



# **Retina Australia**

## **Annual Report 2025**







# **Our Vision**

**A World Without Inherited Blindness**

# **Our Mission**

**Our Mission is to support people affected by inherited retinal diseases**

# **What We Do**

**Retina Australia accelerates medical research development in inherited retinal disease through the funding of an annual Research Grants Program and contributes directly to research as committee advisors and project partners. It also communicates opportunities for individuals to participate in research projects and clinical trials to further promote research progress.**

**As the peak national membership body, Retina Australia offers a comprehensive, evidence-based information platform on inherited retinal diseases and other retinal dystrophies. It facilitates peer support groups, provides enquiry assistance, and connects individuals with professional and community support services.**

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# *Impact*

# Message from the Chair



It has been a privilege to complete another year as Chair of Retina Australia. I am genuinely pleased at the progress being made towards achieving the organisation's goals as set down in the Strategic Plan in accordance with our Mission which is "to support people affected by inherited retinal diseases".

I am also extremely proud that I have been able to contribute to Retina Australia as it has developed into the organisation it is today, full of hope for the future, and prepared to embrace change as the recent developments in inherited retinal disease research lead to clinical trials in Australia and the potential for treatments.

Thanks to the dedication and fundraising efforts of so many volunteers across Australia since 1983, and due to the generosity of donors in recent years, Retina Australia has had an amazing impact in driving research developments. Consequently, since 1989 we have provided in excess of \$6.6 million in grants to support Australian researchers to investigate various aspects of inherited retinal diseases.

During the previous twelve months I have represented Retina Australia at various events hosted by the Centre for Eye Research Australia in Melbourne, the Save Sight Institute in Sydney, Vision 2020 Australia in Melbourne, as well as the Blind Citizens Australia Convention celebrating their 50 years in advocacy for people who are blind or have low vision. I have also been involved in regular virtual global meetings with Retina International, as a delegate for Retina Australia, to discuss items of mutual interest affecting affiliated organisations throughout the world.

While the year has seen Retina Australia continue to fund research, provide information through our website, webinars and newsletters, and support members and others affected by inherited retinal disease, we have also continued to establish stronger connections with potential benefactors and various members of the pharmaceutical industry. Retina Australia has also participated in advisory committees for new research projects and is highly sought after to provide references for, and support of, researchers applying for government grants.

*(Pictured from left to right) Clockwise from the top: Retina Australia Board Directors at the recent Strategic Planning Day: Ian Kelly, Associate Professor Anai Gonzalez-Cordero, Dr Ceecee Britten-Jones, Dino Farronato, Josh Ginpil, Leighton Boyd AM, Rosemary Boyd OAM, Stephen Miners*

To this end, I would like to acknowledge Julia Hall, CEO, for the positive impact she has continued to make since commencing in the role in October 2022. In implementing the strategic plan, and leading its review, Julia has provided a clear direction for the organisation and as a result we are in an increasingly strong position with an ability to provide a positive influence across the sector.



I would like to thank our volunteer Board, Josh Ginpil, deputy chair, Ed Tarrant, treasurer, Rosemary Boyd OAM, company secretary, Dino Farronato, Ian Kelly, Stephen Miners, Associate Professor Anai Gonzalez-Cordero and Dr Ceecee Britten-Jones for their advice and effective governance in leading Retina Australia over the past twelve months.

Thank you also to Jane Cherry and Lindsay da Costa who retired in October 2024 and to Riccardo Natoli who relinquished his position on the Board in February 2025. These former directors were dedicated to Retina Australia over a number of years, and I would especially like to recognise Jane, who served on the Retina International Youth Council as well as providing invaluable support and contribution to communications, especially through social media.

Financially, Retina Australia remains in a sound position with healthy organisational reserves consolidated by good financial management. We appreciate the ongoing support of our members and donors who have continued to assist our cause.

I would like to thank others who have helped Retina Australia in our achievements this year, particularly our committed staff: Julia Hall, Junxia Xu, and Sally Turnbull, who retired in December 2024, our committee members, and of course, our members. Our members remain at the centre of Retina Australia's endeavours, and I thank you for your ongoing support and dedication to improving the quality of life for all those living with inherited retinal disease.

Thank you for your continued membership and support.

Leighton Boyd AM  
Chair, Retina Australia

# CEO Report



## KEY HIGHLIGHTS

- Retina Australia reported a net surplus of \$43,584 for the year ended 30 June 2025.
- Two new research grants were funded totalling \$120,000.
- There was significant increase in reach with a near doubling of website users, a 20% increase in subscribers and 142% annualised growth rate in enquiries.

Building on the foundations from the past two years, 2025 was another solid year for Retina Australia.

Retina Australia reported a net surplus of \$43,584 in FY2025. Excluding the one-off gift in will received in FY2024, the net surplus was up substantially on last year. Significant growth in Grant Income, Corporate Sponsorship and Interest Income drove this strong result, while also offsetting a 6% increase in Total Operating Costs providing for growth in projects and programs.

Two \$60,000 research grants were awarded in 2025, both targeting the development of potential new treatments. They are building on the scientific foundations of the one existing gene therapy, with the goal of finding treatments for other inherited retinal diseases (IRDs).

The aims of these grant projects are also aligned with the outcome of the “Top 10 Research Priorities for Inherited Retinal Diseases” study, completed during the year, in which Retina Australia was involved. The study identified the number one priority as being “What treatments can safely prevent, slow down or stop vision loss that occurs for someone with an IRD?”.

This priority was determined from the perspective of individuals with lived experience, guardians, carers and families and health professionals together for the first time in Australia, rather than by researchers. It reaffirmed that Retina Australia’s Research Grants Program reflects the current views and interests of people affected by inherited retinal diseases.

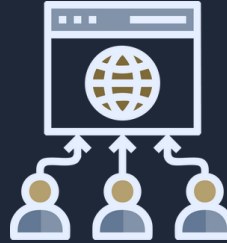
I had the pleasure of attending the launch events of two reports resulting from projects that Retina Australia contributed to as Steering Committee advisors, the “Top 10 Research Priorities for Inherited Retinal Diseases” and “The Geographic Atrophy: We Can’t Wait and See” report.



