

# My MS prog-blog

The ezine for people with progressive MS

Issue 4, October/ November 2015



**Hello and welcome to the fourth edition of my free ezine for progressive MSers. My name is Ian Cook. I'm an MSer from Britain. My MS is secondary progressive.**

In this issue are details of some amazing news to come out of the forthcoming ECTRIMS MS conference in October – namely that Ocrelizumab works in primary progressive MS. See page 7 for details of this incredible story.

Inside too is some surprising news on baclofen, cladribine and sativex. There's more too - a feature looking at my experiences of Wii Fit – a video game that can help prog-MSers and which is helping keep me walking. Check it out on pages 4 and 5. Also look at my thoughts on moving to a retirement village – which offers care, but at a cost. See page 8.

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

**IN  
THIS  
ISSUE**



[Feature](#)

**Wii Fit helps to keep prog-MSers like me on our toes**

[Pages 4-5](#)

**OCRELIZUMAB WORKS IN PPMS p7**

## **Baclofen may help slow MS progression, Gabapentin may help too**

**A drug commonly taken to relieve MS spasms and spasticity may help protect nerves and slow down progression, according to research published recently in the journal Brain.**

Researchers found that a reduced level of gamma-aminobutyric acid (GABA) is associated with physical disability in progressive MS. Baclofen, one of the main drugs used to treat MS spasticity, is derived from GABA and there is a theoretical possibility that baclofen could boost GABA levels and thus help to stop MS progression. The same may apply to gabapentin which has been shown to increase GABA levels in the brain.

Gavin Giovannoni Professor of Neurology at BARTS thinks this may be a possibility: “I suspect that baclofen is neuroprotective and may slow progression,” he says. But he admits there is a lack of hard evidence. “This is because pharma and neuros don't follow people to collect this data,” he says.

*For details of all news stories go to pages 12-14*

## **Cholesterol and lipids link to progression**

**High levels of cholesterol and other lipids (fats) can lead to high levels of disability and progression in MS, according to Australian researchers.**

A group of 178 Tasmanian MSers were studied for three years in the research. MSers with the worst lipid profiles were found to have the highest levels of MS disability and disease progression.

Last year a UK study involving 140 MSers found that statins, drugs which lower cholesterol, may slow brain shrinkage in people with MS. A small but statistically significant improvement in one disability scale and one symptom scale was also found in MSers taking cholesterol lowering statins.

## Cladribine could be a new treatment option for progressive MS

**Cladribine, a disease modifying drug that has been used successfully to treat chronic progressive MS, is awaiting regulatory approval by the European drugs regulator as a new MS treatment . There is a possibility the drug could be prescribed to patients with progressive MS.**

Cladribine, which is made by German pharmaceutical giant Merck, was used to treat MS patients from 2010 to 2011. In 2011 the drug was withdrawn from the market. This decision was unexpectedly reversed in September 2015.

The decision to bring Cladribine back to market will be welcomed by progressive MSers because two separate pieces of academic research carried out in the 1990s showed patients with chronic progressive MS had better outcomes when treated with Cladribine than those who received a placebo.

## New stem cell trial for prog-MS starts in Bristol

**A new stem cell trial is to take place in Bristol looking at whether repeated bone marrow stem cell transplants can lead to long lasting improvements in progressive MS.**

The phase II trial will explore the feasibility of repeated stem cell transplants and is an extension of an earlier phase I trial which showed some improvement in six patients treated for the first time. The six patients who took part in the original trial will be recalled to have a sample of bone marrow cells extracted, filtered, “cleaned up” and then re-injected. Trial patients will be monitored at six months and again at one year to look for any improvements.

The original phase 1 trial showed some improvements in the clinical disability scores of the patients treated.

*More details of news stories on pages 12-14*



## Is Wii Fit the best form of exercise for a prog MSer? I think it definitely is!

Before my MS became progressive I used to enjoy going for a run each week. Then, as it progressed, exercise became difficult, dangerous and disappointing. I found I could do less and less. So, for the past three years I have avoided any real exercise.

But I know that I should be doing more. So this Summer I started to look for a form of exercise that is achievable, safe and fun. In Wii Fit I think I have found it - the perfect video exercise routine for prog-MSers – at least for those of us who can still stand.

What I particularly like about Wii Fit is that it comes with its own balance board (*pic top left*). This is a huge plus for us prog -MSers who not only have to contend with problems exercising, but also with balance problems.

Wii Fit - pronounced wee fit - is a fitness and balance game made by the Japanese computer giant Nintendo and it works with the company's popular Wii gaming console. It is now found increasingly in MS physiotherapy groups and exercise classes. MS researchers have praised it too.

