



# VisionVoice

Autumn Edition 2018

## Australia Day award recognises a sight saving leader



Professor Paul Mitchell – an Australian champion of ophthalmic research – is typically humble about recently being named an Officer of the Order of Australia (AO), drawing attention towards the need for further research into macular disease.

He said he was “surprised and delighted” to be honoured in the Australia Day Honours List for distinguished service to ophthalmology, particularly in the management of age-related macular degeneration, and his research into public health and ophthalmic epidemiology.

“This award is a reflection on my research, but also honours the contributions from the people and organisations that I’ve worked with. While I am delighted on a personal level, there’s still a big job ahead of us.”

While acknowledging that he may need to consider retiring “at some time”, Professor Mitchell is still working at a pace that would tire people half his age. “There’s plenty to do and we can’t really rest at any point,” he said.

He cited the continuing treatment gap for atrophic (dry) macular degeneration and reaching diabetic patients to ensure they receive regular, optimal eye health therapy as two of the big, unmet challenges.

## May is Macula Month

**We’re shaking up our annual awareness campaign and moving from one week to a whole month – Macula Month.**

Building on the success of past years, Macula Month (1-31 May), will be raising awareness of all macular diseases, including age-related macular degeneration, diabetic eye disease and other less common diseases of the macula. “Are you at risk of macular disease?”. It’s the question we’ll be asking Australians to answer this May. Macula Month is an opportunity for everyone in our community to get involved to reduce the incidence and impact of macular disease. Find out how you can reduce your risk with our checklist on page four.

### Macula Month



# CEO Update

In my first update in the role of CEO, I would like to acknowledge the work of Julie Heraghty in her 13 years as champion for the Foundation. I feel extremely privileged to be working with you all to advance the cause of the macular disease community, and I feel very humbled by the well wishes I have received in the past three months since I commenced with the Foundation.

My father lived with age-related macular degeneration in Ireland, so I share a similar story with so many of you. There were many things I didn't understand about my father's condition or how to navigate the aged care system to get the support he needed to continue to live independently at home. I had so many questions I wanted to ask but couldn't because there wasn't a Macular Disease Foundation equivalent in Ireland.

In my role as CEO, I want to make sure every Australian affected by macular disease knows that we are here to support, provide guidance, answer questions, and be your voice for change. I am also very interested in learning more about you via our supporter survey many of you would have received over the past month. If you have not already returned your survey, I urge you to respond to this survey or call the Foundation if you need assistance completing this over the phone. The information you share is critical to understanding the issues that matter most to you and to inform our work.

I hope you enjoy our newly designed newsletter, *Vision Voice*. If you have a story to share or would like to hear about a certain issue which affects you, please contact us on 1800 111 709 or email [info@mdfoundation.com.au](mailto:info@mdfoundation.com.au). We'd love to receive your feedback.



Dee Hopkins  
Chief Executive Officer

## Australia Day award recognises a sight saving leader contd.

At Macular Disease Foundation Australia, we make no secret of our admiration for Professor Mitchell. He is an extraordinarily dedicated, passionate and humble giant of ophthalmology – both in Australia and internationally.

His enormous body of work as a clinician, researcher, educator and advocate has impacted the lives of people all over the world.

Despite his extraordinary workload, he has generously acted as the National Research Advisor and been an active member of the Medical Committee for Macular Disease Foundation Australia since its inception in 2001.

Professor Mitchell is perhaps best known for initiating and leading the landmark Blue Mountains Eye Study (BMES). The BMES commenced in 1992 and is internationally recognised as one of the most significant ophthalmic epidemiology studies ever conducted.

It continues to provide a wealth of vital information on the incidence, prevalence and impact of a range of potentially blinding eye diseases.

Among his other activities, he has also conducted considerable research into childhood eye conditions and has a strong and ongoing interest in Indigenous eye health.

**Congratulations,  
Professor Paul Mitchell AO.  
An honour well deserved.**

## Mythbusters - Diabetes and Eye Tests

**Myth:** I only have mild diabetes. I'm not at risk of diabetic eye disease.

**Fact:** "Mild" diabetes doesn't really exist. Diabetes is always serious. Everyone with diabetes is at risk of diabetic eye disease, and needs to have a regular, comprehensive eye test.

**Myth:** My eye tests for diabetic retinopathy have been clear for 15 years, so I don't need to worry any more.

**Fact:** The longer you have had diabetes, the greater the risk that you will develop retinopathy, and the MORE important it is to have a comprehensive eye test, even if tests have always been clear in the past.

