

Retina Australia

Annual Report 2024



Our Vision

A World Without Inherited Blindness

Our Mission

Retina Australia is a national charitable organisation dedicated to supporting 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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Message from the Chair



It was with great pleasure that I announced the commencement of celebrations for the 40-year anniversary of Retina Australia at the Annual General Meeting held in October 2023. The 40-year theme continued throughout the year, and I am extremely proud that I have contributed to Retina Australia as it has developed into the organisation it is today, full of hope for the future, and buoyed on by recent developments in inherited retinal disease research.

Thanks to the dedication and fundraising efforts of so many volunteers across Australia since 1983, Retina

Australia has had an amazing impact in driving research developments. Consequently, from 1989 we have provided over \$6.5 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 Canberra, as well as the Retina International World Congress, hosted by Fighting Blindness Ireland, which took place at the Dublin Royal Convention Centre.

These events have highlighted the dedication to retinal research across the globe, and clearly indicate that there have been significant research developments recently, including the testing of potential treatments through clinical trials, some of which involve the participation of members of Retina Australia. It is exciting that in the not-too-distant future there may be treatments available for specific inherited retinal diseases and the hope that further developments will result for other forms of these diseases.

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 established stronger connections with potential benefactors and various members of the pharmaceutical industry.

To this end, I would like to acknowledge Julia Hall, CEO, for the positive impact she has made since commencing in the role. In implementing the strategic plan, Julia

has provided a clear direction for the organisation and as a result we are in an increasingly strong position to provide a positive influence across the sector.

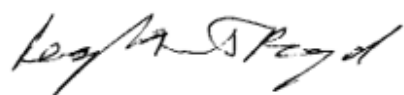
I would like to thank our volunteer Board, Josh Ginpil, Deputy Chair, Ed Tarrant, Treasurer, Rosemary Boyd OAM, Company Secretary, Jane Cherry, Lindsay da Costa, Dino Farronato and Riccardo Natoli for their advice and effective governance in leading Retina Australia over the past twelve months.

Thank you also to Peter Maas who retired in October 2023 and to Dr Heather Mack AM who relinquished her position on the Board in July 2023. These former directors were dedicated to Retina Australia over a number of years, and I would especially like to recognise Peter, who in his role as Deputy Chair, provided invaluable support and contribution to governance and communications.

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 all of those who have helped Retina Australia in our achievements this year, particularly our committed staff: Julia Hall, Sally Turnbull and Junxia Xu, 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



Pictured below: From left – Josh Ginpil (Director), Dino Farronato (Director), Leighton Boyd AM (Chair), Ed Tarrant (Director), Sally Turnbull (Administration Officer), Julia Hall (CEO), in front from left – Rosemary Boyd OAM (Company Secretary) and Lindsay da Costa (Director)



CEO Report



FINANCIAL HIGHLIGHTS

- Retina Australia reported a net surplus of \$312,386 for the year ended 30 June 2024, up from \$15,891 last year.
- Key benefits resulted from new revenue streams, improved investment income and full year cost benefits from operational efficiencies implemented in the prior year.

2024 has been another year of successful development for Retina Australia, particularly as we continue to make significant progress toward our strategic goals in support of Australians affected by inherited retinal disease (IRD).






At our October 2023 Annual General Meeting, we celebrated Retina Australia's 40 year anniversary. This was a significant milestone and we recognised the dedicated State based volunteers whose initiative to raise money to fund Australian research into inherited retinal disease for so many years, has continued to this day with lasting positive outcomes. Thank you to those who sent stories reflecting upon Retina Australia's impact, both personal and research related, and kind words of congratulations.

Tough economic conditions and the cost of living crisis continued to be a significant challenge impacting general individual donations, which is Retina Australia's greatest source of revenue. We have however, been able to deliver another consecutive year of surplus while still maintaining current levels of funding for our Research Grants Program.

This year's result of \$312,386 represents Retina Australia's record net surplus, resulting from a combination of growth in new income streams particularly our Gift in Will campaign, the launch of first time awareness and fundraising promotions, diversification of revenue sources, full year benefits received from the reinvestment of cash assets into higher yielding opportunities, and full year cost savings resulting from the office restructure and the implementation of operational efficiencies last year.

Retina Australia was able to maintain its level of research funding with two new grant projects awarded in 2024. We were delighted to hear that one of the projects funded in 2023, *Establishing novel AAV gene editing for Usher syndrome* by Dr Anai Cordero-Gonzalez, has already received a subsequent grant of \$850,000 - representing financial leverage of our initial grant of \$55,774 by over 15 times.