# 2025 A Year in Review



- **\$120,000** research grants awarded
- **10** new research project and clinical trial listings



- **98%** more website total users than last year
- **64%** more page views



- **6** research project partnerships
- Contributed to **2** reports and **3** peer reviewed research publications



- **12** monthly newsletters delivered
- **20%** newsletter subscriber growth
- **50%** average open rate
- **15%** average unique click-through rate



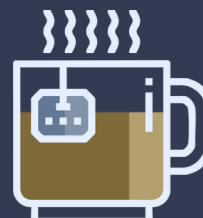
- **142%** annualised growth rate in enquiries
- **38%** queries related to clinical trials and treatments
- **15%** related to research and clinical trials



- **100%** webinar satisfaction rating of very good to excellent



- **15** Community Billboard event listings
- **12** recurring event listings



- **7** Friends of Retina Australia Perth events
- **>16 years** running the Telelink Support Group



# CEO Report

We welcomed the subsequent announcement in January 2025, that the Therapeutic Goods Administration (TGA) approved SYFOVRE® (pegcetacoplan) for the treatment of adult patients with geographic atrophy (GA), a significant milestone as the first and only approved treatment for GA in Australia. This treatment provides the only current opportunity to slow vision loss, helping to preserve both quality of life and independence for those affected, offering hope to the over 75,000 Australians living with GA, a severe form of age-related macular degeneration.

In addition to funding research grants, Retina Australia was a project partner on another three research projects. Our IRD Research Project and Clinical Trial Register listed 10 new projects providing information on programs open for participation, with continuing listings of another 6 projects to assist in recruitment to drive research progression. We also commenced a project with the Centre for Eye Research Australia and One Right Eye to develop educational materials for retinitis pigmentosa and Stargardt disease.

As the Australian member organisation, Retina Australia strengthened its collaboration this year with Retina International, the global, patient-led umbrella non-profit organisation supporting research and advocacy for both rare and common retinal degenerative diseases. Cross promotion of research ideas, projects, communications, webinars and events, has provided our community with the valuable insights and opportunities for access to international developments.

Collaboration and partnerships also extended to support services with the creation of the Community Billboard in January 2025. The Billboard was established to promote education and social events provided by other community organisations for people living with low vision and blindness and has proven a popular resource for our community. We also express our continued appreciation of the Perth Bush Walkers Club who continue to support our Friends of Retina Australia group in their activities.

Retina Australia has significantly increased its reach in the community, with a near doubling of website users in the past year, a 20% increase in subscribers while maintaining an open rate of 50% for our newsletters, and a 142% annualised growth rate in our enquiries. This can be attributed to the success of our awareness campaigns such as World Retina Day, World Sight Day, and Retinitis Pigmentosa Awareness Month in February, along with participation in events such as the RANZCO Congress 2024 in Adelaide, the Vision 2020 Australia Parliamentary Friends event in Canberra, and the University of Melbourne Doctor of Optometry Student Conference in Melbourne.

# CEO Report

## Strategic Plan Summary 2023–2025



### Research

To fund high quality Australian research into the detection, better treatments, and prevention, with the hope of progression towards cures into inherited retinal diseases



### Information

To be an accurate, accessible and comprehensive source of information on inherited retinal disease



### Support

To facilitate meaningful social connections for people with IRDs, and their families and carers



### Sustainability

To ensure ongoing viability and therefore our ability to continue to support and positively impact the IRD community



### Governance

To continuously improve and strengthen organisational governance

## 2023–2025 Strategic Plan – 3 years in review

2025 also saw the completion of our Strategic Plan 2023–2025.

- 2023 started with the development and implementation of Retina Australia's first Strategic Plan. This began with the establishment of governance and organisational policies, a rebrand and website relaunch, internal restructuring to improve operational efficiency, and strategic reinvestments to maximise balance sheet leverage.
- 2024 focused on the update and delivery of comprehensive information and educational content on inherited retinal diseases, delivery of more regular research updates moving to monthly newsletters, and increased community awareness with the development of new campaigns and new partnership initiatives.
- 2025 culminated in a year of further research partnerships to accelerate disease understanding and treatment discovery progress, development of new education and information content, commitment to awareness activities to increase our reach in the community, and the initiation of testing innovation to expand impact with minimal resources, such as the viability of using artificial intelligence (AI) to provide time, cost and marketing efficiencies.

# CEO Report

## Key highlights over the past three years include:

- Retina Australia celebrated 40 years of dedicated support to people affected by inherited retinal diseases.
- Retina Australia funded six new research projects totalling \$348,282.
- As project partners or committee advisers, Retina Australia contributed to 3 peer reviewed publications and 2 study reports, and saw the development of the IRD Research Project and Clinical Trial Register with 18 project listings over 21 months.
- A new comprehensive information web platform for IRDs, designed for accessibility was developed, monthly newsletters were established attracting significant average engagement of 50%, and 6 webinars and engagement events to provide research updates were delivered.
- The success of our awareness projects and campaigns have been evidenced by a 29% increase in our subscribers and >142% annualised growth rate in enquiries.
- Three consecutive years of net surpluses, after 5 previous years of net deficits, have been delivered while continuing to fund the Research Grants Program at consistent levels, strengthening the organisation's financial position.
- FY2025 Retained Earnings totalled \$290,184, representing significant growth of 455%, up from a deficit of \$81,677 in FY2022, resulting in Net Assets of \$1,581,702.

I am particularly proud that the progress made to deliver on the operational progress toward our Strategic Plan 2023–2025, was achieved with an average of 1.3 FTE staff. Retina Australia is now in a strong operational and financial position to embark on its new Strategic Plan for 2026–2028.

A warm and heartfelt thank you to our Chair, Leighton Boyd AM and Company Secretary, Rosemary Boyd OAM, your dedication to Retina Australia is unwavering. Thank you also to the Directors for their contributions to strengthening the governance of the organisation. To Jun, our wonderful and long serving Finance Officer, and to Sally, our Administration Officer who retired in December 2024 – your hard work is very much appreciated, we have achieved so much together over the past 3 years. A sincere thank you to our members, donors, volunteers and partners. We really depend upon and greatly value your contributions, which enable us to continue to support the inherited retinal disease community.



Warmest regards,

A handwritten signature in black ink, appearing to read "Julia Hall".

Julia Hall

Chief Executive Officer, Retina Australia



# 2023 – 2025 in Review





# Research

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# 2025 Research Grants

## New grants awarded



### **Advancing Usher syndrome type 1B gene therapy with split intein**

Usher syndrome type 1B (USH1B) is caused by mutations in the *MYO7A* gene. While gene therapies using adeno-associated virus (AAV) have worked for other genetic diseases, the *MYO7A* gene is too large for a single AAV to deliver. Attempts to deliver it in two parts have had limited success.

This study explores a new approach that joins split proteins efficiently. The aim is to deliver the full *MYO7A* protein in a mouse model of USH1B through a less invasive injection into the eye, which could lead to better treatment outcomes.

