

E-NEWS



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NEW DEPUTY CHAIR AT RETINA SOUTH AFRICA

Mrs Mariza Jurgens was recently elected Deputy Chair of Retina South Africa. She succeeds Anton Van Rooyen who retires from this position after many years of loyal service. Anton will remain an active member on the Governance and Marketing Sub Committees. Mariza was Chair of the previous North Gauteng Branch of Retina South Africa and also served as Deputy Chair of the National Committee before her husband's International Diplomatic duties took them abroad. She was very active in the Charities sector in the UK and she brings this wealth of experience to her other role of Head of Fund Raising and Marketing Sub Committee. We thank her for her energy and commitment to Retina South Africa.



DIS-CHEM RIDE FOR SIGHT 2024

The Dis-Chem Ride for Sight was held on Sunday 18 February at Boksburg City Stadium.

The event was a huge success, and we thank Dis-Chem Pharmacies, the Dis-Chem Foundation, Ensure Gold, and DS 24 for their sponsorship and support. There were numerous secondary sponsors whose details can be found on our website. The 2740 cyclists who participated were all impressed with the quality and safety of the event. Grateful thanks to our organising committee Renier van den Berg, Hamnet, Springs Wheelers, Road Rangers, Rob van Deventer, 2nd Boksburg Scouts, Marshals from Knights of Pendragon Rotary Club, Colin de Bruin and friends, Cosnath Zitha and his



Johnny Koen, the Master of Ceremony, engaged in conversation with Lisa Bone, winner of the Lic Ladies Category

CONTACT US:



Johnny Koen, the Master of Ceremony, engaged in conversation with Bradley Scott, the winner of the Lic Elite & Under 23 Category.

Combi, the Athletic Clubs of Kathlehong and Gallopers, and the hundreds of loyal volunteers who make this event happen.

This year Linsay Engelbrecht joined our team and took on the challenge of recruiting volunteer pilots and people with disabilities to participate, with amazing results.

PEDALLING TOWARDS INCLUSIVITY

Empowering Para Cyclists at the Dis-Chem Ride For Sight

By Linsay Engelbrecht

In the vibrant world of cycling, the winds of change are blowing, steering the sport towards inclusivity and accessibility for all. Nowhere is this more evident than in the inspiring journey of Retina South Africa's involvement in the Dis-Chem Ride for Sight event.

At the heart of this initiative lies the Para Category, a platform designed to welcome para cyclists, hand-cyclists, and tandem teams. Its significance extends far beyond the realm of sport; it symbolises a beacon of inclusivity, where barriers are shattered, and opportunities abound. Setting an ambitious goal of 100 para participants by 2025, Retina South Africa embarked on a journey to transform this vision into reality.

Harnessing the Power of Communication: Leveraging social media, WhatsApp surveys, and direct communication with all stakeholders, we recruited volunteers and VIP's to join this empowering movement.

Generous sponsors ensured that financial barriers were overcome, covering entry fees, transportation, and essential cycling gear, making participation a tangible possibility for all.

Tailored training sessions and adaptive equipment provision equipped new riders with the skills and tools necessary to embark on their cycling journey with confidence. Implementation of accessibility measures at the event venue ensured that physical barriers did not hinder participation, reaffirming the event's commitment to inclusivity & safety.

The fruits of these efforts were nothing short of remarkable. The 2024 edition of the Dis-Chem Ride for Sight witnessed a surge in para individual participation, with 31 para entries and 52 participants overall. From the 116km race to the 8km event, individuals with visual impairments and physical disabilities showcased their determination and spirit, crossing finish lines and breaking barriers.

Beyond the race itself, the community rallied behind the cause, exemplified by the R30,000 raised in just seven days through fundraising initiatives, demonstrating the profound impact of collective action.

Going forward we need you all to join the "Save Our Sight" Team.

Whether you have a retinal condition, are a friend or family member or simply an individual passionate about fostering inclusivity, there's a place for you within this dynamic team.

