

## **RETINA SOUTH AFRICA**

### **Chairperson's Report: Annual General Meeting, 19 July 2025**

**Delivered by Mariza Jurgens**

**Good morning, esteemed members, staff, and supporters of Retina South Africa. As Chairperson, I am deeply honoured to present the 2024–2025 Chairperson's Report at today's Annual General Meeting.**

**This year has been a transformative one for Retina South Africa, defined by significant achievements and strategic advancements to secure our future. I assumed the role of Chairperson three months ago, following the appointment of our former Chairperson, Manny Moodley, as CEO. Manny, a Stargardt's patient and member since age eight, who brings unparalleled insight to his new role, reinforcing our commitment to being a patient-led organisation. Sonya Lee Mahabeer stepped into the role of Deputy Chairperson, and together, we have addressed succession planning for our long-serving Management Committee, a key pillar of our risk mitigation strategy.**

#### **Fundraising Success**

**Our fundraising efforts have reached new heights this year, driven by the appointment of Linsay Engelbrecht as Events Manager. Traditional events such as the Golf Day and Ride for Sight were complemented by new initiatives, including Ride Joburg, Bowls for Sight, a festive raffle, and the innovative Zanzibar raffle, generously sponsored by our founding Chairperson, Gordon Cousins, whose continued support we deeply value. These efforts increased our events fundraising income from R700,000 in 2023–2024 to between R1.1 and R1.2 million this year. With Linsay's momentum, we are confident in surpassing these figures in the coming year.**

#### **Enhanced Patient Services**

**We have strengthened our patient services with the addition of Lizzie Rankapole, a health worker sponsored by African Tikkun. Lizzie's internship, concluding in September, has been invaluable, and we aim to sustain this partnership. Our social workers and counsellors provide invaluable counselling and support to around**

**400 patients annually and we have had 89 new members join since September 2024.**

### **New Staff**

**Magda van der Merwe, with over 30 years of banking experience, has joined to manage raffle registrations, trust applications, and compliance, and fund allocation. Her role supports our Treasurer, Jean Bowler. Natley Reddy serves as Personal Assistant to the CEO and handles general administration, further bolstering our operations.**

### **Grant Achievements**

**A landmark R1.8 million grant from the Chan Zuckerberg Initiative has propelled our work on inherited retinal conditions and modernised our operations. This funding is updating our website, last refreshed in 2014, and upgrading software, hardware, and cloud services, with additional support from Microsoft and TechSoup for cybersecurity and patient database enhancements. Other grants include R100,000 from Japan's Rare EAS Grant, funding from the National Lotteries Commission, and ongoing support from Bayer and Roche. A grant from Costello Medical will enhance our marketing materials, improving social media engagement, podcasts, and our forthcoming dynamic website.**

### **Global Advocacy**

**Retina South Africa has amplified its global presence. Manny represented us at Roche International's patient board meeting in Rome, in June, advocating for expanded retinal treatments across Africa, where we remain the continent's only retinal patient organisation. I attended the World Health Organization's Technical Advisory Group meeting in Geneva, contributing to the upcoming update of the assistive technology products list, which will benefit our patients.**

### **Communications**

**Our newsletters have expanded from four eNews editions annually, to twelve annual editions with the introduction of eight Out of Sight editions, supported by a new sponsor, Neutrogena, enhancing member engagement. A monthly SMS to members also enhances our member contact. The old share call number has been replaced**

with a WhatsApp number to facilitate improved member communication.

### **Research Advancements**

We invested over R500,000 in retinal research at the University of Cape Town this year, supporting cutting-edge scientific work. Three key projects stand out:

1. A new gene identified in the U.S. 18 months ago showed a 30% positive result for retinitis pigmentosa in individuals of black ancestry. Our pilot project, testing 32 DNA samples in South Africa, yielded only one positive result. This is probably due to genetic variances between Northwest African populations arriving in the U.S. and the historical migration of Central/Southeast African populations to the south. This gene mutation has been added to UCT's Next Generation Sequencing panel for ongoing tracking.
2. A UK-based genetic treatment for a rare form of Leber Congenital Amaurosis (AIPL1), affecting approximately three newborns annually in South Africa, is under focus. We are raising awareness among paediatricians and ophthalmologists to ensure early identification, genetic testing, and access to sight-saving treatment before age four, when the treatment becomes ineffective.
3. We are promoting awareness of Tinlarebant, an oral drug showing promising results in clinical trials for vision protection in young people with Stargardt Disease with an ABCA4 mutation, nearing registration.

### **Patient Outreach**

Our patient services division delivered a successful week-long outreach in KwaZulu-Natal, engaging patients, caregivers, and eye care professionals. Supported by the Chan Zuckerberg Initiative, we will expand this initiative, starting in the Western Cape in September. The Management Committee appointed Caryl Baum to represent Retina South Africa on the Consumer Committee of the South African National Council for the Blind, ensuring better

**access to consumer goods for individuals with low vision and blindness.**

**Gratitude and Transition**

**I extend my heartfelt gratitude to the Management Committee—Deputy Chairperson Sonya Lee Mahabeer, Secretary Claudette Medefindt, Treasurer Jean Bowler, and all members- for their unwavering commitment. My thanks also go to our exceptional staff and members for entrusting me with this role. As I relocate to Warsaw for my husband's new diplomatic placement, I am confident that the incoming Chairperson will receive your full support to continue this vital work.**

**Thank you.**