



Spring Newsletter 2024

Dear members,

Welcome the Retina International Spring Newsletter 2024.

The Retina International Team is delighted to update you our members and stakeholder on our activities as we look forward to meeting many of you at the RIWC which will take place next month in Dublin.

Retina International is always happy to share your activities or promote upcoming events so feel free share with us by emailing to andrew.ryan@retina-international.org

Team Updates

- Andrew Ryan has joined the team as our new Communications and Engagement Officer

Manifesto

- Retina International launches European Election Manifesto that Calls on Eye Care to become a Public Health Priority. To Read more, please click here: [Retina International — Manifesto \(retina-international.org\)](https://retina-international.org)

RIWC

- Retina International World Congress is fast approaching within the next month. If you have not registered for your ticket, then do so. It promises to be a great few days at the Dublin Convention Centre! [Retina International World Congress hosted by Fighting Blindness - Hosted by Fighting Blindness \(crowdcomms.com\)](https://crowdcomms.com)
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Professor Jose Sahel Receives Scientific Award from Rare Disease Europe.

Professor José-Alain Sahel, M.D., co-chair of the Retina International Scientific and Medical Advisory Board (SMAB) was the recipient of the Black Pearl Award for his contribution to science.

The award ceremony was hosted by EURORDIS to mark Rare Disease Day, which takes place on the last day of February each year, this year on February 29th and celebrates scientists, policy makers, industry and patient advocates who work to bring about positive change for all who live with a rare disease.

Professor Sahel is a distinguished professor, chairman of the Department of Ophthalmology, and The Eye and Ear Foundation Endowed Chair at the University of Pittsburgh School of Medicine, and an adjunct professor of Robotics and Bioengineering at Carnegie Mellon University, Pittsburgh. He is an emeritus professor of Ophthalmology at Sorbonne Université and was the founding director of The Vision Institute (Sorbonne Université, Inserm, CNRS) Paris, France (till 31 December 2020).

Trained at Paris University Medical School, Louis Pasteur University in Strasbourg, and Harvard University, Dr. Sahel is a clinician-scientist conducting research on vision restoration focusing on cellular and molecular mechanisms underlying retinal degeneration and development of treatments for currently untreatable retinal diseases.

As the founder of the Vision Institute in Paris and the new Vision Institute in Pittsburgh, Dr. Sahel has conducted and overseen more than 80 clinical trials on retinal conditions, some of them within the most advanced areas of biomedical technologies (first in human trials in retinal implants, gene therapy, stem cell therapy, optogenetics).

With over 700 peer-reviewed articles and 40 patents, he is a prolific researcher and has co-founded companies developing innovative vision restoration therapies. His esteemed memberships include the Académie des Sciences-Institut de France, the Académie des Technologies, the Association of American Physicians, the American Ophthalmology Society, the German National Academy of Sciences Leopoldina and the National Academy of Inventors.

The EURORDIS Scientific Award recognizes Dr. Sahel's excellence in scientific research in the field of rare diseases, with a primary focus on retinal diseases and inherited retinal degenerations. His pioneering efforts in research and his relentless pursuit of understanding the genetic and molecular foundations of these conditions have been truly outstanding.

Professor Sahel's collaboration with international organisations and institutions has played a pivotal role in advancing the diagnosis and treatment of rare eye diseases. His dedication has translated into meaningful improvements in the lives of patients worldwide,

and for this, we would like to honour his ground-breaking achievements.

Pictured on the night are Professor Sahel, Ms. Avril Daly who is CEO of Retina International and current president of EURORDIS and Professor Bart Leroy from the University of Ghent.



Retina international Board of Directors Meeting in Potsdam Germany. April 2024

The Board of Directors of Retina International met for the first time at the Potsdam Scientific meeting organised by the Foundation of Pro Retina Germany, on April 13th and 14th .

Chair, Franz Badura hosted the meeting attended by Manny Moodley , Vice Chair, Jeremy D'Souza, Treasurer, Jason Menzo, Caisa Ramshage and David Sanchez. The meeting was also attended by Avril Daly CEO, Sinead Stafford, Operations Manager, and Katharina Deindeorfer, PA to the CEO.

The meeting provided an opportunity for the Board of Directors to review the current Retina International Strategic Plan which is now in its final year. The Board and executive have agreed to commence the development of a new strategic plan to take the organisation from 2025- 2030. This process will involve consultation with all existing members of the

organisation, the SMAB and partners in order to ensure that it is fit for purpose and useful for the community at large.

