



Retina Australia Annual Report 2023



Our Vision

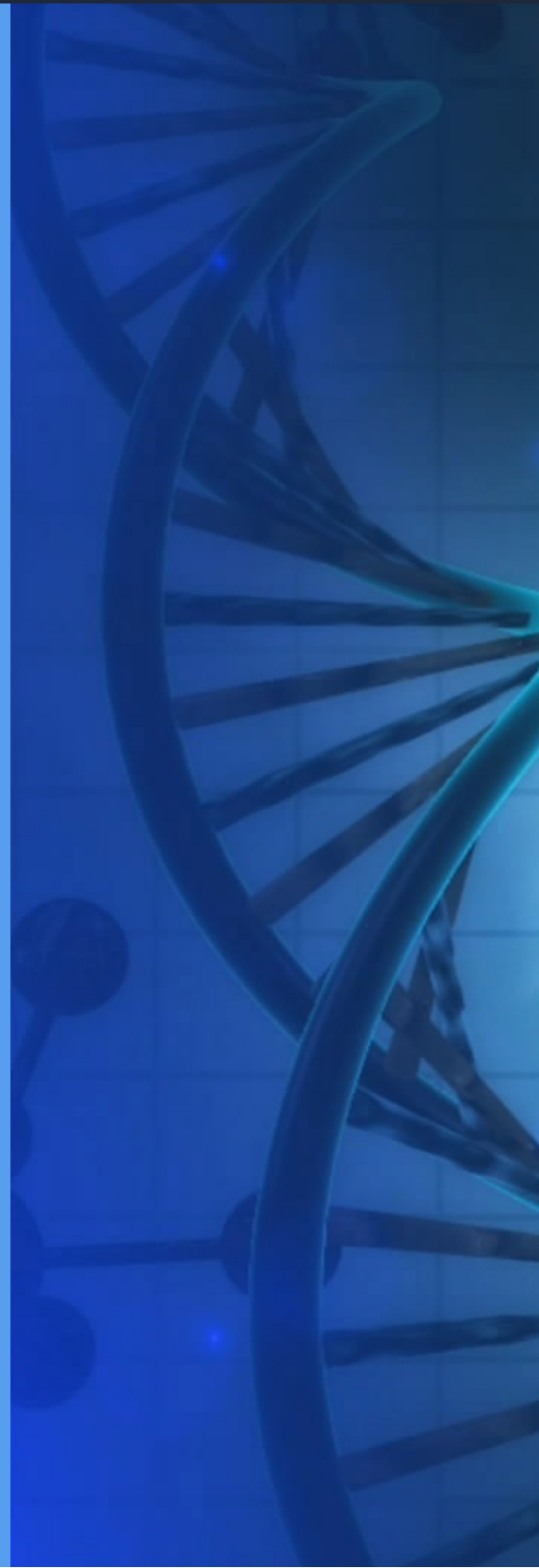
A World Without Inherited Blindness

Our Mission

Retina Australia is a national charitable organisation dedicated to supporting people affected by inherited retinal disease

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Message from the Chair

The aftermath of the coronavirus pandemic continued to linger during the past 12 months while the transition to recovery gathered pace in the community. In some respects, this has echoed the experience of Retina Australia, particularly from an organisation perspective as we build on the foundations established during previous years.

While the year has seen Retina Australia continue its positive work in support of members and others affected by inherited retinal diseases; provide information through newsletters, webinars and through our new website; and continue to fund research; we have also undertaken important, transformative approaches to our strategy, and operational structures.



I would like to acknowledge our inaugural CEO, Julia Hall, who joined us in October 2022. Julia's immediate enthusiasm to ensure we make a positive impact has been exceptional. The Board and I have thoroughly enjoyed working with Julia and the contribution she has made to drive our strategic approach that will provide a clear direction for the next 3 years. It is a truly exciting time for the organisation as we are placed in a strong position to enhance our influence across the sector.

I am extremely proud to be leading Retina Australia in this our 40th year of operation and would like to thank our volunteer Board, Peter Maas, Deputy Chair, Ed Tarrant, Treasurer, Rosemary Boyd OAM, Company Secretary, Josh Ginpil, Jane Cherry, Lindsay da Costa and Associate Professor Heather Mack AM for their advice and effective governance in leading Retina Australia.

