



# My prog-MS ezine

For people with progressive MS  
and other interested people

Issue number 7, April/ May 2016

**Hello and welcome to the latest edition of my free ezine about progressive MS and MS progression in general. My name is Ian Cook. I'm a 57 year old secondary progressive MSer who lives in Birmingham, UK .**

In this issue are six pages of important prog-MS news stories plus two features about issues that matter to me and will doubtless affect others too. The first feature on page 4 is about a cheap eye test you can get at high street opticians showing MS progression. The second feature is about bladder problems which have bedevilled me recently. This bladder feature (Page 9) shows a fairly graphic image relating to my MS-affected bladder so be warned!

All that remains for me to say is welcome and please send this ezine to all other MSers, MS nurses and neurologists in your address book, and we can share our knowledge about what it's actually like to live with prog-MS.

**IN  
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ISSUE**



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**Why going for a pee can become such a hassle in progressive MS**

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- **The £50 eye test that shows progression, p4**
- **New PPMS drug could be in UK in 2017, p2**

## **Ocrelizumab fast-tracked by US regulator – 2016 release date likely - but UK situation less certain**

**The US Food and Drugs Administration (FDA ) has granted a new experimental drug ocrelizumab a fast-track status known as 'breakthrough therapy designation' for primary progressive MS.**

This means the drug could be in US clinics in six to seven months instead of the usual 10 to 12 months.

If all goes to plan, ocrelizumab could be available for primary progressive American MSers as early as the second half of 2016 although the UK watchdog, the National Institute for Health and Care Excellence (NICE), will have to assess if it is cost effective for NHS patients.

Ocrelizumab may also be available for people with secondary-progressive MS who are experiencing relapses. Sadly ocrelizumab has not been studied so far in people with secondary-progressive MS who are not experiencing relapses so the situation here is unclear.

Writing in his blog (ms research blogspot) on April 5 Prof. Gavin Giovannoni said the following about the likely UK situation: “If all goes well, we should be able to start prescribing ocrelizumab to MSers in about 18-24 months. The problem with having to wait 24 months is that we are disadvantaging a relative large group of pwMS.”

Prof Giovannoni is keen to see a higher profile given to rituximab - another drug similar to ocrelizumab to treat PPMS. But a recent trial into rituximab in SPMS has just posted negative results (See page 11)

***For details of sources for all news stories go to page 13***

## **Epilepsy drug could slow MS disability progression**

**A medicine commonly used to prevent seizures in epilepsy also has the potential to slow the accumulation of disability in MS, according to a study published in the March 2016 edition of Lancet Neurology.**

The study, a phase 2 clinical trial, involved 86 people experiencing early symptoms of acute optic neuritis. On average those who received the epilepsy medicine which is called phenytoin had 30% less damage to the nerve fibre layer in the eye compared to those who received placebo. The study was originally presented to the American Academy of Neurology Annual Meeting in April 2015 but the research has just been published.

Commenting on the findings researcher Dr Raj Kapoor said: “Protecting nerve fibres from damage during the course of MS has the potential to prevent disability, which is a key goal of MS research. If further studies of this or similar neuroprotective approaches are successful it could change the future for people with MS.”

## **Plant extract may slow brain shrinkage in prog-MS**

**A chemical extracted from a plant widely grown in India and Sri Lanka is to be tested as a treatment for brain shrinkage among patients with progressive MS,**

The chemical called andrographolide is found in the plant *Andrographis paniculata*, native to India and Sri Lanka, where it has been traditionally used to treat infections and some diseases. Mostly the leaves and roots are used for medicinal purposes, but the whole plant is also used in some cases. The purpose of the study which will take place in Chile is to compare the efficacy and safety of andrographolide versus a placebo as a disease modifying drug for progressive MS. Earlier trials showed it was effective in a mouse model of MS.