It works by linking your own movements on a balance board to those of an onscreen character as you take part in a simple fitness activity like hula hooping or heading a ball. **Ctd on page 5**

## Features

## Wii Fit



Above: left – Wii Fit hula hoop game where you swivel your hips, centre: balance board , right players rank their scores .

*Continued from page 4.* The key to Wii Fit is the balance board - a white mat roughly the size of bathroom scales which is connected to the TV. (*Centre pic above*) As you move on the balance board the on-screen character moves too (*pic left*) following your every movement precisely. It may sound slightly strange but you soon get the hang of it.

Among the various balance games my favourite is “Penguin Slide” which involves being an onscreen penguin catching flying fish on a floating ice sheet. (Yes, Wii Fit can sometimes be surreal!)

All the games are simple to follow and you soon get the hang of them. Useful information appears on the TV and you can see your score while doing the exercises. Wii Fit might not suit everybody with MS but for those that can stand it is great fun and a great help in improving agility and balance. Personally speaking I have found Wii Fit brilliant for both.

And research continues to show that Wii Fit actually works. Earlier this year a study of 50 people with MS – several of whom had prog-MS - showed that those who used a system such as Wii Fit had faster and more accurate steps when tested. They also had better balance and walked faster.

The researchers also found significant improvements to reaction time and in manual dexterity suggesting the stepping exercise also improved the thinking skills needed to reduce the risk of falling. During the six month follow up participants who had used Wii Fit had fewer falls than those in the control group. *Further details of Wii Fit on p13.*

## **MS plaques change as illness progresses - lesions become less active**

**White matter lesions or plaques – the defining feature of MS - seem to change from active areas of inflammation to “smouldering, inactive or shadow plaques” as the illness progresses.**

That is the finding of research published in the Annals of Neurology which looked at 2,000 plaques found in 120 MSers. Active plaques were most often found in early disease, whereas at later stages smouldering, inactive and shadow plaques predominated.

Among secondary progressive (SPMS) patients who still had relapses all plaque types were found including active plaques. SPMSers without relapses had predominantly inactive plaques. Men displayed a higher proportion of smouldering inactive plaques than women.

## **Sativex may improve walking – researchers say**

**Sativex - The medicinal cannabis mouth spray - improved walking in a group of 20 MSers who were unable to walk more than 200metres without resting. That is according to research published in the Journal of Neurology.**

There was also an increase in stride length and walking speed among the MSers taking Sativex who had an average disability EDSS score of 5.3 which means they could walk without aid or rest for only between 100 and 200m.

The improved walking is thought to be due to changes in the pelvic area, hip rotation and knee flexion-extension after the 20 MSers took Sativex or Nabiximols as it is called in the US. The improved walking may result from less spasticity.

*For details of all the stories go to pages 12-14*

## **Ocrelizumab set to become first treatment for primary progressive MS**

**Ocrelizumab, an experimental new MS drug, has been found to be effective in treating primary progressive MS.(PPMS) The drug has been shown to reduce levels of disability in those receiving it.**

That is the main finding of a Phase III trial and news about it will be announced on Saturday October 10 at the forthcoming ECTRIMS conference in Barcelona. The trial results will show that in a study called Oratorio the drug significantly reduced the progression of clinical disability sustained for at least 12 weeks compared with placebo in those with PPMS.

Makers Roche say Ocrelizumab is the first investigational medicine to show positive study results in treating primary progressive MS. Roche will submit data to global regulatory authorities in early 2016. Ocrelizumab is given as an intravenous infusion every six months.

## **ECTRIMS may report on AIDS drug trial in MS**

**The ECTRIMS conference may also give an indication of whether the trial of an AIDS drug Raltegravir has been successful in treating MS.**

First results coming from the INSPIRE project are due to be presented at the conference which runs from October 7 -10. The INSPIRE project explores the idea that MS may be caused by an inherited retrovirus which may be treatable by anti-retroviral AIDS drugs.

There is no early indication of whether the trial has been successful but another project exploring the same idea is being trialled in Switzerland in MS patients including several with progressive MS. The INSPIRE presentation is listed on page 27 of the 2015 ECTRIMS programme

*More information on all news stories – pages 12-13*



## Should a 57 year-old man with prog-MS (like me) move into a retirement village?

A few days ago I read a report about a new retirement village opening locally. I asked myself whether I would be better living in such a place rather than continuing to live alone in my own home.

I may only be 57, but age can be deceptive if you have prog-MS. Yes, there may be three years 'til my 60th birthday but I now have the mobility of a 90 year old man. My uncle aged 89 is far more mobile than me – he plays snooker and golf, also dances whereas I struggle to walk to the shops. My uncle lives in a retirement village, he loves it.

