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## **WORLD RETINA WEEK 23-29 SEPTEMBER**



## **LOVE YOUR EYES - KIDS**

Retina South Africa supports the theme for World Sight Day – October 10th, **Love your Eyes - Kids**. Our focus is the alarming increasing rate of Myopia [short sightedness] in children caused by excessive screen time and we are encouraging parents to use World Retina Day – September 28th as a screen free day for their families. The dangers of the blue light emitted by digital screens are also concerning. We are appealing to parents to encourage at least 2 hours outdoor play or activity every day. Untreated myopia is causing irreversible retinal damage globally, and in an increasingly younger population. Consult your eye care professional.

We at Retina South Africa are deeply concerned about the dramatic increase in myopia in children and the risk of permanent damage to the eyes.

[READ MORE](#)

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## ANNUAL GENERAL MEETING

The 2024 AGM was held on July 27th at Sami G Office Square, Wilbart.

The well attended meeting was a hybrid one with members and guests both in the room and online via Zoom. Chairman Manny Moodley presented a very encouraging annual report and the Treasurer, Jean Bowler presented the most favourable financial report since the Covid Pandemic. Karen Denton, Head of Advocacy and Awareness was the MC and she also organised a fun spin and win competition. Top prizes of electronic visual devices were sponsored by Sensory Solutions who also displayed their latest devices. Also on display was the amazing Onyx reading device presented by Sir Nicholas and Jeanne Rose. This device has shown amazing results for people with central vision loss.



Pictured: Delegates at the AGM Meeting



Pictured: Left to Right: Manny Moodley, Karen Denton and Jan Bowler



Pictured: Left to Right: Lindsey Engelbrecht, Manny Moodley and Karen Denton

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## SOUTH AFRICAN OPTOMETRIC SOCIETY CENTENNIAL



Pictured: (Left to Right) Nivien Subramany (SAOA), Manny Moodley, Claudette Medefindt

We hosted a very successful awareness table at this important congress and met dozens of practising Optometrists and trade representatives. As at every congress networking allows you to rekindle old contacts and foster new friends.

At the Gala dinner Retina South Africa was honoured with 3 special awards as Friends of the SAOA for 26 years of collaboration. One award for the organisation and a personal one to our Chair, Manny Moodley and one to Claudette Medefindt. Thank you SAOA.

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# SAVE OUR SIGHT CAMPAIGN



## A Big Thank You.

Thank you to everyone who supported our cash prize draw of R500 per draw. Members who paid their annual fee before the end of June received a free entry. Six draws have already taken place, with six more to go. We will be starting a new round of this competition in early January.

If you would like to enter, please use the Shop Tab on our website, select the SOS Campaign, and donate R250 per ticket, or click on the BUY NOW button below. Submit your details to be included in the draws for 2025.

BUY NOW

Members of Retina South Africa who pay their 2025 membership fees by March 2025 will receive a free entry starting January 1st and will be eligible for the 2025 draws. Please ensure that the payment is clearly marked as fees for 2025.

MEMBERSHIP FEES

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# DIS-CHEM FOUNDATION SWING FOR SIGHT



The Dis-Chem Foundation Swing For Sight 2024 golf day, held on Tuesday 3rd September, at the Royal Johannesburg Golf West Course, was a tremendous success. An amazing R212,000 was raised in support of Retina South Africa's mission to fight blindness. With 136 players and approximately 35 sponsors, the event featured celebrity participants, exciting challenges, and a para golf team.



The enthusiasm, support, energy and dedication of the management and staff at Dis-Chem Pharmacies and Foundation ensured the

event's success. Highlights included Protea Cricketer Temba Bavuma winning both the Nearest to the Pin challenge (African Hills Safari Lodge Weekend) and the Pink Ball Challenge (A Boat Cruise).

Special guests like Danny K and top executives from Dis-Chem added to the prestige, while para golfers, all visually impaired, from Retina SA participated with their guides, making it a truly inclusive event. Huge thanks to Works Group for sponsoring golf shirts for all players. Thank you Dis-Chem, sponsors and players for taking us one step further in our quest to eliminate retinal blindness.

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## PARA LAWN BOWLS

There are still places left for this fun event to be held on Sunday October 6th at the Edenvale Bowling Club. In the world of para sports, lawn bowls is one of the sports where inclusivity, skill, and determination allows partially sighted people to excel. Our own superstars Linsay Engelbrecht and Mariza Jurgens will be in attendance, but this event is designed for everyone experienced bowlers or novices, whether fully or partially sighted.

[READ MORE](#)

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## WORLD RETINA DAY SPECIAL EVENT

World Retina Day is being observed on Saturday 28th September. To celebrate we are having a Spin for Sight at the Bryanston Virgin Active Sports Club. The event is powered by the [Specialist Eye Centre](#) and supported by [Virgin Active Bryanston](#). Please join us.