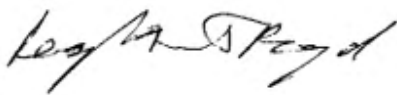
Thank you also to Mary-Anne Carmody and Julie Demarte who relinquished their positions on the Board prior to the 2022 AGM and Jessica Coleman in April 2023. These former directors were dedicated to Retina Australia over many years and provided invaluable support and contributions to governance and communications.

Our Committees have continued their valuable contribution and the insight, expertise, collaboration and exchange of ideas emulating from these groups has supported the work of the Board immeasurably.

Financially, Retina Australia is 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 during difficult times.

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 Board, our committee members and of course, our membership. 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



Board of Directors



Leighton Boyd AM
Chair



Peter Maas
Deputy Chair



Rosemary Boyd OAM
Company Secretary



Ed Tarrant
Treasurer



Jane Cherry
Director



Lindsay Da Costa
Director



Josh Ginpil
Director



Dr Heather Mack AM
Director

CEO Report

FINANCIAL HIGHLIGHTS

- Retina Australia reported a net surplus of \$15,891 for the financial year ended 30 June 2023.
- This is its first net surplus since 2017, and was up from a net deficit of \$31,447 in FY2022.
- Benefits were gained from an internal review and significant focus on maximising operational efficiencies.

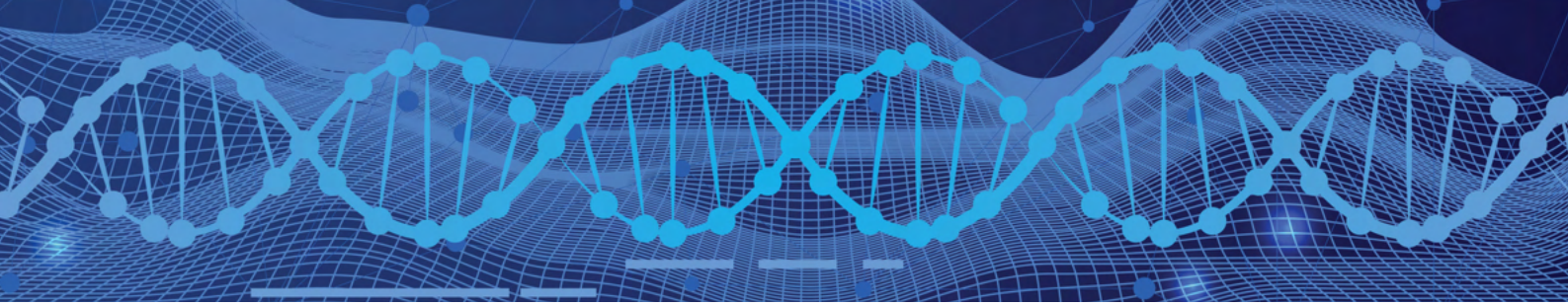
STRATEGIC PLAN AND PROGRESS

It has been an exciting, busy and progressive first nine months since commencing at Retina Australia. We have achieved not only the financial milestone of a first time net surplus in six years, but also made significant progress in our Strategic Plan.

Key highlights for the year include:

- In October 2022 we re-established and confirmed our Vision, Mission and key core Values of Excellence, Integrity, Respect, Collaboration and very importantly, being Patient-Centred.
- A new Strategic Plan 2023-2025 was developed and approved in November 2022.
- We migrated our workplace to a digital platform using the cloud-based services of SharePoint and OneDrive in Microsoft 365 to drive operational efficiencies.
- A new bi-annual newsletter, the Retina Reporter, was developed and launched in December 2022 in our rebranded identity.
- In April 2023, we launched our newly upgraded and rebranded website, designed and certified AA compliant with WCAG 2.1 global accessibility guidelines.
- A complete review of our Research Grants Program was conducted in April 2023. It reconfirmed our targeted areas of research into the detection, prevention, finding better treatments and ultimately cures for inherited retinal diseases. It was also updated to strengthen and maintain our rigorous governance processes to support our independent expert committee to ensure we continue to fund the highest scientific quality research.