A key issue discussed by the board was membership. The board reviewed the tiers of membership and the potential to reduce fees going forward, it is critical that changes to the fee structure does not compromise the sustainability of Retina International which has had the same fee structure since it was a volunteer organisation. The board and executive believe that in order to make Retina International a more inclusive organisation that has the ability to ensure that newly formed national charities and foundations as well as disease specific organisations have the opportunity to come under our umbrella and work collaboratively as we enter into a crucial phase in research and therapeutic development for the retina community at large.

The board will present their plans for strategic and membership review at the Continuous Education Programme at the RIWC on June 6th 2024.



We are delighted to share that a detailed agenda for the upcoming Retina International World Congress is available.

We are gathering the top experts in the field of vision research in Dublin this June 5 - 8 - and we want **you** to be a part of this monumental event.

[Registration is now open](#) for interested participants as we work towards Targeting the Cure this June

Agenda Highlights:

Speakers:

Eminent speakers include [Professor Frans Cremers](#), [Professor Jane Farrar](#), [Professor Jean Bennett](#), [Dr Daniel C. Chung](#), [Professor John G. Flannery](#), [Dr Leah Byrne](#), [Professor David Keegan](#), [Mr Franz Badura](#), [Professor Hélène Dollfus](#), [Professor Bart Leroy](#), [Dr Tiarnán Keenan](#), [Mr Mark Cahill](#), [Professor Isabelle Audo](#) and many more leading experts in the field of vision research and advocacy.

Friday, June 7: Targeting the Cure; the Future of Vision Research

- Morning Session: Therapeutic Development
- Mid-Morning Session: Gene Agnostic Therapeutic Approaches
- Afternoon Session: Genetic Architecture of Retinal Degenerations & Diagnostic Methods

Saturday, June 8: The Cure is Waiting; Making it Happen

- Morning Session: Mental Health and Vision Loss
- Blind Guys Chat: Live Podcast
- Afternoon Parallel Sessions: IRDs and AMD

Don't also miss out on the Spanish Sessions in the Congress:

[Spanish Panel Unveils Cutting-Edge Insights on Inherited Retinal Diseases at RIWC24 - Fighting Blindness](#)

You can find the full agenda [on our website here](#).

Please contact riwc@fightingblindness.ie with any further queries relating to #RIWC24.

Fighting Blindness are also delighted to say that they will also host a Public and Patient Involvement (PPI) breakout workshop during the event programme for Saturday, June 8.

This 2-hour interactive session will highlight the importance of involving the patient voice or lived experience of sight loss in health research. This will also include a group exercise to discuss priorities and best practices for PPI in research. The overall goals of this workshop are to spread awareness of PPI in research and provide an opportunity for patient organisation representatives, those living with sight loss, and researchers to come together and discuss these important topics to support patient-centred outcomes in research.

Please note that spaces are limited for this workshop. If you would be interested in attending this session, please email riwc@fightingblindness.ie.



Retina International Launches European Election Manifesto

2024 has been ladled, the year of the election, as more political elections will take place across the globe this year than in any other in modern times.

Elections give advocates the opportunity to outline key policy goals and seek political action in the development and implementation of legislation that can have positive societal change. In April, RI published as suite of campaign tools to be used in the European Parliament elections which take place in June.

The Manifesto and supporting tools focus on the unmet need of those living with late stage AMD, both Geographic Atrophy and wet AMD. The three key asks were highlighted the RI

Burden of AMD and GA study published in 2022 and were ranked and elaborated by RI's membership, ensuring global resonance and a featuring transferable call to action that is relevant in all regions.

Our Goals

Click on our Goals below to read!

