

# RETINA REPORTER

Retina Australia's Bi-Annual Newsletter

JUNE 2024



## CONTENT

- Research Project and Clinical Trial Register
- Message from the CEO
- Research Update Event
- 2024 Annual Appeal
- Research Grants Program
- Retina Australia Research Grant Impact Reports
- Research Grant Impact Highlight
- In Focus: Geographic Atrophy
- Research Insight: Optogenetics win for retinitis pigmentosa after changing primary endpoint
- World Sunglasses Day
- Research Project and Clinical Trial Register – Summary of Register

## Research Project and Clinical Trial Register

The success of research projects and clinical trials are essential to the progress of finding new treatments for inherited retinal diseases (IRDs). Retina Australia's IRD Research Project and Clinical Trial Register aims to provide information about programs that are currently recruiting participants. We recommend seeking advice from your ophthalmologist regarding participation where appropriate.

You can find a summary of projects that are currently open for participation on the last page of this newsletter or refer to [www.retinaaustralia.com.au](http://www.retinaaustralia.com.au) for full details.

# Message from the CEO



Increasing awareness and information about inherited retinal disease (IRD) has been a strong focus this year. We kicked off with our new Retinitis Pigmentosa Awareness Month campaign in February. Thank you to those who donated and to everyone who organised Do It in The Dark (DITD) events to raise awareness and funds for Retina Australia. It was our first time at the Rare Disease Expo in Perth and we extend a warm thanks to ConnectGroups for supporting our presence. I also had the pleasure of meeting the Friends of Retina Australia Perth group for a lovely morning tea during my visit in February.



In March, Retina Australia took part in a plenary panel discussion and led a retina group workshop the next day at the Janssen ANZ Annual Company Conference. Through our involvement on the Vision Loss Priority Setting Partnership, we engaged with patients and families at the IRD Patient Day in Sydney, hosted by the University of NSW and the Children's Medical Research Institute. Just recently, we held our own Research Update event in Canberra, kindly sponsored by Apellis.

Our newsletters have given further attention to improving the understanding of IRDs and providing updates on latest research developments. Our last two Research Insight feature articles have offered simplified explanations into the complex research process, thanks to the support from PYC Therapeutics.

We receive many inquiries about treatments and clinical trials. Our website now has a new section on Emerging Treatments, along with information on Clinical Trials, Genetic Testing and the IRD Research Project and Clinical Trial Register. We are proud to be a Partner Organisation in the recently awarded \$1.5 million NHMRC grant for a genetic blindness study led by Professor Deborah Schofield, Director of GenIMPACT.

Successful research projects and clinical trials are crucial for discovering, developing, and delivering new treatments. If you would like to support this progress, you may consider participating in research. Alternatively, you can support Retina Australia in funding and facilitating research by donating to our 2024 Annual Appeal. Thank you so much for your kind support.

Warmest regards,

A handwritten signature in cursive script that reads 'Julia Hall'.

Julia Hall  
Chief Executive Officer

Pictured on the next page: Clockwise from the top: Plenary panel at the Janssen ANZ annual conference; Friends of Retina Australia Perth group morning tea; Leighton and Rosemary Boyd at the Patient Engagement Day in Sydney; Janssen staff taking on the DITD puzzle challenge and Retina Australia member, Brian Light (seated front left hand side), hosting a DITD lunch with friends for Retinitis Pigmentosa Awareness Month.

# Message from the CEO



# Research Update Event



## **Emerging treatments in geographic atrophy, a late stage of age-related macular degeneration (AMD)**

by Dr Carla Abbott, Centre for Eye Research Australia and the University of Melbourne



## **Using the Message of Exercise to Prevent Blindness**

by Nick Bariesheff, Australian National University



## **How targeting inflammation can protect against retinal degeneration**

by Dr Adrian Cioanca, Australian National University

On 16th May 2024, Retina Australia was delighted to welcome attendees at our Patient Engagement Event – Research Update. The event was held in Canberra at the John Curtin School of Medical Research and was also streamed live via webinar.

