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EDITORS NOTE

Warm greetings, readers!

This is my final letter from South Africa, as I'll be relocating to Poland at the end of the month for four years—exciting times ahead! In this edition, don't miss our Zanzibar raffle, a fantastic fundraising project with a chance to win a trip for two next March. Also, mark your calendars for Retina South Africa's Annual General Meeting on 19 July. Included is an update on the latest scientific research in the retinal ophthalmological field.

Thank you for your continued support—it's a privilege to share this journey with such an inspiring community!

Mariza Jurgens
Editor

ANNUAL GENERAL MEETING

The AGM will be held on 19 July at 10h00 at the Sami G Office Square, Traning Room, 1st Floor, 80 Greenvale Road, Wilbart, Gauteng at 10h00. This is a hybrid meeting.

To attend in person, please reserve your place by **14 July 2025** by emailing: headoffice@retinasa.org.za.

To join via Teams use the following link: http://bit.ly/46do37d

After the business meeting, a panel of experts will answer questions about treatments, clinical trials, genetics, accessibility, Para Sports, lifestyle, nutrition and disability insurance.

The South African National Council for the Blind (SANCB) Assistive Technology Centre (ATC) will showcase cutting-edge assistive technologies designed to enhance independence and quality of life for individuals with visual impairment. Partners of the SANCB ATC will include:

• PDC – demonstrating the innovative SEVA AI Smart Glasses
• AFROTECH – showcasing the advanced Ray-Ban Meta AI Smart Glasses.

Sensory Solutions will also be demonstrating their latest assistive technology and Sanlam will provide information on all aspects of insurance and Wills.

For more details visit www.retinasa.org.za

ACCESSIBILITY PARKING

New National Disability Parking Disc Enhances Access for Visually Impaired South Africans On December 2, 2024

A landmark amendment to the National Transport Act was signed, effective from December 3, 2024, introducing a standardized National Disability Parking Disc across South Africa. This new legislation is a game-changer for persons with visual impairments, as it explicitly includes all individuals with disabilities requiring parking discs—not just those with physical impairments.

For Retina South Africa members, this opens up greater access to accessible parking, fostering independence and ease of travel. Previously, inconsistent municipal parking discs created confusion, with some visually impaired individuals facing challenges in securing recognition.

READ MORE

ZANZIBAR RAFFLE

Your Chance to Win Paradise - And Change Lives

Picture this: toes in the sand, warm island breezes, and seven nights of barefoot luxury at Michamvi Sunset Bay Resort in Zanzibar. Full board. Return flights included. Your own quiet stretch of beach, and sunsets that wash the world away.

Now imagine this:

Every R100 ticket supports the vital work we do to empower people living with retinal vision loss and blindness, through advocacy, para sport development, and community support.

• Tickets are limited (and they're going fast)
• Travel Dates: 21-28 March 2026
• Draw Date: 30 January 2026
• Whether you win or not, your ticket brings someone closer to independence and hope. That's powerful.
• Paradise with purpose - it's one simple choice away

P.S. The raffle is open to the public. Share it with friends, colleagues, and family—we need your help to make this campaign a success!

WHATSAPP GROUPS

Are you a member of one of our dedicated WhatsApp groups? Whether you are a young job-seeker, need a study bursary, or a parent of a low vision child looking for peer support - these groups can help you. Contact us at Headoffice@retinasa.org.za.

RETINAL REALITIES PODCAST

Episode 26: From Canvas to Counselling

Meet Alexandra Makhlouf - Johannesburg-based artist turned aspiring therapist - whose personal journey through vision loss led her to redefine healing through psychology. In this moving episode, she opens up about mental health, disability and the power of art and connection.

Do you have an inspiring story to tell, please contact us.

Please follow Retinal Realities on **Facebook**, **Instagram** or **Twitter** to stay informed when a new episode is posted.

The Retinal Realities Podcast is also available on the Retina SA YouTube Channel **@RetinaSA** under playlists.

Please like and subscribe!

RESEARCH NEWS

By Claudette Medefindt

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

CRISPR EDITING SAVING LIVES

Meet KJ Muldoon, an American baby who received the first personalized CRISPR gene editing therapy, to treat this rare disease- Carbamoyl Phosphate Synthetase 1 [CPS1] Deficiency.

This disease is caused by a mutation that leads to toxic and fatal build-up of Ammonia in the blood. KJ was too young for a liver transplant and so the amazing medical team at the Children's Hospital of Philadelphia [CHOP] set out to find a treatment and save this young boy's life.

They identified the gene, personalised the gene editing procedure and obtained registration within six months - a task that normally takes years. At seven and eight months old he received two treatments of the CRISPR base editor bound to a very specific targeting guide sequence using lipid nanoparticles (LNPs). Two months after the second infusion, KJ went home for the first time with his parents after almost a year in hospital. His progress is being carefully monitored.

Photo Source - Inside Precision Medicine

READ THE FULL ARTICLE

WHAT THIS MEANS FOR RETINAL PATIENTS

Opinion piece by Claudette Medefindt

The article above shows the power of personalised medicine - a treatment designed for a specific gene mutation. With over 300 gene mutations causing various forms of retinal degenerative conditions, it is highly unlikely that this will become a reality for all the genetic variants. However, many rare and severe retinal conditions are in advanced clinical trials. A “Stop the Loss” approach may become a necessity for many other conditions.

