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RETINA E-NEWS to YOU

AMD NEWS

Interview with Dr Peter Kaiser

Dr Peter Kaiser of the Cole Eye Institute at the Cleveland Clinic Foundation in Cleveland, Ohio, USA, is one of the most respected, acknowledged and published clinicians working in the field of Age Related Macular Degeneration and Diabetic Retinopathy world wide. He was the key note speaker at the annual congress of the South African Ophthalmology Association held in Sun City in February. Dr Kaiser took time out of his busy schedule to speak to Retina E-News.

Q There is so much controversy about what treatment should be used for Wet AMD – Lucentis or Avastin. What should patients know?

A: The main issues are safety and cost. Lucentis was developed for use in the eye and all the safety studies were done and the data shows that the drug is safe to use. Avastin was developed for use in colo-rectal cancer and the possible effect of strokes or cardiovascular disease were thus not an issue. I always say “What would I use on my own Mother” - obviously the safest and most effective treatment available. However, that is not to say that Avastin doesn't work because we know that it does and it is a lot cheaper. But what price can you put on vision.

Q: There have been issues about patients receiving inadequate advice over the “informed consent” before the use of Avastin. How do you inform your patients?

A: I tell my patients about the data from the trials that have been conducted. That Lucentis is safe and it works and that Avastin also works but we don't know how safe it is. That there is a difference in cost but if you can afford it Lucentis is better and safer. It is also important to know that if your doctor uses Avastin on you and the results are poor, switching to Lucentis can improve the results. I have numerous patients that I have switched with good results.

Q: What about future treatments for AMD?

A: The anti- VEGF [Vascular Endothelial Growth Factor – Ed]

treatments [like Lucentis] are not a cure, we are only treating the symptoms and even after prolonged treatment the CNV [the Choroidal Neovascularisation-Ed] is still there. There are also new anti-VEGF treatments under trial. One of these is VEGF TRAP. The binding affinity of Lucentis is 5 to 20 times that of Avastin but the VEGF TRAP has a binding affinity of 10 to 20 times better than that of Lucentis. [The better the binding affinity, the less the VEGF can attach to the blood vessels causing leakage – ED]. This may lead to longer times between injections. Moreover, you will need less Lucentis than Avastin and you will probably need less VEGF TRAP than Lucentis to treat a given amount of CNV or leakage. In wet AMD pericytes surround the blood vessels blocking the Anti VEGF drugs from getting to the binding sites. Anti-PDGF drugs strip the pericytes from the CNV and allows better binding of anti-VEGF therapies. Combination treatments of anti-VEGF and anti-PDGF (platelet derived growth factor) appear to cause CNV regression which is not seen with anti-VEGF alone. This means that we are no longer treating only the symptoms but also the problem.

Q: When should patients opt to discontinue Anti-VEGF treatment?

A: While some patients regain vision on Anti-VEGF treatment some do not. When this happens, I test to find out why. Some patients continue to show a swelling in the Retina as measured by OCT [Ocular Coherence Tomography] but their vision remains stable- you cannot call that a failure. Maintaining vision is still a good result. AMD is a chronic disease and these treatments will be long term - they are treatments and not cures.

Q: What is the most exciting therapy that patients can look forward to in the next few years?

A: The combination of Anti-VEGF and radiation therapy is under trial and will probably become available in the next 2-3 years. People are scared of radiation but the new devices deliver small doses to targeted areas. There appear to be no complications and again we see the CNV disappear.

So really effective treatments for Wet AMD are right around the corner.



Dr Peter Kaiser pictured with the editor of E-News Claudette Medefindt at the OSSA Congress held in Sun City in February

LIVING WITH AMD

To view this excellent 35 minute DVD by the Macular Disease Society go to: www.maculardisease.org/template.asp?section=000500030007

OSSA CONGRESS 2010

The Annual Ophthalmology Congress was held in Sun City from the 10th to the 14th February 2010. Our awareness table was well frequented and dozens of information booklets, posters and Amsler grids were handed out. We also had numerous requests for inclusion on our mailing list for this newsletter. Retina featured prominently on all the various programs and the standard of papers given was very good.

Dr Peter Kaiser's presentations on AMD were all excellent and very well attended. It is gratifying to note the increased interest that the new Anti-VEGF treatments have brought to retinal conditions in general and AMD in particular. With particular interest to Retinal patients was a presentation on the new accommodating intraocular lens. IOL's are implanted after cataract surgery and these new self focusing lenses sound marvelous. Sadly it would seem that retinal patients should not have these lenses implanted. Before you have cataract surgery discuss your options with your Eye Specialist.

Our awareness table, and congress fees were sponsored by the Ophthalmology Society of South Africa and our accommodation was



sponsored by the Southern Sun Hotel group. We extend our sincere thanks to them and also to the congress organizer Ryhno Kriek for facilitating this sponsorship and his kindness to us. The next OSSA congress will be held in March 2011 in Port Elizabeth.

