September 2023

Volume 51

E- NEWS

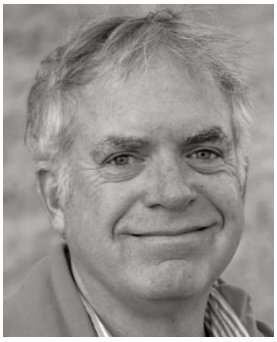
RETINA SOUTH AFRICA

a Cure in Sight for Blindness

CONNECT WITH US

ANNUAL GENERAL MEETING

The 44th AGM of Retina South Africa was held on Saturday 12 August. The meeting was kindly hosted by Bayer SA and remote members joined via Zoom. Manny thanked our excellent guest speakers:



Professor John Flannery, UCLA, Berkley

Elizabeth Louw, Orientation and Mobility

Alani Ferreira – Paralympic Swimmer

Recordings of the guest speaker's presentations are available on YouTube- Retina South Africa, AGM. Manny Moodley chaired a very successful meeting and presented a painting to Bayer to thank them for their ongoing support of our work. The incoming Management Committee are:

Manny Moodley - Chairman

Anton van Rooyen Vice Chairman

Jean Bowler - Treasurer

Claudette Medefindt Secretary

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Caryl Baum

Sonya Lee Mahabeer

Mariza Jurgens

Renesh Singh

SUB COMITTEES WITHIN RETINA SA - An opportunity to get involved.

Applications are now open to members who are keen to join our advisory Sub-Committees.

The various sub-committees are:

- **Advocacy, Awareness and Education**
- **Fundraising and Marketing**
- **Governance and Risk Management**
- **Science and Patient Services**
- **Youth.**

If you would like to be involved fill in this online form. https://forms.gle/RnZm5BHjt8bw4Jhz7. Should you be selected to join a specific Sub-Committee, you are expected to attend a monthly online meeting and make an effort to contribute to the chosen Sub-Committee. Your commitment is key!

RETINAL REALITIES PODCAST SUCCESS

Our Podcast interviews have been very successful. We were rated the no 1 podcast in the category RETINA by the international rating agency, FeedSpot on 4 August.

Congrats to the team involved in the production and a big shout out to all the people who were interviewed. Listen to these short inspirational interviews on Spotify, YouTube or wherever you find your podcasts.

If you have a story to tell, please contact us. The production of Retinal Realities is supported by an educational grant from Roche Products.

SWING FOR SIGHT 2023

The second Dis-Chem Foundation Swing for Sight will be held on Tuesday 5 September at the Royal Johannesburg Golf Club, Linksfield.

The inaugural event in 2022 was a huge success, and we hope this year will be as successful. The bar has been set very high for this year's event.

Organisers Linda and Sharon have been hard at work organising this year's event with the help of the staff at Dis-Chem, a special thanks to Dalya Vosloo Sacks.

We are grateful to our sponsors, Dis-Chem Foundation, for their generous support. Without them, this event would not be possible.

DIS-CHEM RIDE FOR SIGHT 2024

The 35th Dis-Chem Ride for Sight, will be held on 18 February 2024. We thank Dis-Chem Pharmacies for once again sponsoring this important event. Would you like to become involved? Contact headoffice@retinasa.org.za.

COMMUNITY OUTREACH

A very successful awareness and screening day was held at Charlotte Maxeke Academic Hospital CMAH), Johannesburg on June 29th. Vision Works kindly sponsored the retinal screening and over 300 hospital staff and patients queued patiently for advice and free screening. Pictured here are CMAH staff with Karin from Vision Works and Retina South Africa staff – Karen. Lindiwe, Victoria and Claudette.

MAKING WAVES IN THE POOL

We are so proud of Alani Ferreira, Danika Vyncke and Nathan Hendriks for their outstanding performances at the Para Swimming World Championships which were held in Manchester recently.

Their hard work and dedication have paid off and they have achieved some amazing results. Alani won a Bronze medal in the Woman's SB12 100m breaststroke.

We wish them all the best for their future swimming endeavors and qualifying for the Paralympics in Paris 2024.

We know they will continue to make us proud and we look forward to seeing their continued success.

RESEARCH NEWS

AGE RELATED MACULAR DEGENERATION [AMD]

- **NEW TREATMENT FOR ADVANCED AMD**

  IZERVAY has been approved by the FDA [USA] for the treatment of Geographic Atrophy, [GA] secondary to Advanced Dry AMD. Vision loss from GA is caused by the accumulation of toxic deposits underneath the retina called drusen. The approval results from two Phase 3 clinical trials, where the drug slowed the growth rate of lesions in the central retina.

  The company Astellas expects IZERVAY to be available in the USA shortly. The treatment is administered through intravitreal injections, injections made in the soft gel in the middle of the eye, in a doctor's office. IZERVAY is designed to work by inhibiting the C5 protein, which is part of the complement system. Researchers believe that the overactive complement system, part of the body's immune system, is a key culprit in the development of AMD. While the complement system plays an important role in fighting off viruses, bacteria, and other pathogens, it can be damaging when overactive, as in AMD.