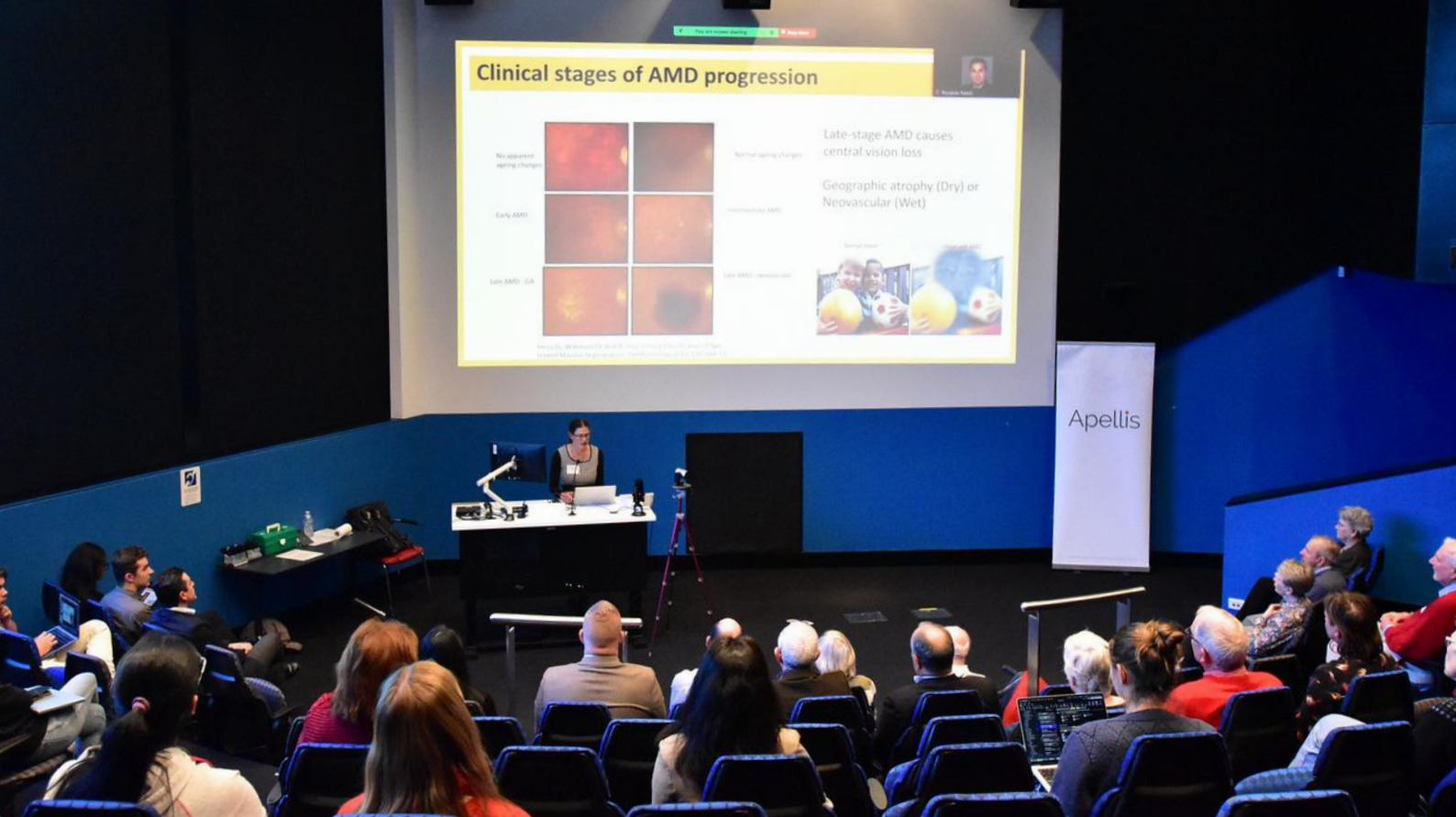
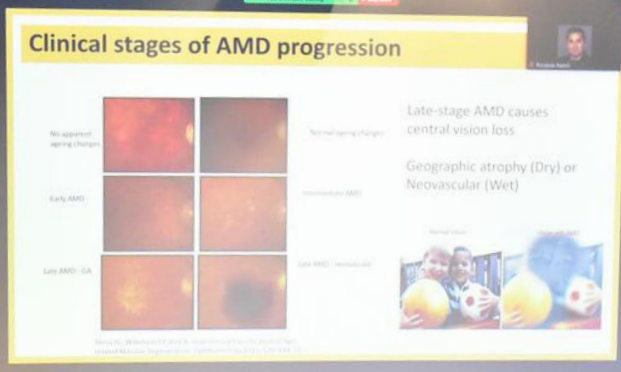
Our three speakers, as noted above, were extremely interesting, informative and engaging. Dr Abbott spoke about the emerging treatments coming to Australia for geographic atrophy. This talk also covered diagnosis, the patients that these potential new treatments would be best suited for and opportunities to be involved in cutting-edge clinical trials. From Nick we learned how exercise may protect the eye from damage, and Adrian reported on his 2023 research grant project from Retina Australia which resulted in the discovery of three molecules which may hold a key to targeting inflammation that leads to loss of vision in age-related macular degeneration (AMD). Post presentations, attendees were offered the opportunity to take a tour of the extensive research lab facilities.

Retina Australia would like to sincerely thank our Key Sponsor, Apellis, for its support for the event. Our warm appreciation also extends to the volunteers at Clear Vision Research, and the John Curtin School of Medical Research (JCSMR) at the Australian National University as our Event Hosts.