[BOOK NOW](#)

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## GET EDUCATED

Karen Denton is our head of Education and Awareness and a skilled educator. Catch her Back to Basics mini webinars on a journey to learn about vision and retinal degeneration.

[LISTEN HERE](#)

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## RETINAL REALITIES PODCAST



For Podcast fundies. We've just recorded the 21st episode of our series, Retinal Realities, featuring author Lee-Anne Hunt. In this episode - Navigating Blindness with Grace, Sonya Lee Mahabeer chats with Lee-Anne about her book, "What Every Blind Person Wants You to Know", offering valuable insights for families and employers alike.

EPISODE 21

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## RESEARCH NEWS

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

### AGE RELATED MACULAR DEGENERATION (AMD)

#### AMD AND YOUR DIET

The role of nutritional factors in the transitioning between early, mid and late stages of AMD are being studied.



A report was recently published in the American Journal of Clinical Nutrition by Professor Johanna Seddon. Dr Seddon has been studying retinal disease and nutrition for many years. This report shows a significant benefit from the inclusion of leafy green vegetables, other foods also high in Lutein and Zeaxanthin, and Omega 3 fatty acids.

### **READ FULL REPORT HERE**

[The Role of Nutritional Factors in Transitioning between Early, Mid and Late Stages of Age-Related Macular Degeneration: prospective longitudinal analysis](#)

## **NEW TREATMENT TARGET FOR AMD**

In Wet AMD new blood vessel growth [neovascularisation] is often accompanied by the growth of fibroblast cells which produce collagen and other proteins. These cause scarring [fibrosis]. Professor Yuqing Huo, at Medical College of Georgia's Vascular Biology Center has published a paper showing how this process could be blocked reducing the growth of these rogue blood vessels.

[FULL ARTICLE](#)

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## **NEW APPROACH FOR AMD**

Clinical trials for a new treatment for dry AMD have been announced.

This approach involves the use of light therapy (Lumithera Valera Light Delivery System).

In a small trial of about 100 participants, 55% were found to have an increase in vision of at least five letters on the eye chart. The group receiving light therapy did not develop more Drusen (waste deposits found in the retinas of people with AMD) in the eye compared with a

similar number of people in the control group. It is hoped that further trials utilising this new approach will continue to give promise for better vision for the many people with dry AMD.

READ MORE

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## RETINITIS PIGMENTOSA (RP)

OCUGEN have expanded their clinical trial for Retinitis Pigmentosa [RP] and Leber Congenital Amaurosis [LCA].

Seven new study sites have been selected for an extended phase 3 trial for OCU400 treatment for RP and LCA.

Patients need to have a confirmed genetic diagnosis of two mutations in the NR2E3 genes in Recessive RP or a Dominant NR2E3 gene or a Dominant Rhodopsin gene RHO for RP. Patients need to have a BCVA [Best Corrected Visual Acuity] of 20/50 or less or a visual field of less than 20'.

For LCA a genetic diagnosis of the CEP290 gene mutation. Is required. Various other age and health criteria apply.

See also [www.clinicaltrials.gov](http://www.clinicaltrials.gov) or [www.fightingblindness.org](http://www.fightingblindness.org)

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## LCA10 AND USH2A RNA (ANTISENSE OLIGONUCLEOTIDE) THERAPY

Théa has launched a new business unit, Sepul Bio, to continue clinical development of two RNA therapies: Sepofarsen for people with LCA10 caused by the IVS26 mutation in the CEP290 gene, and Ultevursen for people with exon 13 mutations in the USH2A gene. Both therapies, originally developed by ProQR, had shown efficacy

in clinical trials. ProQR made a business decision to leave the ophthalmology space and subsequently licensed Sepofarsen and Ultevursen to Théa.

Retina South Africa is in consultation with Sepul Bio to explore how South African patients can participate in these trials.

## **DO YOU HAVE A GENETIC DIAGNOSIS?**

[CONTACT US](#)

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## **OPTOGENETICS**

### **THREE COMPANIES ARE CONDUCTING CLINICAL TRIALS FOR THEIR OPTOGENETIC THERAPIES FOR ADVANCED RP**

GenSight, Bionic Sight, and Nanoscope have each launched clinical trials for their optogenetic therapies for RP and potentially other retinal diseases. The treatments are designed to provide vision to people who are completely blind from conditions such as Retinitis Pigmentosa and Usher Syndrome. GenSight and Bionic Sight are designed to work by bestowing light sensitivity to ganglion cells in patients who have lost all their photoreceptors. Nanoscope is targeting bipolar cells. All three companies have reported some modest restored vision in their early stage trials.

