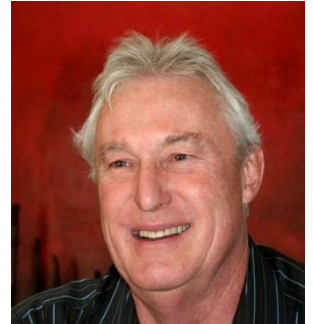




TRIBUTE TO JEFF MATTHEE

Jeff Matthee, Chairman of our Board of Trustees, passed away suddenly on March 6. He was a director of Malherbe, Rigg and Ranwell legal firm for many years and offered Retina South Africa free legal advice for the past 20 years. He was involved with many NPO's, Rotary, rehabilitation services and children's homes. He was an amazing man, kind, generous and incredibly astute. He will be sorely missed. Our condolences to his wife Sally, his children and grandchildren.



Jeff Matthee

DIS-CHEM RIDE FOR SIGHT



The 33rd Dis-Chem Ride for Sight was held on February 20. The event was Covid vaccine compliant with reduced participation allowed. Despite the restrictions a very successful ride was held with 2500 participants.

The winner of the 116km Super Classic was Josh van Wyk and ladies winner was Carla Oberholzer.



Josh van Wyk – 116km
Mens Winner



Carla Oberholzer – 116km
Ladies Winner

Retina South Africa would like to thank our headline sponsor Dis-Chem Pharmacies and the Dis-Chem Foundation.

Thanks to:

- **Sponsors**
 DS – your life demands, Vita-Thion, Transact, Biogen, Unitrans, Vision Works, Youthful Living, DS Omega 3, SugarLean, CycleLab, Michamvi Sunset Bay Resort, MoreCorp, Venter Trailers, Sealy Posturepedic, Moscon Group, Dorhmehl Phalane Property Group, Avon Mitri, Low Vision Care Centre, 2Thai4 Restaurant, Elizabeth Manor Sandhurst, Livall Helmets, KosMos Manor Guest House, Linden Cycles, Summer Place Umzumbe, Pick n Pay Towers, Cycle Events, Bene Spring Water, Tusk Photo, Burnshield, Emperors Palace, Pump Technologies, Levtrade International, Actop Asphalt, Carnival City, Banana Energy Bar.
- **Our loyal cyclists**
- **Rotary and running clubs for their excellent marshalling**
- **Our water table convenors Alida Waldeck for Vision Works , Kgosi Mmoloke for Amandla TM Group, Ella Groenewald for the Heidelberg Ladies, Brian Duthie for the Golden Oldies Hockey Club and Nelanie van den Berg for the Marais Viljoen High School**
- **Our media partner Platinum Gold Radio**
- **Students of St Dominic's, Boksburg for manning the medal tables**
- **Our amazing volunteers**
- **Our organising committee for their professionalism and dedication: Hamnet Emergency Communications, Springs Wheelers, Accident Angels Road Rangers, Dial a- medic, East Rand Cycling, Benoni Red Cross, Arthur and Jean Bowler, Rob van Deventer, Marian Nickless and family and many others**
- **Our wonderful staff and**
- **Our Safety Officer Renier van den Berg who held it all together.**

OSSA Congress 2022



Claudette & Karen at OSSA Congress 2022 – held at Sun City

The 50th Congress of the Ophthalmology Society of South Africa was held at Sun City from 9 – 13 March.

Thanks to RK Communication who kindly sponsored our 2 delegates and an awareness table. Both Karen Denton, Head of Advocacy and Education and Claudette Medefindt, Head of Science gave presentations to the satellite program. Karen spoke on the dual pandemics of Covid and Diabetes and the risks to vision loss and serious health complications, while Claudette promoted

the use of the Vula App for the easy referral of RD patients by the eye care profession.

YOU, DIABETES and YOUR VISION

Retina South Africa has embarked on an awareness initiative to alert the public to the growing danger of Diabetes and the resultant loss of vision and other serious health problems involving heart, liver, kidney, limb amputations etc. This virtual lecture has been given to:

- Social Workers at the Gauteng Department of Social Development
- Health Promoters forums in the Gqeberha area

Various groups of the University of the 3rd Age - a retirement group for active minded seniors

RESEARCH NEWS

Retinitis Pigmentosa [RP]

The biotechnology company Aldeyra Therapeutics has launched a Phase 2 clinical trial of ADX-2191, an intravitreal injection of methotrexate, for people with autosomal dominant retinitis pigmentosa caused by the P23H mutation in the rhodopsin gene. The three-month trial will be held at Duke University USA and will enrol eight patients. Four will receive monthly injections of ADX-2191, and four will receive injections twice each month. The trial will evaluate the safety and tolerability of ADX-2191. Aldeyra plans to report trial results in the second half of 2022.