By participating in events, fundraising, and advocating for inclusivity, team members play an integral role in furthering the organisation's mission. If you're interested in becoming a part of this transformative journey or wish to learn more about how you can contribute, contact me, Linsay Engelbrecht at events@retinasa.org.za or WA me at 084 554 9227.

Whether it's lending a helping hand at races, offering administrative support, or spreading awareness, every contribution matters.

Together, let's continue towards a future where barriers are replaced with opportunities, and every individual, regardless of ability, can thrive. Join the "Save Our Sight" Team today and be a catalyst for change in the journey towards inclusivity and empowerment.

PARA LAWN BOWLS



Pictured here from Left to Right: Mariza Jurgens (Vice Chairperson Retina SA) and Linsay Engelbrecht (Events Coordinator)

In the world of para sports, lawn bowls emerges as a shining beacon of inclusivity, skill, and determination. Recently, members of Retina South Africa, Mariza Jurgens and Linsay Engelbrecht, showcased their exceptional talent at the SA Lawn Bowls Open Championships for the disabled held in Cape Town.

Blind Bowls is divided into categories which denote various degrees of vision loss, with "B" for the completely blind. Mariza, a seasoned bowler, clinched a well-deserved silver medal in the Singles Division of her classification. Meanwhile, Linsay, a relative newcomer to the sport, stunned the competition by clinching gold medals in both the Singles and Pairs divisions. Her unexpected triumphs left her feeling immensely proud and fuelled her determination to pursue her bowling future. Linsay describes the experience as surreal, emphasising the intense competition and the invaluable lessons learned along the way. We extend sincere

congratulations to them both on their success. All para lawn bowlers with visual impairments are assisted by their dedicated, sighted, directors guiding them with precision and expertise. Linsay attributes much of her success to her director [and husband], Deon Engelbrecht, whose impeccable directing and unwavering support was a huge part of their success.

As we celebrate the achievements of Mariza and Linsay, let us also celebrate the spirit of resilience, perseverance, and camaraderie that defines para lawn bowls. Their success serves as a beacon of inspiration for para-athletes everywhere, reminding us all that with dedication and determination, anything is possible on the green.

UPCOMING EVENTS

Retina South Africa is excited to announce a lawn bowls fundraiser on the 23rd of June 2024 at the Edenvale Bowling Club in Gauteng. We invite you to join us for a fun day out and experience the joy of lawn bowls first-hand. The cost is R300.00 per person, which includes a light lunch, and a prize-giving ceremony after the event. All equipment will be provided on the day. Please let us know if you'd like to join us, so we can ensure we have adequate directors available to assist anyone who requires one.

On September 3rd our Annual Swing for Sight Golf Day will be held at Royal Johannesburg, Linksfield. We need sponsors, players and prizes, please. On 28 September our 2nd Spin for Sight will be held at Virgin Active, Bryanston: The Virgin Active 94,7 Ride Joburg will be held on 17 November. Cyclists are invited to ride for the Retina South Africa team, to support our Save Our Sight Program through a Charity entry. Contact Linsay.

Other events being considered are a Saddle up for Sight equestrian event. We would also like to spin these events out to other areas and need local co-ordinators to work with our dynamic team. For more information on any event contact Linsay at events@retinasa.org.za

HOW ELSE TO GET INVOLVED

By Karen Denton- Head of Education and Awareness

Join us for our varied, and exciting programmes that are designed to make a difference to you and your family members:

1. Our Retinal Realities Podcast Series covers different aspects that impact Retinal Vision loss. Professionals, people with low vision, people from different backgrounds, and different walks of life share their stories in short snippets. Tell your story- contact Karen@retinasa.org.za or sandy@retinasa.org.za

2. We plan to present a series of informative webinars to provide essential aspects of living with a visual impairment. However, rather than Retina SA telling you what you need to know, please contact us at and tell us what you would like us to discuss.
3. Finally, we have planned number of very short, easy to follow discussions that will be presented live on Zoom. Each “Back to Basics” chat will be 10-15 minutes long and will introduce everything important to know about eyes. This will be a weekly session on Thursday evening starting in May. Please register your interest with Karen and tell us what time is most suitable. Open to all.