Dr Louis Kruger one of South Africa's most renowned retinal specialists pictured at the congress with your editor

FANTASTIC DIS-CHEM RIDE FOR SIGHT 2010

The 22nd Dis-Chem Ride for Sight was held on Sunday the 21st February at Boksburg City Stadium. Almost 5000 cyclists pedalled the 116km Super Classic or the 63km Vita-thion Challenge. The number of entrants was a slight increase over the 2009 field and this is very encouraging in light of the dwindling numbers in other cycle events. Christoff van Heerden, fresh from his victory in the South African Championships, was the winner of the main event, while the ladies trophy went to Jennie Stenerhag from Sweden. The event received extensive media coverage and Dis-Chem sponsored a special program on the event which was broadcast on MNet Supersport 24

times between the 11th to the 23rd March. The program also featured interviews with Professor Raj Ramesar, our CEO Ebrahim Patel and your editor. In order to make the road safer Dis-Chem also repaired all the pot holes on the route. We are indebted to Dis-Chem for this fantastic sponsorship and their support of our vision. Thanks also to all our other sponsors: Vita-thion, Biogen, Piz Buin, Cellfood, Marcus Rohrer Spirulina, Aminostim, Transact, Tour de Frans, RaceTec, CycleEvents, PowerAde, Nestle (Bar1), Mongoose, MTN, Wilderness Safaris, Venter Trailers, Rotary Watches, Think Bike, Bravo Group, Dial-a-Bed, Grafton Everest, Sealy Posturepedic, Emperors Palace, Kenwood, Steinhoff, Polaroid, City Lodge, Cape Storm, Southern Sun, Liquor City, Michelle's Travel, Bollè, Matopi Lodge, Pick n Pay Towers, Tempest SixT Car Hire, GetPix Photographic studio, 1Time Airlines, Rock Lodge, Birchwood Hotel, Designer Group, Continental Tyres, Villa Rostrata, Beachcomber Travel, Cathedral Peak Hotel, Indaba Hotel, Simba Chips, Voith South Africa and The Spar.

Our helpers are a crucial part of the event and Springs Wheelers, Alberton Amateur Radio Club, Red Cross, Wits Department of Physiotherapy, Rotary and Lions Service Clubs and our loyal volunteers cannot be thanked enough. Some of them have been with us for 22 years and others are recent recruits in the fight against Retinal Blindness. Together they ensure the continuation of our research project at the University of Cape Town.



A jubilant Christoff van Heerden with the Ernest Hunt Trophy, winner of the 2010 Dis-Chem Ride for Sight

Picture Courtesy of GetPix

UPDATE ON RETINAL RESEARCH

STEM CELLS

Dr Stephen Tsang and colleagues from the Edward S Harkness Eye Institute, Columbia University, USA will give an update on their research to the 2nd Annual Ocular Disease Drug and Discovery Conference in Boston, USA on May 27th . Their research focuses on using Embryonic Stem Cells that have been reprogrammed to emulate Retinal Pigment Epithelial Cells. They have transplanted these cells into mouse models of RP with reported improved visual function.

USHER SYNDROME

Dr Ray Lund at the Casey Eye Institute at the Oregon Health and Science University has successfully slowed the progression of vision loss in animal models of Usher Syndrome Type 2A. The mouse model, a first for Usher Syndrome, was developed by Dr Li Tiansen from Harvard Medical School. The successful use of neural stem cells is also showing promise in the treatment of other diseases such as Parkinson's Disease. The results of this study were published in the December 2009 issue of the Journal of Investigative Ophthalmology & Visual Science.

LCA UPDATE

The successful gene replacement therapy trials to treat the RPE 65 form of Leber Congenital Amauroses continue to progress with positive results. The team at the Children's Hospital of Philadelphia [CHOP] have applied to the American FDA to treat the second eye of patients who have had successful treatment to one eye. Their submission was due to successful results from animal model studies. In these studies no detrimental immune response was observed after treatment of the second eye.

ARVO AWARD FOR PROFESSOR ROBIN ALI

Retina South Africa congratulates Professor Robin Ali, the leader of the team at the Institute of Ophthalmology, University College of London, that performed the first LCA gene replacement therapy. He is to be honored by the ARVO Foundation for Eye Research. He will receive the AFER/Pfizer Ophthalmics/Carl Camras Translational Research Awards at the ARVO Conference in Fort Lauderdale in May this year.

Professor Ali and his team at the University College, have also successfully silenced the Peripherin Gene in a mouse. The gene was knocked out by a vector mediated delivery of a segment of RNA. This "offers an alternative therapeutic strategy for the treatment of dominant retinopathies". The article is published in the latest edition of Gene Therapy.

