

RETINA SA - E-NEWSLETTER

Finding treatments for retinal blinding conditions such as
Retinitis Pigmentosa, Macular Degeneration, Macular
Dystrophies and allied retinal conditions



EDITORIAL

by Claudette Medefindt

TRIBUTE TO JAMES CAPE



Retina South Africa sadly announces the passing of our Chairman James Cape in July 2021. James was Chairman of Retina South Africa for 15 years and will be sorely missed.

James Cape was an active and dedicated member of the Retina South Africa team since the early 1980's. He served on both regional and national committee in various roles such as Treasurer, Vice Chairman, Branch Chairman and was elected National Chairman in 2006.

James had a long and successful career in corporate banking and he brought his expertise and dedication to Retina South Africa.

He was the driving force in uniting the foundation to be one, strong, national organisation backed with a robust and comprehensive governance code. The strategies, policies and documents he instituted will ensure the health of the Foundation far into the future.

He also led the formulation of a new Mission and Vision which reinforced our focus on finding treatments for retinal vision loss. He spearheaded the establishment of a dynamic, secure patient registry to which we have now linked our digital voting process.

He was very proud of the Management Committee elected in 2020 which was the first democratically elected MC in the history of the Foundation. He would be equally proud of the new MC that was elected on August 14th.

NEW MANAGEMENT COMMITTEE

Retina South Africa is pleased to introduce the newly elected MC:

Chairman: Manny Moodley, Attorney, from Cape Town.

Vice- Chair: Anton van Rooyen [re-elected], Assistive device and technology expert, from Gqeberha.

Treasurer: Jean Bowler [re-elected] professional accountant, Germiston.

Secretary: Claudette Medefindt [re-elected] Patient Counsellor, Benoni.



National Management Committee Members: Top Row - Left to Right: Jean Bowler, Lishavia Mahabeer, Samantha Daniels, Alani Ferreira, Sonya Mahabeer, Claudette Medefindt.

Bottom Row - Left to Right: Kgosi Mmoloke, Anoop Narotam, Manny Moodley (Chairman), Anton van Rooyen (Vice Chairman), Zazi Gumede.

MANNY MOODLEY

Manny Moodley has Stargardt Disease and has been an active member of the Foundation since his teens. He has held many roles including that of Vice - Chairman of the Foundation and Chairman of the Western Cape branch. He is an attorney at law and has served on committees of numerous disability organisations including the Executive of the National Council for the Blind, the Cape Town Society for the Blind, and is a trustee on the Carel Du Toit Trust. He is passionate about advocacy, inclusion, and equality for people with disabilities. He is also interested in research to find treatments for inherited retinal disorders. His steady hand and wise counsel will be a huge asset to the Foundation going forward in these challenging times.

ANTON VAN ROOYEN

Anton Van Rooyen has been active in Retina South Africa for many years. He has been a member of the MC for years and was elected as Vice -Chair 5 years ago. The PE Office falls under his jurisdiction. He is a user and expert on technology and assistive devices to help low vision patients. He is also a brilliant guitarist and was a professional musician for many years. He plans to be active in the governance portfolio. Anton has Stargardt Disease.

JEAN BOWLER

Jean Bowler is a volunteer with no history of vision loss in her family. She has been the Treasurer of Retina South Africa through most of the past 20 years. She heads up the finance divisions of various companies and her expert fiscal control has ensured a history of financial governance in Retina South Africa that is totally flawless.

CLAUDETTE MEDEFINDT

Claudette Medefindt has been a volunteer with the Foundation since its inception. She is a trained counsellor with a passion for the science of retinal degeneration. She is Head of Science and Patient Services for Retina SA and serves on the board of Retinal International. Claudette has Retinitis Pigmentosa [RP].

ALANI FERREIRA

Alani Ferreira is a professional swimmer who has just been selected to represent SA at the Tokyo Paralympics. She has a BCom in Business Management and is now doing her honours degree. She lives in Pietermaritzburg and is a member of the Youth Committee who are mentoring young people with retinal degeneration. She is an inspiring leader with a passion for people. Alani has Stargardt Disease.

ANOOP NAROTAM

Dr Anoop Narotam from Johannesburg has a degree in both Medicine and Physiotherapy. He is inspired by the people that he has met who achieve amazing things despite their vision loss. He is a member of the Youth Committee and hopes to grow Retina South Africa and inspire young patients to dream big and achieve their dreams. Anoop has Stargardt Disease.

KGOSIETSILE MMOLOKE

Kgosietsile Mmoloke is a mining engineer from Johannesburg who recently completed his MBA. He has Cone Rod Dystrophy and is also part of the Youth Committee. His passion is to empower the youth and help them overcome their challenges. He hopes to inspire them to believe there is hope despite having a retinal condition.

