



RETINA E-News

No. 8 December 2008

Seeking a cure for Retinitis Pigmentosa, Macular Degeneration and allied Retinal Dystrophies

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RETINA E-NEWS to YOU

FINAL 2008 EDITION

MESSAGE FROM THE CHAIR



2008 has been a challenging year for the Foundation as funding for research has become even more difficult, taking into account the economic climate of the world's financial standing. This has, thankfully, in no way detracted from this extraordinary year for vision research. Groundbreaking clinical trials in gene therapy and incredible progress in biotechnology, stem cell research and retinal transplantation have brought cures and treatments for retinal degenerative disease in sight.

This is a good reason for all of us to celebrate and revitalise our energy as funding is our only obstacle. It is thus more important than ever that we continue our work to fund the research that will deliver these treatments and cures.

I appeal to all patients to get involved as your contribution in whatever form can make a difference.

Patients, members and committee members you have my eternal gratitude for your commitment, dedication and hard work. We are counting on your continued support, and we are looking forward to another productive year.

May I take this opportunity to wish you and yours all the very best for the coming year and to those of you who celebrate Christmas, may it bring you peace and joy.

SMS CAMPAIGN

In an effort to help raise much needed funds Retina South Africa has launched an SMS fundraising campaign. TV and radio adverts have been featured on various radio and TV channels to encourage the public to support our fight against retinal blindness. The campaign has been supported by Vodacom, Grey World Wide, DSTV, Primedia, Radio Today, ETV, Integrat Systems, Cycle Lab and numerous newspapers and private donors. It's not too late to participate!

SMS the word VISION to 38267

SMS's costs R10 • premium rates • free SMS's do not apply • all prices include VAT. We need your help. Every Rand counts.

RESEARCH NEWS

EXCITING RESEARCH INITIATIVE

The new HOPE FOR VISION newsletter features an article by Dr David Pepperberg, Professor of Ophthalmology at the University of Illinois, Chicago. This article describes an exciting new approach in the effort to bypass dying photoreceptor cells in the retina.

Even in advanced stages of RP or AMD, where the light sensitive photoreceptors, the rods and cones, are no longer functioning, the nerve cells that carry messages to the brain are generally still intact. These post-photoreceptor cells are being used in many areas of research to bypass the inactive rod and cone cells.

Dr Pepperberg's team of neuroscientists, chemists, molecular biologists and bioengineers are constructing and testing light sensitive molecular structures to interface with these functioning nerve cells and restore visual function. This is a novel chemical approach and they are investigating molecules that have previously been used in both biological and non biological systems as the light sensitive component. These molecules will need to bind selectively and tightly to the correct position on the post-photoreceptor cells. To assist in this process partner molecules are being developed which will help to anchor the molecules at the correct protein site.

This chemical approach uses the same basic photo receptor bypass methods being developed by researchers in the Artificial Retina. Other research projects are investigating the use of photo sensitive cells derived from Stem cells to replace dying photoreceptors. Another avenue under investigation uses molecular biology to promote the expression of a new light sensitive protein within the post-photoreceptor cell, thereby reprogramming these post-photoreceptor cells to become photo-responsive.

Why, you may ask are there so many areas of research? Would it not be better to focus on just one area such as gene therapy or the artificial retina? Researchers are not yet sure which approach will work the best. As highlighted in our last newsletter there are many genes causing retinal degeneration, they are involved in many aspects of vision, are expressed in many different retinal cells and in some genetic types the introduction of a new, healthy copy of the gene will not be sufficient to stop the death of the photoreceptors.

See full report on:
www.hopeforvision.org

New chemical approach
to bypass dying photo
receptors

New gene finding important for stem cell research

LCA update

Dr Pepperberg ends his article with this explanation *“Indeed if history is any guide, it is virtually certain that we will attain this goal [of vision restoration] with knowledge gained from multiple lines of study, as well as from totally unexpected findings that could emerge from an even broader range of investigation.”*

NEW GENE FOUND

Researchers in Canada have identified a new gene, Ikaros, which regulates how neural stem cells generate the appropriate cell types in the retina at the right time during normal development. These findings were published in the October issue of *Neuron* and could influence the development of future cell replacement therapies for genetic blindness. The gene was found in the most immature retinal cells in mice while they are still able to produce all 7 different cell types found in the retina. The gene is not expressed later on in the development of the retina when stem cells have already started become more specialized. The research was conducted at the Institut de Recherches Cliniques de Montreal (IRCM), and was funded in part by the Canadian Foundation Fighting Blindness.

LCA UPDATE

The latest results on more successful gene therapy on 3 young adults with Leber Congenital Amaurosis comes from Dr Samuel Jacobson at the University of Florida and Pennsylvania. The 3 young people aged between the ages of 21 to 24 demonstrated improved vision in both bright and dimly lit settings. There are 3 different groups working with the RPE 65 form of LCA, Dr Jacobson’s group, the Children’s Hospital of Philadelphia and Moorfields Eye Hospital in London. [See *Retina E-News* No. 7] They are all studying varying injection sites, dosages and promoters.