**A recording of the event and all presentations is now available to watch on our website at [www.retinaaustralia.com.au](http://www.retinaaustralia.com.au) or click [HERE](#).**

Pictured on the next page: Clockwise from the top left: Bob James with his guide dog, next to Retina Australia members, Warren and Rhonda Colledge; Associate Professor Riccardo Natoli, Head of Clear Vision Research and Retina Australia Director with Jan James and John Barlow with his guide dog, beside Associate Professor Krisztina Valter; Peter Clarke and Dino Farranato, Retina Australia Director, on a lab tour with Clear Vision volunteers, Nick Bariesheff and Rimaz Toto; and Dr Carla Abbott presenting in the Finkel Lecture Theatre at the JCSMR.

# Research Update Event



# 2024 Annual Appeal



## 2024 ANNUAL APPEAL

Help fund critical research into inherited retinal diseases. There is hope in SIGHT.

[DONATE NOW](#)

## Help us accelerate the discovery of new treatments

Inherited retinal diseases (IRDs) result in progressive, irreversible and incurable blindness in children and adults.

IRDs are the leading cause of blindness in working age adults and the second leading cause of blindness in children, with a total estimated lifetime cost of \$5.2 million per person in Australia.

### **BUT THERE IS HOPE IN SIGHT**

There is now one treatment, a gene therapy. Although it is only suitable for a very rare type of IRD associated with the *RPE65* gene, it has opened up a new area of understanding and paved the way for innovative treatments to be developed for other types of IRDs. With continued research and more clinical trials now underway, together we can help find those treatments faster.

Every donation helps. Thank you for your support



[DONATE NOW](#)



All donations \$2 and above are tax deductible  
[www.retinaaustralia.com.au](http://www.retinaaustralia.com.au) (03)9650 5088 [info@retinaaustralia.com.au](mailto:info@retinaaustralia.com.au)

# Research Grants Program



## Applications for funding for 2025 research projects are OPEN

Retina Australia provides funding for Australian medical research into inherited retinal disease through its annual Research Grants Program. It has invested over \$6.5 million in grants to advance research into inherited retinal disease since the program was initiated in 1989. The research focus is on early detection, discovering preventions, and accelerating better treatments with the hope of unlocking cures.

As an independent organisation, Retina Australia is uniquely positioned to select the best and brightest researchers and their ideas, from any research institution in the country, via an open and competitive application process. The selection process is underpinned by an expert Grants Advisory Committee. Committee members are highly respected, credentialed experts in their related fields, and represent different medical research institutions in different states. Meet the current members below.

Applications for grants are reviewed and ranked by the Grants Advisory Committee. The Committee Chair may call on suitably qualified peer reviewers to provide expert comment on individual applications in order to assist the Committee in their consideration and ranking of the applications. These rankings and associated reports are then considered by the Retina Australia Board in determining the allocation of grants for the following calendar year based on available funds.

**Applications for 2025 grants close on 30 June 2024. Head to our website at [www.retinaaustralia.com.au](http://www.retinaaustralia.com.au) for how to apply for a grant or click [HERE](#).**

## Meet our expert Grants Advisory Committee



### **Chair – Professor**

#### **John Grigg**

Head of the Speciality of Clinical Ophthalmology and Eye Health, Save Sight Institute, The University of Sydney



### **Professor**

#### **Erica Fletcher**

Head of Visual Neuroscience Laboratory, Department of Anatomy & Cell Biology, The University of Melbourne



### **Dr Glyn Chidlow**

Research Scientist, South Australian Institute of Ophthalmology and University of Adelaide



### **Associate**

#### **Professor**

#### **Fred Chen**

Head of Research – Ocular Tissue Engineering Laboratory, Lions Eye Institute, Perth

# Retina Australia Research Grant Impact Reports



Retina Australia is delighted to provide final report summaries on the two grant projects awarded in 2023 which are now complete.



## Establishing novel AAV gene editing for Usher syndrome

Chief Investigator

Dr Anai Gonzalez-Cordero, Children's Medical Research Institute (CMRI), Sydney

Co-Investigator

Dr Samantha Ginn, CMRI, Sydney

PhD student Miss Vivienne Kaiser, CMRI, Sydney

Grant awarded - \$55,774 (2023)

### Project Aim

The aim of this project was to establish proof-of-concept for a new type of treatment method using adeno-associated viral vectors (AAV) along with a gene editing tool called CRISPR-Cas9, designed specifically for Usher Syndrome subtype 1 (Usher 1b and 1f subtypes) Australian patients. This treatment was tested on retinal organoids (mini versions of the retina) grown from cells taken from these patients to assess for treatment efficacy.

