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E-News

WORLD DIABETES DAY – 14 NOVEMBER 2021

Guest Editorial - by Karen Denton

The theme for World Diabetes Day (WDD) 2021 is "Access to Diabetes Care". The year 2021 is significant for the diabetes world, as it is the centenary of the discovery of insulin by Banting and Best in a small laboratory in Toronto.

It is notable that a hundred years after this life saving discovery, there are millions around the world who do not receive adequate care.

As many as 20% of people who are diagnosed with Type 2 Diabetes for the first time already have eye damage that they are usually unaware of.

This is of such significance that in 2007 the UN General Assembly adopted a resolution to recognise November 14th as World Diabetes Day (WDD) to highlight 'the urgent need to pursue multilateral efforts to promote and improve human health and provide access to treatment and health-care education.'



Karen Denton (Head of Advocacy & Education)

People with type 1 or type 2 diabetes need ongoing care, support, and education to live a fulfilling, meaningful life and to delay or prevent the complications that impact the individual, the family, and society.

One of the questions that we are frequently asked at Retina SA is 'which is more dangerous, Type 1 or Type 2? The answer surprises many - because it doesn't depend on the type of Diabetes. People who are given the tools to care for themselves, know what to do and how to do it, can live a long, healthy life. However, Diabetes is dangerous and can precipitate short- and long-term problems when there is insufficient care. Sadly, as stated above, many people do not have access to adequate care, and face complications such as heart attacks, strokes, amputations, kidney failure and blindness.

The International Council of Ophthalmology states that " ... one-third of people with diabetes have some form of diabetic eye disease that can lead to vision impairment and blindness. With effective diabetes management and early detection through regular eye exams and timely treatment, almost all vision impairment and blindness from diabetic eye disease can be prevented

If you already have a retinal condition you need to ensure that you protect yourself against the further loss of vision that Diabetes causes. Prevention strategies include:

- Regular exercise
- Healthy food choices
- No smoking
- Control BMI, BP, and Cholesterol
- Get regular eye checks

For further information, referrals, access to counselling, education and advocacy, please email headoffice@retinasa.org.za



Some of our counselling staff available to give you specific advice on the prevention of Diabetes Type 2.

Pictured from Left to Right: Claudette Medefindt (Head of Science), Lindiwe Maredi (Social Worker), Victoria Musimbo (Social Worker) and Karen Denton (Head of Advocacy and Education).

DIS-CHEM RIDE FOR SIGHT IS BACK



The annual Dis-Chem Ride for Sight 2021 was cancelled due to the Covid – 19 restrictions. We are happy to announce that a new date has been set for 20 February 2022.

Our loyal headline partner Dis- Chem Pharmacies will be the naming sponsor once again and we thank them for their phenomenal support over the last 20 years.

The Dis-Chem Ride for Sight has been the major contributor to the Retinal Research Project at the University of Cape Town for many years. Sadly, due to the cancellation of the 2021 event our contribution to UCT was severely affected.

We sincerely hope that the present restrictions remain in place, or improve for 2022 for this will allow the event to be staged.

We are indebted to our volunteer organising committee for their expertise and time that results in an exceptionally well organised and ever popular event. THANK YOU



CLINICAL TRIAL NEWS

We are in negotiations to bring an USHER Type 2 clinical trial to South Africa. Sadly, we estimate that only 10% of eligible patients are registered with Retina South Africa. This exciting trial will use mRNA technology to edit out a section of the USH2A gene that contains the mutation. Are you a candidate?

Usher Syndrome is a genetic condition that causes profound or severe hearing loss from birth.

People with profound hearing loss and minimal speech are usually diagnosed as Usher type 1. Usher type 2 children have moderate to severe hearing loss, but this loss may respond to hearing assistive devices. These children usually have good speech but may have a lisp or slight speech impediment. There is a more rare Type 3.

All 3 types are linked to different genetic mutations. Unfortunately, the difference between them is not always understood and some children may be misdiagnosed as Type 1 when they are actually Type 2. A letter about this probable trial was sent to all the Usher Type 2 patients on our registry and if you did not receive one and suspect that you may be eligible for the trial, please contact us at headoffice@retinasa.org.za

CLINICAL TRIALS PIPELINE

The Foundation Fighting Blindness. USA, is the world's leading private funding source for research to treat, prevent, and cure retinal degenerative diseases. Many of the trials listed on their website were made possible by Foundation support.

See <https://www.fightingblindness.org/clinical-trial-pipeline>

RESEARCH NEWS

Advances in Optogenetics

Various projects are in development to use Optogenetics to restore visual function. In this novel approach a light sensitive molecule is genetically delivered to the neural cells that will then transmit a message to the brain.

GenSight Biologics

GenSight Biologics reported recently on a single patient in their Pioneer study, that was treated with their Optobionic GS030 system which genetically delivers a light sensitive molecule Opsin CrimsonR, derived from an algae to the retinal ganglion cells. These molecules react to amber light and are activated by a specialized pair of goggles transmitting pulses of amber light. The patient who has end stage Retinitis Pigmentosa [RP] was treated by Dr Jose-Alain Sahel, who reported that the patient was able to perceive, locate, count, and touch objects.