So, after reading the newspaper report, I thought I would request a brochure for the local retirement village and when it arrived I read it avidly. I noticed there was a swimming pool, library, restaurant, bar and bistro, and services like a minibus with twice weekly trips to the supermarket – all things that might be useful if, or when, I lose more of my mobility plus my driving licence.

There was also an optional care service too. This provides “discreet and friendly staff” to help with assistance in daily tasks – cooking, cleaning, help getting up and going to bed, live in, sleep in or night care, and someone to pick up prescriptions. There was just one problem and I discovered it the moment I looked at the financial arrangements – cost. *Continued on page 9*



*Ctd from p 8.* In the development you buy a leasehold property and for an additional monthly fee you become a member of the retirement village club with impressive facilities such as a restaurant, bar, bistro and swimming pool.

Of course all these facilities are very nice but they come at a price and this is where my doubts set in, because that price seemed to be a fairly hefty one. To begin with you need to buy one of the leasehold retirement properties and these ranged from a 1 bed apartment at £275,000 to a 2 bed apartment with a regency bay feature at £655,000.

Service charges are not cheap either – amounting to more than £8,000 a year for a two bed property and nearly £9,000 annually for a 3 bed place. An average prog MSer like me would struggle with these prices.

Nevertheless I still feel the idea of retirement villages for prog-MSers is a sound one, if the price is right. When I told my friends about this they said why don't I try and find a place through a housing association that caters for disabled people or even the council. However, I have my doubts whether either of these could deliver the services of my local retirement village.

So I am now looking for other retirement villages - in particular cheaper alternatives to my rather pricey local place. I may only be 57 but I sometimes feel a lot older than my 57 years. So, I wonder if there is such a thing as a retirement village for 57 year olds who are semi-retired on health grounds – a sort of “early retirement” village? *Retirement village information on page 14.*

## **Cerebral cortex brain lesions lead directly to MS disability - study finds**

**Lesions in the brain's cerebral cortex lead directly to MS disability according to researchers who say more accurate imaging will lead to better diagnosis of progression and treatments for it.**

Researchers looking at the cerebral cortex in the brains of 36 MSers found the number and size of lesions were significantly increased in participants with EDSS scores of 5 or more. An EDSS score of 5 indicates people are able to walk without aid or rest for 200m and normally indicates MS has become progressive.

The brain's cerebral cortex is the outer layer of the cerebrum - the front part of the brain. The research was published in the journal JAMA Neurology.

*More details for news stories on pages 12-14*

## **'Cannabis type drug' trial to take place in UK**

**A clinical trial is to take place looking at whether a synthetic cannabis type drug could treat spasms and spasticity in people with MS.**

The drug known as VSN16R isn't actually made from cannabis but stimulates the same cannabinoid receptors (CB1 and CB2) in the brain as cannabis does.

The trial is a Phase II Proof of Concept (Double-Blind, Randomised, Placebo-controlled) Study and will evaluate the efficacy, safety, and pharmacokinetics of VSN16R for treating spasticity in MSers

If you are interested in taking part in the trial then follow this link

<https://clinicaltrials.gov/ct2/show/NCT02542787>



## Please help me to develop this ezine/ blog

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

The aim of this site is to provide news and information for all people with progressive MS.

As well as telling my stories I want to feature other people with progressive MS, print other stories, air other views, hints and suggestions. I would also like to start a website on which the ezine could be housed. So, anyone with good stories for the site, good IT skills – web building ones – are welcome too. Email me for details of all these possibilities at [iancookjournalist@yahoo.co.uk](mailto:iancookjournalist@yahoo.co.uk)

**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 (Dec 2015 – Jan 2016)

It's the drug that's creating a buzz in the MS world - but can you take cannabis legally in the UK? I did.



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**Baclofen/ Gabapentin story**

Sources: 1. <http://multiple-sclerosis-research.blogspot.com/> 30 august 2015

2. Cawley N, Solanky BS, Muhlert N, Tur C, Edden RA, Wheeler-Kingshott CA, Miller DH, Thompson AJ, Ciccarelli O Reduced gamma-aminobutyric acid concentration is associated with physical disability in progressive multiple sclerosis. *Brain*. 2015;138(Pt 9):2584-95. doi: 10.1093/brain/awv209.rug.

**Cholesterol/ fats story**

Sources 1. *Multiple Sclerosis* 2014 Nov;20(13):1737-44. doi:

10.1177/1352458514533162. Epub 2014 May 14. An adverse lipid profile is

associated with disability and progression in disability, MS. Tettey P1, Simpson S Jr1, Taylor B1, Blizzard L1, Ponsonby AL2, Dwyer T2, Kostner K3, van der Mei I4.