- In April 2023 we launched the first edition of the Retina Insider, our e-newsletter.
- We hosted two webinars which included updates from clinical trials, genetic testing, gene therapies, and the latest developments in bionic eye research.
- Over the course of the year we accepted invitations to be a partner organisation on four external research projects for which we provided support for applications, and have also joined two research project Steering Committees.
- Whilst still located in the community heritage building of Ross House, Melbourne, we completed an office restructure in May 2023. This will result in significant ongoing annualised rent savings of around 37% for the next couple of years.
- The net surplus from the 2023 Annual Appeal in June 2023 grew a significant 20% on the prior year with the success of a low-cost digital communication plan and integration cost saving benefits of a newly implemented database system.
- A review and subsequent reinvestment of our financial assets led to a substantial increase in interest income. This maximised balance sheet leverage whilst ensuring a prudent investment strategy.

Now approaching its 40 year anniversary, Retina Australia was originally incorporated, grown and led by dedicated State based volunteers to raise money to fund Australian research. I feel extremely proud to be working with the Retina Australia Board to build on these foundations, to further extend its research impact and continue to support those affected by inherited retinal disease.

I would like to sincerely thank our Chair, Leighton Boyd AM, who is incredibly passionate and devoted in delivering our Mission. The invaluable support of our Company Secretary, Rosemary Boyd OAM, is also very much appreciated, as is that of the other Directors of Retina Australia. A very warm thanks goes to our small part-time but very hard working team, Sally and Jun, it has been a pleasure to work with you both.

To our Retina Australia community, thank you for your support. Your continued interest, engagement, membership and donations, have all contributed to this year's transformation and progress.

Warmest regards,

Julia Hall
Chief Executive Officer
Retina Australia

Our Values



Excellence

We strive to deliver the best outcomes through scientific quality, the highest of standards, positivity, learning and responsiveness



Integrity

We act with honesty, transparency, accountability and reliability



Respect

We welcome and treat all people with dignity, equality, understanding and courtesy



Collaboration

We partner to maximise results for people affected by inherited retinal disease



Patient-Centred

A positive impact on people affected by inherited retinal disease is the focus of everything we do

Strategic Plan 2023–2025

STRATEGIC PILLAR	GOAL	EXPECTED OUTCOMES
Research	To fund the best Australian research into the detection, better treatments, and prevention, with the hope of progression towards cures into inherited retinal diseases (IRDs)	<ul style="list-style-type: none"> • Retina Australia adds value through its independence and therefore its ability to select and facilitate the best Australian research into IRDs • Medical research progress is expected to lead to better quality of life & health outcomes for people affected by IRDs • Research into early detection may lead to earlier treatment to slow down or stop disease progression • Research into prevention may reduce future incidence of low vision & blindness • Ultimately, progression towards cures is hoped to be found • Sector collaboration will ensure research duplication is minimised and the maximisation of research outcomes
Information	To be the leading source of information on IRDs	<ul style="list-style-type: none"> • People living with IRDs will be better informed to make decisions or ask questions about their diseases, potential treatments and ongoing care • People newly diagnosed will be better able to adapt and thrive by being well informed and supported • Information to family & carers is expected to assist in their preparedness and enable better care for those with IRDs • Increased community awareness of IRDs will support advocacy & understanding for people living with the disease
Support	To facilitate meaningful social connections for people with IRDs, and their families and carers	<ul style="list-style-type: none"> • Improved health and wellbeing for people living with inherited retinal disease, and their families and carers • Prevention of mental health issues and/or loneliness for people living with inherited retinal disease • Increased awareness may lead to increased participation in our programs, thereby expanding the reach and positive wellbeing impact in the IRD community
Sustainability	To ensure ongoing viability & therefore our ability to continue to support and positively impact the IRD community	<ul style="list-style-type: none"> • Ongoing investment into medical research will continue the progression into the detection, better treatments, and prevention of IRDs • People living with IRDs, their families and carers, will remain supported and benefit from the information and peer support services and programs of Retina Australia • Financial risk of the organisation will be minimised
Governance	To continuously improve and strengthen organisational governance	<ul style="list-style-type: none"> • While we are pursuing our Mission, our actions reflect our Values with consideration for our environment & our people • The highest standards of integrity, excellence & organisational governance will be maintained • Governance risks minimised • Business risks minimised • Reputation risk minimised • Strategic goals will be met

