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DIS-CHEM RIDE FOR SIGHT 2014



The 26th Ride for Sight was held on February 16th 2014 at the Boksburg City stadium. The event was once again sponsored by Dis-Chem Pharmacies and proudly hosted by the City of Ekurhuleni. More than 5300 cyclists took to the streets of Boksburg to raise funds to bring treatments and cures for retinal blindness to South Africa.

The main event was won by Herman Fouche and the ladies trophy went to Lise Olivier



“Herman Fouche crossing the finish line”



“James Cape, Claudette Medefindt, Kobus and Michelle Van Der Merwe. Kobus & Michelle received a gift from James for 20 years of Volunteering & Supervising for the Ride for Sight Event”

More than R82 000 in cash prizes were awarded to the best road cyclists in South Africa. Fun riders were not forgotten and R90 000 worth of prizes went on a lucky draw basis.

Over 400 volunteers helped on the day and the funds raised are the mainstay of our research and patient services project at the University of Cape Town. This year's allocation takes the total amount that this event has raised for genetic research to over R4,5m.

Thank you to all our sponsors:

- ✓ Dis-Chem Pharmacies
- ✓ Dis-Chem Foundation
- ✓ Cycle Lab Fourways
- ✓ ABI
- ✓ Action Ford
Krugersdorp
- ✓ Bausch & Lomb
- ✓ B-Sure Africa
- ✓ Cycle Events
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Boksburg
- ✓ Palmer Insurance
- ✓ Rob Wyly Trading
- ✓ The Benoni Red Cross
Society
- ✓ Transact
- ✓ Vita-Thion
- ✓ VOITH

SPIN FOR SIGHT

This joint venture between Retina SA and Vision Works has been postponed to coincide with World Retina Week- September 22nd to 28th. Why don't you approach your local gym and Vision Woks branch to organize one in your area? A complete event manual will be available with step by step instructions- **GO FOR IT!!!**

UCT RESEARCH PROJECT UPDATE

The University of Cape Town plays a dual role in retinal research in South Africa -

They identify the exact gene mutation in each family-

- ✓ to confirm a clinical diagnosis
- ✓ to test for carriers in the family for early diagnosis
- ✓ to ensure informed family planning
- ✓ And most importantly to identify patients who will be eligible for upcoming clinical trials. Many patients have been tested and to date 184 families stand to benefit from current gene therapy trials- 5 from the *RPE65* trial, 6 from the *AiPL1*, 6 in the Ushers *MYO7A* trial; and most

impressively 167 in *ABCA4* STARGEN trial.

Some patients have funded their own genetic testing and wherever possible sponsorship of these tests has been sourced. This type of research is also called Translational Research- translating local and international genetic findings to assist our local population. This project is supported by the funds that our members help us raise- and you can assist us with our various fund raising projects [see below].

The other type of research that UCT are involved with is referred to as Blue Skies research- finding novel ways to advance science towards therapy for retinal degeneration. Some projects that they will be looking at this year are:

MD PROJECT

Dr Johann Baard is doing a project to find the factors that protect the South African Black population from Age Related Macular Degeneration. He will be screening different population groups for a specific epigenetic marker linked to the expression of AMD genes in these groups. Dr Baard's study takes us firmly into the brand new science of epigenetics- the molecules that are attached to the DNA that are only now being found to have a profound effect on how genes express in our bodies. The latest research shows that we can positively influence this by diet and exercise. He will also be identifying the gene mutations causing Stargardt Dystrophy in our black population.

DISEASE IN A DISH

Professor Jacquie Greenberg has developed a project to use Induced Pluripotent Stem Cells [iPSC] in an Ataxia project. This will be developed further by an MSc student Ms. Stacey Moses to research the RP13 [Splicesome] gene that Professor Ramesar and his team discovered in 1994.

USHER SYNDROME

An exciting new find in local Usher patients will also be explored- more details in the next ENews.

RESEARCH NEWS

Global causes of Vision loss

The British Journal of Ophthalmology recently published papers on the causes of vision loss in various regions. In the Sub-Saharan African report Macular Degeneration was placed 3rd [at 6,3%] after cataract and refractive error but ahead of trachoma [5,2%] glaucoma [4,4%] and Diabetic retinopathy [2.8%]. The committee preparing "Guidelines for Eye Health in South Africa" recently included retinal degenerative conditions as "an important cause of blindness in the childhood blindness category." They have requested that all State and private hospitals and eye specialists refer RD patients to Retina South Africa.

STEM CELL TRIAL FOR RP

Dr Klassen, University of California, is only about a year away from launching a stem cell therapy to rescue vision in patients with Retinitis Pigmentosa. The novel aspect of this research is that it is going directly from cell based research to the patient. This is circumventing the long held tradition of exhaustive and expensive animal model tests that has preceded any human trials. This therapy will introduce progenitor cells- stem cells that have partially developed into retinal cells- into the vitreous to release growth factors that are known to preserve and rescue existing retinal cells. Dr Klassen did much of his earlier work on mouse models of RD and said "Finally we are getting to the point of where stem cells are poised to do something meaningful in the clinic"

- <http://www.blindness.org>

AEROBIC EXERCISE PRESERVES VISION

Dr Mabelle Pardue, Emory University, recently published a report in the Journal of Neuroscience on the positive affects of exercise on mouse models of RD. Mice exercised on a treadmill for 1 hour per day, 5 days per week over a 4 week period showed twice the number of photoreceptor cells after exposure to toxic levels of bright light when compared to non exercised mice. The exercise produced brain derived neurotrphic factor [BDNF] which is known to prevent photoreceptor degeneration in animal models. The scientists believe the results may translate to humans and this may be a low cost, non invasive intervention that is freely available to all RD patients.