Source 2: <http://www.nhs.uk/news/2014/03March/Pages/Statins-may-slow-progression-of-MS.aspx>

**Page 3**

**Cladribine story** <http://multiple-sclerosis-research.blogspot.com/2014/10/offlabel-cladribine.html>

Two pieces of research I mention are at

<http://www.ncbi.nlm.nih.gov/pubmed/8643695>

<http://www.ncbi.nlm.nih.gov/pubmed/7912347>

News story at

<http://uk.reuters.com/article/2015/09/11/us-merck-cladribine-idUKKCNORB0HF20150911>

### **p3 Bristol stem cell story**

Sources: New trial - <http://bmjopen.bmj.com/content/5/9/e009090.full>

Rice CM, Marks DI, Walsh P, Kane NM, Guttridge MG, Redondo J, Sarkar P, Owen D, Wilkins A, Scolding NJ. Repeat infusion of autologous bone marrow cells in multiple sclerosis: protocol for a phase I extension study (SIAMMS-II). *BMJ Open*. 2015 Sep 11;5(9):e009090. doi: 10.1136/bmjopen-2015-009090.

Original trial <http://onlinelibrary.wiley.com/doi/10.1038/clpt.2010.44/abstract>

### **pages 4-5 Feature Wii Fit**

Wii Fit with balance boards sell for around £35

See

[http://www.amazon.co.uk/s/?ie=UTF8&keywords=nintendo+wii+fit+plus+board&tag=googhydr-21&index=aps&hvadid=25090400406&hvpos=1t1&hvexid=&hvnetw=g&hvrandid=17733069999385984727&hvpone=&hvptwo=&hvqmt=b&hvdev=c&ref=pd\\_sl\\_1vmzt28m85\\_b](http://www.amazon.co.uk/s/?ie=UTF8&keywords=nintendo+wii+fit+plus+board&tag=googhydr-21&index=aps&hvadid=25090400406&hvpos=1t1&hvexid=&hvnetw=g&hvrandid=17733069999385984727&hvpone=&hvptwo=&hvqmt=b&hvdev=c&ref=pd_sl_1vmzt28m85_b)

### **page 6**

#### **Plaques/ progressive lesions story**

Source: Frischer JM, Weigand SD, Guo Y, Kale N, Parisi JE, Pirko I, Mandrekar J, Bramow S, Metz I, Brück W, Lassmann H, Lucchinetti CF. Clinical and pathological insights into the dynamic nature of the white matter multiple sclerosis plaque. *Ann Neurol*. 2015. doi: 10.1002/ana.24497. [Epub ahead of print]

#### **Sativex story**

Source: Coghe G, Pau M, Corona F, Frau J, Lorefice L, Fenu G, Spinicci G, Mamusa E, Musu L, Massole S, Massa R, Marrosu MG, Cocco E.J

Walking improvements with nabiximols in patients with multiple sclerosis. *Neurol*. 2015 Aug 5. [Epub ahead of print]

### **page 7 ECTRIMS stories**

Ocrelizumab story <http://www.roche.com/investors/updates/inv-update-2015-09-28.htm>

ECTRIMS source 1 <http://multiple-sclerosis-research.blogspot.com/2015/07/ectrims-2015what-will-you-look-forward.html>

source 2 <http://www.ectrims-congress.eu/2015/ectrims-2015.html#&panel1-1>

**page 8+9**

### **Retirement villages**

There are now a number of retirement villages which offer places to the over 55s. For details check out <http://www.fifty5plus.com/>

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### **brain lesion story**

Source: Association of Cortical Lesion Burden on 7-T Magnetic Resonance Imaging With Cognition and Disability in Multiple Sclerosis ONLINE FIRST

Daniel M. Harrison, MD<sup>1,2</sup>; Snehashis Roy, PhD<sup>3</sup>; Jiwon Oh, MD<sup>2,4</sup>; Izlem Izbudak, MD<sup>5</sup>; Dzung Pham, PhD<sup>3</sup>; Susan Courtney, PhD<sup>6</sup>; Brian Caffo, PhD<sup>7</sup>; Craig K. Jones, PhD<sup>5,8</sup>; Peter van Zijl, PhD<sup>5,8</sup>; Peter A. Calabresi, MD<sup>2</sup>

JAMA Neurol. Published online July 20, 201

### **Cannabis type drug trial**

If you want to take part on the trial go to <https://clinicaltrials.gov/ct2/show/NCT02542787>

**To Contact me email** [iancookjournalist@yahoo.co.uk](mailto:iancookjournalist@yahoo.co.uk) or via twitter [@iancookMSer](https://twitter.com/iancookMSer)