  More than 10 million people in the USA and 150 million worldwide have AMD. The treatment may take some time before it is available in South Africa.

- **FDA APPROVES HIGHER DOSAGE OF EYLEA FOR RETINAL CONDITIONS.**

Regeneron has announced that the US FDA has approved 8 mg ocular injections of Eylea® (aflibercept) for the treatment of wet Age-Related Macular Degeneration (AMD), Diabetic Macular Edema (DME), and Diabetic

Retinopathy (DR). The new, higher dose, increased from 2 mg, means that patients require injections less frequently for treatment of these conditions.

Eylea was first FDA-approved in 2011 and is available in South Africa. FDA approval for the new dosing regimen was based on results from two clinical trials that enrolled more than 1,600 patients combined. In the two trials, the new, higher dosing regimen with less frequent injection was similar in safety and efficacy to the previous dosing regimen of 2 mgs every 2 months (after 3 initial monthly doses).

Source of these 2 articles Foundation Fighting Blindness

- **AUTOPHAGY IN AMD**

New research into the role of Autophagy sheds more light on the disease processes in AMD. Autophagy is a protective process that prevents oxidative damage in the eye. A paper by Dr Roberto Pinelli, founder of the Switzerland Eye Research Institute, describes the effect of Autophagy and Blue light in the early stages of the production of abnormal substances in various cells in the retina. The waste products begin as Lipofuscin and eventually form Drusen.

"The seminal role of autophagy in sustaining retinal integrity during AMD is likely to be naturally induced by long wavelength light pulses and light-sensitive phytochemicals, which in addition to maintaining retinal structure and visual acuity, also counteract retinal degeneration," Dr Pinelli said "Light and Photobiomodulation are the new horizons for treating AMD and reveal a new way to consider retina management."

Source - Ophthalmology Times Europe July/August 2023

- **PHASE 3 TRIAL FOR GEOGRAPHIC ATROPHY**

Belite Bio, a biopharmaceutical company developing therapies for retinal degenerative diseases, has dosed the first patient in its Phase 3 PHOENIX clinical trial of Tinlarebant for the treatment of geographic atrophy (GA), the advanced form of dry AMD. The global, placebo-controlled PHOENIX trial will enrol approximately 430 people with GA. Patients will be evaluated for two years.

Tinlarebant is an emerging oral medication designed to slow vision loss by reducing the growth rate of lesions, areas of retinal cell loss, associated with GA, a leading cause of blindness in people 55 and older, and Stargardt disease, the leading form of inherited, early-onset macular degeneration. See below.

STARGARDT DISEASE

- **PHASE 3 CLINICAL TRIAL OF TREATMENT TO SLOW STARGARDT**
  Belite Bio, is enrolling adolescent patients (ages 12-18) with Stargardt disease in DRAGON, its Phase 3 clinical trial for Tinlarebant, an emerging oral medication designed to slow disease progression and vision loss.

  Tinlarebant is designed to inhibit a protein known as retinol binding protein 4 (RBP4) to reduce the uptake of vitamin A to the retina, thereby decreasing the production and accumulation of toxic Vitamin A byproducts, which are the hallmark of Stargardt disease.

- **ENCOURAGING RESULTS IN STARGARDT CLINICAL TRIAL**
  The biotech company Alkeus is conducting a multi-centre Phase 2 clinical trial for a drug (ALK-001) that targets the toxic build-up in the retina that is thought to cause degeneration and vision loss. The therapy slowed lesion growth by about 30 percent in earlier trials. The emerging therapy is a modified form of vitamin A, which, when metabolized in the retina, results in much less waste. Scientists developed ALK-001 by replacing hydrogen atoms in vitamin A with deuterium. Known as deuterated vitamin A, it "burns cleaner" than the natural form. Deuterium is a safe, naturally occurring, stable form of hydrogen, which is present in the human body.

  Source- Foundation Fighting Blindness

- **Nanoscope Therapeutics recently announced results of their Phase 2 STARLIGHT clinical trial at the American Society of Retina Specialist in Seattle, USA. Results for MCO-010 in treating Stargardt Disease.**
  Key results from the STARLIGHT clinical trial:

  Patients treated with MCO-010 demonstrated clinically meaningful improvements in best-corrected visual acuity (BCVA)

  A gain in visual sensitivity, as measured by Octopus visual field perimetry.

  No serious adverse events (SAEs) were observed in patients treated with MCO-010 in this study.

