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Dear Members and Friends of Retina South Africa,

As we embrace the cooler days and the promise of winter, I am thrilled to share with you the latest edition of our 'Out of Sight' newsletter. This issue is brimming with updates and opportunities that underscore our commitment to enhancing the lives of those affected by retinal conditions in South Africa.

Mark your calendars! We are delighted to announce the 'Save the Date' for Retina South Africa's Annual General Meeting on 19 July. This gathering is a cornerstone of our community, offering a platform to reflect on our achievements, set future directions, and strengthen our bonds. Details will follow soon, and we look forward to your active participation.

In the spirit of excitement and giving, we are also launching a raffle to win a holiday trip to the enchanting island of Zanzibar. This is a wonderful opportunity to support our cause while possibly embarking on a dream vacation. We encourage everyone to participate and spread the word.

As we move into the winter season, I extend my warmest wishes to you and your loved ones. May this time bring you joy, peace, and the warmth of community. Together, we continue to make strides towards a brighter future for all affected by retinal diseases.

With Kindest Regards

The Editor

SAVE THE DATE - ANNUAL GENERAL MEETING

The Annual General Meeting of Retina SA will be held on the 19 July 2025 at the Retina Offices in Wilbart Germiston.

Nomination for election to the Management Committee of Retina South Africa for 2025/2026/2027 are now open. The elective period is for 2 years ending July 2027.

Please complete the Nomination Form and email it to headoffice@retinasa.org.za by no later than **27 June 2025**

LATEST NEWS

A Vision Beyond Sight

By Sonya Lee Mahabeer - Deputy Chair

As a young adult, my world began to fade before I had fully seen it. The subtle yet persistent loss of vision became a constant in my life - an invisible shadow that followed me through my studies, through friendships, and through moments that were meant to define the person I was becoming. For over a decade, I sought answers.

Specialist after specialist, doctor after doctor, yet clarity — both literal and medical — continued to elude me. It was only after years of uncertainty that I was finally diagnosed with Stargardt's disease. Retina South Africa helped me find purpose in the pain. Through their work, I discovered that education and awareness are vital tools in breaking the silence surrounding visual impairments. I began to see beyond my diagnosis — to understand that while my sight may be limited, my vision for impact, justice, equality and empathy remains boundless.

FULL STORY

Join the Conversation: Shape the Future of Assistive Technologies in Africa

Retina South Africa is excited to share an important opportunity for you to make a difference in the lives of persons with disabilities across Africa and beyond. On June 12, 2025, the World Health Organization (WHO) will host stakeholder engagement sessions in

Africa to discuss the proposed updates to the Priority Assistive Products List (APL). This is your chance to contribute to a global effort to ensure that assistive technologies—vital tools like hearing aids, wheelchairs, communication aids, and more—are accessible, inclusive, and responsive to the needs of our communities.

As a member of the WHO's Technical Advisory Group (TAG), our Chairperson, Mariza Jurgens, recently had the privilege of joining experts in Geneva to review and expand the proposed APL. Their discussions focused on making the list more inclusive, ensuring it reflects the diverse needs of persons with disabilities worldwide. The APL serves as a critical guideline for governments, outlining the assistive devices they should prioritize to remove barriers and empower individuals with disabilities.

REGISTER HERE

Hope on the Horizon for Stargardt Disease: Participate in Pioneering Research and Access Genetic Testing at a Discount

WHY:

At Retina South Africa, we believe that everyone affected by inherited retinal conditions deserves access to cutting-edge treatment and the chance to protect their vision. Today, there is exciting news for our community — and particularly for families affected by **Stargardt Disease Type 1**. A promising new treatment is on the horizon, and we want our members to be ready.

HOW:

Belite Bio, a U.S.-based pharmaceutical company, is leading the **Phase 3 DRAGON Clinical Trial** for a drug called **Tinlarebant**. This daily capsule is designed to **slow the build-up of lipofuscin**, a toxic waste product that damages retinal cells in people with Stargardt Disease Type 1. During the 2-year study, young participants experienced **no loss of vision** and showed **maintenance of healthy retinal tissue** —a remarkable achievement.

Because of its potential impact, the U.S. FDA has granted **Breakthrough Therapy Designation** for Tinlarebant, meaning it will receive **expedited review for registration**. The trial is expected to conclude in **December 2025**, and if successful, the treatment could become available within just a few years.

To ensure that **South African patients are eligible** for this ground-breaking therapy, Retina South Africa, in partnership with the

Department of Human Genetics at the University of Cape Town, is offering a **once-off 40% discount** on the cost of comprehensive **retinal genetic testing** — but only until **August 2025**.

WHAT YOU CAN DO

🌴 Paradise With Purpose: Win a Trip to Zanzibar!

Imagine 7 nights of barefoot luxury at Michamvi Sunset Bay Resort – full board, return flights included, your own stretch of private beach, and sunsets that erase the noise of everyday life.

