vision by replacing degenerated photoreceptor cells. We look forward to reporting future progress with this study in the months ahead." Joining Dr. Pierce as co-investigators are Dean Elliott, MD and Jason Comander, MD, PhD, both of Mass. Eye and Ear and the HMS Department of Ophthalmology.



Olav Hellebø, Chief Executive Officer of ReNeuron, said: “The dosing of the first patient in the Phase I/II clinical trial of our cell therapy candidate for retinitis pigmentosa marks another significant milestone for ReNeuron. Retinal degenerative diseases represent extremely attractive targets for cell therapy approaches, and our program targeting RP benefits from a number of key competitive advantages in terms of the potential mechanisms of action of our hRPC cells and the potential speed of clinical development to market for this program. With the start of this study, we are also delighted to have commenced clinical development activities in the US, a major target market.”

NightstaRx Reports Long-term Benefits of Gene Therapy for Inherited Form of Progressive Blindness

NightstaRx Ltd (“Nightstar”), a biopharmaceutical company specialising in developing gene therapies for inherited retinal dystrophies, has announced the publication by the University of Oxford of promising clinical results and long-term benefits of choroideremia gene therapy in this week’s issue of the New England Journal of Medicine (NEJM). Nightstar is now developing this gene therapy approach and the viral vector known as adeno-associated virus 2 (AAV2) to deliver a copy of the gene encoding Rab-escort protein 1 (REP-1) gene, the mutation of which leads to damage of retinal cells of patients with choroideremia, an inherited form of progressive blindness.



The study enrolled six patients with choroideremia at the University of Oxford’s Nuffield Laboratory of Ophthalmology under principal investigator Professor Robert MacLaren. As published in the NEJM, the clinical research findings demonstrated that five patients who received the full dose of AAV2-REP1 treatment maintained or improved vision in their treated eye for the extent of post-treatment observation (up to 3.5 years). In two patients, a significant improvement in vision of greater than three lines on an eye chart was sustained to the last time point reached. In the untreated eyes, vision declined in five out of the six patients at 3.5 years.



David Fellows, CEO of Nightstar said: “Our mission is to maintain sight in patients suffering from a range of untreatable blinding diseases and the data published in the NEJM demonstrates that the effects of gene therapy are durable and could provide a single treatment for many types of inherited retinal dystrophies.”

“We are continuing to advance our AAV2-REP1 program in clinical trials and concurrently moving forward on two other gene therapy programs for sight threatening diseases in the retina.”

Robert MacLaren, Professor of Ophthalmology at the University of Oxford commented: “Gene therapy has huge potential as a treatment for many patients who are suffering from inherited retinal dystrophies. Although there have recently been questions about the long-term impact of certain gene therapy regimens, we believe we now have strong validation of sustained, long-term efficacy following a single injection of the AAV2-REP1 viral vector.”

CATARACTS

Patients with RP often develop a type of cataract called a subcapsular cataract. When this occurs, the lens becomes cloudy and vision is impaired. Eyeglasses may improve sight when cataracts first develop. Later on, however, surgery may be needed to restore vision.



A cataract is clouding or opacity of the lens inside the eye. It is useful to learn about how the eye works in order to understand what a cataract is.

Inside the eye, behind the coloured part (the iris) with a black hole in the middle (the pupil), is the lens. In a normal eye, this lens is clear. It helps focus light rays on to the back of the eye (the retina), which sends



messages to the brain allowing us to see. When a cataract develops, the lens becomes cloudy and prevents the light rays from passing through.

What are symptoms of cataracts?

Cataracts usually form slowly over years, causing a gradual blurring of vision, which eventually is not correctable by glasses. In some people, vision can deteriorate relatively quickly. Developing a cataract can also cause glare, difficulty with night-time driving and multiple images in one eye which can affect the quality of the vision.

Do cataracts spread from eye to eye?

No. But often they develop in both eyes, either at the same time or one after the other with a gap in between.

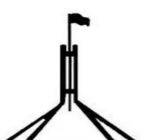
I didn't know that I had a cataract until my optometrist told me - is that normal?

At first you might not be aware that a cataract is developing and, initially, it may not cause problems with your vision. In most cases, eyes with a cataract look normal but, if the cataract is advanced, your pupil may no longer look black and can look cloudy or white.

