



FESTIVE MESSAGE FROM THE CHAIR

From everyone at Retina South Africa, we'd like to say thank you for your continued support and faith in us during 2022.



Manny Moodley

We have undergone some restructuring and have updated our board and subcommittee strategies in order to operate more efficiently and deliver an improved service to our members.

We wish you everything of the best for the holidays, and a prosperous new year. We look forward to engaging with you in 2023!

Manny Moodley



DIS-CHEM RIDE FOR SIGHT

Date: 19 February 2023

Boksburg City Stadium

Thanks to Dis-Chem Pharmacies for once again sponsoring this, our premium fund-raising event. This will be the 34th edition of this popular road cycling event.

Thanks to all our sponsors and key volunteers, we know that a bumper edition will be staged. Contact us for more details.

SWING FOR SIGHT

Date: 6 September 2022

Venue: Royal Johannesburg and Kensington Golf Club.

Thank you, Dis-Chem Foundation, for sponsoring our golf day which was a huge success. A sold-out field with wonderful sponsorship and prizes ensured a truly successful event. Congrats to Linda Vogel, our super-efficient administrator and volunteer Sharon Morrison for superb organisation.



Winning Team: Ascendis Health

Special thank you to Yvette Steward from Dis-Chem and all sponsors, players and volunteers for their support.

SUB COMMITTEES

The Sub Committees have been established and they meet regularly. Their fresh perspective promises changes in many aspects of our work. The Sub committees are as follows: Administration, Advocacy, Education and Awareness, Fund Raising, Governance, Marketing and Media, Patient Services and Science. We also welcome input from our members. Email head office.

The Marketing and Media and Awareness Sub Committees are working together to improve awareness of the many facets of Retinal Vision loss using digital marketing platforms. A grant from Roche has made this new initiative project possible. We have registered a Podcast platform and will use our established YouTube channel to promote these messages. The podcasts will be around 12 minutes long and the videos around 20 minutes.

Do you have a story to tell?

Please contact Claudette on WA 0833065262., or email a short outline of your story to <mailto:headoffice@retinasa.org.za>

PLEASE PARTICIPATE

An international survey to explore the experiences of female carriers of X Linked Retinitis Pigmentosa [RP] or Choroideremia is being conducted by the Centre for Eye Research at the University of Melbourne in Australia.

Female carriers, mothers, sisters or daughters of males affected by these conditions may or may not exhibit symptoms relating to the respective condition. However, there is a risk they may pass the disease-causing gene to their children. There are two questionnaires for this research study: the first survey aims to gather more information about your opinions and knowledge relating to being a female carrier of an X-linked Inherited Retinal Disease; the purpose of the second questionnaire is to understand any effects being a carrier has on your vision and overall lifestyle.

Please assist by clicking here:

<https://tinyurl.com/carriervisionandlifestyle>

RETINA INTERNATIONAL (RI) AMD IMPACT STUDY



RI have published their excellent study on the socio-economic impact of age-related macular degeneration (AMD) in Bulgaria, Germany and the USA.

See the full paper. <https://retina-international.org/amd-impact-cost-of-illness-study/>

RESEARCH NEWS

SYNTHETIC RETINOIDS

The amazing neuroplasticity of the brain has been demonstrated by a team of researchers from the University of California. Their research findings were recently published in *CURRENT BIOLOGY* and shows that some adults can partially recover from inherited blindness.

The team found that the use of chemical compounds that target the retina, called synthetic retinoids, can restore a notable amount of vision in children with LCA. The UCI team then discovered that the treatment could make a difference for adults who have the condition.

“Frankly, we were blown away by how much the treatment rescued brain circuits involved in vision,” said Sunil Gandhi, Professor of Neurobiology and behaviour and the corresponding author.

See: the full article here: [UCI team demonstrates the adult brain has the potential to partially recover from inherited blindness](#)

CRISPR/ Cas9

Editas Medicine, Inc., has announced results from a Phase 1/2 clinical trial to use CRISPR gene editing for the treatment of LCA 10, a CEP 290 mutation. The BRILLIANCE trial of EDIT-101, is designed to repair the IVS6 mutation that is estimated to affect 1,500 LCA10 patients in the U.S alone. The update includes safety and efficacy data from all 14 patients treated in the study to date, which includes 12 adult patients and two paediatric patients.

FOUNDATION FIGHTING BLINDNESS INSIGHTS

A recording of the FFB USA Insights Forum held on 10 November 2022, is now available and includes an excellent research update.

[View Recording and Transcript](#)

OPTOBIONICS

Starlight Clinical Trial

Enrolment for this Phase 2 Clinical trial has now been completed. The MCO-010 optogenetic therapy for Stargardt disease has enrolled 6 patients with advanced Stargardt disease. Results from Nanoscope's Phase 2b RESTORE trial in patients with RP, are expected by midyear 2023.