**Myth:** I have only just been told I have diabetes. I don't need to worry about eye tests for a while.

**Fact:** Up to a third of people already have some diabetic eye disease when they receive an initial diagnosis of diabetes. You should have an eye test

## Education Sessions

Education sessions are your chance to learn more about macular degeneration and meet others who are on a similar journey. At these sessions you will also have the opportunity to view the latest range of low vision aids and technologies from Quantum RLV.

All sessions run for two hours from 10.00am to 12.00pm.

**RSVP essential for those wishing to attend. Please call 1800 111 709.**



immediately you are diagnosed and ensure you tell your optometrist or ophthalmologist about your diabetes.

**Myth:** I am very overweight. I will never be able to lose enough weight to help my diabetes.

**Fact:** A weight reduction of just 5% or 10% can make a meaningful difference to your risk. Weight loss can be difficult, so get help from your GP and involve a dietitian and/or diabetes educator.

Thanks to Dr Peter van Wijngaarden at the Centre for Eye Research for busting these myths. For more mythbusters, go to the Diabetic Retinopathy section of our website.

### Upcoming sessions:

Brisbane (QLD) - 18 April - Redlands Sports Club

Lidcombe (NSW) - 16 May - Dooleys Club

Adelaide (SA) - 23 May - Tea Tree Gully Golf Club

Darwin (NT) - 13 June - Tracy Village Sports & Social Club

Mittagong (NSW) - 20 June - Mittagong RSL Club

Nowra (NSW) - 21 June - Bomaderry Bowling Club

Hurstville (NSW) - 25 July - Club Central Hurstville



# Healthy Choices

## Eat for your Eyes

Good nutrition and a healthy lifestyle go hand in hand with eye health. In celebration of Macula Month, we want you to *Eat for your Eyes* this May.

Adopting the healthy habits below will help reduce your risk of vision loss from macular disease, whether you have been diagnosed with the disease or not.

### How many of these “healthy habits” can you tick off?

- I don't smoke
- I eat a healthy, well-balanced diet
- I eat dark green leafy vegetables and fresh fruit daily
- I eat fish two to three times a week
- I choose low glycemic index (low GI) carbohydrates instead of high GI
- I eat a handful of nuts a week
- I limit the intake of fats and oils
- I keep a healthy lifestyle by maintaining a healthy weight and exercising regularly
- I have a regular eye test and macula check

If you ticked all nine – well done! If you didn't tick all the boxes... now is the time to make changes to reduce your risk, or delay progression, of macular disease. Call the Foundation on 1800 111 709 to find out more.

## Macula Menu e-cookbook

Available from 1 May

This downloadable cookbook is filled with a range of delicious and nutritious recipes from celebrities, chefs, eye health professionals, and a selection of wonderful foodies from the macular disease community. Download your FREE Macula Menu e-cookbook at [www.mdffoundation.com.au](http://www.mdffoundation.com.au) during Macula Month (1 to 31 May).



# Technology & You

Wearable technology is everywhere – from watches that act as an extension of your phone, to bracelets (even earrings!) that act as activity tracking monitors.

Some of the most sophisticated wearable technology devices on the market are designed to assist people with low vision. We investigate some options:



## IrisVision

IrisVision uses virtual reality technology in order to see the surrounding environment and activities such as reading the newspaper or seeing faces. Simple controls on the device allow control of magnification level and to use multiple viewing modes depending on the task at hand.

**IrisVision is available via Vision Australia**  
[www.visionaustralia.org](http://www.visionaustralia.org)



## eSight 3

eSight 3 is a new type of fully portable electronic goggles. A high-resolution video camera on a headset captures live images, which are sent to a tiny computer inside the headset. The vision feed is customised by the user – images can be magnified up to 24x, contrast and colours can be changed for display on two LED screens in front of the eyes. eSight can also be directly connected to a television or computer screen.

**eSight3 is available via Designs for Vision**  
[www.dfv.com.au](http://www.dfv.com.au)



## OrCam MyEye 2.0

A more discreet device, with different functionality, the OrCam MyEye is a wireless smart camera (about the size of a finger) mounted on the frame of the user's glasses. The device reads aloud printed text – from newspapers, books, menus and signs. Faces and products can also be added to its library, allowing it to identify people and objects, including money, barcodes – even colours. The device is activated by the user pointing a finger at the text they want to read. Text is read back to the user by a small personal speaker on the side of the glasses frame.