 Janine Chatterjee Hancock Senior Commercial Director, Immunology & Speciality	 Jane Cherry Director, Retina Australia & Patient Advocate	 Julia Hall CEO, Retina Australia	 Prof John Grigg Head of the Speciality of Clinical Ophthalmology and Eye Health at Save Sight Institute, The University of Sydney	 Prof Robyn Jamieson Head of the Eye Genetics Research Unit at Children's Medical Research Institute and Professor of Genomic Medicine at The University of Sydney
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Pictured above: From left – Jane Cherry (Retina Australia Director), Professor Robyn Jamieson (Head of the Speciality of Genomic Medicine, CMRI), Panel moderator – Janine Chatterjee (Janssen ANZ), Professor John Grigg (Head of the Speciality of Clinical Ophthalmology and Eye Health, Save Sight Institute), Julia Hall (Retina Australia CEO)

Retina Australia plays a vital role in funding early-stage ideas in inherited retinal diseases (IRDs). This initial support helps generate evidence, which researchers then use to secure larger grants to further develop and advance these concepts.

Retina Australia has also been directly involved in research initiatives. We have served as Steering Committee advisors on the *Inherited Retinal Disease Priority Setting Partnership* led by the University of NSW (UNSW) and the Children’s Medical Research Institute (CMRI), and on the Advisory Committee of the *Geographic Atrophy: Social Return on Investment* report sponsored by Apellis.

In response to regular enquiries received, we developed the IRD Research Project and Clinical Trial Register, which lists and summarises programs available for participation. It has been one of our most popular webpages since its launch and feedback from initial listings reflects its important contribution to participant recruitment, which is essential to enable and support research project success.

Another key focus was to increase awareness of IRDs and of Retina Australia, with the aim to grow our reach and impact in the community. We participated in the Rare Disease Expo in Perth hosted by ConnectGroups, the Inherited Retinal Disease Patient & Family Day hosted by the UNSW and the CMRI, and together with Jane Cherry, Retina Australia Board Director, spoke at the plenary panel discussion (as pictured above) and led a retina group workshop at the Janssen ANZ Annual Company Conference.

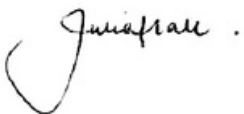
Over the past 12 months, four new key awareness campaigns were delivered. World Retina Day and World Sight Day highlighted the importance of eye health. Retinitis Pigmentosa Awareness Month in February was launched to increase the understanding of the most common type of IRD, and a World Sunglasses Day campaign was initiated, kindly sponsored by Specsavers, to create awareness of the impact of ultra violet light on eye health.

After relaunching our new website last year, including attaining compliance to international accessibility standards, this year saw an evidence-based update of our information and education resources. This has significantly progressed our strategic goal to deliver an accurate, current and evidence based information platform on IRDs and led to significant growth in our website users, page views and engagement.

Thank you to our dedicated Chair, Leighton Boyd AM, Company Secretary, Rosemary Boyd OAM, and all Directors of Retina Australia who kindly volunteer their time and support to the organisation. To Sally and Jun, our two staff members, your efforts and commitment have been integral to our progress.

To our Retina Australia community, your support through membership and donations and your interest through feedback and engagement is greatly valued, thank you. With substantial progress made, we are excited to continue to grow our impact and support to Australians affected by inherited retinal diseases in the coming year.

Warmest regards,



Julia Hall
Chief Executive Officer, Retina Australia

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

2024 Highlights

Research

Two new research grants awarded for 2024
Over \$6.5million awarded since 1989

Committee Advisors to two Research Projects

15 times financial leverage from a 2023 Retina Australia grant

2023 grants deliver new research findings with potential to contribute to finding new treatments

Information

WEBSITE
93% increase in average users per month

WEBSITE
202% increase in average page views per month

WEBSITE
52% increase in average pageviews per user per month

RESEARCH UPDATE EVENTS & WEBINARS
85% very good to excellent ratings on webinars

NEWSLETTERS
53% average unique open rate

NEWSLETTERS
60% average click through rate

Support

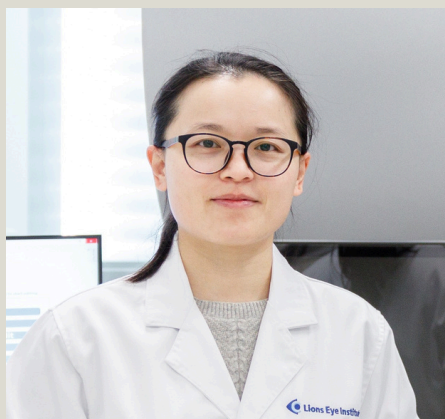
5 star rating of program impact from peer group

Sustainability

Record net surplus
\$312,386

2024 Research Grants

New research grants awarded for 2024



Characterising Stargardt Disease Mutations for Splice Intervention Therapeutics

This project aims to find a treatment for Stargardt disease, an inherited genetic eye condition caused by mutations in the *ABCA4* gene. It will study the specific genetic changes in *ABCA4* that lead to the disease and try to develop a type of treatment called splice-switching antisense oligonucleotides (SS-AONs).