I feel that I need to go to the optometrist more often to get new glasses.

You may need to get new prescription glasses more frequently when the cataract is developing. Eventually, when your cataract worsens, stronger glasses may no longer improve your sight and you might have difficulty seeing things even with your glasses on.

What are the hazards of cataract removal, especially for someone with a retinal degenerative disease?

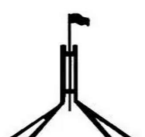
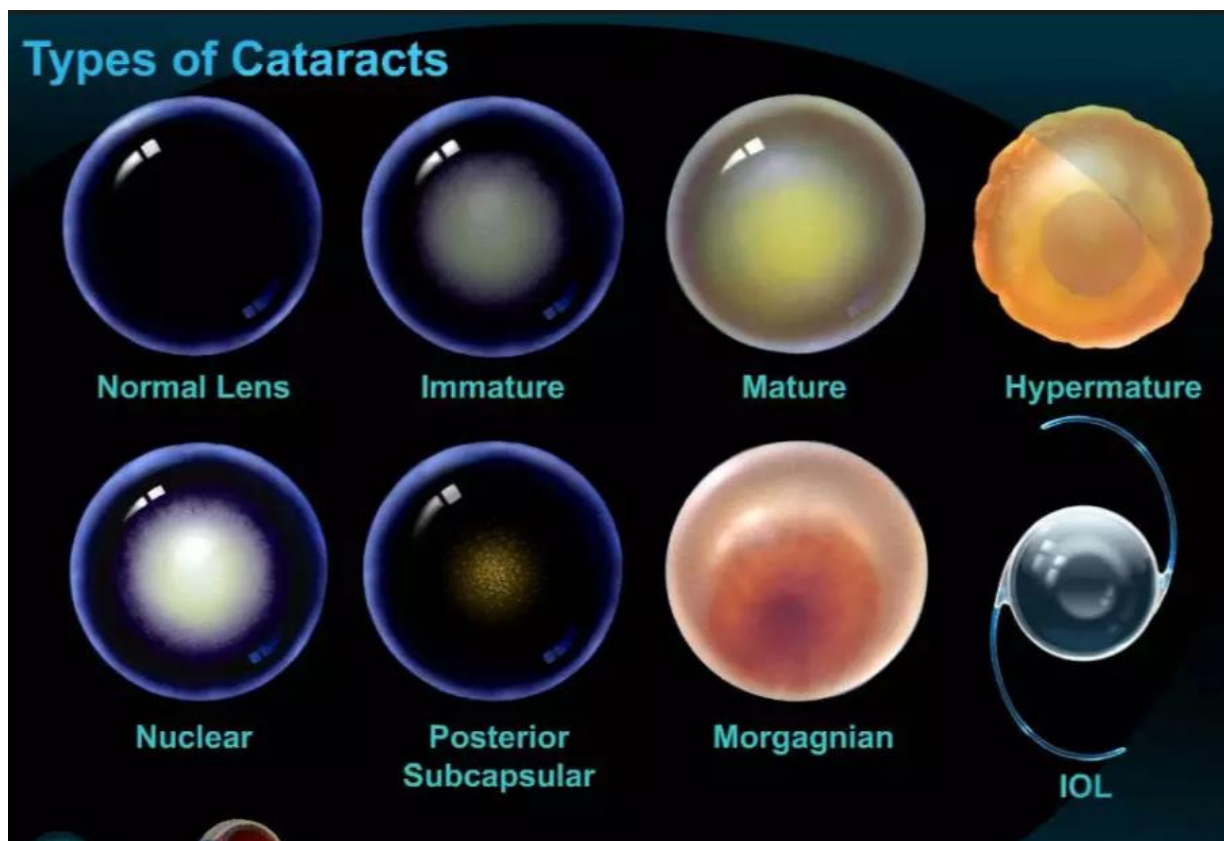


People with retinal degenerative diseases have increased risk of complications from cataract removal, because of the fragility of their retinas. Some complications include: inflammation of different parts of the eye, macular oedema (swelling of central retina), and more difficult management of an existing epiretinal membrane (scar tissue).

How does one reduce the risk of complications?