LISHAVIA MAHABEER

Lishavia Mahabeer lives in Durban and the fact that both her brother and sister have a Macular Dystrophy has inspired her to join Retina South Africa. As a PHD student in Chemistry with a sound background in Biochemistry we know that she will be a huge asset to the Science portfolio.

SAMANTHA DANIELS

Samantha Daniels is a teacher at a Special Needs school in Cape Town. She served as Deputy chair on the Western Cape Committee and was a delegate to the NMC prior to the Constitutional change which amalgamated the Foundation into one organisation. She is a member of the Youth Committee and is now studying inclusivity in Education. Samantha has RP.

SONYA MAHABEER

Sonya Mahabeer is an attorney with a qualification in Financial Planning and has a CFP designation. She works for one of the major corporates in the financial services industry in Cape Town as a legal advisor. Her expertise will be an asset to the Governance portfolio in the MC. Sonya is passionate about creating positive change and hopes to interact with Retina SA members to create a forum where people with vision loss can be supported and understood. Sonya has macular dystrophy.

ZAZI GUMEDE

Zazi Gumede lives in Johannesburg and has worked in the Disability sector for 5 years in both an administrative and legislative capacity. He was deputy chair of the Disability Forum of Johannesburg and is secretary to the disability organisation Powerpath. Zazi has Macular Dystrophy.

AGM GUEST SPEAKER - JONATHAN ABRO

Jonathan Abro was the guest speaker at our AGM held on Saturday 14th August. Jonathan discussed his life in IT with RP. A copy of his presentation is available on our Youtube channel <https://youtu.be/REOdyXPHXE8>.

Apps Jonathan discussed:

SCREEN MAGNIFICATION AND COLOUR INVERSION

Best to start with the built-in magnifier and colour manipulation in Windows, Mac and Chromebooks or, when needing more features, ZoomText is a good package to try. There are others and a quick search will list options available.

SCREEN READERS

Windows, Mac and Chromebooks all have built-in screen readers so, again, a good place to start. For Windows, you need to try and practice.

NVDA

This is a free screen reader and a good next step in using screen readers – see <https://www.nvaccess.org/>

JAWS

This screen reader can also be used in conjunction with ZoomText as a product called Fusion and is the screen reader of choice in many work environments, at home and school as well – see <https://www.freedomscientific.com/products/software/>

LEARN TO TYPE WITH A VARIETY OF TUTOR SOFTWARE:

- BBC Kids - <https://www.bbc.co.uk/teach/skillswise/typing/zjqm92p>
- Mavis Beacon free - <https://www.mavisbeaconfree.com>
- Azabat - <http://www.azabat.co.uk/typing.html>

APPS FOR SMARTPHONES

- Seeing AI for iPhones
- Google Lookout for Android phones
- Envision AI is a pay app for both iPhone and Android
- Be My Eyes
- Mobility and getting about

APPLE MAPS OR GOOGLE MAPS

SOUNSCAPE FOR IPHONE

LAZARILLO FOR IPHONE AND ANDROID

- VO Starter for learning VoiceOver on iPhone

GOOD RESOURCES FOR HELP

- Apple products - <https://www.applevis.com/>
- Android - <https://support.google.com/android/?hl=en-GB#topic=7313011>

BONE-CONDUCTION HEADPHONES - aftershokz - <https://aftershokz.co.uk/pages/brands>

SMART DEVICES - Including Amazon Alexa, Google Home and Smart TV

LOW TECH

- Pen friend - <https://www.rnib.org.uk/rnibconnect/technology/penfriend-3-audio-labeller>

[**Editor's note** - most of the smartphone apps are free but do check prices before downloading. Sophisticated screen readers are expensive but will increase your productivity. Approach your employer to purchase for you under the “reasonable accommodation” provision in the Employment Equity Act.]

PATIENT SERVICES

Much attention is being focussed on supporting our members. This support includes individual counselling, webinars, specialised WhatsApp groups, mentoring by our youth committee and a Youth seminar in Gqeberha.

The WhatsApp groups and webinars are focussed on specific groups of patients e.g. Youth, parents or adults with RD. The youth group leaders have decided to lower the age of patients on the WhatsApp group to 16+. Please contact the office if you would like to be added to an appropriate WhatsApp group.

WHATSAPP GROUPS

RSA Youth Parents is a group for parents of any child with RD. RSA Youth 16+ is for young people with RD from 16 to 35 years. These 2 groups are monitored by the Youth Committee.