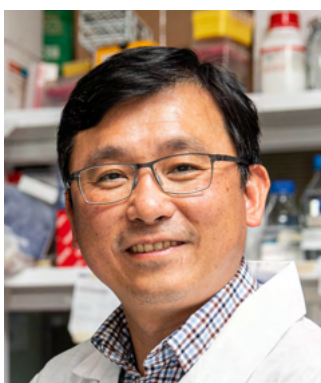
Research Commitment

Retina Australia's Research Grants Program has been awarding funding since 1989

1 Awarded
over
\$6.4 Million
in research
grants

2 Over 140
different
research
projects
supported

3 Over 60
Chief
Investigator
researchers
supported



2023 Research Grant



Chief Investigator

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

Co-Investigator

Dr Samantha Ginn, Children's Medical Research
Institute, Sydney

Grant awarded

\$55,774

Timing

1 Year 2023

Establishing novel AAV gene editing for Usher syndrome

Project Aim

This project aims to evaluate efficacy for Usher 1B and 1F gene therapy using genome editing.

Project Summary

Generated retinal organoids from the Usher patient's own cells will be used to test whether therapies reverse their specific genetic defect. They will be treated using a novel approach which will replace the region of the gene that encompasses the mutation in a permanent manner. The project's results will provide proof-of-concept for AAV gene editing treatments which could treat a number of Usher patients.

Expected outcomes

This project is expected to:

1. generate pre-clinical data and establish efficacy for AAV gene editing to treat Usher patients and other patients with common IRDs
2. provide more access to clinical trials by developing gene editing tools that are suitable and efficacious to use in clinical trials
3. lead to new health technologies embedded in health practice: this study uses stem cells and its derivative organoids which, as new health technologies, will be used for precision medicine functional assays.

2023 Research Grant

Chief Investigator

Dr Adrian Cioanca, John Curtin School of Medical Research, Canberra

Co-Investigators

Associate Professor Riccardo Natoli, John Curtin School of Medical Research, Canberra
Associate Professor Michele Madigan, Save Sight Institute, Sydney
Dr Elisa Cornish, University of Sydney

Grant awarded

\$59,869

Timing

1 Year 2023



Using RNA-silencing to tackle neuroinflammation in retinal degeneration

Project Aim

The aim of this research is to develop a new treatment for retinal degeneration using a type of RNA called silencer RNA.

Project Summary

This study will specifically target a protein called CEBPD, which is known to play a key role in inflammation in the retina. It aims to unpack the role of CEBPD in neuroinflammation by studying CEBPD expression patterns in human age-related macular degeneration (AMD) donor tissue and by modulating its activity in robust animal models of retinal degeneration. Inflammation is a major factor in the death of nerve cells in the retina, which is a major cause of vision loss. By targeting CEBPD, they are targeting the root of inflammation in the retina, which can help to slow down nerve cell loss and preserve vision for those affected by retinal degenerations.

Expected outcomes

This project is expected to contribute to the development of successful therapies for atrophic AMD and other retinal degenerative diseases. This will be possible through the suppression of neuroinflammation by:

- developing a unique method of tackling neuroinflammation by using CEBPD siRNAs and other pharmacological CEBPD inhibitors and
- generating pre-clinical data using a retinal degeneration model that recapitulates key AMD facets including neuroinflammation & progressive focal photoreceptor cell death.