Here's the beautiful part:
Every R100 ticket supports Retina South Africa's sight-restoration programmes. You're not just entering a raffle – you're helping someone see a brighter future.

🗒️ ***Travel dates:*** March 21–28, 2026
🎉 ***Draw date:*** January 30, 2026

We're selling both online and through physical booklets – and while there's no limit to how many tickets you can buy, printed booklets are in high demand.

Want a free entry?
If you'd like to help sell tickets on our behalf, we'd love to hear from you! For every full booklet of 10 tickets sold, you'll receive one free entry into the draw as a thank-you.

✨ Paradise or purpose? Why choose when you can have both.

💙 Questions? Contact us events@retinasa.org.za

P.S. This raffle is open to the public. Share it with your community – together, we can change lives through the gift of sight

Get your ticket today for only R100.

BUY TICKETS HERE

Curious about eye and retinal conditions?

Join our **one-day interactive, hands-on workshop** and explore the fascinating world of vision!

- **Take apart a model eye** to understand its structure and function
- **Solve a detective story** about macular degeneration.
- **Go live online with your group** as we delve into diabetic retinopathy.
- **Uncover the mystery** of Charles Bonnet Syndrome.
- **The Silent Threat on our Plates –** our food, macular degeneration – and dementia
- **Construct DNA** to gain an understanding of genes, plus current and future treatment trends
- **Try out apps and devices** designed to assist with low vision.

Don't miss this engaging experience!

For more information, please contact karen@retinasa.org.za or call 010 497 9489

FUNDRAISING EVENTS

The Dis-Chem Foundation Swing For Sight Golf Day 2025

Date: Tuesday, **Sep 02, 2025**
Venue: Royal Johannesburg Golf Club – *East and West Courses*
Tee-off: 11:00 Shotgun Start
Purpose: Fundraising for sight-saving research and Retina SA's advocacy work

Passionate Volunteers Needed.

We're looking for **6 passionate volunteers** to join us on the green at Retina South Africa's annual **Swing For Sight Golf Day** - proudly supported by the Dis-Chem Foundation**.**

This isn't just a golf event. It's a powerful day of **impact, inclusion, and visibility**.

You'll help run the exciting **Hole-In-One Challenge** across both the East and West courses, meet inspiring players, and engage with supporters from all walks of life.

You'll witness **visually impaired golfers inaction** - breaking barriers and proving that **sport belongs to everyone**.

By volunteering, you become part of our mission to fight blindness and open doors for those living with vision loss.
You're not just giving time - you're giving hope.

Volunteers will receive:
✔ A Retina SA volunteer shirt
✔ Lunch and refreshments
✔ A service letter
✔ A meaningful, unforgettable experience!

Interested? E-mail events@retinasa.org.za to sign up.

Let's show South Africa what inclusion *really* looks like.

Don't Miss the Swing for Sight Action! The thrill, the energy, the unforgettable moments — **Follow us on Facebook** @swingforsight2025. Be part of the fun!

VOLUNTEER

MySchool MyVillage My Planet

WOOLWORTHS ENGEN

TURN EVERY SHOP INTO THE GIFT OF SIGHT

- ✓ SHOP
- ✓ SUPPORT
- ✓ SWIPE
- ✓ IT'S FREE

Simply join by downloading the free MySchool app or click below to get your FREE MySchool MyVillage MyPlanet card.

FREE CARD

Save Our Sight Campaign - Winner

Congratulations to our May winner **Jimmy Ramokgopa**.
A single donation of R250 not only contributes to a great cause, but also enters you into our monthly draw to win R500.

DON'T MISS OUT

UPCOMING FUNDRAISING EVENTS CALENDAR

2 September 2025 - Swing for Sight Annual Golf Day
16 November 2025 - 947 Ride Joburg, Ride For A Purpose

NURTURE VISION

Nurturing Vision Through Nutrition: A Modern Approach to Eye Health and Dry Eye Relief

In today's screen-heavy, fast-paced world, our eyes are under constant strain—from digital glare and artificial lighting to environmental stressors and aging. Nurture Vision was founded on the principle that proactive, science-backed nutritional support can make a meaningful difference in preserving and protecting sight. Their focus is twofold: safeguarding the long-term health of the retina, particularly the macula, and addressing the widespread issue of dry, irritated eyes affecting millions of South Africans daily.

Their flagship Triple Carotenoid Eye Supplement combines lutein, zeaxanthin, and meso-zeaxanthin—three macular pigments clinically shown to enhance visual performance, improve contrast sensitivity, and protect the retina from harmful blue light and oxidative damage.

LEARN MORE

Retina SA Disclaimer

Information disseminated by Retina South Africa is for information purposes only. Readers must discuss any intervention with their Eye Care Practitioner. Information in this Out of Sight Newsletter does not imply that Retina South Africa endorses any particular therapy, intervention or medication. Retina South Africa assumes no responsibility for the use made of any information provided in this newsletter.

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