#### **Chief Investigator**

Dr Jiang-Hui (Sloan) Wang  
– Centre for Eye Research Australia,  
Melbourne

#### **2025 Grant**

\$60,000



### **Therapies for currently untreatable autosomal recessive IRDs**

This project aims to develop gene replacement therapies for autosomal recessive (AR) inherited retinal diseases (IRDs), where no treatments currently exist.

It will focus on targeting genes small enough for adeno-associated virus (AAV)-mediated gene therapy and will target AR IRDs caused by variants in photoreceptor specific genes. The project's approach of investigating novel therapies in retinal organoids will accelerate the development of future treatments for these small-gene IRDs.

#### **Chief Investigator**

Professor Robyn Jamieson –  
Children's Medical Research Institute,  
Sydney Children's Hospitals Network,  
Save Sight Institute, University of  
Sydney

#### **2025 Grant**

\$60,000

# Research Grant Impact Report



## **Chief Investigator**

Dr Elisa Cornish – Save Sight Institute, Sydney

## **Co-Investigators**

Professor Gregg Suaning – School of Biomedical Engineering,  
The University of Sydney

Professor John Grigg – Save Sight Institute, Sydney

**2024 Grant –\$52,639**

## Virtual Reality Assessment of Functional Vision in achromatopsia

### **Project Aim**

This project aimed to develop and validate a virtual reality (VR) mobility task as a surrogate outcome measure to assess functional vision in achromatopsia, and to evaluate the MonCvOne® device as an objective tool for measuring light sensitivity.

### **Project Summary**

- Participants wore a VR headset and used hand joysticks to walk through a virtual room. The VR environment was looking to imitate the MLMT, and the VR task involved navigating a simulated environment with obstacles and changing light conditions, designed to emulate real-world challenges.
- The VR mobility task was well tolerated across age groups and skill levels, with minimal motion sickness and high usability. Patients with achromatopsia demonstrated significantly poorer performance in VR navigation than age-matched individuals with normal vision, especially in high-light settings. The MonCvOne®, a medical device designed to provide a comprehensive, objective, and quantitative assessment of vision, provided unbiased, consistent measures of photosensitivity.

### **Impact**

This study demonstrated that VR-based mobility testing provides a scalable and patient-friendly approach to assessing real-world visual performance in individuals with achromatopsia. It also showed strong potential as a surrogate endpoint in future clinical trials of novel therapies. The MonCvOne® system also proved to be a reliable and repeatable measure of light sensitivity. As a standardised and effective outcome

measure, this VR tool offers a practical solution for global clinical trial implementation, requiring minimal clinical infrastructure while ensuring high reproducibility across sites.

# Research Grant Impact Report

## Chief Investigator

Dr Di Huang – Lions Eye Institute

## Co-Investigators

Associate Professor Fred Chen – Lions Eye Institute

**2024 Grant – \$60,000**

*Special thanks to the Perth Eye Foundation for co-funding this project with Retina Australia*



## Characterising Stargardt Disease Mutations for Splice Intervention Therapeutics

### Project Aim

The aim of this project was to find a treatment for Stargardt disease, an inherited genetic eye condition caused by mutations in the *ABCA4* gene. It studied the specific genetic changes in the *ABCA4* gene to develop a potential type of treatment called splice-switching antisense oligonucleotides (SS-AONs).

### Project Summary

- In this project, the team screened 30 patients with Stargardt disease and identified several *ABCA4* gene variants that disrupted how the gene's message is processed, confirming that faulty splicing plays a significant role in disease development. They then successfully reprogrammed skin cells from selected patients into stem cells, which serve as a powerful platform for generating retinal cells, and studied the effects of these genetic changes more closely.
- Based on computational predictions, the team designed targeted SS-AONs to correct the faulty gene message. When tested in patient-derived cells, these molecules effectively restored the full-length, correct version of the gene message, demonstrating the potential of this approach to correct the underlying genetic defect.

### Impact

Together, the team's findings validate splice correction as a viable therapeutic strategy for Stargardt disease and lay essential groundwork for the development of personalised, gene-based treatments. This research not only advances our understanding of how specific gene mutations contribute to inherited vision loss but also creates a scalable model for testing future therapies, bringing us a step closer to the first targeted treatment for Stargardt disease and offering broader insights into treating other inherited retinal disorders.



# Research contribution

Retina Australia contributed to several projects throughout the year as project partners and committee advisors, which also resulted in published reports, peer reviewed research and a poster presentation.

## Top 10 Research Priorities for Inherited Retinal Disease

The Inherited Retinal Disease Priority Setting Partnership was led by the UNSW Medicine and Health and the Children's Medical Research Institute, and guided by an expert Steering Committee including Retina Australia. This 18-month study identified the Top 10 Research Priorities for Inherited Retinal Diseases from the perspective of individuals with lived experience, guardians, carers and families and health professionals together for the first time in Australia. It is important that research about Inherited Retinal Diseases is guided by what matters most to those who will be impacted by it.

These priorities were found to focus on four key areas: Treatments and cures, Psychosocial wellbeing, Health service delivery, and Symptoms and disease progression. Notably, two of the top three priorities are related to treatments, with another in the top 10 focusing on detection, aligning with Retina Australia's commitment to research funding.

Pictured at the launch event of the Top 10 Priorities for Inherited Retinal Diseases, from left: Associate Professor Anai Gonzalez-Cordero, Children's Medical Research Institute (CMRI), Carly Iles, Vision 2020 Australia, Julia Hall, Retina Australia, Tim James MP, Professor Robyn Jamieson, CMRI; The Children's Hospital; University of Sydney, Dr Eden Robertson, UNSW Medicine & Health; CMRI





# Research contribution

Pictured: Professor Lauren Ayton AM, University of Melbourne and Centre for Eye Research Australia and Julia Hall, Retina Australia CEO presenting the Top 10 Research Priorities for Inherited Retinal Diseases poster at the RANZCO Congress 2024 in Adelaide.