ARGUS 2 NEWS

The USA version of the artificial retina- the ARGUS 2 will soon be commercially available in 12 clinics in the USA. Second Sight has announced that it is now moving into clinical trials with the device for patients with AMD. The FDA last year approved the device for use in patients with advanced RP.

RED WINE GOOD FOR VISION??

Researchers at the University of Mainz recently published a review of studies that showed the protective effects of resveratrol, the polyphenol found in red wine. The paper was published in the Archives of Clinical Exp Ophthalmology. Resveratrol has previously been shown to have anti-oxidant, anti- apoptotic, anti- angiogenic, anti-inflammatory, anti-tumourogenic and vasorelaxant properties. Owing to its vascular-enhancing properties, resveratrol may be effective in the microcirculation of the eye, thereby helping prevent eye diseases such as age-related macular degeneration, diabetic retinopathy, and glaucoma. The researchers recommend human studies to investigate this further- any volunteers??

USHER SYNDROME

Researchers at Mainz University have estimated that the incidence of Usher

Syndrome is 1 in 6000 in the population- this much higher than the 1 in 12000 to 1 in 25000 that was previously used.

They also report on good results in developing a compound that targets nonsense mutations which account for around 20% of all Usher cases. This encourages a “read through” effect which nullifies the gene mutation.

ACHROMOTOPSIA

This recessively inherited condition causes a complete loss of cone photoreceptors. The gene CNGA3 accounts for about 80% of all Achromotopsia and the University of Tübingen, Germany, has succeeded in curing a mouse model with this mutation. This will pave the way for a human gene therapy trial for Achromotopsia in Germany.

RETINITIS PIGMENTOSA [RP]

German researchers at Munich University have announced results of a Gene Therapy to restore vision and delay degeneration in the CNGB1(-/-) mouse Model of RP. The gene replacement therapy led to a substantial delay of retinal degeneration and also long-term preservation of the retina. Treated CNGB1(-/-) mice performed significantly better than untreated mice in a rod-dependent, vision-guided behaviour test.

PHOTOSWITCH NEWS

Photoswitches are molecules that convert cells in the neural layer of the retina to light sensitive cells. Researchers at the University of California are restoring visual function to blind mice with a photoswitch named DENAQ that restores retinal responses to white light of an intensity similar to ordinary daylight. A single injection of DENAQ photosensitizes the blind retina for days, restoring electrophysiological and behavioural responses with no toxicity.

Choriorderemia News

Professor Robert MacLaren from the University of Oxford recently made international news with his new Gene replacement therapy. The results are very encouraging and 9 Patients have been treated. After six months patients showed improvements in dim light vision and two were able to read more lines on an eye chart. The difference in this trial is that the virus, carrying the CHM gene is delivered directly into the photoreceptor cells of the retina.

If you are interested in joining an international CHM network to exchange information and news contact Michael Langsfeld from Germany at chm@pro-retina.de or michael.laengsfeld@gmail.com

OSSA NEWS

The annual Ophthalmology congress was held in the Drakensburg in March. RK Communications, the congress organisers kindly sponsored our awareness table and our congress fees. Our accommodation was sponsored by Champagne Castel Hotel on the slopes of the stunning Champagne Castle peak.

A very successful RSA Scientific and Medical Advisory Board meeting was held at the congress. Professor David Meyer, HOD of Ophthalmology at Stellenbosch University sadly retired from the board. We thank him for his 20 years of dedicated service to finding treatments for retinal degenerative conditions. He is replaced by Dr Robyn Rautenbach the retinal specialist at Tygerberg Hospital. Dr Susan Williams, Wits University is the other new appointee to the board. We welcome them both and thank them for their support of Retina South Africa.

GAUTENG BRANCH NEWS

Brothers Rui and Jorge Faria organized a grueling 4 day Cycle ride from Johannesburg to Umhlanga Rocks in December to raise funds for research into retinal degeneration. Retina Gauteng received a tremendous donation of R22 300 from this event. Thanks to Rui and Jorge, the riders and generous sponsors for this wonderful support. THANKS GUYS!!

FUND RAISING

Retina SA is negotiating with various role players to bring clinical trials to South Africa. We need every member to participate in our fund raising projects to make this a reality. Can you help??

Sell tickets for our car raffle; sign up members to Woolworths My School / My village campaign and nominate Retina SA as a beneficiary; sign up members for our Circle of Light Competition for just R240 per year; organise a Spin for Sight in your area; have a cake sale, garage sale; Dinner in the Dark; get your friends to SMS 'Dream' to 38267 and donate R10 every month.

Organize sponsors for your next endurance event- run, walk, pedal or paddle for Sight. You need the exercise and we need the funds.

All donations over R1000 are eligible for a section 18a tax deductibility certificate.

STAFF CHANGE AT NATIONAL



Denise Jacobs is leaving Retina South Africa after 9 years of dedicated service. She is being replaced by Mandy Burns who is available weekdays on 0860 595959.



THANK YOU BAUSCH AND LOMB

For your continued support of our work.

Pictured at the OSSA congress are :

Juanita Hare, Claudette Medefindt & Marieke van

Nieuwkerk

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