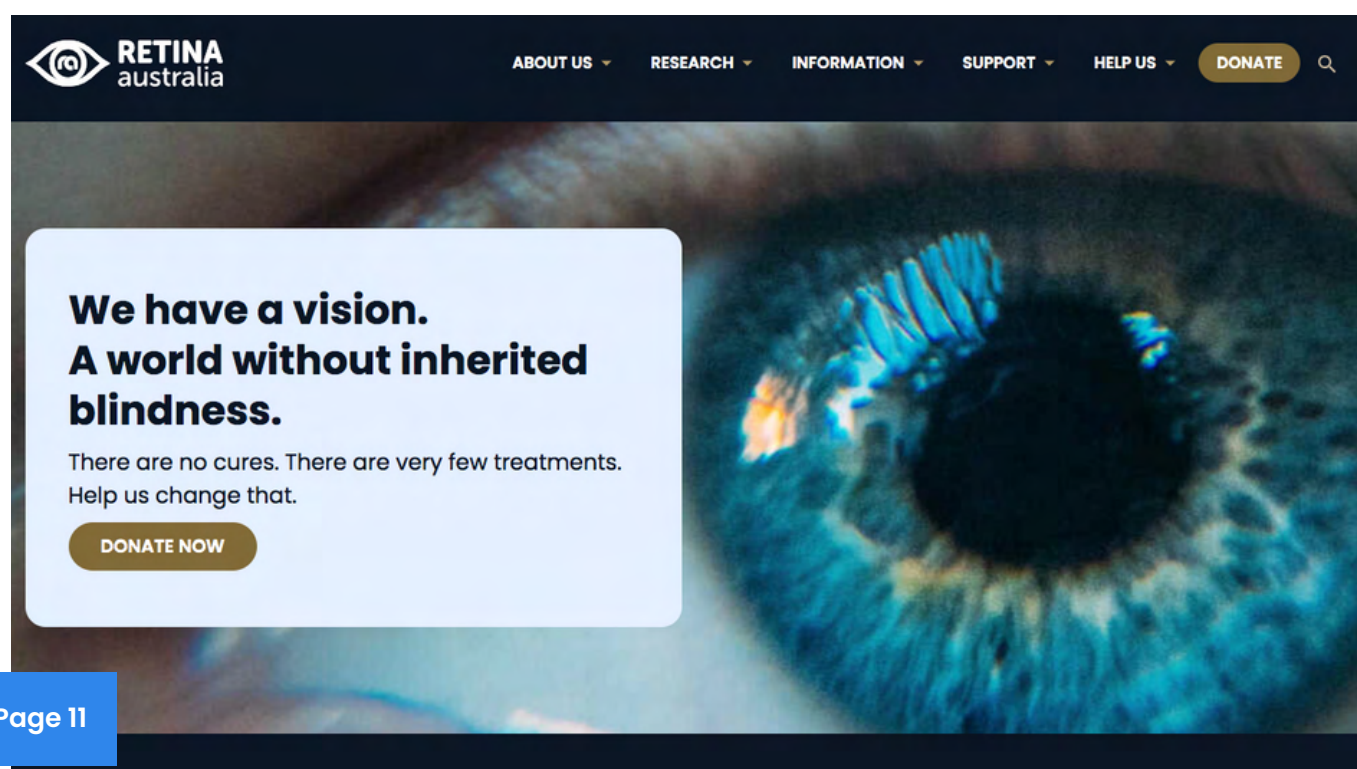
New Website Goes Live

In April 2023, Retina Australia launched its new website. It was rebranded, updated for functionality with new sections of information developed, and designed specifically to meet global accessibility standards.

Key highlights

- New branding colours and font were chosen to meet accessibility standards.
- Existing website sections were expanded and new sections were added including the Research Impact Reports webpage which provides project summaries and impact reports of past Retina Australia Grants recipients.
- A new Blog page has been developed to offer updates of the latest research developments and activities of our members and supporters.
- You can now register for upcoming webinars on our website and also watch recordings of previous webinars.
- After an audit by the Centre for Accessibility Australia, Retina Australia's website was independently rated AA compliant with the WCAG 2.1 standard.
- The new website has seen a substantial increase in reach, both in the number of active users and new users, higher engagement and a reduced average bounce rate.
- We are proud to have been nominated and considered as a Finalist in the upcoming Centre for Accessibility Access Awards for 2023 to be held in November 2023. Thank you to those who nominated Retina Australia.

Retina Australia would like to sincerely thank Janssen Australia for its generous support toward the upgrade of our website.



Newsletters Relunched

Retina Reporter and Retina Insider

2023 also saw the development, redesign, and rebranding of our newsletters.

Retina Reporter

The Retina Reporter is our new bi-annual newsletter, published in December and June each year. It highlights the research projects from Retina Australia's Research Grants Program, along with other topics of interest relating to inherited retinal disease and the activities of Retina Australia. In addition to the digital publication, this report is available to our members in print or audio version when requested.

Retina Insider

The Retina Insider is our new e-newsletter. It aims to update our subscribers on a more regular basis, as and when there are new research developments, to notify of upcoming webinars, research projects or clinical trials that are recruiting participants and other activities of interest.

Both newsletters have been well received with very high engagement rates.



Peer Support Groups



Social Telelink Group

A long time social telelink group, organised each fortnight by volunteer, Rose Petrotta, provides the opportunity for a group of members to catch up every fortnight by phone link up.

Participants call in from around the country including regional Victoria, Melbourne, Tasmania and Queensland, and have enjoyed lasting friendships over many years.