RP 17 RESURRECTED

The Foundation Fighting Blindness [USA] has just awarded a substantial grant to Dr Alison Hardcastle, UCL Institute of Ophthalmology, UK; Dr Susanne Roosing, Radboud UMC, The Netherlands, and Dr Michael Cheetham, UCL Institute of Ophthalmology to Investigate the novel disease mechanism for autosomal dominant RP17 and to explore therapeutic approaches.

The University of Cape Town participated in the original identification of the CA4 gene implicated in RP17. This new project will examine the further structural variants on chromosome 17 that cause RP17. The project is looking for these variants in unsolved RP cases worldwide so that they can help with a clinical diagnosis and identify individuals who could be recruited to a clinical trial as therapies are being developed.

The project will also examine RP17-affected retinas in a dish to understand the impacts of the structural variants. An RP17 mouse model will also be developed for testing a potential therapy.

DIABETIC RETINOPATHY

Study results published in Diabetes Care highlight the importance of maintaining A1c lower than 7% to avoid retinopathy.

“Our study determines accurately the levels of long-term sugar that can avoid complications,” Hans J. Arnqvist, MD, PhD, Professor in the Department of Endocrinology and the Department of Biomedical and Clinical Sciences at Linköping University, Sweden, said in a press release.

“This knowledge can increase a person’s motivation to keep their blood sugar level under control.” *[Editor’s note: If you have a genetic retinal condition, it will not protect you from developing Type 2 diabetes. Have an annual eye check, control your waistline, sugar and red meat intake and have regular exercise]*

CLINICAL TRIALS PIPELINE

Do you know if your specific type of genetic retinal blindness is in clinical trials? Open the link below to see a list of 43 clinical trials from the Foundation Fighting Blindness, USA.

This includes gene therapies, RNA. AON, Gene editing, small molecules, Antioxidants, and other promising interventions.

View the Clinical Trials Pipeline at <https://www.retinasa.org.za/research/clinical-trials/>

Phase 1, and sometimes Phase 2 Clinical Trials are always conducted close to the primary clinic to monitor safety issues. It is only in Phase 2 or 3 that trial organiser's will recruit patients from other sites for a multi- centre trial. This is how we were able to join the Emixustat trial for Stargardt Disease.

If we want to bring more clinical trials to South Africa, we need more patients to register with us who have a genetic diagnosis.

You can also register on the confidential portal <http://www.myretinatracker.org/> that allows trial organiser's to find you.

For more information on genetic testing contact our head office. For more information on clinical trials see <http://www.clinicaltrials.gov/>

ANTI OXIDANT SUPPLEMENTATION

Most researchers agree that oxidative stress is a common pathway for all retinal conditions. Whilst a diet rich in vegetables and fruit will probably be sufficient for healthy retinas, supplementation is now being recommended by many retinal specialists for RD conditions.

Consult your Ophthalmologist and only take supplements that are known not to have an adverse effect on your specific condition. NAC and NACA are in clinical trials for RP conditions.

Occuvite was formulated and tested on patients with AMD and is not indicated for genetic retinal conditions. The locally available Retina Plus is formulated on Retina Complex which showed amazing results in animal models of RP, Usher, and Stargardt Disease. Sadly, the patient trial was discontinued for financial reasons.

THANK YOU

Sincere thank you to all members who paid their 2022 membership fees. Fees for 2023 are due in January. If you are able, please add a donation for research or to subsidise someone who cannot afford membership fees. An invoice for 2023 is attached to this ENews. If you need a fee waiver, please contact Head Office.

We need your help. At NO COST TO YOU please join My School/MyPlanet/MyVillage and nominate Retina South Africa as your beneficiary. Register online at <https://www.myschool.co.za>.

Thank you for your support. Our donation from My School/MyPlanet/MyVillage for October was R3 774.85.

Keep swiping this festive season.

WEBINARS AND SOCIAL MEDIA

Please join our Facebook Group <https://www.facebook.com/groups/27745746726/> or Page <https://www.facebook.com/retinasouthafrica/> to keep up to date on local and international news. Please like and share our Facebook page.

Join one of our WhatsApp groups- Youth, Adults with RD, Parents of RD Children. Contact Head Office for more info at <mailto:Headoffice@retinasa.org.za?subject=Info on WhatsApp Groups>.

Subscribe to our YouTube channel

<https://www.youtube.com/channel/UC54Y69fvfcCrsl8WlIFyIIQ> and catch up on all our great videos.

FREE COUNSELLING SERVICE

Are you a member in good standing? If so, you are eligible for a free personal WhatsApp or Zoom counselling session with condition specific information. E: <mailto:headoffice@retinasa.org.za>

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