The surgery should be performed by someone expert at removing cataracts, using as little light as possible and practical. The patient should be treated aggressively for ocular inflammation before and after surgery. Ideally, the surgeon should be familiar with retinal degenerative diseases, and the special considerations that need to be made when performing surgery on these patients. All people with retinal degenerative diseases should thoroughly discuss the potential risks and benefits of cataract removal with their ophthalmologist.

Source: Retina Australia (QLD)- EYE-Q News Autumn 2016



OPTOMETRISTS URGED TO ALERT PATIENTS TO DANGERS OF EYE RUBBING

There is growing evidence that constant and vigorous eye-rubbing can bring on, or worsen, Keratoconus, which affects around one in every 2,000 people.

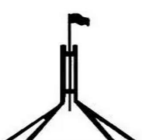


Keratoconus blurs vision by thinning the cornea, the transparent front part of the eye.

As the cornea thins, it begins to distort and bulge, and becomes cone-shaped rather than the usual round shape, leading to vision loss. In its early stages, vision may be corrected with spectacles, although there may be an increased sensitivity to light. As the condition advances, vision may no longer be adequately corrected due to the high irregularity of the cornea. Both eyes are usually affected, but may respond in different ways, and 20 per cent of cases lead to severe visual impairment.

As the condition continues to deteriorate, a corneal graft may be required. According to Clinical Professor Stephanie Watson from the Save Sight Institute, eye rubbing is often caused by allergies, and this can become a problematic habit. In chronic eye rubbers, more severe Keratoconus often corresponds with the dominant hand. The precise cause of Keratoconus is unknown. It is thought that genetic factors may contribute, and that eye rubbing can lead to eye trauma, as well as trigger the release of enzymes which weaken the cornea. Researchers from the Save Sight Institute are working to find new and improved ways to treat the disorder.

Source: mivision - 8 September 2015



TOYOTA'S PROJECT BLAID

Toyota is researching new ways of helping blind and visually impaired people enjoy greater freedom, independence and confidence with a new, wearable mobility device.



Project Blaid reflects the company's commitment to help everyone enjoy the benefits of mobility. The device will help fill the gaps left by canes, guide dogs and basic GPS devices by giving users more information about their surroundings. Worn around the shoulders, it will help wearers better navigate indoor spaces, such as office buildings and shopping malls by identifying features such as escalators, stairs, doors and toilet facilities.

A camera detects the user's surroundings and communicates information through speakers and vibration motors. In turn, the user will be able to interact with the device using voice recognition and control buttons. Toyota plans to develop the device with integrated mapping, object identification and facial recognition functions.

A short video previewing the technology is available at TheToyotaEffect.com, showing a young blind man testing an early-stage version of the device.

Source: RSB Canberra Newsletter 373



Winter Warmer – Farmhouse soup from Siteri Burton

PREPARATION TIME: – 10 minutes

COOKING TIME: – 2 – 3 hours

SERVES: – 6 people



INGREDIENTS:

250 grams Chuck Steak or Gravy Beef

2 medium onions

2 carrots

2 potatoes

4 sticks of celery

1 Swede

2 small Parsnips

½ packet Mixed dried lentils or ½ packet of soup mix

METHOD:

In large saucepan put lentils, meat and diced vegetables

Add about 1 litre of water

Bring to boil

Simmer for 2 to 3 hours

Add salt and pepper to taste



WAYS YOU CAN HELP RETINA AUSTRALIA (ACT)

There are many ways you can help and support us. Listed below are some suggestions.

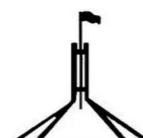
1. Suggest to family and friends that they hold a special event (such as a sponsored walk or fundraising dinner) to support our work.
2. Include a reference to us when updating your Will.
3. Tell your local eye professionals (and your family and friends) if you have found the information provided by Retina Australia (ACT) and its support services useful.
4. Offer your services to a member of the executive as there are numerous small jobs that need to be done. Many of these do not require you to be on a committee.
5. If approached, consider allowing your medical information and DNA to be stored on the inherited retinal diseases database so it is readily available to eye researchers both here and overseas.
6. When you hear that someone in your community has been diagnosed with sight loss, tell them about Retina Australia (ACT) and the support services offered.

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).

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.



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