## Publications from this research

- “Research priorities for Inherited Retinal Diseases in Australia: A James Lind Alliance Priority Setting Partnership”, Robertson, Eden Grace; Hetherington, Kate; Ayton, Lauren; Boyd, Leighton; Feller, Hollie; Hall, Julia; Grigg, John; Jamieson, Robyn; Karandrews, Sally; Gonzalez-Cordero, Anai (2024)
- Medical Journal of Australia: “Dismantling Barriers to Research and Clinical Care for Individuals with Vision Impairment”, Robertson, E.G., Hetherington, K., Prain, M., Hall, J., Boyd AM, L., Boyd OAM, R., Shepard, E., Feller, H., Karandrews, S., O'Hare, F., Yamamoto, K., Simunovic, M.P., Jamieson, R.V., Ma, A., Ayton AM, L. and Gonzalez-Cordero, A. (2025)
- BMJ Open: “Australian Research Priorities for Inherited Retinal Disease Research: A James Lind Alliance Priority Setting Partnership”, Robertson, E.G., Hetherington, K., Prain, M., Ma, A., Ayton, L.N., Jamieson, R.V., Shepard, E., Boyd, L., Hall, J., Boyd, R., Karandrews, S., Feller, H., Simunovic, M.P., Grigg, J.R., Yamamoto, K., Wakefield, C.E., & Gonzalez-Cordero, A. (2025).
- A Poster on the Top 10 Research Priorities for Inherited Retinal Diseases was presented at the RANZCO Congress 2024 in Adelaide (as picture above).



## Geographic Atrophy: We Can't Wait and See

Along with other leading organisations in the eye health and vision care sector, Retina Australia was a member of the Advisory Committee for the development of the report, “Geographic Atrophy: We Can’t Wait and See – The Case for Action”.

The report presents study findings from both a financial analysis and a Social Return on Investment (SROI) highlighting the urgent need for action and the significant social value of preserving vision for individuals affected by GA, with \$2.21 of social value created for every \$1 invested. The report was officially launched at Parliament House in Canberra on 11 September 2024 with the support of the Parliamentary Friends for Eye Health and Vision Care, led by Co-chairs Ms Meryl Swanson MP and Dr David Gillespie MP. The report was sponsored by Apellis Australia.



(From left to right) Dr Amanda Ruth (Director Corporate Affairs, Access & Policy, Apellis Australia), Ms Libby Croker MP, Dr Kathy Chapman (CEO, MDFA), Dr David Gillespie MP, Ms Meryl Swanson MP, Chris Edwards (Vision Australia), Judy Hatswell (CEO, Sight For All), Julia Hall (CEO, Retina Australia), Carly Iles (CEO, Vision 2020 Australia) at the launch of the Geographic Atrophy, We Can't Wait and See report at Parliament House, Canberra

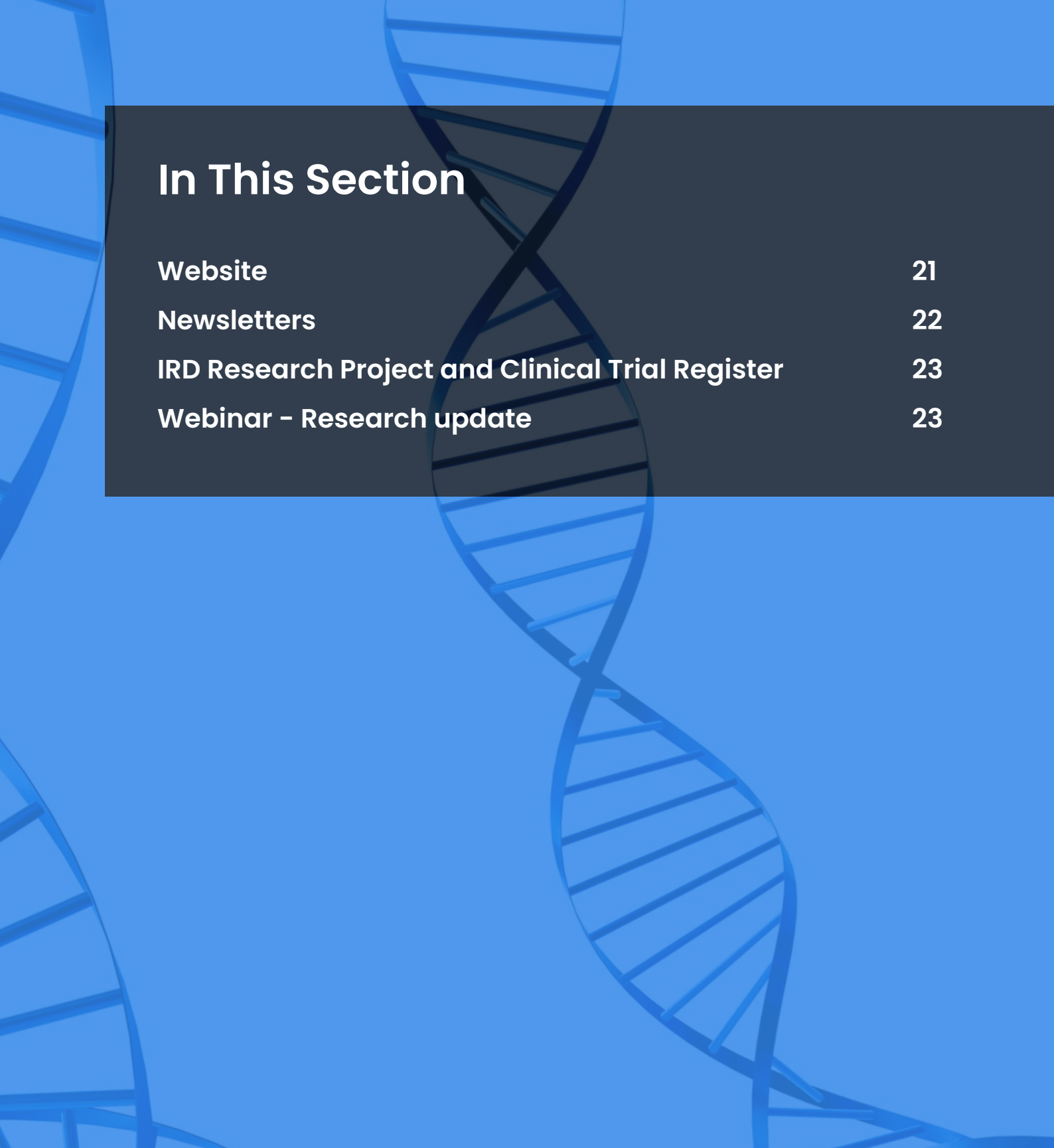
## Other research contributions

Retina Australia has also been a Steering Committee member or project partner on the following ongoing projects:

- “Translation of precision medicine into clinics for genetic blindness: from diagnosis to clinical management and therapies”, a \$1.4M NHMRF grant funded project led by Professor Deborah Schofield, Director, Macquarie University Centre for Economic Impacts of Genomic Medicine (GenIMPACT).
- “National Platform for Therapeutic mRNA Development”, a \$4M MRFF grant funded project led by Professor Thomas Preiss, Director of Shine Dalgarno Centre for RNA Innovation.
- “IRD and AMD perspectives in Stem Cell Therapies”, a MRFF grant funded project led by Associate Professor Anai Gonzalez-Cordero, Unit Head of Stem Cell Medicine at CMRI, The University of Sydney.