Promoters control gene expression – the amount of protein that the gene instructs the retinal cells to produce. Researchers want to identify which promoter will lead to just the right amount of protein that needs to be produced. Multiple studies should ultimately lead to optimal treatment. Continued success in these LCA studies will also pave the way for developing gene therapy to treat other forms of Retinitis Pigmentosa, Usher syndrome, Stargardt disease, Choroideremia, and other retinal degenerative conditions.



You can view two short videos of the Phase 1 Gene Therapy Trial on line at www.blindness.org. Go to Videos, click on ABC News and then on Top 10 Videos. Click on Giving Eyesight to the Blind, or go to Good Morning America. - Information from Foundation Fighting Blindness, USA

This is an actual photograph of the delivery of a working copy of the RPE 65 gene to one of the patients in America. – Source Mailonline, Daily Mail UK

HONOURING OUR OLYMPIC STARS

Retina South Africa watched the recent Paralympics in Beijing with great interest. Two of our young members were competing and both won medals in their respective events. Ilsa Hayes from Port Elizabeth won a silver medal in the 100 meter track event and a gold medal in the long jump. Both these results were also her personal bests. Gavin Kilpatrick and his pilot Mike Thompson took the bronze medal in the 1000m track sprint after crashing dramatically out of the silver event.



Gavin Kilpatrick [right] on the podium at the Paralympics in Beijing.

Ilsa Hayes being congratulated by former President Nelson Mandela on achieving her gold medal.



CONGRATULATIONS to these two young “STARS”, both of whom have Stargardt Dystrophy - a juvenile form of Macular Degeneration.

WORLD RETINA WEEK – SEPTEMBER 2008

Retina SA would like to thank Bausch and Lomb, producers of the Occuvite range of supplements for AMD for sponsoring posters and pamphlets for World Retina Week. They have also sponsored the printing of an update of the popular booklet on Macular Degeneration which is now once again available from the national office on request. Thanks also to Novartis Ophthalmics for their sponsorship of posters and pamphlets and Specsavers (through Ink and Print Port Elizabeth) for sponsoring the printing of the Retinal Fact Sheet.

CHAIRMAN’ S AWARD FOR AFRIGIS

Claudette Medefindt presented the Chairman’s award to Magnus



Rademeyer, MD of AfriGis, Pretoria in November for their sponsorship of a segment of the UCT Retinal Research Project for 2008. AfriGis also has a proactive policy in the employment of people with low vision and they are therefore doubly deserving of this award.

Tax certificates can be arranged for significant sponsorship of the research project. Contact the National Secretary for details.

ASSISTIVE TECHNOLOGY

Vodacom Launches Three New Speaking Phone models

Vodacom has launched three new Vodacom Speaking Phone models as part of its drive to make cellular communication accessible to people with disabilities, specifically customers who are blind or partially sighted. The first Vodacom Speaking Phone has been available to Vodacom customers since 2005, however, the three new speaking phones offer customers a choice of handsets that best meet their specific requirements.

Text-to-speech software, preloaded on the speaking phone at NO additional charge to the customer, converts information displayed on the cellphone screen to speech. Partially sighted customers are able to more easily make and receive calls and are able to compile, send and receive SMS messages, access their list of contacts as well as battery life information and signal strength. The three new speaking phones include the Nokia E65 and Nokia E51, both of which have a 2 Megapixel Camera, Wi-Fi, Email and a MicroSD Slot. The E65 comes with Office Applications while the E51 can synchronise with Outlook and Pim Settings. Also included is the very popular Nokia N82 which is fitted with a five Megapixel Camera, Integrated 2-Year Voice Navigation, 16 Million Colour Display and a Video Capture facility. Wrapped up with this ideal little number is a 2GB Memory Card for additional storage space.

The Vodacom Speaking Phones are available on Vodacom Contract, Top Up and Prepaid packages at participating Vodacom approved outlets. For more information, please contact the Specific Needs Contact Centre on 12580, free from Vodacom cellphones, or on 082 12580 from any other phone (standard rates apply). Customers can also send an SMS to 12580 (free from a Vodacom cellphone) or email to 12580@vodacom.co.za. Information is available on the Vodacom website: www.vodacom.co.za under the Specific Needs section.

The Amigo video magnifier- Reviewed by Duncan McAllister

Speaking cell phones at no extra charge!

Like many others I have had mixed fortunes with low-vision equipment. Herewith some advice:

- before buying a product, first thoroughly test it to see whether it works for you in your own environment. Preferably borrow a demo model for a trial period.
- do not buy the first product you see. There is a wide range of equipment available, the technology is continually advancing, and you should not settle for anything second-rate.