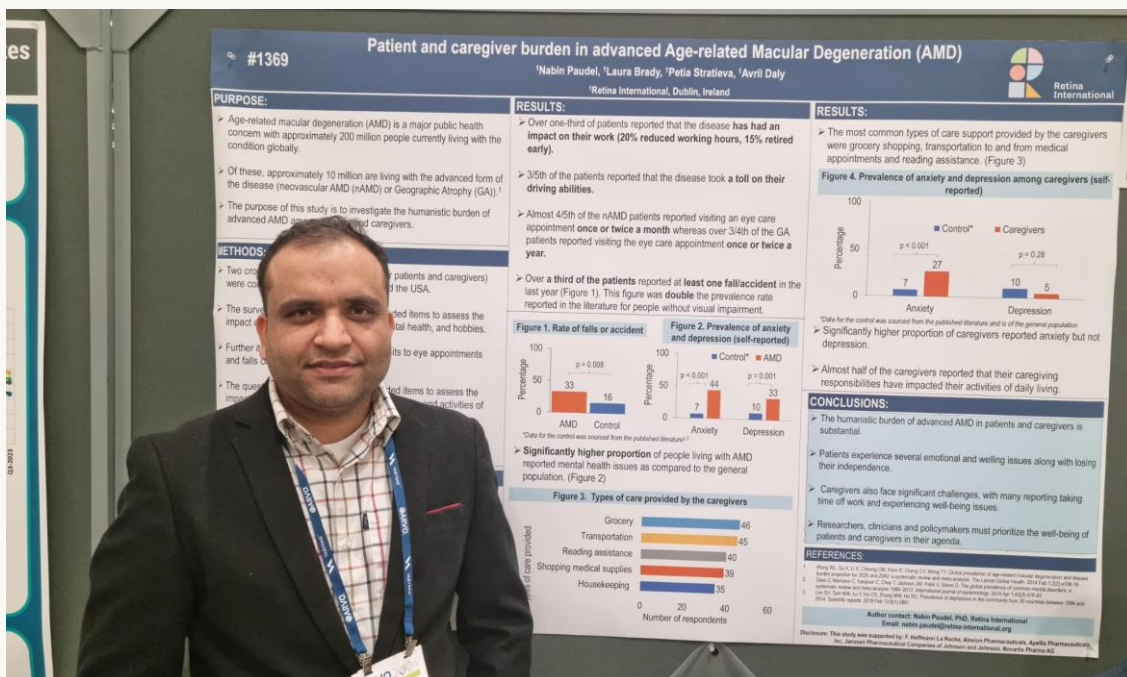
1. [Early detection and access to treatments and rehabilitation services.](#)
2. [Research and innovation for AMD.](#)
3. [Mental health needs of people living with AMD and their caregivers.](#)

A step-by-step approach has been developed by RI to assist patient groups, researchers, clinicians and industry partners in their efforts to reach out to local candidates, and political parties in the run up to the European Parliament elections, which take place in June.

We are asking all candidates for the European Parliament Elections, both sitting MEPs and new Candidates, to sign our **Pledge**. By signing the pledge, candidates are agreeing to support actions outlined in the Manifesto if they are elected.

The Pledge and the other materials are available [Click Here Election Manifesto](#) and are attached to this mail for your convenience.

If you have any questions, contact andrew.ryan@retina-international.org



ARVO Update

The ARVO annual meeting 2024 in Seattle, Washington, USA that was held from 5-9th May, 2024 was attended by RI's Head of Research and Programs Dr Nabin Paudel and RI's Chairperson of the Board of Directors Mr Franz Badura. Dr Paudel and Mr Badura engaged in several key activities throughout the conference duration including attending key seminars and paper presentations, presenting posters, and organizing the Scientific and Medical Advisory Board meeting. Dr Paudel presented 2 posters in the areas of AMD, namely the burden of late-stage AMD in patients and caregivers and enhancing clinician-patient communication in AMD care – insights from patients and clinicians. Both posters were well received and the poster on the burden of AMD was awarded the hot topic. The Scientific and Medical Advisory Board meeting was a great success with over 60 scientists, clinicians and RI member representatives attending the session. In the SMAB meeting, key scientists provided latest updates on clinical trials in the areas of IRDs and AMD. The meeting also discussed several key challenges in retinal research and development such as the future of gene therapy for IRDs and the potential of use of combination therapies. In a nutshell, it was a very productive event for RI. Full report of the ARVO meeting including key abstracts and the details of the SMAB meeting will be sent out separately to our membership at a later date.



PEDALLING TOWARDS INCLUSIVITY

Empowering Para Cyclists at Dis-Chem Ride For Sight

By Linsay Engelbrecht

In the vibrant world of cycling, the winds of change are blowing, steering the sport towards inclusivity and accessibility for all. Nowhere is this more evident than in the inspiring journey of Retina South Africa's involvement in the Dis-Chem Ride For Sight event.

At the heart of this initiative lies the Para Category, a platform designed to welcome para

cyclists, hand-cyclists, and tandem teams. Its significance extends far beyond the realm of sport; it symbolises a beacon of inclusivity, where barriers are shattered, and opportunities abound. Setting an ambitious goal of 100 para participants by 2025, Retina South Africa embarked on a journey to transform this vision into reality.

Harnessing the Power of Communication: Leveraging social media, WhatsApp surveys, and direct communication with all stakeholders we recruited volunteers and VIP's to join this empowering movement.

Generous sponsors ensured that financial barriers were overcome, covering entry fees, transportation, and essential cycling gear, making participation a tangible possibility for all. Tailored training sessions and adaptive equipment provision equipped new riders with the skills and tools necessary to embark on their cycling journey with confidence.

Implementation of accessibility measures at the event venue ensured that physical barriers did not hinder participation, reaffirming the event's commitment to inclusivity & safety.