***For details of all news stories go to page 13***



## The £50 eye test that shows you how fast your MS is progressing

**Until recently the letters OCT meant nothing to me. Then a few years ago while at an opticians I discovered OCT stands for Optical Coherence Tomography.**

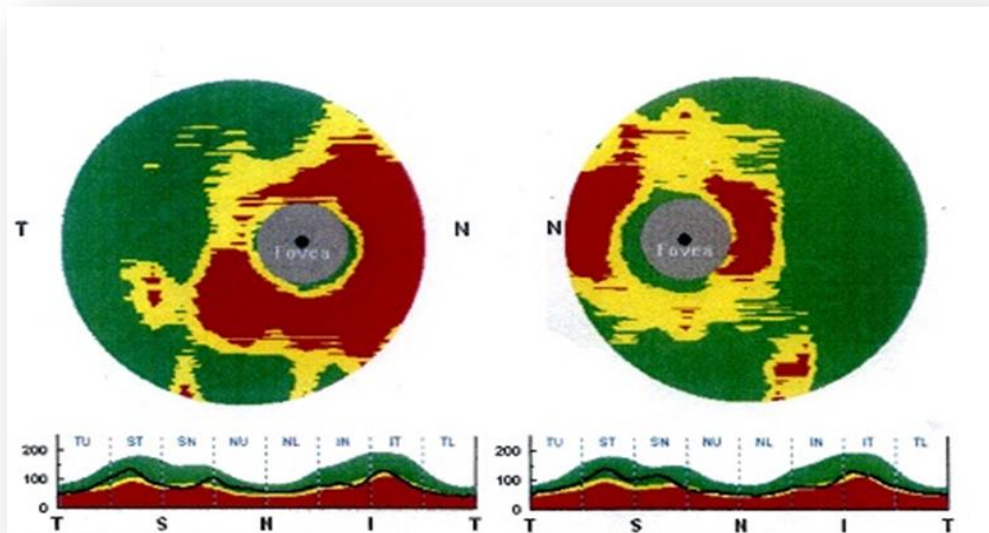
OCT is an eye scan that can cost as little as £50 and can provide a fast and effective way of monitoring the progression of your MS. It is now available at many high street opticians like my local one (left).

Most people going for OCT scans at high street opticians are people with diabetic retinopathy, glaucoma or macular degeneration. But OCT is also useful for us MSers too because a scan can show in superb detail the thickness of the retinal nerve fibre layer (RNFL) which lies just behind the retina and connects the retina to the optic nerve. This nerve layer thins as MS progresses, so measuring its thickness can tell you how fast your MS is progressing.

The scan itself is a beam of infrared light which is flashed across your eyes for a few seconds giving a 3-D image of the retina and the layer of RNFL cells just behind the retina. (See pictures on next page ) For the scan you just sit upright in a chair and stare into the scanner which looks exactly like any other equipment you see in a high-street opticians.

While staring into the scanner a 3-D image of your retinas and retinal nerve fibre layers is made. Both eyes are scanned separately and the whole thing takes just a couple of minutes. It is painless and, unlike an MRI scan, there are no claustrophobia issues. It costs about £50 and after the scan you get a sheet of paper containing images of your retinal nerve fibre layers.

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Above is a picture of the first scan I ever had – in Poland in 2011. The big circular pictures at the top are my retinal nerve fibre layers seen from the front. There are three colours used : red , yellow and green. The colours show the thickness of the nerve fibre layers behind the retina. – it’s a sort of “traffic lights system”. Red indicates serious thinning, yellow is intermediate damage and green is normal. As well as the big images two little long images below it are a cross section of the RNFL in each eye. If you look closely you’ll see a black squiggly line showing the depth of the RNFL in both my eyes –it’s dipping into the yellow and red areas confirming RNFL thinning in both eyes.

RNFL thickness is measured in units called microns. A healthy adult should I believe have an RNFL thickness of 90-100 microns ( $\mu\text{ms}$ ). One scan done in 2012 measured the thickness, of my right eye at 83  $\mu\text{ms}$  and my left eye 84  $\mu\text{ms}$  (well below 90-100.) My latest scan carried out at my local opticians in Birmingham in April 2016 done using a slightly different machine to the Polish one above showed the RNFL in my left eye had thinned further to 73  $\mu\text{ms}$  and my right eye had thinned even more to 66  $\mu\text{m}$ ! That is MS progression for you!