I had been looking for a portable video magnifier since I lost my ability to read printed text. The little Eschenbach prism magnifier which served me well for many years eventually just did not give me sufficient contrast. I resorted to scanning documents, converting them to a negative image (black background with white writing) or to text using optical character recognition (OCR) software. I would then load them onto my 24" LCD computer screen. Converting to text in MS Word was ideal for reading a large number of pages, because you can wrap the text to the window which makes reading much faster by avoiding back and forth scrolling. This is time-consuming and is often not possible or practical. For example, if you need to look up a phone number you can hardly scan the entire directory, and you cannot scan a menu in a restaurant, a till or credit card slip in a shop, a label or serial number on a gadget or a gauge on a piece of equipment. I sometimes have to give lectures at venues away from my office, and needed a magnifier to read my brief notes.

Last year I bought a video magnifier at a cost of R6 500, but I found that the screen was too small and it lacked sufficient contrast. I returned it for a refund and replaced it with the Amigo which is made by Enhanced Vision, a US-based company. At around R15 000 (the price may vary depending on the exchange rate) it cost more than double the other model, but at least I could read with it.

Main features:

- 6.5" screen (16.51 cm)
- 5 colour viewing modes
- 3.5 – 14X magnification (up to 40X on a 20" TV)
- Freeze picture
- Rechargeable battery on board plus a spare battery with a separate charger. Each battery is good for 1.5 hours of continuous use.
- Can also be run off the mains power supply
- Can be linked to a TV or LCD monitor with video input
- Handy pouch with carrying strap
- Two-year warranty

The unit is definitely portable and easily fits in a briefcase. It is also reasonably light at 600g.

It is very easy to operate. There are two little wheels on the side which

Interesting Links

Retina International
Foundation Fighting
Blindness
AMD Alliance
International

control the level of magnification and colour viewing mode respectively.

There are five magnification levels, ranging from a minimum of 3.5X to a maximum of 14X which is more than adequate. It can also be connected to a TV or LCD screen with video input and connects easily to my Samsung 24" LCD computer monitor which then allows increased or reduced magnification. Reduced means a much larger image on my monitor. You can choose between five viewing modes:

- full colour, black and white, high contrast white background with black text, high contrast black background with white text; blue background with yellow text or black background with yellow text.

Having the ability to change the colour setting is useful when reading a magazine that has black or white text on varying background colours.

The high-contrast negative image is impressive – it is comparable to what you would get on a computer screen.

The freeze picture feature is very useful as it enables you to take a temporary picture of what you are viewing. This is handy for looking up a phone number, which you can freeze and then dial at your leisure. I have also used it to freeze an SMS on my cell phone and to take pictures of labels, serial numbers, gauges and even toolbar button descriptions on your computer screen. The Amigo's screen is hinged, so you can lift it and view an image without having to look at it from above. This is also handy when using the freeze picture feature.

Limitations:

Like all low-vision equipment the Amigo has its limitations. I could not read my credit card numbers with it because of the colours on the cards, which are designed to block scanning. I have used it to read my cell phone screen but it is not easy because the light on the phone switches off after a few seconds - far better to use a cell phone with text-to-speech software. I also found it difficult to read on curved surfaces such as a bottle. The Amigo comes with a writing stand but I was unable to use it because it does not work with the negative image mode, and only a small part at the bottom edge of the screen is visible, and there is very little room to place your pen. Perhaps if you can read on a white background and have a stump-like pen and small hands you might have more success! But at least the Amigo can be used to position a ruler or signature card where you need to sign.

Overall I have been very happy with my Amigo. In a nutshell:

The Good:

- Excellent contrast on a decent size screen, 5 viewing modes including negative image, Good magnification range, Freeze picture, Compact size and portable, 3 hours of continuous use without charging, Two-year warranty

The Bad:

Are your details correct?

- Price, A bit heavy (600g), Could not write with it.

Before you splash out R15 000 consider whether you need the convenience of being able to read on the go. You may do better with a desktop model with a sliding table.

Need more info?

You can download the users' manual from the Enhanced Vision website.

<http://www.enhancedvision.com/assets/sites/5/userFiles/downloads/Amigo%20User%20Manual.pdf>

The local agent is Sensory Solutions.

<http://sensorysolutions.co.za/LowVisionOutline.htm>

PATIENT REGISTRY

We all know that treatments for some forms of retinal degeneration are now only a matter of time and money. When patients are selected for genetic tests or for future multi centre treatment trails it will be from our patient registry. Are your details current and accurate?

If ANY of your details have changed (address / phone no's / e-mail), please inform us at national@rpsa.org.za or fax 011 622 6277 so we can update our database accordingly.

MY ASPIRATIONS FOR THIS NEWSLETTER

“Put it before them briefly so they will read it, clearly so they will appreciate it, picturesquely so they will remember it and, above all, accurately so they will be guided by its light.”

- Joseph Pulitzer (1847-1911)

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