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FOREWORD

Welcome to our world.

By Caryl Baum, Chairperson, Retina South Africa

When I accepted the position of Chairperson, I committed to ensuring that Retina South Africa remained responsive to the needs of our members and focused on its mission. Over the past three months, we have strengthened healthcare partnerships through our work with McCord's Hospital in KwaZulu-Natal, expanded awareness among healthcare

professionals at the SAOA Conference, and continued to promote initiatives that improve access to information, support, genetic testing, accessibility, and inclusion for people living with retinal conditions.

Member engagement remains at the heart of our work. More than 90 members attended our KwaZulu-Natal outreach event, while our **Living Well with Retinal Vision Loss** e-workshop series continues to receive excellent feedback.

The **Dis-Chem Swing for Sight Golf Day** was also a successful fundraising and awareness event, and we continue to build partnerships with healthcare professionals, low-vision practitioners, and service providers to expand support for our members.

This period also brought important staff changes. We bid farewell to Karen Denton, our valued Education and Advocacy Officer, and thank her for her dedication and contribution to Retina South Africa.

We are pleased to welcome Lauren Jonas, a Disability and Inclusion activist committed to advancing inclusion and positive change, and Primrose Gura, our new Planned Giving Officer, who launched our first **Giving Tuesday campaign**, Your Rand, Their Sight, to raise funds for genetic testing for families affected by inherited retinal conditions. I am also delighted to announce that **Dis-Chem Ride for Sight 2027** has officially been launched.

Don’t forget our raffle and stand a chance to win a holiday to **Zanzibar**. Check out our website and social media for all the information. My sincere thanks to our CEO, staff, volunteers,

Board, Exco, donors, and sponsors for their continued commitment.

Most importantly, thank you to our members and their families. Your support makes our work possible.

As Ryunosuke Satoro said, “Individually, we are one drop. Together, we are an ocean”

EDITORIAL

Optogenetics: from Nobel Prize to vision restoration

By Claudette Medefindt

The 2026 Nobel Prize in Physiology or Medicine was awarded jointly to Karl Deisseroth, Peter Hegemann, and Georg Nagel for their discoveries concerning light activation in retinal cells and the development of optogenetics. Their work transformed a basic biological discovery in a single-celled algae into one of the most exciting technologies in modern medicine.

What this means

For people living with retinal vision loss, this Nobel Prize is especially significant. Optogenetics is no longer just a remarkable and promising laboratory tool used by neuroscientists. It is now being tested in people with conditions such as Retinitis Pigmentosa (RP) and Stargardt disease (STGD), with several clinical trials reporting encouraging improvements in visual function.

Read more about Optogenetics

Limitations of optogenetics

Despite the excitement, optogenetics is not a cure. Several challenges include: visual acuity remains limited, the quality of restored vision varies, the brain must adapt to a new source of visual input, and long-term durability is still being studied. Some systems require specialised goggles or light-enhancing devices.

Nevertheless, the progress made over the past decade has exceeded what many experts thought was possible and is a testament to the ingenuity of the human mind.

Is gene therapy being abandoned?

- Gene therapy still holds the promise of the restoration of natural vision but requires some existing photoreceptors, while optogenetics uses different surviving neural cells to restore vision.
- Gene therapy is generally only for a specific gene or gene mutation, while optogenetics is gene agnostic (independent).
- Gene therapy appears to be more effective in early disease, while optogenetics will probably restore functional vision despite major photoreceptor loss.

For the inherited retinal disease community, optogenetics has opened a new path to treatment. For decades, patients reaching advanced stages of RP, Stargardt Disease and other retinal dystrophies were often told there was nothing left to treat once

photoreceptors had been lost. Optogenetics now challenges that assumption.

Rather than trying to rescue dying photoreceptors, researchers are converting surviving retinal cells to perform a completely new role. It is a striking example of scientific ingenuity: transforming retinal neurons that were never intended to detect light into a new visual system.

> **Editor's note:** Optogenetics is one of several promising approaches being developed for inherited retinal diseases. Others include gene replacement therapy, gene editing, RNA therapies, stem-cell approaches, and retinal prosthetic technologies. Together, they are rapidly transforming what was once considered an untreatable group of conditions into one of the most active fields in modern medicine.

RESEARCH

Research News

PLEASE NOTE- Retina South Africa does not endorse any treatments or supplements discussed in this E-News. Please consult your eye care professional.

Calling all patients with Leber Congenital Amaurosis (LCA)

Retina South Africa needs ALL patients (from 5 years old) with Leber Congenital Amaurosis to contact us urgently. We have been invited to recruit patients with a specific LCA mutation to be assessed for inclusion in an important clinical trial.

