



NEW MANAGEMENT COMMITTEE

The Annual General Meeting of Retina South Africa was held on the ZOOM platform on Saturday 13 August.



*Manny Moodley -
Chairman*

Manny Moodley was re-elected Chairman. Manny has an LLB Degree and is a practicing lawyer in Cape Town. In 2019 Manny was elected as Deputy Chair of Western Cape Provincial Executive Committee of the South African National Council of the Blind. Manny was Chairman of the Western Cape branch of Retina South Africa until their incorporation into the new national structure. He has served on the National Management Committee of Retina South Africa since 2014. Manny was recently elected as a Director of Retina International. Manny has Stargardts Disease.



*Anton van Rooyen -
Vice Chairman*

Anton Van Rooyen was re-elected Vice Chair. He owns Sight Seekers, consultants, and suppliers of assistive solutions for the Visually Impaired. He is affected by Stargardts Disease. Anton has been an active member of Retina South Africa for many years and offers practical advice to RSA members on the use of assistive technology. Anton is a professional musician and an accomplished guitarist who has played in all the major South African cities and in neighbouring Southern African countries.



*Jean Bowler -
Treasurer*

Jean Bowler was re-elected Treasurer, a role she has held since 1990. She is Financial Director and Financial Manager of various companies. She volunteers her spare free time to keep close financial check on the finances of Retina South Africa.

She is meticulous and her fiscal control is exemplary. Her contribution to Retina South Africa over the last 32 years is beyond measure as neither her nor her family have a retinal condition.



Claudette Medefindt
- Secretary

Claudette Medefindt was re-elected Secretary. She has been a fulltime volunteer with Retina South Africa since 1980. She is Head of Science and Patient Services. She recently retired as a Director of Retina International. She is secretary to Retina South Africa's Scientific and Medical Advisory Board and lectures on inherited retinal conditions. Claudette writes and edits the quarterly E-News. Claudette is a trained peer counsellor and counsels newly diagnosed patients. Claudette has Retinitis Pigmentosa.



Sonja Lee Muhabeer

Sonja Lee Muhabeer was re-elected to the MC. She has been a member of Retina South Africa since 2015. Sonja has an LLB Degree and also has Post Graduate Diplomas in Conveyancing and Financial Planning. For the last elective period Sonya has been a stalwart member of the Governance Committee and is totally dedicated to the work of Retina South Africa. Sonja has Macular Dystrophy.



Caryl Baum

Caryl Baum is a newcomer to the MC but not to Retina South Africa. She has been a member since 2020 and is currently serving on our Advocacy sub-committee. Caryl is a retired Legal Advisor, having been involved in law for over 40 years. Caryl is married and has 2 amazing children, who with their spouses and 3 adorable grandchildren reside in Australia. Caryl's hobbies include collecting of antique and miniature perfume bottles, art, scrapbooking and crystals. Caryl maintains contact with residents in old age homes (especially those without families in South Africa). Caryl has AMD (Dry).

Management Committee and Action groups

It is hoped that the new smaller MC will be far more agile and be able to focus on Strategy and Advocacy. The Sub Committee structure introduced last year has shown tremendous promise and these groups will continue as ACTION groups this year. This gives all members the opportunity to become involved in an area where they have an interest and expertise. Action groups will include – Advocacy, Governance, Marketing, Fund raising, Patient education and support, Youth, Science etc. Are you willing to commit a few hours a week to making a difference? Please contact Linda at headoffice@retinasa.org.za or WhatsApp Claudette on 0833065262. Promising clinical trials will soon become available as treatments. We need to ensure that all RD patients have access to these long-awaited therapies.

SCIENTIFIC AND MEDICAL ADVISORY BOARD

We welcome two new members to our SMAB.



*Professor John G
Flannery & Claudette
Medefindt*

John G Flannery, Professor of Optometry and Neuro Science at UCLA, Berkley. John is Professor of Neurobiology, Dept. Molecular & Cell Biology and is Associate Director of the Helen Wills Neuroscience Institute. Prof Flannery's research covers a wide range of the anatomy and physiology of the eye and the retina, including diagnostic techniques in retinal imaging, electrophysiologic testing and new genetic approaches. Structure and function of the early visual pathway including retinal ganglion cells, optic nerves, lateral geniculate nucleus, and visual cortex in the brain; pupillary responses.

He is one the pioneers of Optogenetics- where researchers are bestowing light sensitivity to retinal neural cells to restore vision.

In collaboration with his Co-Principal Investigator Dr Isacoff, they use mammalian cone opsins to target ganglion cells, restoring vision in mouse models of inherited retinal diseases. In most cases, this approach is independent of the mutation that caused the photoreceptor degeneration.