Chief Investigator

Dr Di Huang
Lions Eye Institute, Perth

Co-Investigator

Associate Professor Fred Chen, Lions Eye Institute, Perth

2024 Grant

\$60,000



Virtual Reality Assessment of Functional Vision in Achromatopsia and Albinism

This project aims to assess whether a virtual reality (VR) mobility and environmental background lighting assessment tool can pick up changes in functional vision and light sensitivity to be used for measuring clinical trial success of new developing treatments.

Chief Investigator

Dr Elisa Cornish
Save Sight Institute, Sydney

Co-Investigators

Professor Gregg Suaning, The University of Sydney
Professor John Grigg, Save Sight Institute, Sydney

2024 Grant

\$52,639

Research Grant Impact Report



Chief Investigator

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

Co-Investigator

Dr Samantha Ginn, CMRI

2023 Grant - \$55,774

Grant leverage
of 15 times with a
\$850,000 grant
subsequently
received to continue
research

Establishing novel AAV gene editing for Usher syndrome

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 Outcomes 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 and to understand if it is effective in disease treatment.

Impact

The project showed promise for using AAV vectors and CRISPR-Cas9 technology to treat Usher Syndrome, laying the groundwork for future clinical applications that could restore vision and prevent further sensory loss.

Research Grant Impact Report

Chief Investigator

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

Co-Investigators

Associate Professor Riccardo Natoli, JCSMR
Dr Michelle Madigan Save Sight Institute, Sydney
Dr Elisa Cornish, University of Sydney

2023 Grant – \$59,869



Using RNA-silencing to tackle neuroinflammation in retinal degeneration

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

- 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.

Impact

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.

Information and Education

With a strong focus on providing evidence-based information on inherited retinal disease and other retinal dystrophies, summarising scientific and medical research into comprehensible updates, and other related information of interest, all delivered in accessible formats, Retina Australia has been successful in further increasing its significant communication engagement levels to new highs (highlighted on page 6).

Website

As part of the website content update conducted, new information and education areas were added including emerging treatments, the IRD Research Project and Clinical Trial Register, and a new section on other retinal dystrophies which includes age-related macular degeneration (AMD) and geographic atrophy (GA).

Newsletters

In 2024, 11 newsletters were produced (up from 4 in the prior year) delivering 25 new blog articles in addition to other articles of organisation activities. Blog articles included research updates on both domestic and international projects, research insight articles aimed at increasing understanding of clinical trials and research processes, and campaigns to drive IRD awareness.

Research Update Events and Webinars

Two research update events were held, one of which was an in-person event in Canberra (as pictured below) which was also live streamed via webinar. Updates included introductions to stem cell and gene therapies, emerging treatments on GA, how targeting inflammation can protect against retinal degeneration and how using the message of exercise may prevent blindness. We thank all our guest speakers for their informative and engaging presentations.



IRD Awareness



Pictured clockwise from top left :

- World Sight Day campaign - Love Your Eyes, featuring Retina Australia's CEO and Board members
- Retina Australia Chair, Leighton Boyd AM, Retina Australia Company Secretary, Rosemary Boyd OAM, and Dr Anai Gonzalez-Cordero at the Inherited Retinal Disease - Patient and Family Day
- Janssen ANZ staff participating in the Do It in The Dark puzzle challenge and the Annual Conference
- ConnectGroups Rare Disease Expo
- Staff at Grill'd Southern Cross raising awareness in February for Retinitis Pigmentosa Awareness Month as part of its Local Matter charity program.



Peer Support Groups

Friends of Retina Australia Perth (FRAP)

By Angela Boothroyd, Group Convenor

The FRAP group had another very enjoyable bush walk season thanks to our dedicated and caring volunteers from Perth Bush Walkers (PBW) club.

The July 2023 walk was a test for our balance on gravelly paths through pleasant bushland (thank goodness for hiking poles) and a steep descent to Nyaania Creek. August saw us tackle part of the Bibbulmun track, successfully

negotiating tree roots, rocky steps and low hanging branches. In September we were rewarded with a comparatively easy 10km walk through a riot of wildflowers and gushing waterfalls. Our October "bushwalk" was a 10km riverside ramble through some of our southern suburban parks, ending the 2023 season with a celebration brunch at a riverside café.

After a long, hot summer we were pleased to start our 2024 season in May with a walk in the Trigg Bushland where we saw some magnificent Tuarts, Rottnest Pines and grass trees and followed the crest of one of the few remaining parabolic dune systems in Perth. Our June walk was an 8km section of the Bibbulmun Track.