FDA Approves Genentech's Susvimo for Treating Wet AMD.

The US Food & Drug Administration (FDA) has approved Susvimo™, Genentech's Port Delivery System (PDS) with ranibizumab, for the treatment of wet age-related macular degeneration (AMD).

Susvimo is a refillable capsule the size of a grain of rice which provides continual release of ranibizumab, a protein that blocks the growth of vision-robbing, leaky blood vessels which are the hallmark of wet AMD. The device is implanted near the surface of the eye during a one-time, surgical procedure. The device may only need to be refilled twice per year. The device is not yet available in South Africa.

Patients who have wet AMD should know that if their current Anti-VEGF treatment is not effective, they should consider changing to an alternative treatment. They should discuss this with their Ophthalmologist.

Retina South Africa has done extensive Advocacy work in ensuring that these alternative treatments are fully funded by medical aids. After meetings with Retina South Africa, Discovery Medical Aid now funds these alternate treatments in full, irrespective of the scheme.

Prozac may be the first treatment for Dry Age-Related Macular Degeneration

The repurposing of existing drugs that may prove beneficial in retinal disease receives extensive attention. The possible use of Fluoxetine, the antidepressant commonly known as Prozac, is now a promising drug emanating from this approach. What is of interest is how this was identified.

Traditional approaches to drug development are very expensive and time-consuming. Generally, a new drug takes 10 to 12 years to develop and costs \$2.8 billion. Prozac was studied in the laboratory and in animal models. To confirm their findings researchers turned to big data mining. They examined insurance records and found that clients who were being treated with anti-depressants had a substantially lower incidence of dAMD. Dr Bradley Gelfand from the University of Virginia said "Our identification of the unrecognized therapeutic activity of an existing FDA-approved drug using big data mining, coupled with demonstrating its efficacy in a disease-relevant model, could greatly accelerate and reduce the cost of drug development".

Dr Gelfand was involved earlier this year in using a similar approach to determine that HIV drugs known as nucleoside reverse transcriptase inhibitors, or NRTIs, may be useful against dry macular degeneration as well. "While we have had a great deal of success with the approach of using real-world patient data, we may have only begun to scratch the surface of finding new uses for old drugs," said Gelfand, of UVA's departments of Ophthalmology and Biomedical Engineering.

"It is tempting to think about all the untapped therapeutic potential of medicines sitting on pharmacy shelves."

Source: [Neurosciencenews.com](https://www.neurosciencenews.com)

Atsena Therapeutics Gene therapy for X-Linked Retinoschisis (XLRS)

XLRS is a retinal disease that causes a splitting of retinal layers leading to significant vision loss. XLRS is caused by mutations in the gene RS1, which produces a protein called retinoschisin that plays a critical role in the maintenance of the retinal structure and cell-to-cell adhesion.

In XLRS the mothers carry a copy of a defective gene and may pass this on to their sons. The condition is usually diagnosed in boys before the age of 10. XLRS is thought to affect one in 5000 to 25 000 boys.

Previous gene therapy trials showed disappointing results but in this Atsena trial the therapy is injected underneath the retina. This appears to deliver the treatment to the exact spot needed - the cavities in the central retina caused by the splitting of retinal layers. The gene therapy uses a specially designed adeno-associated virus delivery system (AAV.SPR) that can reach the fragile fovea, the tiny pit in the central retina responsible for visual acuity, without an injection in the foveal region.

NEED GENETIC TESTING

Please contact head office to discuss various pathways to getting a genetic test. To participate in clinical trials and have access to gene specific therapies you do need a genetic diagnosis.

EDUCATION AND AWARENESS

WhatsApp Group

There are 3 age-appropriate WA groups that RSA administers. Youth 16+, Adults with RD and Parents of Young RD youth. If you would like to join WA your full name, mobile number, and WA group to 0833065262.

Retina SA Youth Webinar

The Retina SA Youth Team are very excited to share that we had our very first interactive webinar on the topic of Blind Dating on 4 November. We believe that this would be a popular topic to discuss sharing our own experiences, discussing the challenges, as well as trying our best to give advice. The webinar was a great success with attendees even requesting a part 2. Thank you to everyone who joined and we are hoping to see more of you next time.

You can contact us on our email youth@retinasa.org.za

The next webinar will be held on Tuesday 30 November and the topic is Inclusivity and Accessibility. The link has been emailed to all members.

The final Webinar for the year will be on Saturday 4 December at 16h00. Topic is Living your best life with RD. The speakers will all be RD patients who will give short presentations on how they cope, and achieve, with RD. The link will be emailed and on our Facebook page and group.

Be motivated, educated and inspired. Questions by email or on the day are invited. This is a free, open access webinar with no prior registration.

WHAT'S HAPPENING IN THE EASTERN CAPE

Welcome Lwandisa Davids

Welcome to Lwandisa Davids who has joined Retina SA as an Orientation and Mobility practitioner. Lwandisa is stationed at the PE Office.