The fruits of these efforts were nothing short of remarkable. The 2024 edition of the Dis-Chem Ride For Sight witnessed a surge in para individual participation, with 31 para entries and 52 participants overall. From the 116km race to the 8km event, individuals with visual impairments and physical disabilities showcased their determination and spirit, crossing finish lines and breaking barriers.

Beyond the race itself, the community rallied behind the cause, exemplified by the R30,000 raised in just seven days through fundraising initiatives, demonstrating the profound impact of collective action.

Going forward we need you all to join the "Save Our Sight" team.

Whether you have a retinal condition, are a friend or family member or simply an individual passionate about fostering inclusivity, there's a place for you within this dynamic team. By participating in events, fundraising, and advocating for inclusivity, team members play an integral role in furthering the organisation's mission. If you're interested in becoming a part of this transformative journey or wish to learn more about how you can contribute, contact me, Lindsay Engelbrecht at events@retinasa.org.za or WA me at 0845549227. Whether it's lending a helping hand at races, offering administrative support, or spreading awareness, every contribution matters.

Together, let's continue towards a future where barriers are replaced with

opportunities, and every individual, regardless of ability, can thrive. Join the "Save Our Sight" team today and be a catalyst for change in the journey towards



PARA LAWN BOWLS

In the world of para sports, lawn bowls emerges as a shining beacon of inclusivity, skill, and determination. Recently, members of Retina South Africa, Mariza Jurgens and Linsay Engelbrecht[on right], showcased their exceptional talent at the SA Lawn Bowls Open Championships for the disabled held in Cape Town.

Blind Bowls is divided into categories which denote various degrees of vision loss, with "B" for the completely blind. Mariza, a seasoned bowler, clinched a well-deserved silver medal in the Singles Division of her classification. Meanwhile, Linsay, a relative newcomer to the sport, stunned the competition by clinching gold medals in both the Singles and Pairs divisions. Her unexpected triumphs left her feeling immensely proud and fuelled her determination to pursue her bowling future. Linsay describes the experience as surreal, emphasising the intense competition and the invaluable lessons learned along the way. We extend sincere congratulations to them both on their success. All para lawn bowlers with visual impairments are assisted by their dedicated, sighted, directors guiding them with precision and expertise. Linsay attributes much of her success to her director [and husband], Deon Engelbrecht, whose impeccable directing and unwavering support was a huge part of their success.

As we celebrate the achievements of Mariza and Linsay, let us also celebrate the spirit of resilience, perseverance, and camaraderie that defines para lawn bowls. Their success serves as a beacon of inspiration for para athletes everywhere, reminding us

all that with dedication and determination, anything is possible on the green.



Retina Australia Spring Update 2024

Retina Australia is delighted to announce two new Research Grant recipients for 2024. The new projects will focus on Stargardt disease and Virtual Reality Assessment of Functional Vision in achromatopsia.

[Characterising Stargardt Disease Mutations for Splice Intervention Therapeutics](#)

Grant of \$60,000 awarded to Chief Investigator – Dr Di Huang, Lions Eye Institute, Perth

This project aims to find a treatment for Stargardt disease (STGD1), by studying the specific genetic changes in the *ABCA4* gene that lead to the disease. It will then look to develop a new type of treatment called splice-switching antisense oligonucleotides (SS-AONs) for STGD1.

Stargardt disease is an inherited retinal disease that affects the macular, resulting in loss of central vision. Common initial symptoms include difficulty reading or recognising faces. Blind spots can occur, and these may increase in size over time. The condition can be slowly degenerative and progressive, and colour vision may be affected in the later stages of disease. There are currently no treatments for Stargardt disease.

[Virtual Reality Assessment of Functional Vision in achromatopsia and albinism](#)

Grant of \$52,639 awarded to Chief Investigator – Dr Elisa Cornish, Save Sight Institute, Sydney

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 in patients with achromatopsia and albinism, to be used for measuring clinical trial success of new developing treatments.

Achromatopsia is a rare inherited retinal disease which leads to the cone photoreceptors not functioning resulting in poor or no colour vision, as well as low vision. There are currently no treatments for achromatopsia.

Congratulations to our successful researchers and their teams. We look forward to hearing about the impacts that these projects have in the search for future treatments for inherited retinal disease. For further information about Retina Australia's research program visit our website - <https://retinaaustralia.com.au/research/>



Retina UK

Retina UK invite you to register for their Conferences in September 2024 in Manchester and online. They are free to attend.