NEW LASER FOR DRY AMD



Professor John Marshall a senior Ophthalmologist at Kings College, London has developed a way of "cleaning" the debris that accumulates in Bruchs Membrane in the retina in Age Related Macular Degeneration. His pioneering technique uses a

painless "short pulse" laser to help the eye's waste disposal system

do its job after it has been weakened by age. Professor Marshall has invented other unique ocular systems including the Scanning Laser Ophthalmoscope. Professor Marshall is a member of the Scientific and Medical Advisory Board of British RP Fighting Blindness and of Retina South Africa.

Sources: The Observer and Mail Online, UK.

CATARACT INFORMATION

Issued by the American Foundation Fighting Blindness.

To help people with retinal degenerative diseases better understand issues related to cataracts and their removal, Foundation-funded clinicians Richard Weleber, M.D., of the Casey Eye Institute, Oregon Health & Science University, and Jacque Duncan, M.D., of the University of California, San Francisco, provide the following answers to commonly asked questions:

1. Why do people with retinal degenerative diseases get cataracts more frequently than the general population?

A: Researchers don't know for certain, but they believe that more frequent cataract formation occurs because degenerating photoreceptors cause chronic, low-level inflammation in the eye. The cataracts are somewhat similar to the type that patients with Uveitis get. (Uveitis is swelling and irritation of the uvea, the middle layer of the eye.)

2. What are the hazards of cataract removal, especially for someone with a retinal degenerative disease?

A: People with retinal degenerative diseases have increased risk of complications from cataract removal, because of the fragility of their retinas. Some complications include: inflammation of different parts of the eye, macular edema (swelling of central retina), and more difficult management of an existing epiretinal membrane (scar tissue).

3. How does one reduce their risk of complications?

A: The surgery should be performed by someone expert at removing cataracts, using as little light as possible and practical. The patient should be treated aggressively for ocular inflammation before and after surgery. Ideally, the surgeon should be familiar with retinal degenerative diseases, and the special considerations that need to be made when performing surgery on these patients.

4. Does the type or extent of retinal disease impact the decision to have a cataract removed?

A: Yes. The extent and location of damage to the retina will certainly

Interesting Links

www.retina-international.org

www.fightblindness.org

www.amdalliance.org

www.Novartis.com

affect the decision process. The Eye Specialist will consider the odds that vision will be improved following the surgery, and whether the benefits of surgery outweigh the risks. All people with retinal degenerative diseases should thoroughly discuss the potential risks and benefits of cataract removal with their ophthalmologist.

FUND RAISING NEWS

- Huge thanks to Novartis for renewing their sponsorship of the E-News for 2010. They are also sponsoring a delegate to attend the Retina International Congress in Italy in June. We truly appreciate their support.
- Thanks to Standard Bank for a generous donation towards our research fund. A special thank you also to our member Mr S. Jordaan who won an internal bank competition and nominated Retina as the recipients of the donation.
- Thanks also to Kalene Roux, wife of Ophthalmologist Dr Charl Roux, for organizing a "Concert on the Water" on the farm Idille near George. The evening of music and dance was thoroughly enjoyed by the 140 people who attended. One wrote ecstatically - "The light classical works were sensitively chosen, the musicians a delight, the amazing ballerina magical, fragile, her arms delicately hypnotising the audience in excerpts from Swan Lake and then, so sensuous during the Tango! Where did they find her? The audience loved the whole experience, meticulous attention to every detail, generosity and a warmth not found in large cities – all



remained for coffee and koeksusters and wine on the terrace – amid lots of rejoicing that we live where we do!

Thank you to Kalene and family for donating the proceeds from such a special evening to Retina South Africa Fighting

Blindness. We believe it is going to be an annual event. Good Luck!

Brent, Kalene, Benjamin, Leanne and Ingrid, entertaining the audience.

RETINAL PATIENTS GROUP

Want to have your say about retinal degeneration and how it affects your life? Now you can post your opinions and experiences on FACE BOOK: www.facebook.com or TWITTER at www.twitter.com/retina_sa.

Getting Started

- Users must first have a Facebook Profile or create a new Facebook

Account/Profile. Users must also have an eMail address.

- Open the Internet (Internet Explorer, Mozilla etc.)
- Type in the URL www.facebook.com and press Enter or click on the Refresh  icon to open the FACEBOOK page.
- Existing Facebook users type in your EMAIL ADDRESS and PASSWORD and click on the Login button. If you are new to Facebook SIGN UP - fill in your details and click on Sign Up (NB. your password is case sensitive).
- On the Facebook home page search for the group called Retina SA-Fighting Blindness.
- If you wish, Join the Group.
- The Facebook Wall [TAB] is visible and open to any member accessing this group. Users can *write something...* new or add a *comment* to an existing feed.
- Under Discussions [TAB] Start a New Topic, alternatively participate in an existing Discussion (post your "story" or "comment").
- Also check out Retina Branch Events [TAB], Photos [TAB] and Videos [TAB] when available.

WEBSITE UPGRADE COMING SOON

Look out for our new improved website www.rpsa.org.za in the coming months.



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