Additional peer reviewed research co-authored by Retina Australia:

- Disability and Health Journal, “Navigating a hidden disability – Lived experiences and challenges of adults with early stage inherited retinal diseases”, Mariam Bakir, Eden G. Robertson, Ruofei Trophy Chen, Bao N. Nguyen, Bronwyn McFadyen, Eve Makrai, Leighton Boyd, Rosemary Boyd, Sally Karandrewsi, Lauren N. Ayton, Alexis Ceecee Britten-Jones



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# *Information*



# Information

## Website

### Expanding our information and education about IRDs

Retina Australia continued to update its website for the latest news and research developments in inherited retinal diseases with 38 new blog posts published during the year.

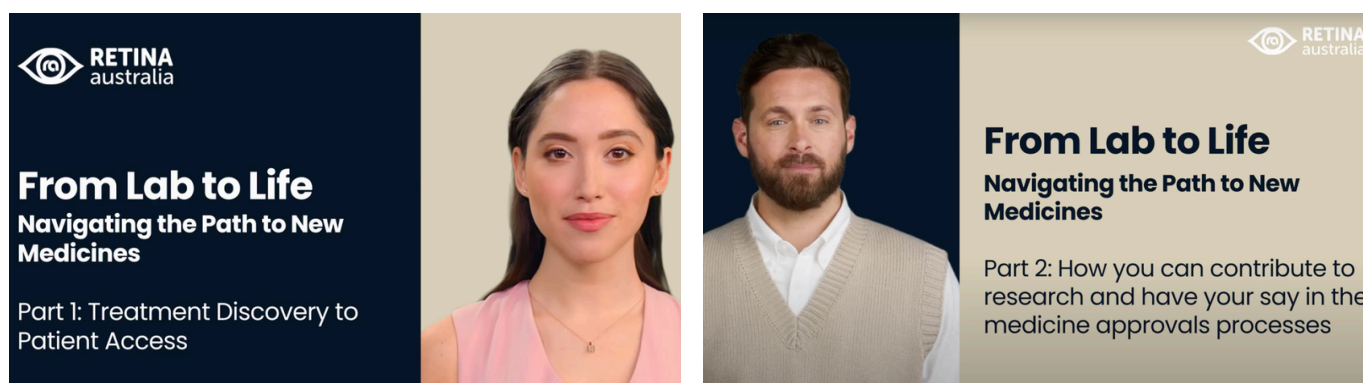
We also developed new webpage content such as the “From Lab to Life” section informing and educating about the medicines approval process.

With the aim to provide alternative ways to view the information, we created two new videos to provide summaries of the “From Lab to Life” content in accessible formats. We used AI in the production of these videos, with AI avatars as commentators of the summarised information, which provided benefits in time and cost efficiency, and in production flexibility.

### Helping more people

For a rare disease community, we were pleased that our website received nearly 28,000 visitors in FY2025, a substantial increase in almost double the visitors in the prior year. Total page views experienced a similar increase, with over 71,000 total page views compared to just under 44,000 in the prior corresponding period. We attribute this significant 64% growth to a combination of increased awareness of Retina Australia and from regular content being provided each month.

The most visited webpages included our resources on inheritance patterns, the anatomy of the eye, retinitis pigmentosa (RP) and gene therapy, as well as the IRD Research Project and Clinical Trial Register.



Pictured above: Poster frames of the two new videos produced and published on the website – “From Lab to Life: Navigating the Path to New Medicines, Part 1 and Part 2”.



# Information

## Newsletters

### Retina Insider and Retina Reporter

Retina Australia produced and delivered 12 newsletters during the year. The subscriber base for our monthly email newsletter, the Retina Insider, and our biannual newsletter, the Retina Reporter, increased by 20% in FY2025. Our Retina Reporter newsletter continues to be delivered in print and audio versions to our members who request this form of delivery for easier accessibility.

The average open rate of the newsletters was 50%, with an average unique click-through rate of 15%. These figures are both significantly higher than the not-for-profit averages by 40% and 3% respectively (as per Mailchimp).

The newsletters included 88 articles on a range of topics including updates on local and international IRD research projects, published peer reviewed research, research insight articles, calls for participation in current studies, information about research projects and clinical trials, Retina Australia's awareness campaigns, and invitations to events and webinars.

### Retina in Focus – Newsletter for ophthalmologists

In a pilot project, Retina Australia also delivered a series of four newsletters targeted to ophthalmologists. The goal was to increase information and education of IRDs, and to also promote awareness of Retina Australia, not only as the national organisation representing Australians affected by IRDs but as a reliable source of information on IRDs. Content included summaries of presentations from the RANZCO Congress 2024, which were well received, evidenced by a 59% unique open rate, greater than the average electronic direct mail open rates of 40-45% of the medical delivery platform used for the delivery of the newsletters.



Pictured:  
Professor John Grigg,  
presenting at  
RANZCO  
Congress which  
was  
summarised in a  
Retina in Focus  
newsletter

# Information

## IRD Research Project and Clinical Trial Register

One of our most popular resources is our IRD Research Project and Clinical Trial Register which aims to provide information about research projects and clinical trials open for participation. It addresses one of the most common enquiries we receive and the need for a central listing of research projects and clinical trials on IRDs, delivered in an accessible format, and written in lay terms for easy understanding. The Register listed 10 new projects this year. Most of these projects are still ongoing but those that have been completed, have led to published peer reviewed research.

### Aria Research – Pilot clinical trial success

Of note was the pilot clinical trial study by Aria Research which was listed on our IRD Research Project and Clinical Trial Register to assist with participant recruitment. Aria Research has since been awarded a \$2M grant from the NSW Medical Devices Fund to continue the development of the ARIA spatial computing smart glasses that deliver Vision via Sound™ for blind people, transforming one's visible surroundings into a rich, three-dimensional auditory landscape that enables a detailed spatial perception without eyesight.

**“Your efforts have played a CRUCIAL ROLE in ensuring that the trial reached a broader audience, enabling us to advance our research objectives and potentially make significant strides in the co-design with the Aria device. Please extend our thanks to your entire team for their hard work and dedication. “**  
**Aria Research Clinical Team**

## Webinar

### Cell therapy, genetic research and a patient's perspective

Retina Australia hosted an engaging webinar during the year with three speakers:

- Associate Professor Gonzalez-Cordero from Children's Medical Research Institute presented her research on developing universal cell therapy for inherited retinal blindness using stem cell-derived organoids.
- Dr Ceecee Britten-Jones from University of Melbourne and Centre for Eye Research Australia, outlined her team's genetic research on IRDs, including work on the VENTURE registry and efforts to improve diagnosis and treatment access.
- Dino Farronato, Retina Australia Director shared his experience living with retinitis pigmentosa, his participation in the VENTURE study, and his commitment to supporting others and advancing research.