## **X-LINKED RETINOSCHISIS**

Atsena Therapeutics: People who are affected by juvenile X-linked retinoschisis (XLRS) and their family members, should contact Atsena to share information of:

- Focus groups or patient advisory boards in which you may be able to participate.

- Updates related to an ongoing Phase I/II gene therapy clinical trial for XLRS.
- Surveys to understand the lived experience of individuals with XLRS or caregivers for individuals with XLRS.
- Opportunities to share your story with gene therapy researchers at Atsena.

Email to: [Patients@AtsenaTx.com](mailto:Patients@AtsenaTx.com). Your name and contact information will not be shared with any additional parties. Or visit their website at [www.atsenatx.com](http://www.atsenatx.com).

## CLINICAL TRIALS INFORMATION

Details of 49 clinical trials are listed on the Foundation Fighting Blindness website <https://www.fightingblindness.org/clinical-trial-pipeline>

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## ANTIOXIDANTS SLOW RETINAL DEGENERATION

Professor John Nolan from the Nutritional Research Centre in Ireland gave a superb presentation on vision and nutrition to the Low Vision Centre of learning in August. [https://www.youtube.com/watch?v=\\_mnqxsKhl-8](https://www.youtube.com/watch?v=_mnqxsKhl-8).

Professor Nolans research has focused on the protective effects of Lutein, Zeaxanthin and MesoZeaxanthin on AMD.

**[Editor's note-** Retina Plus has been used by patients with genetic retinal conditions for many years. Anecdotal evidence suggests the same protective effect. Please discuss with your eye care professional]

At Case Western Reserve University and the Cole Eye Institute researchers have studied data from 200 000 people. Some AMD patients took melatonin supplements. Melatonin helps regulate your circadian rhythms – your biological clock that your body uses to



decide when to release hormones and other molecules that affect your health, sleep patterns etc. Melatonin is produced by the body but is often taken as a supplement for insomnia or jet lag. The researchers found that there is a correlation between melatonin and a lower risk of AMD. This may be due to the fact that Melatonin is also a powerful antioxidant. More research is needed to establish the facts, so please speak to your eye care professional.

READ MORE

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## MY SCHOOL/MY VILLAGE/MY PLANET



Pictured: Three boys holding a large MySchool/MyVillage/My Planet Card

We still need your support to grow this income stream. Nominate Retina South Africa as a beneficiary AND remember to swipe your card. Join at any Woolies store or online at [www.myschool.co.za](http://www.myschool.co.za).  
**NO COST TO YOU!**

JOIN NOW

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# **FINDING HOPE AFTER DIAGNOSIS: A FAMILY'S JOURNEY WITH RETINITIS PIGMENTOSA**

At Retina SA, we understand that a diagnosis of Retinitis Pigmentosa or any form of vision loss can feel overwhelming. This heart felt story from one of our patients shows how, through the support of our peer counseling program, hope and a brighter future are possible.

## **PATIENTS STORY**

"Thank you for the Teams meeting with our family. It has completely changed our perspective and given us hope for the future. At diagnosis, my brother was told he had Retinitis Pigmentosa, he was going blind, there was no cure, and nothing could be done. My brother was absolutely devastated. It was only after a second opinion that we felt a bit of relief and found out about Retina SA. It was nice to know that an organisation existed that helps people with vision loss.

The call was amazing. The peer counselor was so patient and accommodating. The presentation was excellent, and we really appreciated the time taken to explain everything, ensuring we understood all the details. We were made to feel comfortable and confident enough to ask questions without feeling stupid for asking. It was a great motivation to know that the counselor had the same disease my brother has, but it has not stopped her from living a full life. That was an extremely powerful realization for us to have, especially because a month ago, my brother thought that, at the age of 36, his life was over. The care and compassion shown to us were remarkable, and the counsellor has helped our family more than she will ever know.

- RB, Durban

This story is a powerful reminder that life doesn't stop with vision loss.  
Our community is here to support you, every step of the way.

**Need support?** Reach out to us for peer counseling, attend one of our upcoming events, or explore how you can connect with others facing similar challenges. You're not alone - hope and help are always available at Retina SA.

## **FREE PATIENT SUPPORT SERVICES**

**ViaTeams, Zoom, WhatsApp or in the Office**

Contact Retina South Africa for individual or family advice, support, counselling, or referral to specialist service providers. Contact the office on [headoffice@retinasa.org.za](mailto:headoffice@retinasa.org.za), call 0860595959 or contact us via our website [www.retinasa.org.za](http://www.retinasa.org.za).



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Tel: +(27) 114501181 | Email: headoffice@retinasa.org.za  
www.retinasa.org.za

Our mailing address is:

Retina South Africa  
2nd Floor, Sami-G Office Square  
80 Greenvale Road  
Wilbart, Germiston,  
Gauteng, South Africa

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