Professionals' Conference – Friday 27 September 2024

The focus of our Professionals' Conference 2024 will be the impact of living with inherited sight loss. This understanding is designed to support the professional community in their work with individuals living with these conditions. The programme includes:

- An overview of the services available from Retina UK and how they can be accessed by the professional community.
- The value of peer support, specifically how connecting with others living with similar conditions can improve health and wellbeing.

- Equality, Diversity, Inclusion and Accessibility with speakers from SeeAbility and Bame Vision.
- The outcome from a study published in December 2023 on “The Humanistic Impact of X-Linked Retinitis Pigmentosa (XLRP): Results from the Explore Xlrp-2 Retrospective Chart Review and Cross-Sectional Survey of Patients and Caregivers in 10 Countries”.

To find out more and to register for our Professionals’ Conference on Friday 27 September, please visit: RetinaUK.org.uk/event/professionals-conference/

Annual Conference – Saturday 28 September 2024

Our Annual Conference is eagerly anticipated by our community, volunteers and staff. It is designed to inform and update delegates about our work and to provide an opportunity for them to network, reconnect with old friends and make new ones. The 2024 programme includes:

- Our three funded PhD students, who will introduce their projects in conversation with Professor Graeme Black, Honorary Consultant Genetics and Ophthalmology at Manchester University NHS Foundation Trust.
- Our latest funded research projects and the potential benefits this work may have for our community.
- The value of peer support, specifically how connecting with others living with similar conditions can improve health and wellbeing.
- Our ever-popular research Q&A. Panel participants will include Professor Graeme Black and Dr Panos Sergouniotis.

To find out more and to register for the Annual Conference on Saturday 28 September, please visit: RetinaUK.org.uk/event/annual-conference/.



Firstly, we're thrilled to announce a new collaboration with the Association Restaurantes Para Todos. Together, we've presented a project to CINFA and PROTOS aimed at adapting restaurant menus for individuals with low vision and blindness. To make these projects a reality, we need your support through popular votes. You can cast your vote for CINFA (voting open until May 15th) here: <https://lavozdelpaciente.cinfa.com/admin/gusto-por-la-inclusion---programa-de-accesibilidad-en-restaurantes-21466?contestTitle=4-edicion-la-voz-del-paciente---vota-por-tu-proyecto&contestId=20983>

And for PROTOS (voting open until July 15th)
here: <https://a.cstmapp.com/promotions/entries/973709/>
(search for FARPE to vote).

Additionally, we're excited to invite you to a webinar on May 21st titled "Discovering Age-Related Macular Degeneration: Diagnosis and Treatment. A Dialogue with Specialists,"

with the support of Retina Internacional. The event will take place online via Zoom at 18:30 Spain time (11:30 in Bogotá, 12:30 in Santiago de Chile, and 13:30 in Buenos Aires and Sao Paulo). The webinar, spanning an hour and a half, is tailored for individuals affected by age-related macular degeneration, their families, members of the associative movement, professionals, and anyone interested in Spain and Latin America.

Age-Related Macular Degeneration (AMD) and Geographic Atrophy are eye conditions significantly impacting the quality of life, particularly in older individuals. This webinar will delve into these conditions, covering diagnosis, treatment, and future perspectives. Renowned specialists, Dr. Isabel Pinilla and Dr. Jordi Monés, will lead the dialogue, moderated by David Sánchez, president of FARPE and board member of Retina Internacional. You can register for the webinar here: <https://forms.gle/diNZ1TXJA9MZbbU49> with registrations open until May 20th. The webinar will be in Spanish. For those unable to attend, we will upload it to YouTube.

Webinar Recap: "From Diagnosis to Management": Our collaborative effort with Retina International brought forth insightful discussions on Hereditary Retinal Dystrophies, featuring distinguished speakers such as Dr. Carmen Ayuso García, Dr. Rosa Coco Martín, and Dr. José María Millán Salvador, with moderation by David Sánchez, President of FARPE and board member of Retina International.

The webinar covered crucial topics ranging from advanced diagnostic technologies to emerging therapeutic approaches like gene therapy. We also delved into the challenges faced in research and clinical management while exploring avenues to enhance the quality of life for individuals affected by these conditions

Furthermore, we're continuing our #vocesquetransforman campaign, where we aim to amplify the voices of those affected and their families through written or video testimonials. We invite anyone interested to participate by sending their submissions to our email: farpe@retinosisfarpe.org.

Thank you for your continued support, and we look forward to your participation in these initiatives!



Retina International CEO Avril Daly, pictured with the Executive Director of The EMA, Emer Cooke at Farmleigh House Dublin on Rare Disease Day 2024.



Queen Latizia of Spain and David Sanchez pictured at a rare disease day event in Madrid





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