RETINITIS PIGMENTOSA

PYC Therapeutics, an Australia-based developer of RNA therapies, has launched a Phase 1 clinical trial for its RNA therapy known as VP-001 for people with Retinitis Pigmentosa 11 (RP11) which is caused by mutations in the gene PRPF31. The 20-person clinical trial is taking place in the US and the first patient was dosed at the Retina Foundation of the Southwest in Dallas. VP-001 is administered through an intravitreal injection. Investigators will be evaluating safety as well as a number of measures of retinal structure and visual function.

"We are delighted to initiate a clinical trial of the first therapy specifically for RP11 patients," says Sri Mudumba, Ph.D., Chief Research and Development Officer at PYC. "We believe our innovative RNA therapy and delivery technologies are ideal for targeting inherited retinal diseases. These conditions are a critical unmet need." PYC has reported that approximately 1 in 100,000 people have RP11. That equates to nearly 80,000 people affected worldwide.

PYC's emerging therapies are designed to modify RNA, the genetic messages that cells read to make the proteins which are critical to the health and function of all the cells in the body. By modifying RNA, protein expression can be boosted or reduced, depending on the therapeutic need.

In people with RP11, one copy of their PRPF31 gene is normal and producing a relatively normal level of protein while the other PRPF31 copy is mutated and not producing sufficient protein. The overall reduced level of PRPF31 protein for RP11 patients leads to retinal degeneration and vision loss. Researchers from PYC found that by downregulating the activity of a different gene, CNOT3, they could boost PRPF31 protein expression. So, they developed VP-001, a tiny piece of synthetic genetic material designed to alter the RNA expressed by the gene CNOT3, thereby increasing PRPF31 protein expression.

[Editor's Note PRPF31 is the same family of genes as PRPF8 [RP13] and this mutation was identified by the Department of Human Genetics at UCT].

OPTOGENETICS

In advanced cases of retinal degeneration, the photoreceptors degenerate and are eventually no longer able to respond to light. In Optogenetics researchers aim to bypass the photoreceptors and confer light sensitivity to other, intact retinal neural cells such as Ganglion cells and Bipolar cells.

- **BIONIC SIGHT**
  All 12 patients dosed thus far in a Phase 1/2 clinical trial for Bionic Sight's emerging optogenetic treatment have demonstrated significant vision improvements. Those receiving the highest dose of the therapy had the most vision restored. The trial, which began in March 2020, is ongoing at Ophthalmic Consultants of Long Island. The four top responders in the trial gained the ability to recognize shapes and objects with a success rate from 80 to 100 percent. Prior to treatment, their success rate was much lower, equivalent to just guessing (25 percent correct when given four choices and 12.5 percent with eight choices). These four top responders also showed improvement in visual acuity as measured using the ETDRS chart (standard eye chart). Two patients went from not being able to see anything on an eye chart to correctly reading the second line.

  How does it work?

  Bionic Sight's approach involves two components. A one-time optogenetic treatment that enables the expression of a light sensitive protein in retinal ganglion cells which survive after photoreceptors are lost to an advanced retinal disease like RP. Secondly a device, worn like a pair of glasses, that captures the scene a person is looking at and generates vision-enabling code, which is sent to the light-sensitive ganglion cells, and then on to the brain. The Bionic Sight device produces neural impulses, similar to those produced by normal ganglion cells in the healthy retina. Dr Sheila Nirenberg believes that utilizing the retina's normal code can lead to better vision for patients.

USHER SYNDROME

Usher Syndrome is RP accompanied by hearing loss with Usher Type 1 having profound hearing loss. Researchers report success in the rescue of hearing by base editing in a humanized mouse model of Usher syndrome type 1F. This is caused by mutations in the PCDH15 gene.

A base editor was packaged into dual Adeno-Associated Virus (AAV) vectors and they were delivered into cochlea's of newborn mice with the PCDH15 mutation. This is a significant step towards treatment of this serious condition.

FALLEN HEROES

Beppie Summersgill, former chair of the old Gauteng branch of Retina SA and Amy Jooste long time committee member of the old North Gauteng branch both passed away recently. Thank you for your dedication and passion, RIP. Condolences to the families.

TECHNOLOGY ASSISTANCE

Using your SMART phone and devices in a SMART way will change your life. Leon and the other directors at LCSAT are available for free assistance – either Android or IOS phones, laptops or PC's. Many apps and programs are free so anyone can improve their communication skills. Contact them for assistance, they provide community training and educational development.

"Our aim and vision is to train visually impaired people how to use their devices and also provide information and advice on what is available to assist them in their daily lives." Website- https://www.lcsat.co.za/

MYSCHOOL/ MY PLANET

WE NEED YOU! Please nominate Retina South Africa as a beneficiary on My school either in store at Woolworths or on the website www.myschool.co.za at NO cost to you. You can change and add up to 3 beneficiaries. Thank you.

PATIENT SUPPORT SERVICES

Remember to contact Retina South Africa for advice, support, counselling, or referral to specialist service providers. Contact the office on headoffice@retinasa.org.za , call 0860595959 or contact us via the website www.retinasa.org.za

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