Battens Disease

Neurogene is to launch a Gene Therapy Clinical Trial for Children with Batten Disease. This will be a phase 1/2 clinical trial for mutations in the CLN5 gene. The company expects to start the trial during the first half of 2022.

Batten disease is a group of genetic, neurological conditions that usually cause a variety of challenging symptoms, including seizures, declines in movement and cognition, and vision loss due to retinal degeneration. Batten disease is usually diagnosed in children and leads to reduced life expectancy. The condition is caused by the inability of cells to break down waste. Lysosomes, which dispose of and recycle waste in cells, and don't function properly in Batten disease, leading to the accumulation of waste products called lipofuscins. About 14 genes, when mutated, are associated with Batten disease. Neurogene's CLN5 gene therapy trial is for children between the ages of 3 and 8. Participants will receive a single injection of the gene therapy to the eye (intravitreal delivery) and a single injection into the ventricles of the brain (intracerebroventricular delivery). The treatment uses a human-engineered adeno-associated virus (AAV) to penetrate

cells with healthy copies of CLN5 to augment the mutated copies. *[Source Foundation Fighting Blindness]*

PROQR- Disappointing Illuminate results

ProQR has published the top-line results from the Phase 2/3 Illuminate Trial of Sepofarsen in CEP290-mediated Leber Congenital Amaurosis 10 (LCA10).

Illuminate did not meet its primary endpoint of Best Corrected Visual Acuity (BCVA) or you might know it as the eye chart, as well as secondary endpoints. No benefit was observed in either sepofarsen treatment arm versus the sham treated control arm. Earlier studies of this RNA therapy were very encouraging.

Daniel A. de Boer, Founder and CEO of ProQR Therapeutics stated “ProQR was founded with the goal of developing RNA therapies for patients with high unmet medical need, and we will continue to advance our robust pipeline of therapies for genetic eye disease. We are deeply grateful to all the participants, their supporters, and investigators who participated in the Illuminate study.”

Possible new pathway to treatment discovered

Researchers at the University of Rochester [USA] may have found a way to revive some vision loss caused by age-related macular degeneration and Retinitis Pigmentosa (RP). The drug disulfiram – marketed under the brand name Antabuse – used to treat alcoholism, may hold the key to restoring retinal vision loss. Michael Telias, assistant professor of Ophthalmology said “We knew the pathway that the drug disulfiram blocks to treat alcoholism was very similar to the pathway that’s hyper-activated in degenerative blindness. We expected some improvement, but our findings surpassed our expectations. We saw vision that had been lost over a long period of time preserved in those who received the treatment.”

In research involving mice, researchers found disulfiram helped restore some vision by suppressing the sensory noise in the inner retina caused by dying photoreceptors in the outer retina that is brought on by the progression of outer retinal degeneration, where the light-sensing photoreceptors slowly die. In past research Telias found that as photoreceptors die off it disrupts the function of the inner retina. This causes the sensory noise that ultimately becomes a barrier between the surviving photoreceptors and the brain.

This latest research, led by Dr Richard Kramer, professor at the University of California, Berkeley, and Dr Michael Goard, Assistant Professor at University of California, Santa Barbara, found that disulfiram can target that sensory noise, allowing the surviving photoreceptors in the outer retina to complete the signal to

the brain and ultimately restore some vision. They found that nearly blind mice, treated with disulfiram, were much better at detecting images on a computer screen.

“Treated mice really see better than mice without the drugs. These particular mice could barely detect images at all at this late stage of degeneration. I think that that's quite dramatic,” said Kramer. “If a vision impaired human were given disulfiram and their vision got better, even a little bit, that would be a great outcome in itself. But it would also strongly implicate the retinoic acid pathway in vision loss. And that would be an important proof of concept that could drive new drug development and a whole new strategy for helping to improve vision.” The researchers are planning to conduct a clinical trial of disulfiram on patients with RP. The trial would be carried out on a small set of people with advanced, but not yet complete, retinal degeneration. Disulfiram does have some severe side-effects if alcohol is consumed while taking it – including headache, nausea, muscle cramps and flushing. But if disulfiram can improve vision, more targeted therapies could be sought that don't interfere with alcohol breakdown or other metabolic functions. The researchers have already tested an experimental drug named BMS 493 that inhibits the receptor for retinoic acid, and they have also used gene therapy to knock down the receptor. Both of these procedures also dramatically improved vision in mice with RP.

New research on Geographic Atrophy [GA]

GA is a severe form of Age Related Macular Degeneration [AMD] that is at present untreatable. Research has established that the complement system, a part of the inflammatory system, goes awry and causes GA.