The rules of the regulatory bodies such as the FDA in the USA is also being discussed and more realistic endpoints must be considered. The recent failure of the LUMEOS Phase 3 clinical trial by Johnson & Johnson shows that a new approach maybe needed. This phase three clinical trial tested botaretigene sparoparvovec (Bota-vec), a gene therapy to treat X-linked Retinitis Pigmentosa (XLRP) caused by mutations in the RPGR gene. The trial failed to meet the primary endpoint of improving vision-guided mobility. However, secondary endpoints showed improvement, with 22 out of 55 treated patients benefiting on multiple endpoints. Johnson & Johnson is “evaluating the clinical relevance of secondary endpoint improvements and considering strategic options for Bota-vec.” A new phase three trial would need a huge additional investment for any Pharma company wishing to pursue this promising intervention. We sincerely hope that Bota-vec does not end up discarded, like many other promising interventions over the years.

FULL ARTICLE

STOP PRESS

Endpoints News has just published an article on this subject, with impactful patient contributions, with input from Retina International SMAB Co-Chair, José-Alain Sahel (pictured right - source Endpoints News.)

SMAB Co-Secretary, Dr. Rachel M. Huckfeldt, and Foundation Fighting Blindness [USA] CEO, Jason Menzo.

The article is titled: **Advocates urge J&J to 'put everything on the table' for gene therapy despite failed trial.**

It includes a moving story of rescued vision by a recipient of the intervention in the trial. Patients, researchers and advocates are imploring J&J to apply for approval of the gene therapy known as bota-vec.

"Before Johnson & Johnson gives up on that, they should discuss with the FDA," said José-Alain Sahel, chair of the ophthalmology department at the University of Pittsburgh. "They should put everything on the table."

For the full article, register on End Points News.

REGISTER

NEW GENE FOUND

A NEW TYPE OF USHER SYNDROME?

Variants in the AGBL5 gene have been connected to autosomal recessive Retinitis Pigmentosa [RP] with hearing loss. This article was published in the European Journal of Human Genetics (2025) 33:727 – 737.

JUST ONE CHILD

Leber Congenital Amaurosis [LCA], is a group of serious, early onset Inherited Retinal Degenerations [IRD]. The RPE 65 variant is treatable by the gene replacement therapy marketed by Luxturna. This is extremely expensive and is not available in South Africa. Another rare form of LCA, LCA4 is caused by a mutation in the AIPL1 gene. This ultra rare LCA is being successfully treated in the UK. Babies with LCA4 have a small central island of photoreceptors at birth, that may be rescued by a gene replacement therapy during the first few years of infancy. This small window closes after the age of four and then vision is totally lost. Retina South Africa estimates that there may be a handful of young LCA4 children, in South Africa, under the age of three eligible for this sight saving intervention.

We need to find these few precious babies that have the AIPL1 gene. Can you help us find them?

The early symptoms of LCA are:

- Severe vision loss at birth.
- Nystagmus [Jerky eye movements],
- Sluggish or near-absent pupil responses to light,
- Extreme light sensitivity [photophobia].

Can you help us find them?

CONTACT US

TIME IS RUNNING OUT

Retina South Africa is collaborating with the University of Cape Town to offer members of Retina South Africa, a 40% discount on the costs of genetic testing. The test will cost R6000 including the cost of the Oragene saliva kit but excludes genetic counselling costs. Kits must be ordered and returned to Retina South Africa by the end of July. Genetic counselling is required prior to testing and costs are usually re-imbursed by medical aids.

Contact denise@retinasa.org.za for a referral.

The progress towards registration of the drug, Tinlarebant, to treat Stargardt Disease, makes genetic testing an urgent necessity for young people with this condition. Only those with a confirmed ABCA4 genetic test result will benefit from this treatment.

CLINICAL TRIALS UPDATE

Retina – International publishes an excellent list of current clinical trials.

CLINICAL TRIALS

Nurture Vision's Premium Omega-3 for Visual Clarity and Everyday Vitality

At Nurture Vision, we believe in holistic wellness, starting with scientifically backed nutrients that support both eye health and overall wellbeing. Our Premium Omega-3 supplement is specifically formulated to deliver a therapeutic daily dose of 2000 mg of fish oil, containing 810 mg of EPA and 612 mg of DHA. These essential fatty acids are well-established in clinical research for their ability to reduce inflammation, support retinal integrity, and relieve dry eye symptoms.

DHA plays a vital structural role in the retina, while EPA helps regulate inflammation and promotes healthy tear film stability; making this an ideal solution for those facing screen fatigue, dry eye, or early signs of visual strain.

But the benefits go far beyond vision. Omega-3s also contribute to heart health, cognitive function, joint flexibility, skin health, and mood balance; making this supplement a smart, all-round addition to your daily health routine. Nurture Vision Omega-3 is sugar-free, free from heavy metals and contaminants, and manufactured to the highest international quality standards. Whether you're safeguarding your vision or supporting your overall health, Nurture Vision's Premium Omega-3 provides a trusted, all-in-one solution for daily, long-term wellness.

Retina South Africa Disclaimer

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