Friends of Retina Australia Perth

The Friends of Retina Australia Group Perth (as pictured above) continued to meet for bush walks followed by morning tea. Retina Australia has been able to support these events through generous donations.

Since the walks began 3 years ago, participant numbers have grown each year to now 19 vision impaired walkers and a group of dedicated sighted guides from the Perth Bushwalkers Club. The group is kindly organised by volunteer, Angela Boothroyd.

All vision impaired walkers have commented on how beneficial these walks have been for their physical and mental health.

Our Supporters

We would like to sincerely thank our Major Donors and Supporting Donors, including our anonymous donors, for their support to Retina Australia.

THANK YOU TO OUR MAJOR DONORS

- Roy Edwards



THANK YOU TO OUR SUPPORTING DONORS

- Leighton & Rosemary Boyd
- Warren Colledge
- Paul & Cherie Daniel
- John Giles
- Ritesh Hargovind
- Richard Rigby
- Peter Symons

THANK YOU TO OUR VOLUNTEERS

In addition to our volunteer Board of Directors, we warmly thank all our 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
- Ciaran Doyle
- Barbara Hutchinson
- Mark Wong

Other volunteers

- Angela Boothroyd
- Dr Catherine Civil
- Alex Dottore
- Andrew Hall
- Tamzin Hall
- Rose Petrotta

THANK YOU TO OUR MEMBERS

Thank you to all Retina Australia members. We value your support and engagement in our community.

Our Alliances

Retina International

Retina Australia is a Member of Retina International. Retina International is a global umbrella organisation for patient-led charities and foundations that support research into rare, genetically inherited and age-related forms of retinal disease. Retina International is a registered charity in Ireland.



Retina Australia also has representatives on the Boards and Committees of Retina International:

- Ms Jane Cherry is Vice Chair of the Board of the Retina International Youth Council (currently also a Board Director of Retina Australia)
- Professor Erica Fletcher, University of Melbourne, is a member of the Retina International Scientific & Medical Advisory Board (representing as a member of Retina Australia's Scientific & Medical Advisory Committee, and is also a member of Retina Australia's Grants Committee)
- Professor Michael Kalloniatis, University of New South Wales, is a member of the Retina International Scientific & Medical Advisory Board (representing as a member of Retina Australia's Scientific & Medical Advisory Committee)
- Mr Jeremy D'Souza is a Director on the Board of Retina International (previous Retina Australia Board Director and Treasurer)

Other memberships



- Retina Australia is a member of the Ross House Association and our office is located at Ross House, Flinders Lane Melbourne.
- Retina Australia is an Associate Member of Vision 2020 Australia. Vision 2020 Australia is the national peak body for the eye health and vision care sector.
- Retina Australia is a member of the Centre for Accessibility Australia, a non-profit organisation that promotes accessibility throughout Australia.

Financial Summary

SUMMARY PROFIT AND LOSS STATEMENT

PROFIT AND LOSS SUMMARY	FY2023 30 JUNE AUDITED	FY2022 30 JUNE RESTATED
Income		
Donation income	681,986	698,032
Grant income	73,529	31,770
Membership income	6,345	6,554
Other income	108	0
Interest income	22,783	4,256
TOTAL INCOME	784,751	740,612
Expenses		
Research grants	(117,753)	(139,253)
Project and program costs	(24,630)	(25,470)
Fundraising contractors	(441,296)	(446,621)
Administration	(167,333)	(143,424)
Other expenses	(17,848)	(17,291)
TOTAL EXPENSES	(768,860)	(772,059)
PROFIT/(LOSS) FOR THE YEAR	15,891	(31,447)
Other comprehensive income	0	0
TOTAL COMPREHENSIVE NET INCOME/(DEFICIT) FOR THE YEAR	15,891	(31,447)

SUMMARY BALANCE SHEET

BALANCE SHEET SUMMARY	FY2023 30 JUNE AUDITED	FY2022 30 JUNE RESTATED
ASSETS		
Cash and cash equivalents	1,206,781	1,209,637
Other current assets	39,161	47,313
Non-current right-of-use assets	12,734	0
TOTAL ASSETS	1,258,676	1,256,950
LIABILITIES		
Current Liabilities	20,499	42,941
Non current liabilities	12,445	4,168
TOTAL LIABILITIES	32,944	47,109
NET ASSETS	1,225,732	1,209,841

Contact Us

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