Adults with RD is a group for adults over 35 with any form of retinal vision loss. The success of an WA group depends on the participation of the group members. It's up to you to create a dynamic forum for exchange and support.

WEBINARS

Two Targeted Zoom meetings were held in July – one for the parents and one for the youth. Please let us know what topics you would like featured in upcoming Zoom meetings. These meetings are not recorded to ensure privacy but all our webinars are on Youtube. Subjects covered include many aspects of retinal vision loss. See www.retinasa.org.za Learn Tab, select webinars or follow this <https://www.retinasa.org.za/learn/webinars/>

GQEBERHA YOUTH SEMINAR



A very successful Youth Empowerment Conference was hosted by the PE Office in July. This inspirational event highlighted our young members and their many talents. The conference also equipped them to find their purpose, cope with vision loss, deal with the pandemic and their financial and social circumstances.

The young attendees were taken on a journey of self-discovery by Michelle Brown from Browns PR, and Nomalungeso Ntlokwana Career Coordinator from the Nelson Mandela University.

(Pictured is Siyamcela and Thando - 2 participants at the youth seminar)

Gail Cillie and Yonela Hofu from the PE Office team focussed on entrepreneurial skills, the pursuit of career goals and pathways, their right to understand their condition and its impact as well as coping with the challenge of fulfilling their destiny.

The young participants were able to network with their peers, the guest speakers, their teachers and social workers.

The success of the day led to a decision to arrange a follow-up in September. This will deal with Strengths, Weaknesses, Opportunities and Threats by Garth Austin from Zifundise Training and Consulting who specialises in Business Solutions and teambuilding. These initiatives will help in changing attitudes and perspectives and improve the lives of our PE Office Youth.

We need your help to ensure that all South Africans have access to promising therapies to break the bonds of retinal blindness. Donate Today!

WORLD RETINA WEEK - 20-26 SEPTEMBER

International Theme – Love your eyes.



Do you love your eyes?

Are you protecting your vision?

Check the tick boxes and rate yourself here

- ☐ Annual Eye Check
- ☐ No Smoking
- ☐ 7 hours sleep (minimum)
- ☐ Controlled BP, Cholesterol abdominal fat
- ☐ Controlled, steady Blood Glucose
- ☐ Regular exercise
- ☐ Healthy colourful diet
- ☐ Limit screen time (TV, Computer and devices)
- ☐ Stress control
- ☐ Healthy Social Life

If you rate less than 7 out of 10 you need to learn to love your eyes more

RESEARCH NEWS

Nanoscope's Optogenetic Gene Therapy

Nanoscope's Therapeutics announced in June the results of an Optogenetic Gene Therapy trial to restore meaningful vision in 11 Patients Blinded by Retinitis Pigmentosa.

In most cases of retinal photoreceptor cell damage, the neural layer that sends messages to the brain remains relatively intact. These cells do not react to light but research efforts over the past few years are rapidly changing this to make these cells, and particularly the ganglion cells, light responsive.

Nanoscope Therapeutics Inc is developing a gene therapy to deliver a light sensitive molecule [MCO] to the neural cells. They recently announced vision improvements for patients with advanced Retinitis Pigmentosa [RP] in a phase 1/2a clinical trial. The improvements persisted 52 weeks after a single intra vitreal injection of Multi-Characteristic Opsin. This is the first reported clinically meaningful functional improvement by optogenetic therapy.

This vision restoration was observed in normal ambient light using optogenetic gene monotherapy without the need of stimulating retinal implants or external devices such as goggles.

The beauty of this approach is that it would potentially work in patients affected by multiple genetic defect(s) in a mutation-independent manner. Significant improvement in multiple mobility tasks and quality of life measures was reported. A phase 2b, placebo-controlled, double-masked Phase 2b multi-center optogenetic trial is expected to be launched later this year.

NAC Attacks Retinitis Pigmentosa

Retinitis Pigmentosa (RP) is a condition caused by many different genetic defects. The common thread is that each of the genetic defects kill “rod” photoreceptors in the retina — which make up 95 percent of the retina’s light sensitive cells — leaving the other 5 percent, the “cones,” virtually untouched. Oxidative stress is a promising area of research being investigated to preserve cone vision.

Cone Photoreceptors are vital for fine focus vision such as reading, writing and face recognition. A major contributor to cone damage and death is oxidative stress. There is no cure and not a single drug on the market offering hope, but Peter Campochiaro, M.D., Wilmer’s George S. and Dolores D. Eccles Professor of Ophthalmology and Neuroscience are building on their success of a phase 2 trial, Fight RP, to investigate the effect of N acetylcysteine — NAC for short — that reduces oxidative stress and showed some short term protection for cones.