Dr Linett Du Toit

Dr Linett Du Toit is an Ophthalmologist from Cape Town. She completed a retinal fellowship at the University of Cape Town and is now engaged at Tygerberg Academic Hospital. Her main specialities are medical and surgical retina. She is also a senior lecturer at Stellenbosch University. She has a special interest in Ophthalmic Genetics and Inherited Retinal Disease and is currently doing research in this field

ANNUAL GENERAL MEETING SPEAKER



*Jenny Webster-
Guest Speaker -
AGM*

Jenny Webster was the guest speaker at our AGM who enlightened us all with her practical advice on cell phone apps for RD people. She is a motivational speaker and an innovator. She recently won the SAB award for innovations for her design of the pad- perch, a portable hands-free stand that allows the user to use a smart phone or tablet in a very practical way. Jenny can be contacted via her website: www.c-ur-able.co.za.

RETINA INTERNATIONAL CONGRESS

9 to 11 June, Reykjavik, ICELAND 2022

The 21st RI World Congress was held in Iceland in June 2022.



*Claudette Medefindt –
holding her special
recognition award*

Claudette Medefindt, who was privately funded, represented Retina South Africa. The congress which was scheduled for 2020 was postponed due to the Covid Pandemic. The team from Retina International Secretariate in Ireland together with SENA and the Icelandic Retina Association and the Icelandic Society for the Blind organised an excellent congress. Claudette Medefindt who retired from the RI Board received a special recognition award honouring her 40+ years as a patient advocate in South Africa and in the international arena. [Click here](#) to download the RIWC Publication.

BEAT DIABETIC VISION LOSS

A Silent Danger ...

During World Retina Week [19 to 25 September] we will focus on creating awareness of the dangers to vision loss from Diabetes and Obesity.

One of the major complications of Diabetes is vision loss, with a staggering 20% of Diabetics are estimated to have some retinal damage when diabetes is first diagnosed ... and sufferers are unaware of this until the damage is extensive.

Prior to Covid there were an estimated 12.8% of South Africans with Diabetes (IDF 2019). Researchers estimate that up to 50% of people who had a Covid infection could develop Diabetes months after the infection.

Unless people are aware that they are heading into trouble, they are unable to take steps to avoid this lurking danger.

But, with just a piece of string, every one of us can be alert. Simply use the string to measure your waist (where your midline bends naturally) and then measure around your hips (where the leg joins the pelvis). If the waist measurement is smaller than the hips, it's a good sign. If you are over the age of 40 or have an expanding waistline, you should see an eye care professional annually for a retinal screening. Changing your lifestyle could save your vision and your life.

To listen to our webinar on the topic, please visit our Youtube channel on <https://bit.ly/3C8CWc5> or go to our website at www.retinasa.org.za, follow the tab to 'learn', select 'webinars' and choose 'Diabetes, COVID, and the Eye'.

RESEARCH NEWS

Retinitis Pigmentosa [RP]

X Linked RP

MeiraGTx Announces Positive Top-Line Data from the MGT009 Phase 1/2 Clinical Study Demonstrating Safety and Improvement in Multiple Domains of Vision in X-Linked Retinitis Pigmentosa Patients treated with Botaretigene Sparoparvovec (AAV-RPGR) compared to Untreated Randomized Control.

- The primary outcome of the MGT009 study is safety, and botaretigene sparoparvovec treatment was found to be generally safe and well-tolerated
- Significant improvements were demonstrated in multiple different endpoints in botaretigene sparoparvovec-treated patients across each of the three domains of vision: retinal function, visual function and functional vision.
- This Gene therapy is in development for the treatment of patients with X-linked retinitis pigmentosa (XLRP) with disease-causing variants in the RPGR gene. These results were at 6 months after treatment.
- Only males are affected by X linked RP which can cause early and severe vision loss. Dr Michel Michaelides, trial investigator, who is Professor of Ophthalmology, at Moorfields Eye Hospital and University College London, said “These data demonstrate the potential of treatment with botaretigene sparoparvovec to have a life-changing impact on vision in patients with XLRP, for which there is no currently available therapeutic option.”

The Phase 3 Lumeos study (NCT04671433) of botaretigene sparoparvovec for the treatment of patients with XLRP with disease-causing variants in the RPGR gene is actively dosing patients.

Optobionics

Clinical trials of Optobionics for Stargardts Disease and RP

Nanoscope Therapeutics has dosed the first participant in the Phase 2 STARLIGHT clinical trial of its optogenetic therapy for people with advanced Stargardts Disease. Known as MCO-010, the optogenetic therapy is designed for people who have lost most or all their photoreceptors, the cells that make vision possible. The treatment, a small drop of liquid delivered by an intravitreal injection, uses a human-engineered virus to deliver copies of the Multi-Characteristic Opsin (MCO) gene to bipolar cells — cells that don't normally sense light but often survive after photoreceptors are lost to advanced retinal disease.