OCT scans are also generally available at eye hospitals and ophthalmology departments so it’s always worth asking your neurologist or neuro-ophthalmologist. **For more information on OCT go to page 13**

## **Appetite hormone may play role in progression**

**MS progresses with age because people tend to get fatter as they get older. That is the view of researchers who now believe the hormone leptin which influences appetite may play a part in MS progression.**

Fat cells release leptin after a meal to curb the appetite and levels of leptin, which is called the satiety or fullness hormone, also increase during inflammatory or immune responses. It is this which makes researchers think leptin has a role to play in MS progression.

Researchers have also discovered that leptin-deficient mice are resistant to experimental autoimmune encephalomyelitis (EAE), an animal model of MS. Other research from Iran has shown that progressive MSers have elevated levels of leptin

## **Testosterone to be tested on men with prog-MS**

**A group of 96 male MSers including those with primary and secondary progressive MS are to be assessed to see if doses of the male sex hormone testosterone can prevent brain shrinkage.**

The trial which will take place soon at 22 locations in the US will see 48 male MSers receiving testosterone gel delivered by a pump for 96 weeks. A further group of 48 men with MS will receive a placebo or dummy treatment.

A 2014 study published in the journal *Neuroimage Clinical* showed that grey matter loss in brains disappeared when a small group of 10 relapsing remitting male MSers were treated with testosterone. The present trial will use a far larger group of patients. No further details were available as we went to press.

**For details of sources for all news stories go to page 13**

## **Ageing ovaries may signal MS progression**

**Ageing ovaries are linked with higher levels of MS-related disability and a reduction in grey matter volume, independent of a woman's age and MS disease duration, a new study says.**

The study was presented at Americas Committee for Treatment and Research in Multiple Sclerosis (ACTRIMS) Forum 2016 by Jennifer S. Graves, MD, from the University of California, San Francisco (UCSF), School of Medicine.

"We know women have more relapses and inflammation, but men may have earlier or faster progression. After the age of 50, however, women 'catch up' with men in terms of disability," Dr Graves said. "The age at which disability starts to accelerate, therefore, seems to correspond to the peri-menopausal period (The period around the menopause). Ovarian aging may have a role in the transition of phenotype ( type of MS) for women," she said.

## **MS progression unaffected by number of pregnancies**

**Having more than one child does not appear to affect the level of disability in mothers with MS, according to new research.**

Researchers led by Emanuele D'Amico of the University of Catania, Italy, assessed disability progression in women with MS who had one or more child following their MS diagnosis.

Overall, the researchers found no difference in disability between mothers of one child and mothers of two or more children. There was, however, a non-statistically significant trend indicating that women with more than one child took a longer time to reach an EDSS disability score of 4 ( Able to walk without aid or rest for 500m) compared to women who had only one child.

***For further details on all new stories go to page 13***



## My neurogenic bladder – a cautionary tale for other secondary progressives

In 1986, aged 27, I found myself regularly getting up at night to go to the loo. I also started to notice my flow was, well, more a dribble.

I hadn't yet been diagnosed with MS, that didn't come for another seven years, so I didn't know what to make of things. At the time I didn't think it was worth seeing my GP. Instead I devised my own solution. I just strained harder and harder to pee.

But I soon realised that the harder I strained the less came out. So in desperation I adopted the opposite approach - relaxing rather than straining, and taking my time, sometimes listening to calming music while the contents of my bladder just dribbled into the toilet. I have heard this called "tantric peeing" and the technique seemed to work for me. It never crossed my mind that what I was doing was only partially emptying my bladder.

I had a wake-up call in 2008 when I started to get repeated UTIs (urinary tract infections) and felt forced to seek help. My GP prescribed me several different antibiotics and sent me to see a urology nurse. When I told the nurse about my toileting technique her face just dropped. In a flash she had the ultrasound scanner out and a quick bladder scan showed that I was leaving 250 ml of urine – the contents of half a bottle of mineral water- in my bladder after peeing. I was told in future I would have to self-catheterise daily. That should have been the end of this story because the urology nurse said self-cathing would make my bladder better. Sadly it didn't - bladder infections continued, sometimes as often as weekly. **Continued on page 9**

**Please note page 9 shows a graphic image relating to my bladder problem**





I also started to see occasional “blobs” of stringy white matter dropping in the toilet bowl while I was peeing. And sometimes they were big blobs about the size of a 5p piece. (See picture left ).