**OrCam is available via Quantum RLV**  
[www.quantumlr.com.au](http://www.quantumlr.com.au)

**All these devices require quite significant financial investment (\$4,000 - \$14,000) and may not benefit all individuals. If you have an interest in learning more about these technologies, please call MDFA on 1800 111 709 or contact the providers directly.**



# Book Club

## First Person by Richard Flanagan



In 2014, Australian author, Richard Flanagan, won the Man Booker Prize for his novel *The Narrow Road to the Deep North*. (If you haven't read it, do yourself a favour – it's brilliant). But back in 1991, Flanagan was a penniless, married, almost-novelist, who

was commissioned to ghost write the autobiography of one of Australia's most notorious con men, John Friedrich, who took his own life before the book was completed.

Flanagan's latest novel, *First Person*, draws upon this real life story and is filled with as much intrigue as the actual event.

In this book, a young penniless writer, Kif Kehlmann, is contracted to write the autobiography of notorious corporate criminal, Siegfried Heidl. About to go to trial for defrauding the banks of \$700 million, Heidl proposes a deal: \$10,000 for Kehlmann to ghost write his memoir in six weeks. The Kehlmann and Heidl story is a roller coaster. Heidl is involved with the CIA, he has faked his own death to escape an embezzlement charge in Germany, and he somehow manages to emerge in Australia as a completely different person, conning politicians, bankers and many of the Australian society elite.

If it wasn't a mirror reflection of what happened in 1991, you'd think it was true crime fantasy. Or is it?

### Reviewed by Jim, MDFA volunteer

Thanks to our friends at Bolinda Audio for supplying a copy of *First Person* for Jim to review.



# Eyes on Research

## Squalamine eye drops for wet AMD fails phase 3 studies

We have been reporting for several years in the annual research update about an investigational treatment called squalamine eye drops for people with wet age-related macular degeneration (AMD).

It was hoped that squalamine, when used in conjunction with anti-VEGF injections, would improve the efficacy of the treatment. However, it was announced in January that, despite seemingly favourable results in earlier trials, a larger 237-patient phase 3 registration trial did not show any additional benefit.

Squalamine had been under development for over 20 years with several variations of the drug tested in AMD and other indications. It is unlikely that any further testing of the drug will be conducted in AMD.

This is a further reminder of both the challenges of research and the importance of continued investment.

## NSW-based carers required for research project

The **Caring for the Carer** research project, led by Associate Professor Bamini Gopinath from Westmead Institute for Medical Research, is still looking for participants to support this new study.

The research study will examine improving the emotional wellbeing among family carers of people with age-related macular degeneration (AMD). Participants will receive a program that is aimed at improving carer well-being including learning to better cope with sadness or anxiety due to their caring role.

The study is currently limited to those living in NSW, although it is hoped to ultimately have national implications.

If you are a NSW-based carer of someone with AMD and would like to learn more about this study, please contact us on 1800 111 709.

# Progress into stem-cell based treatments

Recent news circulating from the UK has reported on the 12 month results of the first two people implanted with stem-cell derived RPE cells as part of the London Project to Cure Blindness, being conducted at the University College London and Moorfields Hospital.

A man in his 80s and a woman in her 60s received a new stem cell-based treatment for age-related macular degeneration (AMD).

While this is a very exciting and important study, it is still early in the development of this technology. Only two people have received this particular treatment so far, which involved the implantation of RPE cells under the retina. Assuming the studies continue to go well, the researchers stated that they hope an 'off-the-shelf' treatment may be available within 5 years, though this might be optimistic.

At this time, there are no comparable human trials with this technology in Australia. The Foundation is however funding a study that is using similar technology to better understand the underlying causes of the disease but this research project does not involve treating humans.

It should also be noted that while this treatment was in people with severe wet AMD, other similar studies are underway treating people with severe dry AMD.



## LUXTURNA (voretigene-neparvovec-rzyl)

In late 2017, the first gene therapy for a rare, inherited disease known as biallelic RPE65 mutation-associated retinal dystrophy was approved by the FDA in the USA. Although this condition is very rare, the treatment, known as Luxturna is the first example of a new type of treatment that is likely to have much wider application in the future for a broad range of other serious eye diseases that are caused by a single gene defect. This includes conditions such as Stargardt's disease and Best's disease, which are forms of macular degeneration affecting younger people.