### Project Results and Impact

- The process of growing retinal organoids in the lab was improved ensuring the optimal production of photoreceptor cells, and other types of retinal cells.
- Safe viral vectors known as AAVs were developed to repair specific sections of genes associated with Usher Syndrome. The most effective guide RNAs, which act like messengers in the cells, were identified to assist in the gene editing process (genetic scissors), enabling efficiencies in treating retinal organoids in the lab.
- The research demonstrated strong cutting efficiency in the treated retinal organoids, indicating the potential effectiveness of the gene editing approach. The use of small fat particles called lipid nanoparticles (LNPs) was successfully tested and therefore may be a new way to deliver gene therapy to the retina without keeping the gene-editing tools working for too long which may increase the risk to disruptions in the DNA.
- Specific biomarkers were identified, and tests were created to check whether the gene therapy was working. These tests help us understand if the gene therapy is effective in treating the disease.

**Access the Final Report [HERE](#) or at [www.retinaaustralia.com.au](http://www.retinaaustralia.com.au).**



# Retina Australia Research Grant Impact Reports



## Using RNA-silencing to tackle neuroinflammation in retinal degeneration

Dr Adrian Cioanca - John Curtin School of Medical Research (JCSMR), Canberra

### Co-investigators

Associate Professor Riccardo Natoli, JCSMR, Canberra

Dr Michelle Madigan Save Sight Institute, Sydney

Dr Elisa Cornish, University of Sydney

Grant awarded - \$59,869 (2023)



## Project Aim

The aim of this project was to develop a novel approach to treat age-related macular degeneration (AMD) by targeting the complex biological pathways that lead to neuroinflammation in the retina. The study focused on molecules present in two types of retinal cells, Müller glia (support cells in the retina that keep it healthy) and microglia (the “immune” cells of the retina).

## Project Summary and Impact

- Three key molecules that drive inflammation in the retina were discovered. Consistency in response of these molecules to retinal damage by mouse models of retinal degeneration and human AMD retinas supports the credibility of the mouse model as representative of human disease. This suggests that the biological processes seen in the mouse model are probably comparable to those in humans.
- It was successfully shown that by blocking these molecules with a special type of molecule called siRNA (small interfering RNA), the activity of these three molecules was lessened, indicating reduced inflammation. The treated animals responded better to light, suggesting their retinas were still working well. In addition, the layer of the retina where photoreceptor cells are located was thicker in the treated mice, suggesting that fewer cells died and more cells survived, which could mean better vision.

This project addressed a critical gap in AMD treatment by targeting the inflammatory processes at their molecular roots. By focusing on transcription factors in Müller glia and microglia, this research has the potential to yield a novel class of therapeutics for AMD.

**Access the Final Report [HERE](#) or watch a video presentation [HERE](#).  
Both are available on [www.retinaaustralia.com.au](http://www.retinaaustralia.com.au).**

# Research Grant Impact Highlight



It is with pleasure that Retina Australia highlights the impact of a previous Retina Australia Research Grants Program recipient.



## **Retina Australia Research Grant Awardee**

Associate Professor Lauren Ayton, from the Centre for Eye Research Australia (CERA) and University of Melbourne, has received two grants from Retina Australia, one in 2014 and another in 2021. Both have led to progress in research developments, multiple research publications and significant additional support, with a combined funding leverage of over 23 times to date.

## **Validation of novel outcome measures for use in vision restoration clinical trials – \$39,630 grant (2014)**

A/Prof Ayton was awarded this Retina Australia grant to substantiate new outcome measures for the assessment of low vision.

### Research Impact of the 2014 grant

- Two new tools for low vision assessment were developed: the Impact of Vision Impairment – Very Low Vision (IVI-VLV) quality of life questionnaire, and the Low Vision Assessment of Daily Activities (LoVADA) observed task tool. Both are now used in both research and industry clinical trials worldwide
- An additional paper was published into the psychosocial considerations in potential bionic eye recipients
- IVI-VLV was highlighted in a gold standard consensus paper in 2020 as being one of the only validated quality of life tools for people with ultra-low vision
- A/Prof Ayton and her team have just started a new project using the IVI-VLV to assess the effectiveness of low vision therapy in a large study in Scotland

### Funding Leverage of 2014 grant

Following on from this initial grant from Retina Australia, A/Prof Ayton has been successful in obtaining further funding to continue her research:

- \$1,534,523 from a National Health & Medical Research Council (NHMRC) investigator grant, to explore “Saving sight through novel biotech innovations for inherited retinal disease” (2022-2026)
- \$78,000 from a CERA Philanthropic Grant, to determine “Reliability of a novel multi-sensory tool for functional assessments in the real-world” (2023)
- \$43,590 from the Manchester-Melbourne-Toronto International Research Fund, for “Improving care for children with inherited retinal diseases” (2023)

# Research Grant Impact Highlight



- \$10,000 from the Queensland University of Technology Faculty of Health Pilot Grant, to explore “Concept mapping to design contemporary vision-related performance endpoints for novel eye therapies” (2019)
- \$8,390 from the Victorian Optometrists Training and Education (VOTE) grant, to investigate “Understanding how vision loss impacts our patients’ visual enjoyment” (2024)

## **Improving sensory substitution low vision devices through novel software adaptation - \$40,643 grant (2021)**

This grant was awarded to investigate the efficacy of sensory substitution devices (SSDs), and to improve their function using novel software adaptations.