The company says that MCO-010 will enable the recipient's bipolar cells to sense ambient light, thereby working as a backup system for lost photoreceptors. The

approach doesn't use goggles or eyewear to enhance the visual information coming into the retinas.

The company has also completed enrolment in the Phase 2b RESTORE clinical trial of its optogenetic therapy for people with advanced retinitis pigmentosa (RP). The company plans to report results from RESTORE in the first quarter of 2023.

[Source: Foundation Fighting Blindness.org]

AGE RELATED MACULAR DEGENERATION (AMD)

Creating a wet AMD drug using flower compounds - from the Macular Society News.

Researchers at the University of Surrey are looking at whether a group of compounds called 'homoisoflavanoids', found in rare hyacinth plants, may be able to stop blood vessel growth in the macula.

Professor Dulcie Mulholland, who is leading the research which has been funded by the Macular Society, said her team is looking to create a library of homoisoflavanoids to test which are the safest and best at stopping blood vessels growing. According to Professor Mulholland these compounds would make it cheaper, more accessible and less invasive compared to eye injections. And, as the compound works through a different mechanism to anti-VEGFs, this would benefit those that do not respond well to the existing drugs.

VISIONARIES HUB

Caryl Baum our newest MC member, is one of the RD patients featured in the Visionaries project. This is a collaborative project of Retina International in partnership with Roche. This website is designed to capture the daily realities of people living with low vision and their loved ones through the power of storytelling. The Visionaries Hub is an accessible online support resource for the low-vision community.

[Click here](#) to visit the Visionaries Hub.

CONGRATULATIONS TO OUR ATHLETES

Commonwealth Games

Retina South Africa members excelled at the recent Commonwealth Games. Alani Ferreira finished seventh in the women's 50m freestyle swimming S13 final. Lindsay Engelbrecht finished fifth in the Triathlon and Para Triathlon Women's PTVI – Final. Gavin KilPatrick finished seventh in the Triathlon and Para Triathlon

Mens PTVI – Final. Sadly Jaco Smit, who did well in his heat, did not make the finals of the 100m sprint.

World Parasurfing

Michele Macfarlane represented South Africa at the World Parasurfing competition.

EASTERN CAPE OUTREACH

It is with great sadness that we announce the closure of the office of Retina South Africa in Gqeberha [Port Elizabeth].

Fund raising during and post the Covid Pandemic has had a very negative effect on our fundraising capabilities and the funds to sustain these operating expenses are unavailable. In general Retina South Africa needs more members to get involved in support groups and fund raising.

The My School/My Village project raises over R36 000 per year but with more support could easily double or treble this amount. Members can assist by nominating Retina South Africa as a beneficiary at www.myschool.co.za.

Every time you swipe your card Retina SA receives a small donation from the retail outlet. It does NOT COST you a cent.

Want to contribute more? Join FRIENDS4SIGHT and make a monthly donation. Enrol your family and friends. Email Linda at headoffice@retinasa.org.za for more information or donate via our website <https://www.retinasa.org.za/donate-now/>.

WEBINARS AND COMMUNICATIONS

All our past webinars or podcasts are available on our [Youtube Channel](#) or go to our website at www.retinasa.org.za, click on the Learn Tab, select Webinars. We will be launching a new monthly webcast series - Retina Realities. Are there any particular topics you would like us to feature or do you have an interesting story to tell?. Contact us please. These sessions will be via a ZOOM video, will be pre-recorded and available on our Youtube Channel. PLEASE subscribe. When we have enough subscribers, we will start earning money from our webcasts. Recommended this month - Living your best life with RD on the [YOUTUBE Channel](#).

SOCIAL MEDIA

Please join our Face Book Group

<https://www.facebook.com/groups/27745746726/> or Page

<https://www.facebook.com/retinasouthafrica/>. Keep up to date on local and international news. Join one of our WhatsApp groups - Youth, Adults with RD, Parents of RD Children. Please share our Facebook page.

FREE ZOOM COUNSELLING SERVICE

Are you a fully paid-up member of Retina South Africa [or have applied for a fee waiver], you are eligible for a free personal Teams or Zoom Counselling Session with information specific to your condition. Email: headoffice@retinasa.org.za

YOUTH GROUP

We need new convenors for this group. Would you like to encourage dialogue and support among the youth with retinal vision loss? Please email us at headoffice@retinasa.org.za or call or WhatsApp Claudette on 0833065262 for more information.

DIS-CHEM FOUNDATION SWING FOR SIGHT

The golf day will be held on Tuesday September 6th. Thanks to the tremendous support from Dis-Chem we have a full field. They have also facilitated fantastic prizes. Thank You Dis-Chem and the Dis-Chem Foundation.

IS YOUR MEMBERSHIP UPTO DATE

Only members in good standing are eligible to stand for election, nominate MC members or serve on committees. Is your membership current? Contact Linda to find out. Annual membership fee is only R240. Email headoffice@retinasa.org.za

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