Genes deliver instructions to enable normal development and functioning of the body, however tiny changes or mutations in a gene can result in incorrect instructions being given. The RPE65 gene is involved in the production of a protein essential for normal vision. Mutations in the RPE65 gene result in significant vision loss, which progressively deteriorates over time.

This new therapy is given as a single injection directly under the retina and works by delivering a 'normal' copy of the RPE65 gene to the retina, which takes over the function of the defective gene. Research has shown that this therapy has the potential to significantly improve functional vision.

Gene therapies using similar technology to Luxturna are being developed for other inherited conditions caused by specific gene mutations. However, it is still unknown when these therapies will become available. Nevertheless, Luxturna's approval is certainly very encouraging, as it demonstrates that this technology can work.

It should be noted that this therapy is not appropriate for age-related macular degeneration as this is not caused by a single gene mutation, but is influenced by a wide range of many genetic variations. Research is underway to develop other types of gene therapy for age-related macular degeneration and we will keep you abreast of any new developments as they come to light.



In the lead up to the 2019 Federal Election, 2018 will be an important year for MDFA's advocacy efforts, as we continue to work to achieve positive changes that benefit the macular disease community.

This year, our primary goal will be to secure Commonwealth Government commitment for the establishment of a national aids and equipment program that provides low vision aids and technologies. The introduction of the NDIS has only benefited those before the age of 65 years who acquire legal blindness, or have certain genetic eye conditions which would eventually lead to blindness.

Those who are excluded from the NDIS have to either seek low vision aids and technologies from state and territory government aids and equipment programs, or the Commonwealth Government's aged care programs; all of which have inconsistent levels of low vision support, resulting in your location of residence and age determining how well you see.

Our vision for a national aids and equipment program is one that ensures people who need low vision aids and technologies will be able to obtain them, regardless of their location, age, severity of vision loss, or cost of the equipment. We hope you will continue to support us in 2018 as we work to make this goal a reality.



## Advocacy & Representation

As the national peak body for macular disease, the Foundation provides advice and information to government and other stakeholders to support the best interests of all those affected by macular disease.

Below is just a few of the recent recommendations.

### Complementary medicines assessment

We recommended the Therapeutic Goods Administration (TGA) improve aspects of the registration process and medical claims of evidence-based complementary medicines.

### Listing of Ozurdex for retinal vein occlusions (RVO)

We supported the Pharmaceutical Benefits Scheme (PBS) listing of Ozurdex to treat RVO, which would provide ophthalmologists with another treatment option for this condition.

### Aged care assessment process

We recommended that the assessment form for My Aged Care include questions that identify clients' low vision needs and then refer them for specialised low vision assessments.

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### Medicare rebates for item 105

Many of you would now have heard about the removal of a Medicare benefit for item 105 - (continuing consultation), when performed at the same time as an eye injection.

The government's view is that the Medicare benefit for the injection should already capture a consultation component, and billing a full separate consultation is therefore not considered appropriate. The intent of the change was not for additional out-of-pocket costs to be passed onto patients, but rather, that practitioners would cease to bill the consultation items altogether.

**Please contact us for a copy of MDFA's updated Eye Injection Treatment Costs and Rebates fact sheet or the Government's fact sheet which addresses this matter.**

## The Larapinta Challenge July 26, 2018

Grumpy and his Girl Guides (aka Jeff Barber and his daughters Jenny, Cathy and Siobhan) completed the Larapinta Trail last year and fundraised for the research into macular degeneration. Jeff has lived with dry aged-related macular degeneration since 2004 and is legally blind.

Jeff's loss of vision had affected his confidence, so his daughters took charge and together they walked the Larapinta Trail. This year, we invite you to do the same.

Completing the trek was an achievement Jeff is very proud of, "The trek proved to me that there are still many things out there that can be achieved and enjoyed. A new wave of optimism has washed over me thanks to my three daughters and wife".

If the Larapinta Trail has been on your bucket list for a while, why not have this life-changing experience and support the Foundation at the same time. For more information, please call the Foundation.



Grumpy and his Girl Guides on Mt Sonder at sunrise.





Rita in Santiago de Compostela, Spain.

## Research is the key to ending generational blindness

When Rita Walton's elderly mother lost her sight it was "just one of those things...we didn't know about macular degeneration in those days."

Now 86, Rita's own sight started to fade ten years ago. She and two of her six siblings became legally blind with different forms of macular degeneration – making her family a classic example of the hereditary nature of macular degeneration.