### Research Impact of the 2021 grant

- Used a world-class gait and mobility laboratory at the Department of Physiotherapy, University of Melbourne, to develop new measures, which we can use to validate low vision devices
- Trials of devices including tactile, auditory and ultrasound aids were completed
- A student will complete his PhD in June 2024, based on the work from this grant
- The grant work has or will directly contribute to four scientific papers, three conference presentations and several community engagement events
- An industry clinical study (Bionic Vision Technologies) has been completed, with interest from other companies
- A collaboration with the Department of Physiotherapy and the Department of Biomedical Engineering, University of Melbourne, has recently led to a \$200,000 grant to update the motion tracking system used in this study

### Funding Leverage of 2021 grant

Further funding received to continue the research from this seed grant included:

- \$1,534,523 from a National Health & Medical Research Council (NHMRC) investigator grant, to explore “Saving sight through novel biotech innovations for inherited retinal disease” (2022–2026)
- \$176,248 from the University of Melbourne Research Infrastructure Investment Fund (RIIF) Collaborative Equipment Grant (CEG) for motion analysis equipment
- \$30,000 from Bionic Vision Technologies to complete a validation study of a prototype device, using the study protocols developed during the 2021 grant

A/Prof Ayton and her team are now involved in several projects including the VENTURE IRD natural history study, a new project using advanced whole genome genetic sequencing to try and solve IRDs of unknown cause, studies into the experiences and clinical aspects of female carriers of X-linked IRDs, and research into the impact of IRDs, vision loss, and emerging treatments such as gene therapy.

# In Focus: Geographic Atrophy



## What is Geographic Atrophy?

Geographic atrophy (GA) is an advanced form of age-related macular degeneration (AMD). AMD is a disease that occurs in people above 50 years of age that causes the gradual and permanent loss of sight due to blurring or loss of central vision which affects the ability to read and see faces.

There are different stages of AMD. These are categorised using the Beckmann classification based on the clinical examination or evaluation of a fundus photo, which is a photo taken of the rear of the eye to identify lesions. AMD has 3 distinct stages, early, intermediate, and advanced. The early and intermediate stages of AMD are less likely to cause changes in the vision.

There are two forms of advanced AMD:

1. Geographic atrophy (GA) ('dry' AMD) occurs when the photoreceptors and retinal pigment epithelium (RPE) cells at the macula die over time, causing a gradual, painless but permanent loss of central vision. The macula is the central part of the retina that processes what you see directly in front of you, that is, your central vision. It allows you to achieve high-resolution vision and accounts for your ability to read, recognise faces and to see the world in detail and colour.
  - o GA is a progressive disease that leads to irreversible central blindness over time. The severity of the visual disability associated with GA secondary to AMD is evidenced by the median time to progression to legal blindness estimated at 6.2 years.
2. Neovascular AMD ('wet' AMD) occurs where new blood vessels grow into and under the retina, which can leak and cause bleeds leading to sudden vision loss and distorted vision.

## How many people live with GA?

It is estimated that there are up to 100,000 Australians living with GA. This is based on an average of a 1-2% population estimate of late-stage AMD and that GA appears to occur in a proportion equal to that of those with neovascular AMD.

Worldwide, there are an estimated 5 million people living with GA.

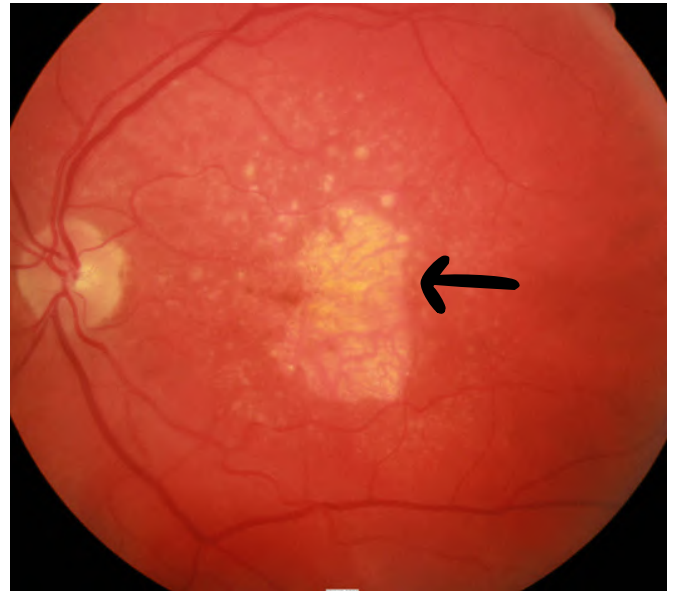
- The incidence of GA is also more prevalent in the European population compared to the Asian, African, and Hispanic populations.
- The incidence of GA has been shown to increase four-fold every ten years from the ages 50 to 80 in the European population.
- As the ageing population globally is estimated to increase over the coming decades, the incidence of GA is therefore also projected to rise.