YOUTH GROUP

BY Sonya Lee Mahabeer

Y – Yearning; O – Optimism; U – Unleashes; T – Transformative; H - Hopes

Join the vibrant and dynamic community of the Retina SA Youth Group, where we champion the spirit of resilience and empowerment among young individuals facing visual impairments. Our mission is to foster a supportive environment that uplifts, encourages, and motivates youth on their journey through the challenges of visual impairment. Through engaging discussions, workshops, and events, we tackle topics ranging from honing work skills to navigating the emotional landscape of living with a visual impairment. From managing dating life to confidently addressing visual impairment in the workplace, we cover it all. At Retina SA, we're not just a group; we're a family—a family that believes in the power of a strong mindset to conquer any obstacle. So, if you're a youth with a visual impairment seeking guidance, support, and a sense of belonging, reach out to us. Together, we'll navigate the path forward, proving that with determination and community, anything is possible. As the saying goes, "Although the world is full of suffering, it is also full of overcoming it." Join us at Retina SA where challenges are met with strength and education. Remember, you're never alone in your journey. Stay strong, stay inspired, stay connected. Please feel free to contact us: sonya@retinasa.org.za or Sonya – 081 466 3055.

STARGARDT CLINICAL TRIAL FEEDBACK

If you participated in the SeaSTAR [Acucela] trial you may have had a letter from the trial organiser. If not, please respond to Monique:

I am Monique Bäcker from the University of Cape Town (UCT). I am conducting research in partial fulfilment of my degree in MMedSci Genetic Counselling.

You are invited to participate in this study exploring the expectations and experiences of individuals who participated in the first gene-based clinical trial in South Africa. This trial was a first for South Africa, let alone Africa. It is hoped that this opens the doors for South Africans to access future clinical trials.

Gene-based therapies hold much hope for better health care. This study therefore aims to provide insight into individual's experiences and perspectives on their health care journey through a clinical trial. The hope is that individuals will share their perspectives on the trial recruitment and information, their decision making for wanting to participate, as well as their view on the clinical trial experience. This information can assist health care providers in providing better patient centred care and assist clinical trial organizations in conducting and designing clinical trials in the future.

The study involves an MS Teams interview of around 45 minutes to share your experiences. If you can participate, please contact me via email, SMS, or WhatsApp and I will contact you to discuss the study in more detail.

I hope that you will consider participation in my study.

Thank you.

Researcher, Monique Backer

Email: bckmon003@myuct.ac.za; Mobile: 071 430 8266

Ed Note: For a copy of this letter in Afrikaans please contact Retina South Africa.

MEMBERSHIP FEES

An invoice for the annual R240 membership fee is attached to this ENews. All members who pay their fees before the end of May will go into a draw for a prize of R500. For an extra R250 you can join the Save our Sight competition for the next 12 months and you will be eligible for every monthly draw.

Donations towards our upliftment and genetic diagnosis fund for impoverished families are also welcomed.

If you cannot afford the annual fee, please complete the fee waiver form to remain a member in good standing.

RESEARCH NEWS

➤ **X LINKED Retinitis Pigmentosa [RP] TRIAL**

Beacon Therapeutics is seeking participants with X-linked RP who have a mutation (or defect) in the RPGR Gene for their Multi-Center, Phase 2/3 Vista Trial.

To be considered you must:

- Have a diagnosis of XLRP confirmed by an Ophthalmologist.
- Have a mutation in the RPGR gene confirmed by genetic testing. You may qualify for no-cost genetic testing.
- Be male between the ages of 12 and 50 years.

The Vista trial is studying an investigational gene therapy called AGTC-501 which is designed to provide a healthy version of the mutated RPGR gene to allow the cells in the retina to make a healthy RPGR protein.

The purpose of this trial is to assess how well 2 different doses of AGTC-501 might work to preserve and/or improve vision and other symptoms of XLRP when compared to study participants who have not received AGTC-501.

If you are interested in learning more, please visit: www.vistatrial.com. This trial is sponsored by Beacon Therapeutics, an ophthalmic gene therapy company founded to restore and improve the vision of patients with both prevalent and rare retinal diseases that result in blindness.