Survey feedback reflected a high rating of the webinar being informative, with 100% of survey respondents rating the webinar satisfaction as very good to excellent.

# Support

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# Peer Support Groups

## Friends of Retina Australia Perth (FRAP)

By Angela Boothroyd, Group Convenor

2025 began with the sad news of the passing of our beloved friend and inaugural Friends of Retina Australia Perth (FRAP) convenor, Lyn Lepore, after her brave battle with cancer. Her beautiful qualities of positivity, determination and caring were evident to the end and an inspiration to us all. A morning tea in her honour was held in April and was well attended.

The FRAP Group had another very enjoyable bush walk season thanks to our dedicated and caring volunteers from Perth Bush Walkers (PBW) Club. We have walked through diverse areas around Perth, from coastal bushland to forest areas and riverside rambles. Our expert guides keep us safe while still allowing us to be challenged with a few new and more demanding trails this season.

The walks always end with a gathering for brunch at a nearby café – a wonderful opportunity to swap stories and support each other.

One of this year's highlights was a guided tour of the PULSE 2025 exhibition at the Art Gallery of WA by one of our vision impaired members, Jenna, who is a volunteer guide there. As Jenna amusingly put it, "I know it may seem silly, a blind person leading the blind in a very visual environment, but I would love to stretch myself and offer my interests to a group that may not usually think about heading to the gallery. These tours would not be tactile, but they would be a conversation about art and the gallery."

Pictured:  
Members  
of the  
Friends of  
Retina  
Australia  
Perth  
group  
taking a  
bush walk





# Peer Support Groups



Pictured: The Friends of Retina Australia Perth group out on a bushwalk in Western Australia.

The group of 10 who attended were not disappointed! There were some thought provoking conversations, amazing insights and a request to hold these tours quarterly. Of course, we ended with the obligatory coffee and chat at a nearby café.

## Social Telelink Group

The Telelink group, which has been in operation for more than 16 years, meets fortnightly to discuss items of mutual interest and catch up with the latest news from Retina Australia and Retina International.

Members provide support for each other and, as well as welcoming new members to the group over the years, have individually reached out to others who have been newly diagnosed, helping to sustain them as they come to grips with living with an inherited retinal disease (IRD), or being the parent of a child who has an IRD. Over the years the membership has evolved due to individual circumstances.

However, it is clear that all participants have been enriched by the camaraderie of the group. Members have frequently stated, “how relaxing it is to meet with a group of people who truly understand your frustrations in living with an inherited retinal disease, and who are able to provide encouragement and practical suggestions towards achieving your goals.”

# Other Support Services

## Community Billboard

Retina Australia's Community Billboard was introduced in January 2025. It provides a calendar of activities and events for those with low or no vision, with the aim to provide opportunities that promote learning, wellbeing, participation, and social engagement and connection.



In the six months to 30 June 2025, Retina Australia has shared 15 one-off events and 12 recurring activities from nine community organisations including Blind Citizens Australia, Blind Sports and Recreation Victoria, AlikeWA, UsherKids Australia and DeafBlind Victoria.

The Billboard promoted a variety of events such as trivia nights, advocacy workshops, networking events, bush walks, sports and leisure classes, morning teas and local landmark tours. It has become a popular resource for encouraging community connection with more events added weekly, while working collaboratively with other community organisations to promote their services.

## Enquiries

This year has seen a significant increase in the number of enquiries for assistance requested via email, phone and the website. This has been driven by our awareness campaigns and activities, resulting in an annualised growth rate of 142%.

- Of these, 38% related to clinical trials and treatments for IRDs.
- There was also much interest in research and clinical trials, which accounted for 15% of all queries received.
- One-third of the queries received related to retinitis pigmentosa, with the remainder relating to a wide range of IRDs and retinal dystrophies.

In June 2025, Retina Australia began testing the use of AI technology to provide initial assistance to website users requiring assistance. This process yielded positive results, and we will continue to test and refine this feature on the Retina Australia website in the new financial year to provide operational efficiencies while delivering quality of service.



# Awareness

## In This Section

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# Raising Awareness

**Raising awareness and connecting at events such as the Vision 2020 Australia Parliamentary Friends and RANZCO Congress 2024**



Pictured clockwise from top left :

- Blind Citizens Australia CEO Deb Deshayes, with Retina Australia CEO Julia Hall, in Parliament House at the Vision 2020 Australia Parliamentary Friends event
- Professor Jean Bennett with Retina Australia Company Secretary, Rosemary Boyd OAM and Retina Australia Chair, Leighton Boyd AM
- Retina Australia Directors Dino Farronato and Josh Ginpil with Senator Tammy Tyrrell and Retina Australia CEO Julia Hall in Parliament House at the Vision 2020 Australia Parliamentary Friends event, Canberra
- Retina Australia Chair, Leighton Boyd AM, and Retina Australia Company Secretary, Rosemary Boyd OAM at the RANZCO Congress in Adelaide

# Awareness and Fundraising

**Retina Australia would like to thank our dedicated supporters for their fundraising and awareness efforts**

Retinitis Pigmentosa Month in February was a wonderful opportunity to raise awareness for the most common form of inherited retinal disease. Thank you to Peter, and sisters, Imogen & Ebony, who not only participated in this campaign to raise funds for Retina Australia, but went on to become the faces of our 2025 Annual Appeal, sharing their personal stories.



There are no treatments available in Australia for retinitis pigmentosa, but Peter is hopeful about what the future holds for him and future generations, including his daughter who has the same condition. Peter also identifies the importance of starting with acceptance, from which you can then trust the supports around you, so you can then get on with living your best life.



Click on the QR code on the left to watch a video of his story.



Since their diagnosis four years ago, Imogen and Ebony have been passionate about raising awareness about their condition.

"Being legally blind does not mean that you cannot see anything. It is different for everyone," says Ebony. "And also, it does not mean we cannot live our lives to the fullest."



Click on the QR code on the left to watch a video of their story.