# In Focus: Geographic Atrophy

## How is GA identified

Through a retinal examination by an optometrist or ophthalmologist, GA is identified by areas of retinal thinning associated with loss of photoreceptors and retinal pigment epithelium (RPE).

Over time, this damage to crucial parts of the retina can eventually lead to the loss of these retinal structures, resulting in the distinctly defined areas of cell loss which are characteristic of GA. These areas may have a scalloped or geographic border, which is the reason for the name "geographic atrophy."



Source image: courtesy of Professor Robyn Guymer, Macular Research Unit, Centre for Eye Research Australia

## What are the symptoms of GA

GA often develops gradually over time and may not cause noticeable symptoms in its early stages. This is particularly so if it is only present in one eye to start with, as the other eye will mask the problem. However, as the condition progresses, common symptoms may include:

- Gradual central vision loss which affects the ability to see fine details, read, drive, and recognise faces. This vision loss typically worsens over time as the atrophic areas in the macula expand.
- Blurred or distorted central vision. Straight lines may appear wavy or distorted, and objects may appear less clear or sharply defined.
- Visual distortions such as seeing blind spots or missing areas in the central field of vision. These can interfere with daily tasks that require clear central vision.
- Difficulty with low-light vision or reduced night vision. This can make it challenging to see in dimly lit environments or at night.
- Decreased contrast sensitivity making it harder to distinguish between objects of similar shades or colours. This can impact activities such as reading, driving, and navigating unfamiliar environments.

It is important to note that the symptoms of GA can vary from person to person, and some individuals may experience more severe vision loss than others. Regular eye examinations and monitoring by an eye care professional are essential for detecting and managing GA, as early intervention (once approved and available in Australia) may help slow the progression of vision loss and preserve remaining vision.

# In Focus: Geographic Atrophy



## What is the cause

The development of GA is complex and influenced by various genetic, environmental, and age-related factors.

- **Genetic Factors:** Certain gene variants are linked to a higher risk of developing GA and other forms of AMD. These include those in complement factor H (CFH), complement factor I (CFI), complement component 2 (C2), and complement factor B (CFB). These genes help regulate the immune system and inflammation, which are crucial in the development of AMD.
- **Environmental Factors:** Smoking is the greatest modifiable risk factor associated with an increased risk of GA. Other lifestyle and environmental risk factors include diet and exposure to ultraviolet (UV) light.
- **Ageing:** Ageing is the primary risk factor for GA, however it is non-modifiable, meaning that it is unable to be changed or controlled. As people age, cellular processes in the retina, including the function and maintenance of RPE cells, become less efficient. Over time, the build up of cellular damage and oxidative stress contributes to the degenerative changes observed in AMD and GA.
- **Inflammation in the retina** can lead to RPE dysfunction, photoreceptor damage, and ultimately, the formation of GA lesions.

## Social impact of GA

GA can make it difficult for individuals to perform everyday tasks independently, significantly affecting their daily functioning and quality of life. People living with GA may find certain activities challenging such as reading, driving, watching television, completing household chores, recognising faces, and the ability to perceive non visual communications. More light may be needed for tasks such as reading, typing, or sewing, and many people experience blurred vision, sensitivity to light, colour vision defects, progressive visual loss, a restricted visual field, and poor contrast vision. GA may also impact a person's ability to work, including volunteering which may lead to reduced community participation.

The impact of visual impairment goes beyond daily tasks. GA can cause emotional distress or even depression, anxiety about the future, frustration, and a sense of dependency on others. In addition, older adults with vision loss often have poorer physical and cognitive abilities, making them more susceptible to comorbidities, disability, and increased mortality.

Visual impairment, particularly the near vision impairment characteristic of GA, is also a risk factor for frailty and increases the incidence of falls among the elderly. Falls are a significant public health concern worldwide, with a substantial portion attributed to visual impairment, including GA and AMD.

# In Focus: Geographic Atrophy



## Emerging treatments in GA

There are now two treatments for GA which have been approved in the US. These aim to slow progression of the disease rather than stop or reverse it. They both use complement inhibitors that target the complement pathway, which plays a role in the immune response. By reducing the activity of this pathway, the medicine aims to reduce inflammation and retinal damage in order to slow down GA progression and preserve vision.

### 1. Pegcetacoplan (Syfovre, Apellis)

Pegcetacoplan involves monthly or every-other-month intravitreal injections, which uses a fine needle to deliver the medication directly into the eye. It was approved for use in the US by the Food and Drug Administration (FDA) in February 2023. It is now being evaluated for use in Australia by the Therapeutic Goods Administration (TGA).