Finally, a urologist who specialises in MS or “neurogenic” bladders saw me urgently and suggested a cystoscopy. This

is where a super-thin camera is inserted through your urethra into your bladder for the urologist to have a look around . The problem was found – I had a “trabeculated bladder” which can happen in prog- MS.

“Trabeculation” means the bladder wall muscle has thickened over time, usually because the bladder has been overfilled or not fully emptied. The bladder wall assumes an irregular criss-cross ridged pattern and I think the “trabeculated” bladder wall is where the white blobs were coming from. The urologist urged me to self-cath more often and I did, but the UTIs continued.

Finally after much badgering of the hospital I was put under a general anaesthetic and given a bladder “washout”. This is where water is used to “hose down” the insides of your bladder to get rid of all the white blob debris that can build up in a neurogenic bladder over time leaving it prone to infections. The washout must have done the trick because post-op I haven’t had a UTI in six months (touch wood).

And that is the end of my story. I suppose the moral is don’t ignore your MS bladder for years like I did because your problems will only get worse. Actually there is another moral - don’t place your faith in tantric peeing- try self cathing instead. It’s far more effective, believe me.

***For further information and details of a youtube video on a trabeculated bladder go to page 13***

## **Myelin making cell transplants planned in US research**

**A multi-million dollar research project is to take place in New York state USA to assess the safety of implanting human Oligodendrocyte progenitor cells (OPC) into the brains of patients with progressive MS.**

Oligodendrocyte progenitor cells (OPC) are cells which mature into oligofendrocytes –cells which make myelin. Three universities in New York State (Upstate Medical University, University of Rochester, and University at Buffalo) will treat 20 patients with non-relapsing secondary progressive with the cells.

The project which is a phase 1 trial will aim to determine safety and the maximum tolerated dose for cells injected into the white matter during four transplants. No further details were available as we went to press.

## **Fingolimod trial fails in Primary Progressive MS**

**A trial of Fingolimod, the immune system modifying MS drug effective in relapsing remitting MS, has failed to show any effects in primary-progressive MS.**

Researchers studied 970 people with primary-progressive MS (from 18 countries, where one group received a placebo or dummy pill and the rest received Fingolimod. The two groups were monitored for 3 to 5 years but no change was found in clinical or disability outcomes.

Although the results are negative, one positive finding is the observation that drugs which protect brain cells are probably better candidates for trials in progressive MS than drugs like Fingolimod which act on the immune system. This suggests inflammatory processes in the brain may be different or even less active in progressive MS than relapsing-remitting MS.

***For further details of all news stories go to page 13***

## Molecule ‘induces remyelination’

**A UK study has identified a molecule that can repair myelin in spinal cord injury, something that may have long-reaching implications for developing new treatments for progressive MS .**

Scientists behind the new study which was carried out in London found that a molecule called neuregulin-1 can induce remyelination in Schwann cells. These are cells which myelinate nerves in the peripheral rather than the central nervous system where the work is done by a class of cells known as oligodendrocytes.

According to the study’s senior author Elizabeth Bradbury, professor of Regenerative Medicine & Neuroplasticity at King’s College London, the research has wider implications for other disorders of the central nervous system where there is demyelination , such as MS.

## Rituximab MS trial halted due to poor results

A small clinical trial of Rituximab, a possible new progressive MS treatment, has been stopped early due to poor results.

The trial was looking at how effective Rituximab is in reducing the number of harmful immune cells in a group of 27 secondary progressive MS patients as well as its effect in decreasing nerve damage.

The results were published in an article, titled “Insufficient disease inhibition by intrathecal rituximab in progressive multiple sclerosis,” published in the journal *The Annals of Clinical and Translational Neurology*.

Elsewhere in medicine Rituximab is used to treat leukaemia.

***For further details of all news stories go to page 13***



## Help me develop this ezine

I am a journalist who loves writing news and features. And having had progressive MS for ten years I have lots to write about.

However, the aim of this site is to also to provide news and information for all people with progressive MS and that includes you.

So please send me your stories, air other views, give me hints and suggestions. I would love to start a letters page so please send me in your views or interesting stories for publication. Over the next month or so I will also launch a website to go with this ezine. Work is well advanced for the site.