Please act now. This window is closing soon.
Contact: **denise@retinasa.org.za** or WhatsApp **083 306 5262**

TINLAREBANT

This is a pharmaceutical intervention to slow the degeneration of the Retinal Pigment Epithelial (RPE) cells in the retina. This damage causes the loss of vision in Stargardt Disease and other ABCA4 gene-linked dystrophies such as Cone or Cone Rod Dystrophy. Belite Bio has applied for registration of the product in the USA, EU and other countries. We have offered to assist in the registration of the product in South Africa.

Watch the Macular Society interview with Dr Michaelides

BEACON VISTA TRIAL FOR X-LINKED RP

The Beacon phase 2/3 VISTA gene therapy trial for X-linked RP showed a favourable gain of Low Luminance Visual Acuity in both the high and low dosage groups. This is a significant result for the treatment of the RPGR form of X-linked RP, where males only are generally affected and females carry the gene mutation. **See more on the VISTA trial**

More research news

Search for your specific condition:

- **www.fightingblindness.org** (research and clinical trials pipeline)
- **www.clinicaltrials.gov**

AWARENESS

World Retina Week: 21 to 27 September

- Retina South Africa collaborated with the South African Optometric Society and Vision Works Optometrists to offer

free retinal screening countrywide. We also used the platform to promote our free **Living Well with Vision Loss digital workshops**. These covered a wide range of topics: anxiety and fear, genetic and clinical facts of retinal degeneration, para-sports, mobility, assistive devices, and employment and empowerment. These are all available on Retina South Africa's YouTube channel, and the final two, Age-Related Macular Degeneration (AMD) and Diabetic Vision Loss, and Reading with Low or No Vision, will follow.

- A multimedia campaign supported our message with media interviews on various platforms, a vibrant social media campaign and PSA adverts on DStv.
- The National Department of Health supported us with a Facebook post on 29 September.
- We partnered with Roche Products during Eye Care Awareness Month, and this led to two of our AMD members being interviewed by BBC International Radio. Their spotlight on AMD was fuelled by the retirement of Dame Judi Dench due to her inability to read her lines because of advancing AMD.

A sincere thank you to all the participating optometrists, collaborators and the media for their participation in our awareness during World Retina Week and Eye Care Awareness Month.

IN THE NEWS

Orbis supports retinal screening

People living with diabetes in the Tshwane district will now have access to state-of-the-art artificial intelligence-enabled screening machines designed to support early detection of diabetic retinopathy.

The Gauteng Department of Health, in partnership with Orbis International, has established screening centres at Tshwane District Hospital, Laudium Community Health Centre, Eersterus Community Health Centre and Bophelong Clinic. These will strengthen the early detection of diabetic retinopathy and ensure patients receive timely referrals and treatment before the condition progresses to severe vision impairment.

Diabetic retinopathy damages the blood vessels of the retina and often develops without noticeable symptoms in its early stages, making regular screening essential for people living with diabetes.

OUTREACH

Durban delivers: Retina SA’s KZN outreach makes waves



Over four action-packed days in August, the Retina SA team took our message to KwaZulu-Natal, starting on 26 August with an Awareness Day at McCord's Hospital. We saw patients, doctors, nurses and optometrists, spreading our message of support and hope. We also demonstrated the amazing Umsizi Reader App.

SAOA Conference

At the South African Optometric Association Conference (27–29 August), 106 delegates visited our stand to engage and collaborate. We were able to emphasize our message of the support that we offer to all RD patients, including diabetic retinopathy, age-related retinal conditions and inherited retinal diseases. Presentations by Manny, Victoria and Linsay drew delegates straight to our stand, and a few new members joined

on the spot! A contact made at the conference also led to the team being invited to a Department of Health event.

Community at the heart of it all.
We finished on 29 August with our KZN Members Meeting at Tape Aids for the Blind in Durban. There, almost 90 eager guests connected with us and one another and explored assistive technology and support services from seven exhibitors.

The ripple effect
The momentum hasn't stopped. Since the outreach, an optometry group has invited Retina SA to partner with it on outreach and awareness programmes across three provinces, and planning meetings are already under way.

The takeaway? When we show up in person, people connect, and new partnerships follow. Thank you, KZN.

We'll be back!

EVENTS

Join us for the 38th Dis-Chem Ride for Sight



Sunday, 21 February 2027 | Carnival City, Brakpan

This iconic event moves to Carnival City in Brakpan after 17 years at Boksburg City Stadium. The new venue affords more space for the race village, sponsors, medical support, recovery areas and the growing number of riders, families and para-cyclists.

The Dis-Chem Ride for Sight is still organised by, and for people affected by retinal conditions, with proceeds going directly to Retina South Africa. Every entry supports education, advocacy, patient support and research into treatments and potential cures for inherited retinal diseases.