### 2. Avacincaptad pegol (Izervay, Iveric Bio)

Avacincaptad pegol is also administered via monthly intravitreal injections. It was approved for use in the US by the Food and Drug Administration (FDA) in August 2023.

## Late-stage clinical trials in progress

In Australia, a Phase 3 trial called Phoenix is testing an oral tablet for GA treatment called Tnlarebant (Belite Bio). A trial in Phase 2 called ALXN2040-GA-201 is testing an oral medication called Danicopan (Alexion Pharmaceuticals) and another Phase 2 trial called Parasol is testing a gene therapy vector called JNJ-81201887 (Janssen). There are other international and domestic clinical trial studies targeting the complement system, using neuroprotective agents, and also testing ocular gene therapies and stem cell therapies that may provide other future treatments for GA.

## Clinical care

It is recommended that patients see their optometrist or ophthalmologist for further information. The Royal Australian and New Zealand College of Ophthalmology (RANZCO) recently updated its Referral Pathway for AMD management which advises referral to an ophthalmologist if patients with GA are interested in learning more about potential GA treatments to enable informed decision making.

**For a research references, please click [HERE](#)  
or refer to the Retina Australia website at [www.retinaaustralia.com.au](http://www.retinaaustralia.com.au).**

In Focus Sponsor



## Optogenetics win for retinitis pigmentosa after changing primary endpoint



In our March e-newsletter, the Retina Insider, we published a [Research Insight](#) article about the importance of selecting appropriate clinical trial endpoints, which may involve novel test modalities to ensure clinical trial success. However, in a recent clinical trial testing a new gene therapy treatment for [retinitis pigmentosa \(RP\)](#), it was a change from a novel primary endpoint back to a more traditional measure that has led to trial success.

Nanoscope Therapeutics has developed a potential new treatment called MCO-010 for RP, an inherited retinal disease causing vision loss. This treatment is a particular type of gene therapy called "optogenetics" that uses an AAV (adeno-associated virus) vector to deliver special proteins to the eye to help cells detect light. Unlike any existing treatments, MCO-010 is targeted at treating all patients with RP, not just those with a specific gene mutation. This is also known as a mutation-agnostic gene therapy.

In this two-year clinical trial, called RESTORE, two doses of MCO-010 were compared to a sham treatment in 27 people with RP. A sham treatment is also known as a placebo or control treatment, which does not contain the active ingredient, and provides a comparison to help evaluate the efficacy of the MCO-010 in improving vision for patients with RP.



## Optogenetics win for retinitis pigmentosa after changing primary endpoint

Originally, the trial was testing the treatment's effectiveness using the Multi-Luminance Mobility Test, which is a relatively new way of assessing improvements in navigation after treatment. The MLMT results were assessed at week 52, but it did not show clear results.

In January 2024, Nanoscope changed the primary endpoint of this Phase IIb trial back to a more traditional test of best-corrected visual acuity (BCVA), a vision test that measures how well people can see with the best possible correction, usually glasses or contact lenses.

The company reported in late March 2024 that both doses of MCO-010 led to significant improvements in visual acuity at week 52. The low dose failed to beat the control at week 76, however the high dose did show significantly better results than the control.

It is worth noting that the people who received this therapy had very poor vision at baseline (light perception only), and the improvement in their vision would still not allow them to read letters on a visual acuity chart. However, it had restored form vision and given them a significant improvement in sight.

Nanoscope presented the results of their trial at the recent Association for Research in Vision and Ophthalmology (ARVO) meeting in Seattle, USA, on 6 May 2024. Friend of Retina Australia, Associate Professor Lauren Ayton from the Centre for Eye Research Australia and University of Melbourne, was in the audience and was impressed with the results.

Associate Professor Ayton commented, "While the treatment is not yet able to restore vision to the stage where people can read letters on a chart, the results are very exciting. One of the most interesting outcomes for me is that people were able to perceive colours with the treatment. For example, one of the recipients of the therapy was then able to see and detect the colours of the handholds he used at rock-climbing, which he had not previously been able to do."

Nanoscope is now planning to submit for approval from the Food and Drug Administration (FDA) in the US for their treatment later this year. If approved, MCO-010 could be a groundbreaking treatment for RP, offering hope for those with this condition.

# World Sunglasses Day



## Pop on some cool shades on 27 June 2024 and raise awareness for World Sunglasses Day!

### Protect your eyes

Did you know that nearly 1 in 4 Australians do not wear sunglasses outside during the day? For World Sunglasses Day 2024 on 27 June, join us to raise awareness about the importance for everyone to protect their eyes from damaging ultra violet (UV) rays.

Long term exposure to too much UV light has been associated with developing permanent damage to the eye, with evidence showing that greater sunlight exposure can lead to an increased risk of age-related macular degeneration (AMD). Ultraviolet radiation is also a risk factor for damage to the retinas of children.

