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Welcome to the inaugural edition of Retinal Insight, Retina South Africa's dedicated newsletter for eye care professionals. We are excited to establish a vital channel of communication that bridges clinical practice with the latest advancements in retinal care and support.

At Retina South Africa, our mission has always been to support research, to advocate for better services for retinal patients and to ensure counselling and support services empower patients and improve their quality of life. Through Retinal Insight, we aim to deepen your understanding of our multifaceted role and to collaborate with you to improve the patient journey and ensure equal access to clinical trials and ensuing treatments.

In addition, this twice-yearly newsletter will keep you abreast of cutting-edge developments in retinal research, including updates on emerging therapies, genetic discoveries, and global clinical trials. Whether it's breakthroughs in gene-editing technologies or new trials for conditions like Stargardt Disease and Retinitis Pigmentosa, our goal is to equip you with timely, actionable information that can enhance patient outcomes.

We invite your feedback and contributions to future issues. Please share your thoughts or suggest topics.

Warm regards,

Claudette Medefindt

Head of Science | Retina South Africa

Exciting News on Retinal Research

BREAKING NEWS!!!

STEM CELL CLINICAL TRIAL

A clinical trial sponsored by Sumitomo Pharma America, are enrolling individuals with Retinitis Pigmentosa (RP) in Massachusetts and Minnesota, USA.

This trial will test the implantation of DSP-3077, a retinal sheet derived from Induced Pluripotent Stem cells (iPS cells) generated from a donor, as a potential treatment for RP. The primary objective of the trial is to evaluate the safety of the one-time surgical procedure into the sub retinal space.

This is a gene agnostic trial for Americans with a clinical diagnosis of RP who have BCVA in the worse eye between hand motion level and approximately 20/200. They will require follow up for 5 years. Issues such as connectivity and rejection will be closely monitored.

Although South African patients are not eligible at this stage this research could help advance and improve future care for all RP patients.

[READ MORE](#)

Support Your Patients with Retina SA

We provide a needs-based support and referral system for patients with all retinal conditions, ensuring they receive the care and resources they need. Our services include:

- Psychosocial Support: Counselling to address emotional and mental health needs.
- Workplace and Education Support: Interventions to enhance accessibility and accommodation.
- Mobility and Technology Training: Guidance on adaptive tools for independence.
- Genetic Testing: Facilitation to a genetic diagnosis, to ensure access to gene specific trials and ensuing treatments, and to engender informed reproductive choices.
- Peer Support: Connecting patients with others facing similar challenges.
- Digital Reading Solutions: Tools to improve access to information.

Who to Refer:

Patients with Diabetic Retinopathy, Age-Related Macular Degeneration (AMD), Retinitis Pigmentosa, Stargardt Disease, Usher Syndrome, Cone/Cone-Rod Dystrophy, Achromatopsia, or other Inherited Retinal Diseases (IRDs).

How to Refer:

Download the free VULA App (available on all app stores), register with your HPCSA or practice number, select Retina SA, and submit patient details. It's quick, secure, and ensures your patients get comprehensive care. Start referring today!

VULA APP QUICK GUIDE

WHY Your Referral Makes a Difference

- **Unlocking New Treatments:** Genetic testing connects patients to life-changing clinical trials and therapies. We facilitate testing for both private and low-income families.
- **Access to Clinical Trials:** Our growing registry ensures patients are considered for cutting-edge trials, offering hope for better vision.
- **Driving Change:** Our privacy-protected patient registry—the only one of its kind in South Africa—powers advocacy and influences policies to improve retinal care.

Special Offer: Affordable Genetic Testing

In collaboration with the University of Cape Town and an international Institute, we offer advanced genetic testing (Next Generation Sequencing) for all inherited retinal disease genes at R6000—a 40% discount. This test identifies specific genetic mutations, opening doors to personalized treatments. Limited sponsored slots are available for low-income patients. Act now—offer ends 15 September 2025! Contact: denise@retinasa.org.za

URGENT: Help Children with LCA4

We have a rare opportunity to treat children under four with Leber Congenital Amaurosis (AIPL1 gene mutation), a severe retinal condition causing blindness. Early referral can connect these children to potentially sight-saving therapies. Please refer eligible patients immediately via the VULA App. Queries to claudette@retinasa.org.za

Exciting Updates In Retinal Research

Stay informed about breakthroughs that could transform patient care:

- Belite Bio's Tinarebant has FDA Breakthrough status, with Phase 3 trials showing promise. Encourage genetic testing to confirm ABCA4 mutations for trial or treatment eligibility for Stargardt or Cone – Rod patients
- Ocugen's GARDian3Trial (OCU410ST) targets Stargardt disease, reducing lipofuscin deposits in the retina for better outcomes.
- Retinoschisis: Atsena Therapeutics' ATSN-201 trial now expanded to Phase 1/2/3. This combination approach reduces trial time and may fulfil registration criteria.
- Usher Syndrome: Anew genetic discovery links AGBL5 variants to retinitis pigmentosa with hearing loss, potentially identifying a new Usher subtype (Eur J Hum Genet, 2025;33:727–737).
- CRISPR Breakthrough: First personalized gene-editing therapy successfully treated a child with CPS1 deficiency [metabolic disease] - highlighting the future of gene editing medicine.

Clinical Trials Update

Foundation Fighting Blindness publishes an excellent list of current clinical trials.

[CLINICAL TRIALS LIST](#)

World Retina Week: 21-28 September 2025

Theme: Love Your Eyes, Test Your Eyes

Retina South Africa in collaboration with Vision Works, and the SA Optometric Association are promoting free vision screenings during World Retina Week and Eye Care Awareness month.



Participating optometrists www.vision-works.co.za and info@saoa.org.za will use fundus cameras to identify at-risk patients and refer them to ophthalmologists for specialized care.

**Stay Connected with Retina South Africa for the latest updates on retinal care,
patient stories, and research breakthroughs**

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