Social Telelink Group

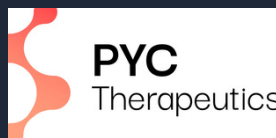
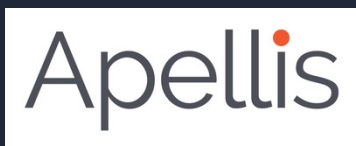
For more than 15 years, the fortnightly telelink group has been meeting over the phone to provide peer support, share stories and catch up with the latest news from Retina Australia. Members come from all over Australia, and discussions include tips about everyday living with retinitis pigmentosa as well as providing support for those who have recently been diagnosed. They have benefited from hearing about the experiences of those who have lived with the condition for many years, and in turn have been able to share their experiences with others joining the group after them. As one member comments: "I feel like I really, really know them even if I haven't met them in person. It's not all doom and gloom at all – we rally together and think it's not that bad – it has made me see that things are possible when I hear from others about what they have achieved."



Our Supporters

Retina Australia sincerely thanks our generous donors and partners
for their support to Retina Australia

THANK YOU TO OUR MAJOR SUPPORTERS



Gift in Will

- Estate of Leonard Charles Hovell

SUPPORTING DONORS

- Mark Banks
- Maureen Beitz
- Leighton & Rosemary Boyd
- Warren and Rhonda Colledge
- Professor Sue Fletcher
- John Giles
- Stephen and Lynette Ginpil
- Richard Rigby

We would also like to thank our donors who wish to remain anonymous

ASSOCIATE SUPPORTERS



SUPPORTING PARTNERS



Australian National University



The John Curtin School of Medical Research

THANK YOU TO OUR MEMBERS

We greatly value your support and engagement in our community.



Governance & Volunteers

Board of Directors



Leighton Boyd AM
Chair



Josh Ginpil
Deputy Chair



Rosemary Boyd OAM
Company Secretary



Ed Tarrant
Treasurer



Jane Cherry
Director



Lindsay da Costa
Director



Associate Professor
Riccardo Natoli
Director



Dino Farranato
Director

**Retina Australia warmly thanks its volunteer Board of Directors
and all our other dedicated volunteers**

Grants Advisory Committee

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

Scientific and Medical Advisory Committee

- Associate Professor Fred Chen
- Dr Glyn Chidlow
- Professor Erica Fletcher
- Professor John Grigg
- Professor Michael Kalloniatis
- Professor David A Mackey AO

Other Committee volunteers

- Rajeev Chandra

Other volunteers

- Dr Angus Barber
- Angela Boothroyd
- Dr Catherine Civil
- Dr Alex Dottore
- Dr Tamzin Hall
- Rose Petrotta
- Hope Smith
- Rainie Wang
- Perth Bushwalkers Club

Our Fundraisers

Retina Australia is incredibly grateful to our wonderful fundraising champions, thank you so much!



Pictured clockwise from top left:

- The Milk Runners ran at the Ballarat Marathon event
- Nick Bariesheff ran a half marathon at the Canberra Marathon event
- Jane Cherry undertook a baking challenge
- Josh Ginpil ran a half marathon at the Canberra Marathon event
- Marissa Ellis ran a half marathon at the Sydney Marathon event
- Stewart Crewe and the Australian Women's Kayak Team (Aly Bull pictured) ran a Do It in the Dark awareness campaign
- Brian Light hosted a Do It in The Dark lunch with friends

Financial Summary

SUMMARY PROFIT AND LOSS STATEMENT

PROFIT AND LOSS SUMMARY	FY2024 30 JUNE (\$)	FY2023 30 JUNE (\$)
Income		
Donation income	934,814	681,986
Grant income	57,700	73,529
Membership income	6,409	6,345
Corporate sponsorship income	17,690	0
Other income	387	108
Interest income	49,466	22,783
TOTAL INCOME	1,066,466	784,751
Expenses		
Research grants	(114,141)	(117,753)
Project and program costs	(45,150)	(24,630)
Fundraising contractors	(391,891)	(441,296)
Administration	(178,611)	(167,333)
Other expenses	(24,287)	(17,848)
TOTAL EXPENSES	(754,080)	(768,860)
TOTAL NET INCOME FOR THE YEAR	312,386	15,891

SUMMARY BALANCE SHEET

BALANCE SHEET SUMMARY	FY2024 30 JUNE (\$)	FY2023 30 JUNE (\$)
ASSETS		
Cash and cash equivalents	1,517,647	1,206,781
Other current assets	74,764	39,161
Non-current right-of-use assets	5,788	12,734
TOTAL ASSETS	1,598,199	1,258,676
LIABILITIES		
Current Liabilities	53,628	20,499
Non current liabilities	6,435	12,445
TOTAL LIABILITIES	60,081	32,944
NET ASSETS	1,538,118	1,225,732

Contact Us

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RETINA
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