For people living with an inherited retinal disease, extra care should be taken to protect the retina.

- Research has shown that in the case of some types of inherited retinal diseases such as Stargardt disease, UV sunlight may increase the toxicity of the waste products accumulating in the retina.
- Sunglasses will also help relieve discomfort from glare, which can be a common symptom with some types of inherited retinal diseases such as achromatopsia.

To reduce risks, it is recommended to wear sunglasses when outdoors.

World Sunglasses Day  
Support Sponsor

Specsavers

# World Sunglasses Day



## Do I need to wear sunglasses in winter?

Even though UV levels are higher in summer than winter, Australia experiences some of the highest levels of UV radiation in the world.

Optometry Australia encourages Australians to wear sunglasses all day and all year round. "Maximal UV exposure for skin is 10 till 2 but because our brow blocks a lot of direct UV rays entering the eyes in the middle of the day, maximal ocular exposure happens when the sun is lower on the horizon, which is why it's still important to wear sunnies in winter".



In addition to recommending protecting the eyes when the UV level is 3 or above, the Royal Australian and New Zealand College of Ophthalmologists (RANZCO) recommend protecting eyes from UV at all times for certain activities such as skiing, boating and going to the beach, as snow and water are highly reflective surfaces and because UV levels are higher at higher altitudes.

## What sort of sunglasses should I wear?

Choose sunglasses or UV protective eyewear that meet the Australian/New Zealand standard AS/NZS 1067:2003 Sunglasses and Fashion Spectacles. All sunglasses sold in Australia must be tested and labeled according to this standard.

It is recommended to look for a lens category of at least 2 or preferably 3 or 4 to reduce glare and provide good UV protection.

**For research references, please click [HERE](#)  
or refer to the Retina Australia website at [www.retinaaustralia.com.au](http://www.retinaaustralia.com.au).**

## Need a new pair of sunnies?



Get 15% off sunglasses and readers at  
[Good Citizens Eyewear](#)  
Use the Code : RETINA15

**100% recycled PET  
frames**  
**One plastic bottle is  
recycled into one pair of  
very cool sunglasses!**



# Research Project and Clinical Trial Register



## Summary of Projects Currently Recruiting Participants

**An Observational Clinical Trial of PRPF31 (RP11)** – Sponsor: PYC Therapeutics

**Disease:** retinitis pigmentosa **Participants:** Carriers, Patients

This study aims to observe the progression in patients with the inherited retinal disease (IRD) retinitis pigmentosa 11 (PRPF31 or RP11) over the period of four years.

Recruiting: Centre for Eye Research Australia, East Melbourne, Victoria and Lion's Eye Institute, Western Australia. Contact: quokka@lexitas.com

**The Victorian Evolution of Inherited Retinal Diseases Natural History Registry (VENTURE)**

**Study** – Sponsor: Centre for Eye Research Australia, University of Melbourne

**Disease:** All inherited retinal diseases **Participants:** Carriers, Patients, Family

The VENTURE registry collects retrospective and prospective clinical and genetic information from people living with an inherited retinal disease.

Recruiting participants in Victoria. Contact: IRD@groups.unimelb.edu.au

**The Australian Inherited Retinal Disease Register (AIRDR) and DNA Bank** – Sponsor: Sir Charles Gairdner Hospital, Perth, Western Australia

**Disease:** All inherited retinal diseases **Participants:** Carriers, Patients, Family

The primary aim of the AIRDR is to characterise the genetic spectrum of IRDs in the Australian population in order to guide research into treatments and cures for IRDs.

Recruiting participants Australia wide. Contact: SCGHMTP@health.wa.gov.au

**Save Sight Institute IRD Registry** – Sponsor: The University of Sydney, NSW

**Disease:** All inherited retinal diseases **Participants:** Carriers, Patients, Family

IRD management involves detailed ophthalmic structural and functional assessment.

Recruiting participants in New South Wales. Contact: ssi.operations@sydney.edu.au

**Assessing the caregiver experience for patients with inherited retinal disease (IRD) diagnosed in childhood** – Sponsor: University of Technology, Sydney

**Disease:** All inherited retinal diseases **Participants:** Parents and Guardians

The study aims to explore how caring for a person diagnosed with an IRD as a child impacts the carers' life and if the impact changes as the child gets older.

Recruiting participants Australia wide. Contact: Maria.H.Kokoszka@alumni.uts.edu.au

**For more project details, click [HERE](#) or refer to our website at [www.retinaaustralia.com.au](http://www.retinaaustralia.com.au).**

**SUBSCRIBE TO RETINA AUSTRALIA'S NEWSLETTERS**

Click [HERE](#) to sign up, use the QR code, or head to [www.retinaaustralia.com.au/subscribe](http://www.retinaaustralia.com.au/subscribe)