Lwandisa Davids

In August Lwandisa presented a Vision Rehab Workshop and demonstrated various O and M and Skills of daily living tips. These included tracking and tracing, money identification and cane and sighted guide techniques. She rounded off by showing some SDL and colour contrast utilisation. This equipped those who attended with a set of foundational skills to use their residual vision to monitor and be safe in their environment.

Contact Lwandisa on 041 363 0146

Bowling and Bonding—Saturday 20 November 2021

A day of bowling and bonding was held on Saturday 20 November 2021 at Westview Village Sports Club. Apologies that this went to press too late for you to attend this year.

Breakfast with Ophthalmologists from the Provincial Hospital

The PE staff organised a working breakfast with the Ophthalmologists from the Provincial Hospital. Staff members Yonela Hofu and Lwandisa Davids highlighted the life changing roles they play in the lives of the visually impaired as Social Worker and Orientation and Mobility practitioner.

Youth Empowerment Project

Grateful thanks to Garth Austin from Zifundise Training and Consulting for taking our Youth Empowerment project one step further by presenting a SWOT Analysis Workshop to 50 youthful delegates. Delegates were empowered to learn to recognise that the right Attitude goes a long way in understanding the practicalities of assembling a SWOT analysis for their personal lives and entrepreneurial endeavours. Zifundise Training and Consulting specialises in Business Solutions and Teambuilding.

AMD OUTREACH IN THE EASTERN CAPE

The team in Port Elizabeth gave presentations to various retirement facilities and groups in the Eastern Cape in September.

Port Alfred

Gail Cillie and Lwandisa visited the Port Alfred Settlers Park Retirement Village. They discussed the impact of Age-Related Macular Degeneration to the very appreciative villagers, their carers, and nursing staff. Lwandisa utilised the opportunity to do assessments for potential training in O and M.

Galvandale

The PE team educated the elderly about vision loss. The 10 steps to LOVE YOUR EYES was a feature of the talk.

Harvest Christian Church

Gail Cillie gave a in your vision presentation on Age Related Macular Degeneration-Identifying changes and what to do about it. She also took them through the Indicators, Diagnosis, Treatment Options and Rehabilitation Process.

JOB OPPORTUNITIES

A new Foundation to support Disabled Job seekers has been launched: Capacity Foundation and Capacity Website.

They aim to work with all disability organizations to ensure quality employment opportunities for persons with disability.

Job seekers can register on the Capacity Website: <https://www.capacity.co.za>

Any queries can be mailed to: biancadillon@capacity.co.za

OUR STAR IN TOKYO

Alani Ferreira, one of our Youth team leaders was selected to represent South Africa at the Olympic games in Tokyo. Sadly, she did not win a medal but returned with new SA and African records to add to her vast collection of medals and records.

Tokyo 2021—By Alani Ferreira

I was very blessed and proud to be part of team SA at the Tokyo Paralympic Games this year. Swimming has always been a stress reliever for me, but it has also allowed to me to challenge myself and see what I could really do. Being at the athlete's village at the Games is what I like to describe as the perfect world. It is a place where no disability is ever judged or seen as "weird", and people are viewed as an individual doing their sport at the highest level and not as a disabled person.

Above this, Team SA is basically family to me. Spending three weeks with the swimming team has made us family and I am so privileged to have spent the time with them.

Despite the Covid 19 pandemic, the Games were a great success with athletes doing daily saliva tests and following standard precautions.

The atmosphere of the Games was still as high as years before even with the missing crowds. Incredible performances were seen throughout the sporting codes and it was incredible to be part of the movement, united by emotions.



Alani Ferreira—Tokyo Paralympic Games 2020

Lastly, yes, the cardboard bed is the most comfortable bed I think I have ever slept in, and I was quite upset that I couldn't fold it up and pack it into my suitcase. We were allowed to take our Paralympic duvets though.

Editors note: Alani is such an inspiration to us all. Intelligent, hardworking, motivated, successful and yet so friendly and humble. She is very busy completing her second degree but always find time to reach out and help RD youth in need of some

guidance and mentoring.

AMENDMENTS TO TAX REGULATIONS FOR PARENTS WITH DISABLED CHILDREN

Income Tax

Income Tax Act, 1962

Amended List of Qualifying Physical Impairment or Disability Expenditure – Effective from 1 March 2020—<https://www.sars.gov.za/wp-content/uploads/Ops/Guides/LAPD-IT-G08b-Amended-list-of-physical-impairment-or-disability-expenditure-effective-1-March-2020.pdf>

Summary

The List of Qualifying Physical Impairment or Disability Expenditure has been amended to change the wording in Part F, paragraphs 7 & 8, affecting taxpayers whose children living with a disability attend a private special education needs school.

For more information, see Media Release: Physical Impairment or Disability Expenditure Prescribed by the Commissioner <https://www.sars.gov.za/media-release/physical-impairment-or-disability-expenditure-prescribed-by-the-commissioner/>

And Confirmation of Diagnosis of Disability Form (ITR-DD)

<https://www.sars.gov.za/wp-content/uploads/Ops/Forms/ITR-DD-Confirmation-of-Diagnosis-of-Disability-External-Form.pdf>

The management and staff of Retina South Africa wish you all a safe festive season and a Happy 2022

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