**Thank you also to the many other supporters who raised funds for Retina Australia in events such as the HBF Run for a Reason, Ballarat Marathon, ASICS Runaway Noosa Marathon, ASIC Gold Coast Marathon and the fiscocrem GC30m Main Beach events.**



# Do It in The Dark (DITD)

**Thank you to those who engaged with us in our Do It in The Dark (DITD) activities and helped raise awareness for inherited retinal diseases.**



Pictured clockwise from top left :

- Senator Tammy Tyrrell engaging in the DITD puzzle at PharmAus 2024
- Carly Iles CEO Vision 2020 Australia completing a DITD puzzle at NSW Parliament House eye screening
- Peter Vance with friends wearing DITD glasses and participating in awareness for Retinitis Pigmentosa Awareness Month
- Friends of Peter Vance wearing DITD glasses in a Retinitis Pigmentosa Awareness Month event

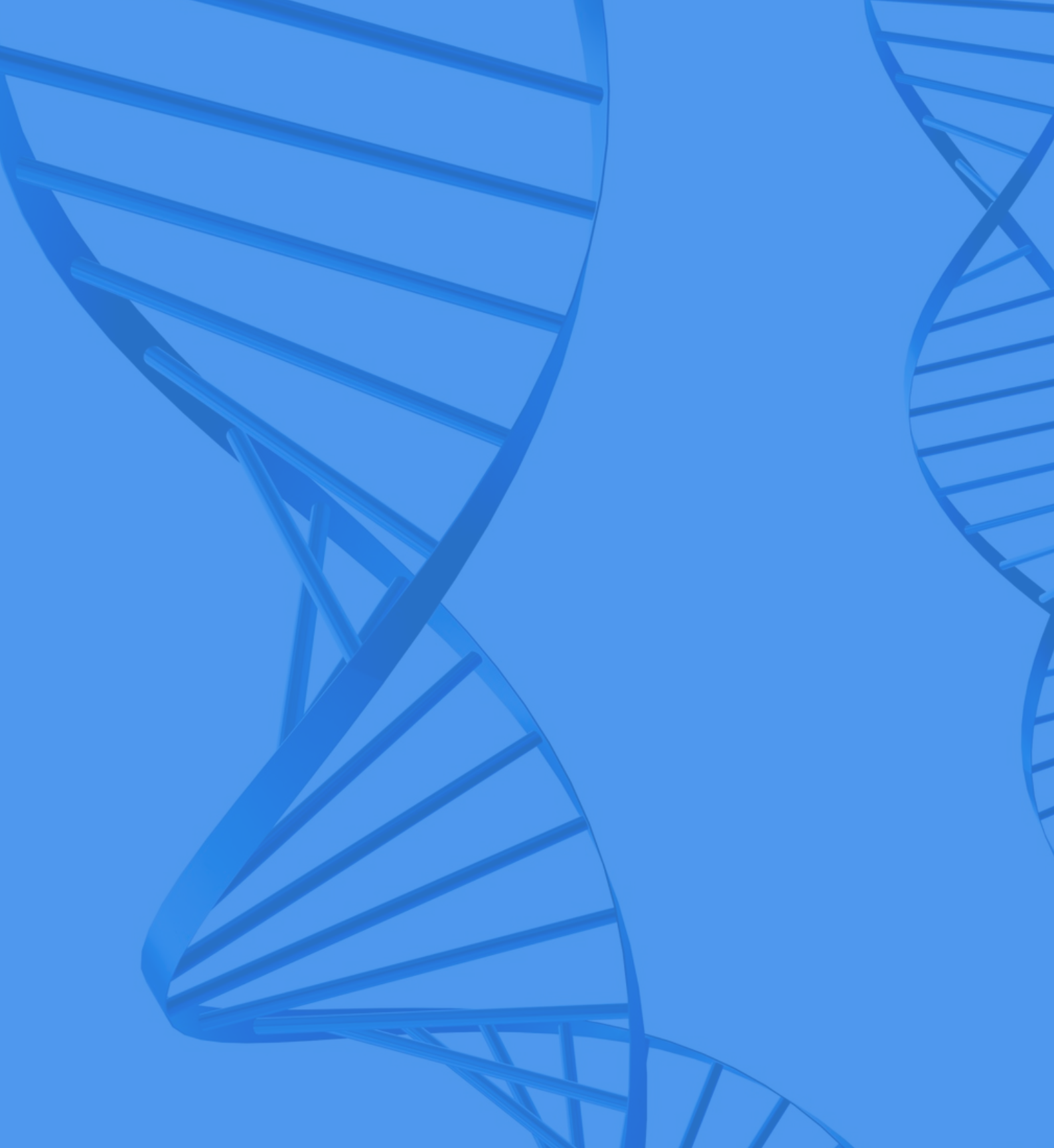


# Do It in The Dark (DITD)



Pictured clockwise from top left :

- Jerome Laxale MP golf putting with Do It in the Dark (DITD) glasses at PharmAus 2024 at Parliament House, Canberra
- Richie Williams MP and Geoff Provest MP wearing the DITD glasses and holding the Retina Reporter newsletter at NSW Parliament House, Sydney
- Attendees at PharmAus engaging in a DITD puzzle
- Professor John Skerritt AM golf putting with DITD glasses at PharmaAus



*Our Supporters*

# Our Supporters

Retina Australia sincerely thanks our generous donors, partners and volunteers for their support this financial year.

## Philanthropic & Corporate Supporters



### Individual Donors

- David and Joy Allen
- Leighton and Rosemary Boyd
- Warren and Rhonda Colledge
- Sue Fletcher
- Stephen and Lynnette Ginpil
- Ritesh Hargovind
- Glenda Oakley
- Richard Rigby

We would also like to thank our anonymous donors for their generosity.