Three distances cater for all levels of cycling: the 121 km Super Classic, 50 km Challenge and a novice 12 km Family Fun Ride All distances include dedicated para-cycling categories. Visually impaired riders on tandems, handcycles and other adaptive equipment are warmly welcomed, supported by sighted pilots and the organising team.

Race Director Linsay Engelbrecht, who lives with Stargardt disease, leads the event alongside a committee that includes many members living with vision loss. This makes the Ride for Sight one of the few major cycling events in the world organised by people who personally understand the realities of sight loss.

Current Entry Fees are R750 for the 121 km; R550 for the 50 km and R160 for the 12km. Children and students, para-cyclists and pensioners wil all receive special rates. Pre-entries receive a Dis-Chem goody bag and a Cycle Lab shopping voucher.

Enter now: **https://tinyurl.com/RideforSight2027**

Raffle tickets are now available for anyone who would like to support our cause.

Why the Ride for Sight Matters

For nearly four decades, this event has raised millions of rands for Retina South Africa's work. It is more than a race, it is a living demonstration that visual impairment does not limit leadership, participation or impact. Whether you are a competitive cyclist, a family looking for a fun day out, a first-time rider or a para-athlete (or pilot), there is a place for you on the start line.

Questions? Event enquiries: rfspa@rideforsight.org.za Online entry queries: info@entries.co.za

We hope to see you at Carnival City on 21 February 2027.

Together we can keep pushing toward better treatments, stronger support and ultimately, restored sight.

GIVING TUESDAY

Help us put genetic testing within reach

For families living with an inherited retinal condition, a genetic test is often the step that turns uncertainty into a diagnosis. On Tuesday 1 December 2026, Retina South Africa takes part in Giving Tuesday for the first time, under the campaign *Your Rand, Their Sight*. We are asking the eye care community to help us make that step possible for more families.

Why the test matters

Inherited retinal conditions can affect a baby, a child or an adult. A genetic test is how a family finds out exactly what they are facing. It can confirm a diagnosis that other investigations could not, receive counselling about how a condition is inherited, and show whether a treatment or clinical trial might be possible.

One family we work with shows what the wait can look like.

When their son was three months old, his eyes moved constantly, drawn again and again to the light. Months of tests followed, including a brain scan, an EEG and an MRI. They ruled out neurological causes but gave no answer about his sight. A genetic test finally gave the family their answer: a rare form of Leber congenital amaurosis.

The access gap

Genetic testing is not covered by medical aid or by government services, so for most families it is out of reach. Some wait years for a diagnosis. Genetic conditions such as Leber congenital amaurosis and Stargardt Disease affect people from infancy to

adulthood, and our campaign follows three real stories across that range: a baby, a child and an adult.

What Giving Tuesday funds

Gifts to the campaign help fund genetic testing, counselling and support for people living with inherited retinal conditions. Any amount helps, and giving is open now. You do not have to wait for 1 December.

How can you help

1. Give. Donate **HERE**
2. Share. Please pass this article to a colleague and share our Giving Tuesday posts with your networks. Use #YourRandTheirSight #GivingTuesday #GivingTuesday2026
3. Refer.

If you see patients or families who could benefit from genetic testing, counselling or peer support, please put them in touch with Retina South Africa.

Thank you for standing with the families who are waiting for answers.

Read more about Giving Tuesday

PEER SUPPORT

New WhatsApp group for people with AMD

Send your name and mobile number to **083 306 5262** to join.

Other WhatsApp groups for peer support: Adults with RD, Youth 16+, Parents of RD children, Stargardt Parents and Work Seekers.

Connect with us

YouTube | **Facebook** | **Instagram** | **LinkedIn**

Contact us

For support, advice and referral to service providers:

WhatsApp: **082 074 7116**
Office: **+27 11 450 1181**
Email: **headoffice@retinasa.org.za**
Website: **www.retinasa.org.za**

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Nuture Vision **Eye Health with Marigold Extract** capsules contain three carotenoids: lutein, zeaxanthin and meso-zeaxanthin. It was developed for people who spend long hours on screens, and for older adults.

Lutein and zeaxanthin are found naturally in the macula, the part of the retina we use for sharp, central vision. They're also found in foods such as spinach, kale and egg yolks.

The formula is designed to:

- support eye comfort during long hours of screen time
- help reduce eye fatigue from artificial lighting
- support clear, comfortable vision
- help protect the macula against oxidative stress

Each capsule contains 10 mg lutein, 2 mg zeaxanthin and 10 mg meso-zeaxanthin, sourced from marigold extract, in a vegetable capsule.

Find out more at nurturevision.co.za

This is a paid sponsorship. Supplements are not a treatment or cure for inherited retinal conditions. Please speak to your eye care professional or doctor before starting any supplement, especially if you take medication or have a medical condition.

CONTACT US

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