This has opened possible treatments for GA, and early investigations led to the identification of 3 specific pathways for intervention. Ongoing trials targeting these pathways include:

- **GTA 005**, where successful phase 3 clinical trials for a once off therapy have led to the treatment being fast tracked by the FDA for registration.
- **Danicopan** – from Alexion Pharma. This is one of the many drugs that are being repurposed from one condition to another. Originally used for nocturnal hematuris and is now in a phase 2 multicentre trial for efficacy and safety. This is a treatment in tablet form and results are expected in October 2024.
- **Apellis** have reported mixed results for APL-2, but plan to submit for registration with the FDA later this year.

EASTERN CAPE OUTREACH

EAST LONDON – December 2021

Gail Cillie and Yonela Hofu visited families in East London to conduct pre-test genetic counselling and delivery of results. We would like to thank Dr Cook for providing the Eye Centre as a venue for this outreach.

Also many thanks to UCT Genetic counsellors Malebo Malope and Robyn Barlow for providing this remote service to these patients who do not have access to these critical services.

HANKEY- December 2021

Organised by Gail Cillie, this outreach allowed an Usher family from the rural Eastern Cape to have access to visual acuity tests. These were done to determine their eligibility for inclusion in future clinical trials. Grateful thanks to Optometrist Mr Owen Tomsett who conducted the tests pro-bono.



Optometrist Owen Tomsett conducting a test on a patient

A follow-up trip in January gave social Worker Yonela Hofu the opportunity for counselling and intervention with members while Orientation and Mobility practitioner Lwandisa Davids assessed members for mobility training.

ADDO - December 2021

Social worker Yonela Hofu visited the rural town of Addo where 14 RD families live. Yonela conducted needs assessments for these patients who all have Retinitis Pigmentosa [RP].

Food hampers donated by the National Lottery Commission, and clothing, toiletries and goods donated by several Port Elizabeth families, organisations and companies were also delivered. During a follow-up trip in February Lwandisa Davids conducted assessments and measurements for canes prior to mobility training.

Jeffreys Bay Support Group

This group met in February and will now meet monthly. Mr Maxisolo Daki who is visually impaired gave a presentation on various useful Smart phone APPS. These included Accessibility Keyboard, Money Cash-reader, Tap-tap See, Audio games, a downloading App, mobility and recording App. *[Editors note: a comprehensive list of useful apps is available on our website or at www.sightseekers.co.za]*

UPCOMING EVENTS IN THE EASTERN CAPE

Thursday 28 and Friday 29 April – Queenstown Outreach

Friday 6 May - Nifti 50's Club Jeffreys Bay

THANK YOU TO OUR SPONORS

- Thanks to Assore Mining Group for their support of our patient services project;
- Thank you to the Mary Oppenheimer and Daughters Foundation for their generous support of our Social Worker Program;
- Thank you to the RED Foundation for their generous support of our genetic diagnosis project for young people from needy families;
- Thank you to the Dis-Chem Foundation who matched donations from the cyclists who contributed to donation draw competition and these funds will also go to obtaining a genetic diagnosis for needy youth.

WEBINARS AND COMMUNICATIONS

- Next webinar will be by the Youth group on careers.
Date :March 29 at 18h00. This is a free open access podcast Join via this link: <https://zoom.us/j/91242389969> .
You may remain completely anonymous, and you only need an internet link and Wi-Fi or enough data to join in the hour-long podcast. Presentations will be by people with various forms of RD talking about their career path.
- All our past webinars or podcasts are available on Youtube - www.retinasa.org.za -Tab learn, select webinars or podcasts.

SOCIAL MEDIA

Please join our Face Book Group where job, internships and bursaries are featured regularly. Like or share our Face book page, subscribe to our Youtube page. We need your support.

FREE ZOOM COUNSELLING SERVICE

Are you a fully paid up member of Retina South Africa [or have applied for a fee waiver] If so you are eligible for a free personal Teams or Zoom counselling session with information specific to your condition. E: headoffice@retinasa.org.za

YOUTH GROUP

Would you like to speak to other young people with retinal vision loss? Email youth@retinasa.org.za. They also have a Whatsapp group that you may like to join. Kgosi, Alani, Anoop or Sam will be happy to speak to you.

UPCOMING EVENT IN GAUTENG

We will be holding a Golf Day in August in Ekurhuleni- the first in 20 years, We need your support. Players, prizes sponsors. Can you help? Please contact headoffice@retinasa.org.za. Thank you.

ANNUAL MEMBERSHIP FEE

Annual membership fee of R240 is now due for 2022. Please see your attached annual invoice. If you cannot afford the fee please apply for a fee waiver. This will ensure that you still have access to free services and are able to nominate and vote for Management Committee members. If possible, please add a donation to our RDD research project. For R250 per year you can also join our Circle of Light competition to win a monthly prize of R500. Our Circle of Light competition is approved by the National Lotteries (Scheme Number 00187/18)

Please send any topics that you would like to see featured in this ENews to <mailto:headoffice@retinasa.org.za>

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