➤ RETINAL GANGLION CELL RESEARCH

Pathways toward effective and ethical human neuro engineering.

Dr. E.J. Chichilnisky from Stanford University, USA, is conducting groundbreaking research into the complex role of retinal ganglion cells in the visual process. Ganglion cells transfer retinal neural signals from the retina via the optic nerve to the brain. He works with donor retinal cells and estimates that there are around 20 types of ganglion cells that process various aspects of the visual information. His aim is to use the results of this very complex research to produce an effective prosthesis that could replace defective retinas.

See this interview on Andrew Huberman's amazing podcast series:

https://youtu.be/oL3SkPV1_Ik

➤ GENE THERAPY PROGRESS

Opus Genetics has announced vision improvements for the first three adult patients in its Phase 1/2 gene therapy clinical trial for Leber Congenital Amaurosis 5 (LCA5). This is a rare, severe, inherited retinal disease. Some of the patients, who had been almost totally blind since birth, can now see and identify objects for the first time. The company has also reported positive safety data for the trial thus far. A higher dose will be used in the next group of adult patients in mid-2024 and there are future plans to dose patients as young as 13 years of age.

Known as OPGx-001, the gene therapy uses a human-engineered Adeno-Associated Virus (AAV) to deliver healthy copies of the LCA5 gene to the retinas of patients, augmenting the mutated copies causing vision loss. The therapy is administered through a one-time injection underneath the retina. Researchers believe gene therapies will be effective for many years, perhaps for the life of the patient.

Although LCA5 patients have severe vision loss at birth, they have surviving retinal structure which researchers believe can be harnessed for improved vision using gene therapy. Source Foundation Fighting Blindness USA.

Ed Note: All people with a retinal genetic disease should have a genetic diagnosis, especially the youth. Sponsorship for qualifying needy families is available. Other families may wish to look at our co-fundraising project to raise funds for their genetic test. If you have a genetic test result, please register at www.myretinatracker.org

➤ **jCYTE PHASE 3 CLINICAL TRIAL TO BE LAUNCHED**

Known as retinal progenitors, the company's jCells® are designed to preserve photoreceptor cells. The cells are injected into the vitreous and this type of injection has a good safety record. jCells are designed to release neurotrophic factors to preserve photoreceptors regardless of the gene mutation causing vision loss.

Previously, jCyte reported that of the 76 patients in the Phase 2b trial, 39% of those that received the highest dose of 6 million cells, had improvement at 12 months post-treatment in Best Corrected Visual Acuity (BCVA) of 10 letters (two lines on an eye chart) or more, with 26 percent improving by at least 15 letters. In the sham group, 19 percent and 8 percent had BCVA improvement of 10 or more and 15 or more letters, respectively. Improvements in contrast sensitivity, kinetic visual fields, and mobility-related visual function were also shown. The lower dose [3 million cells] was shown to be inferior to the 6 million cell dose. Source Foundation Fighting Blindness USA

MYSCHOOL/ MY PLANET

PLEASE consider nominating Retina South Africa as a beneficiary **AND** remember to swipe your card. Join at any Woolies store or online at www.myschool.co.za at NO cost to you. You can have up to 3 beneficiaries. Thank you.

FREE PATIENT SUPPORT SERVICES

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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YouTube channel

<https://www.youtube.com/channel/UC54Y69fvfcCrsl8WlIFyIIQ>.

Facebook Page: <http://www.facebook.co.za/retinasouthafrica>

Twitter: https://twitter.com/Retina_SA

LinkedIn: <https://www.linkedin.com/company/retina-south-africa>

Instagram: <https://www.instagram.com/retinasouthafrica>

Retinal Realities Facebook Page:

<https://www.facebook.com/profile.php?id=100092317787481>

Retinal Realities Instagram Page:

https://www.instagram.com/retinal_realities_sa/

Retinal Realities Twitter Page: https://twitter.com/retinal_reality

Retinal Realities on Spotify:

<https://open.spotify.com/show/39jU3s71N31T5nbsU2pxel>



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