They will soon launch a phase 3 trial, NAC Attack, to determine if long-term treatment can prevent cones from dying and prevent progressive loss of visual field. This is expected to require four years of testing. NAC is already approved by the U.S. Food and Drug Administration (FDA) for treating another condition, and this will accelerate the approval process, as the drug is already shown to be safe. See full article: <https://www.hopkinsmedicine.org/news/articles/nac-attacks-retinitis-pigmentosa>.

[Editor's note: Retina Plus is a locally produced antioxidant that contains Lutein, Zeaxanthin, Alpha Lipoic Acid and L- Glutathione – all natural anti- oxidants. This formula has shown delay in the rate of degeneration in RP and Stargardt Disease in animal models and by anecdotal patient evidence. Contact them at: info@highvibrance.com]

AI and RD

An editorial in the British Journal of Ophthalmology highlights the possible use of Artificial Intelligence to diagnose retinal conditions.

They state that “Traditionally, genotypic diagnosis has been considered ‘nice to have’, but not ‘essential’, with implications usually related to patient prognostication and genetic counselling. However, an accurate genetic diagnosis is now of paramount importance because of rapid advances in potential gene replacement and other therapies for these previously untreatable conditions.”

Prices for genetic testing have drastically reduced. Genetic testing using a Next Generation panel at the university of Cape Town now costs around R11 000, excluding the cost of genetic counselling. Some private genetic counsellors also use American laboratories which do produce faster results. We also have sponsorship from the Mary Oppenheimer and Daughters Trust to fund genetic testing for young people from needy families. Contact the National Office for more details.

Stargardt Disease Update

Professor Frans Cremers from the Netherlands is the undisputed international expert in Stargardt Disease and ABCA4 gene mutations.

He has just published an open-source paper highlighting the genetic variability in the disease. There are now 2 197 known mutations in this gene - the most common gene in Stargardt Disease.

Prof Cremers gives credit to the work done by Stéphanie Cornelis in the understanding of the complexities of the ABCA4 gene mutations. New work done by her and Esmee Runhart, is to classify all ABCA4 variants found in bi-allelic STGD1 cases into severity classes. This will be important to understand the variability in age of onset, disease progression and the complex inheritance patterns of ABCA4 diseases.

INTERNATIONAL YOUTH GROUP

Alani Ferreira is the South African representative to the International Youth Council. She has been selected to represent South Africa at the Paralympic games for swimming in Tokyo. She is currently in Tokyo and we wish her the very best of luck. Read more about Alani's first swim at the games <https://www.businesslive.co.za/bd/sport/other-sport/2021-08-25-alani-ferreiras-first-swim-in-tokyo-settles-her-nerves/>

If you were not able to join the Retina International Youth Conference, please see the recordings here:

Genetic testing: <https://www.youtube.com/watch?v=JsLDSdtOLhw>

Access and enablement: <https://www.youtube.com/watch?v=Md64KH1fFlw>

Research and Innovation: <https://www.youtube.com/watch?v=BNSyG8jwf30>

Remember you can connect with the Retina South Africa Youth Group via the email youth@retinasa.org.za.

HADLEY INSTITUTE

The Hadley Institute offers free training videos in easy to follow and understand step-by-step visual instructions on multiple topics such as *Daily Living, *Adjusting to Vision Loss, *Recreation, *Technology, *Braille and *Working. Use the LEARN tab at the top of the home page.

The Hadley Institute's mission is to create personalized learning opportunities that empower individuals with vision loss or blindness to thrive – at home, at work, and in their communities.

The free training videos gives easy to follow and understand step-by-step visual instructions on multiple topics such as *Daily Living, *Adjusting to Vision Loss, *Recreation, *Technology, *Braille and *Working. Each one consists of various workshops dealing with aspects of that particular category. Visit the Hadley site and learn how to live your life to its full potential, giving you independence and enriching your life.

Click here : <https://hadley.edu/welcome-hadley>

THANK YOU FOR YOUR SUPPORT

We would like to thank the members who have paid their membership fees and donated to the research fund. Only those members in good standing were able to access the voting portal to vote for the new MC. For those who cannot afford the R240 per year membership please apply for a fee waiver.

Thank you to the members who have paid membership fees and donated to the research fund. Due to the Covid Pandemic our special events like the Ride for Sight were cancelled for 2021. This has sadly meant that for the first time we have had to reduce our grant to the University of Cape Town for our research projects.

Please remember to nominate Retina SA as a beneficiary on www.myschool.co.za . They will donate to us at NO COST to you. Remember to swipe at participating outlets. Now more than ever we need your support.

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