### Alliances

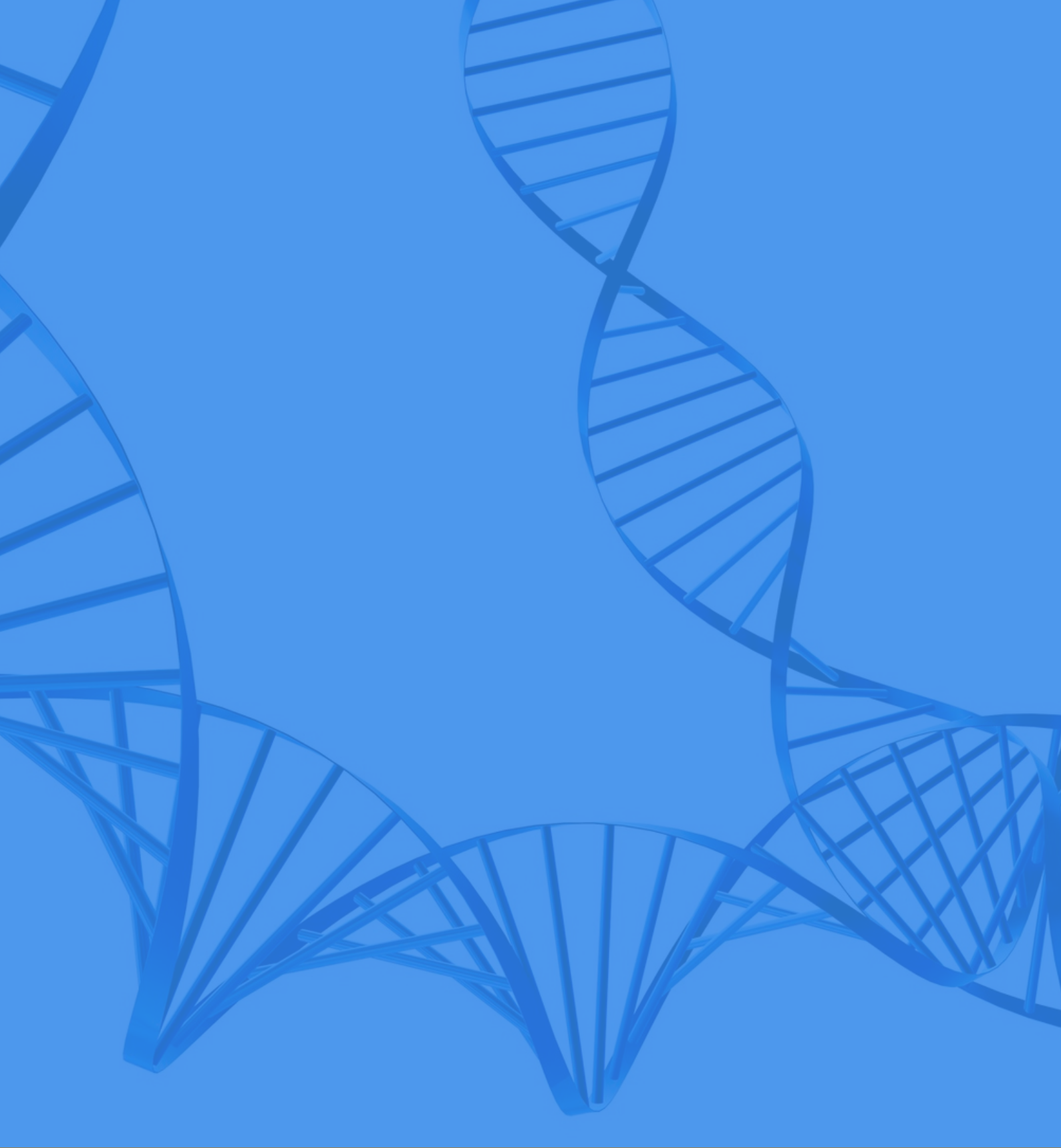
- Retina International
- Vision 2020 Australia
- Ross House Association

### Volunteers

- Angela Boothroyd
- Dr Catherine Civil
- Varnika Khattar
- Rose Petrotta
- Perth Bushwalkers Club

**Thank you so much to our loyal members. We greatly value your support and engagement in our community.**





*Governance*

# Governance

Retina Australia warmly thanks its volunteer Board of Directors and all of our other dedicated committee members.

## Board of Directors

- Leighton Boyd AM, Chair
- Joshua Ginpil, Deputy Chair
- Rosemary Boyd OAM, Company Secretary
- Ed Tarrant, Treasurer
- Dr Ceecee Britten-Jones, Director
- Dino Farronato, Director
- Associate Professor Anai Gonzalez-Cordero, Director
- Ian Kelly, Director
- Stephen Miners, Director

## Grants Advisory Committee

- Professor John Grigg, Chair
- Associate Professor Fred Chen
- Dr Glyn Chidlow
- Professor Erica Fletcher

## Finance, Audit and Risk Committee

- Ed Tarrant, Convenor
- Rajeev Chandra
- Dino Farronato
- Stephen Miners

## Scientific and Medical Advisory Committee

- Professor Lauren Ayton AM
- Associate Professor Tom Campbell
- Associate Professor Fred Chen
- Dr Glyn Chidlow
- Professor Erica Fletcher
- Professor John Grigg
- Professor Alex Hewitt
- Dr Michael Hogden
- Professor Michael Kalloniatis
- Professor David A Mackey AO
- Dr Jon Ruddle



*Financials*



# Financial Summary

## SUMMARY PROFIT AND LOSS STATEMENT

| PROFIT AND LOSS SUMMARY              | FY2025<br>30 JUNE (\$) | FY2024<br>30 JUNE (\$) |
|--------------------------------------|------------------------|------------------------|
| <b>Income</b>                        |                        |                        |
| Donation income                      | 593,786                | 934,814                |
| Grant income                         | 115,960                | 57,700                 |
| Membership income                    | 5,709                  | 6,409                  |
| Corporate sponsorship income         | 55,348                 | 17,690                 |
| Other income                         | 335                    | 387                    |
| Interest income                      | 67,508                 | 49,466                 |
| <b>TOTAL INCOME</b>                  | <b>838,646</b>         | <b>1,066,466</b>       |
| <b>Expenses</b>                      |                        |                        |
| Research grants                      | (116,319)              | (114,141)              |
| Project and program costs            | (137,477)              | (45,150)               |
| Fundraising contractors              | (376,750)              | (391,891)              |
| Administration                       | (141,123)              | (178,611)              |
| Other expenses                       | (23,393)               | (24,287)               |
| <b>TOTAL EXPENSES</b>                | <b>(795,062)</b>       | <b>(754,080)</b>       |
| <b>TOTAL NET INCOME FOR THE YEAR</b> | <b>43,584</b>          | <b>312,386</b>         |

## SUMMARY BALANCE SHEET

| BALANCE SHEET SUMMARY           | FY2025<br>30 JUNE (\$) | FY2024<br>30 JUNE (\$) |
|---------------------------------|------------------------|------------------------|
| <b>ASSETS</b>                   |                        |                        |
| Cash and cash equivalents       | 1,588,624              | 1,517,647              |
| Other current assets            | 39,626                 | 74,764                 |
| Non-current right-of-use assets | 13,160                 | 5,788                  |
| <b>TOTAL ASSETS</b>             | <b>1,641,410</b>       | <b>1,598,199</b>       |
| <b>LIABILITIES</b>              |                        |                        |
| Current Liabilities             | 47,131                 | 53,628                 |
| Non current liabilities         | 12,577                 | 6,435                  |
| <b>TOTAL LIABILITIES</b>        | <b>59,708</b>          | <b>60,081</b>          |
| <b>NET ASSETS</b>               | <b>1,581,702</b>       | <b>1,538,118</b>       |

## **Contact Us**

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