Finally, please send this ezine to all other progressive MSers in your address book so we can raise our profile and lobby for a better life.

If you want to get regular copies of this “ezine” directly then email me at [iancookjournalist@yahoo.co.uk](mailto:iancookjournalist@yahoo.co.uk) and they will be delivered directly to you.

### IN THE NEXT ISSUE (June- July 2016)

**Cooling jackets and other ways to beat the Summer MS heat problems**



**Page 2**

**Ocrelizumab story**

Source: <http://www.nationalmssociety.org/About-the-Society/News/Ocrelizumab-Granted-Breakthrough-Therapy-Designat>

Plus [www.msresearchblogspot.com](http://www.msresearchblogspot.com) 18/02/16

**Page 3**

**Phenytoin story**

Source: [http://www.nationalmssociety.org/About-the-Society/News/Epilepsy-Pill-May-Protect-Against-MS-Related-N-\(1\)](http://www.nationalmssociety.org/About-the-Society/News/Epilepsy-Pill-May-Protect-Against-MS-Related-N-(1))

[http://www.thelancet.com/journals/laneur/article/PIIS1474-4422\(16\)00004-1/abstract](http://www.thelancet.com/journals/laneur/article/PIIS1474-4422(16)00004-1/abstract)

**plant extract story**

Source; <https://clinicaltrials.gov/ct2/show/NCT02273635>

<https://www.ncbi.nlm.nih.gov/pubmed/15331658?dopt=Abstract>

**pages 4-5 Feature on OCT**

1.Feature in Science Daily about OCT scans in MS

<http://www.sciencedaily.com/releases/2007/10/071015193523.htm>

.2.Optical coherence tomography and disease subtype in multiple sclerosis.Calabresi P, Neurology 2007 Nov 27;69(22):2085-92

**page 6 Appetite story**

<http://multiple-sclerosis-research.blogspot.com/2016/02/you-are-what-you-eat.html>

Leptin serum levels in different subtypes of Multiple sclerosis: does leptin play a role in progress of Multiple sclerosis? Sayyed Hamid Zarkesh-Esfahani,<sup>1,3</sup>Ehsan Bahrami,<sup>3</sup>Amir Hadi Maghzi,<sup>2</sup>Masoud Etemadifar,<sup>2</sup> and Mohammad Kardi<sup>3</sup>

[http://www.jimmunol.org/cgi/content/meeting\\_abstract/186/1\\_MeetingAbstracts/44.9](http://www.jimmunol.org/cgi/content/meeting_abstract/186/1_MeetingAbstracts/44.9)

<http://www.nature.com/news/2003/030128/full/news030127-2.html>

### **page 6 Testosterone story**

: <https://clinicaltrials.gov/ct2/show/study/NCT02317263#contacts>

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3952353/>

### **page 7 Ageing story**

Source: Scalfari A, Lederer C, Daumer M, Nicholas R, Ebers GC, Muraro PA. The relationship of age with the clinical phenotype in multiple sclerosis. *Mult Scler.* 2016 . pii: 1352458516630396. [Epub ahead of print]

### **P7 Pregnancy story**

<http://multiplesclerosisnewstoday.com/2016/03/01/ms-progression-apparently-not-affected-number-pregnancies-study-reports/>

### **page 8+9 Feature on neurogenic bladders**

Youtube video is at

Trabeculation and Diverticulum of UB wall by Dr.Robbani, Rajshahi,Bangladesh.

<https://www.youtube.com/watch?v=xKcwT1KJUKA>

### **page 10**

#### **myelin making cells**

[http://www.medscape.com/viewarticle/859546#vp\\_2](http://www.medscape.com/viewarticle/859546#vp_2)

#### **Fingolimod story**

<http://www.msif.org/news/2016/03/10/fingolimod-not-effective-primary-progressive-multiple-sclerosis/#sthash.Xpijt9fr.dpuf>

## **Page 11**

### **Re-myelination story**

Source: Multiple Sclerosis News Today (01/04/16)

### **Rituximab story**

<http://multiplesclerosisnewstoday.com/2016/03/07/progressive-ms-clinical-trial-rituximab-stopped-drug-fails-show-effectiveness/>

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