While it is too late for her own vision, Rita is pinning her hopes on research to ensure macular disease ends with her generation.

"We had no idea it was hereditary. I have seven children and 14 grandchildren and I hope there is a treatment or a cure by the time they might need it. Research is so very, very important – everyone should contribute if they can."

Rita says she just tries to "get on with it and do the best I can". Her latest project is trying to teach "a one-eyed rescue Pomeranian with attitude" to walk on a lead. "He's a beautiful little fellow but he does test my patience," she laughs. "He has put a smile on my face again though."

Always a keen traveller, Rita and her daughter last year visited Spain and Portugal. The active Sydney-sider is now working on building up her muscle strength after a recent fall, aiming for another European adventure later this year.

## Another hole in one

The 11<sup>th</sup> year of the Roth Gair Charity Golf Day on the Mornington Peninsula was another great fundraising success, raising over \$11,000 and tipping the donation of this event to \$125,000 since its inception.

Joined by 120 golfers, this charity golf day remembers the late Roth Gair, Past President of the Lions Club of Forest Hill in Victoria. This annual event continues to celebrate the legacy of Roth and his love for golf before he lost his vision to macular degeneration.

Our heartfelt thanks to Ian Kennedy, the Gair family, the many volunteers from the Lions Club of Forest Hill and Park Orchards, and the generous sponsors and golfers on the day.



Trevor and Ian Kennedy accepting the trophy for winners Ron Wilson Transport.



Please contact us on 1800 111 709 if you would like to receive a free copy of the Family, Friends and Carers Guide.



Pamela and Colin

## For better or worse

A sense of perspective guides Pamela Willmot's approach to being the carer for her husband, Colin, who is legally blind with macular degeneration.

"We've always worked as a team. I get frustrated; I get annoyed; life goes on. He's the one who has patience. I haven't – he will tell you that," she laughs.

Now living in Wonthaggi, in Victoria's Gippsland, after being forced to sell the family farm when Colin's sight deteriorated, Pamela, 75, maintains the house, drives, pays the bills, handles Colin's medication, helps him with their expansive garden – and has even learnt to reverse the caravan!


Colin still uses the ride-on mower – only occasionally ripping up the garden edging – and remains an active gardener.

Pamela snatches time out for relaxing activities such as reading and knitting when Colin is occupied with his interests, sometimes using a two-way radio or phone to keep in contact.

"I'm lucky in lots of ways. I have a good husband who has provided well. There are times in our life when he has kept me going. It's my turn to pay back."



# How can we help you?



**Macular Disease Foundation Australia offers a range of information, valuable guidance and support for you, your family, carers and friends. We encourage you to share this information with anyone you know who is living with a macular disease and who might need our help. All of our services are free.**

## **Toll free Helpline**

You will speak with a qualified staff member who can provide you with information and support. If you have a question, we are here to help at any point of your macular disease journey.

## **Explaining a diagnosis**

If you're newly diagnosed and would like to speak with someone about this, we can help you better understand your diagnosis and next steps.

## **Information about macular disease**

Latest information on a range of macular diseases including risk reduction, treatments, and advice on how best to manage your macular condition. Information available via Helpline, website, and publications (including audio).

## **Navigating Government support systems**

Medicare, NDIS and My Aged Care systems are tricky to understand. If you have

questions about rebates and costs of treatments or access to government support, we can help.

## **Seeking professional services**

If you require information about your closest health professional (e.g. optometrist, ophthalmologist, psychologist or dietitian) we can assist.

## **Accessing low vision services**

Services are available for people with low vision. We can assist you with information to help maintain quality of life and independence.

## **Looking at transport options**

Transport is important to get you out and about, including to your eye care appointment. If you need information about how to access this through government services, we can assist.

## **Connecting with the community**

Sharing your story and talking with someone who also has

been on the macular disease journey can ease the load. We can assist by connecting you with support and community groups.

## **Finding support as a carer**

If you are a family member or friend who cares for someone with macular disease we can provide you with support and assist in directing you to relevant government and carer support services.

## **Translation services**

Information in other languages, including interpreters for Helpline calls.

## **Education seminars**

Knowledge is power and we recommend that you attend an education seminar when we come to your town. This is helpful for you, your family and friends, or someone who might be at risk of macular disease.

**Contact Us:**  1800 111 709  [info@mdfoundation.com.au](mailto:info@mdfoundation.com.au)  @maculardisease

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