

My MS prog-blog

The ezine for people with progressive MS

Issue 1 April/ May 2015



Hello and welcome to my new free progressive MS “ezine”. My name is Ian Cook. I’m an MSer from Britain. My MS is secondary progressive.

Inside are features on how to rent rather than buy a mobility scooter and an easy home test kit to detect a UTI urine infection. Plus trials of six new prog-MS treatments , so please read on.

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Let's start at the beginning , why a free ezine for progressive MSers?

The reason is because I am a journalist who loves writing news and features. And having progressive MS for ten years has given me plenty to write about.

Until 2008 I worked as producer in health and consumer shows for BBC TV and as a print journalist. Then progressing MS made this no longer possible. Now I am a self-employed journalist working from home.

This ezine is my “take” on life with progressive MS. It contains news stories which point to long awaited medical developments and treatments for progressive MS including details of six clinical trials which are underway. There are also two features drawing on my own experience of living with secondary progressive MS looking at practical solutions to problems like lack of mobility and continence issues.

So, please read on and tell other people about this blog. Spread the word, forward this blog to as many people as possible. And help people with progressive MS –people with Primary Progressive, Secondary Progressive and Progressive Relapsing MS be informed.

Please help develop this blog by giving your time or skills

In future editions of this blog I want to feature other people with progressive MS, read about other stories, hear their views and listen to their hints and suggestions. But this requires time and some IT skills that I don't have - so I will need help. Further details how to help me are on page 11.

STOP PRESS Vitamin B7 drug trial for prog MS to report in April – will this be a first treatment?

Results from the trial of a revolutionary new treatment for primary and secondary progressive MS are to be announced in April.

The new treatment, called MD1003, is a high dose form of D biotin, a form of vitamin B7 and a key co-factor for enzymes involved in making myelin. Biotin is also known as vitamin H. Vitamin B7/ vitamin H can be bought over the counter and online. Results of the trial (Phase 3) are due to be presented at the American Academy of Neurology annual meeting on 24 April 2015. A second trial is due to complete by the end of this year. Watch this space!

Parkinson's drug may fight MS progression

People with secondary progressive MS are being enrolled on a clinical trial to test whether a Parkinson's disease drug can slow MS progression.

The study involves 62 patients from the Calgary MS Clinic in Canada who are starting to experience permanent disability but are still able to walk. The drug being tested is called domperidone, and is currently used to treat nausea and constipation associated with Parkinson's Disease.

One very well-known side effect of domperidone is that it increases levels of the hormone prolactin in the blood, and there is evidence that prolactin helps to repair myelin. It is also well known that prolactin is produced in large quantities in pregnancy and the reason why MS often goes into remission in pregnant women may be due to the effects of this hormone.

A paper published in 2007 from the University of Calgary found that in mice prolactin encouraged the spontaneous production of myelin, and when non-pregnant mice with MS-like lesions were injected with prolactin, their myelin was also repaired. The trial is due to complete in January 2019.

Personalised T-cell drug trial to report soon

A major MS drugs firm is helping fund a large clinical trial into a personalised T-cell drug treatment for secondary progressive MS (SPMS) .

Merck Serono, which makes the disease modifying drug Rebif, is paying \$3.5 m to Opexa Therapeutics to support a Phase 2b clinical study of Opexa's personalized MS immunotherapy drug called Tcelna.

Tcelna is made from T-cells isolated from the patient's own blood, which are irradiated outside the body and then reintroduced via injection — a process that triggers the body to react in a “therapeutic” way to its T-cells rather than in a way that triggers an auto-immune “myelin-reactive” response. It is believed that 180 patients have already been recruited for the trial and “top line” results will be announced in 2016.

\$47m for new drug that will treat all MS types

A multi-million dollar deal has been struck between the Swiss makers of a revolutionary new MS drug suitable for progressive MS and French drugs giant Servier.

The deal will see Servier investing \$47m to fund a Phase IIb trial of the new drug called GNbAC1. The drug has been developed by Swiss firm GeNeuro who will also be entitled to up to \$408 million in future development, sales and royalties. Servier will have the option to become a GeNeuro minority shareholder. GNbAC1 treats progressive as well as relapsing remitting MS.

The new deal shows growing confidence in drugs like GNbAC1 that are based on the theory that MS is the result of an inherited or endogenous retrovirus. This theory proposes that an inherited retrovirus can become re-activated in susceptible people and once reactivated gradually overwhelms the immune system causing MS.



Hire a mobility scooter before you buy one!

A friend of mine watched me “walking” one day and told me I should buy a mobility scooter. That remark really worried me.

It's not just facing up to the fact that progressive MS means my walking is getting steadily worse, or the fact I may soon have to spend thousands of pounds on a mobility scooter.

No, I have accepted both these things. What really troubles me is that I am a novice when it comes to mobility scooters. I know nothing about them and so I am worried about what will happen when a hard-nosed salesman appears at my front door eyeing me up as a potential customer.

I was wondering - is there anywhere I could go and drive a mobility scooter for the day – trying out a selection of scooters cheaply without any pressure to buy one and also somewhere where I was insured to drive one? Then I can become a more informed buyer when that hard-nosed salesman arrives.

Fortunately the answer is yes, there is somewhere. I recently discovered I can do all these things at my local disabled scooter hire (Shopmobility) centre. So I joined Shopmobility in Birmingham UK recently. It cost just five pounds (\$8 US) to join as a visitor, and scoot around for the day. I was able to choose from a variety of different scooters from the deluxe Meyra Cityliner 315 (pictured above) to the smaller and, I think, more user-friendly Shopriders. I was insured and I even got some training in how to use the scooter.



Even better was the fact that my local scheme also gave me free parking at the local city centre car park for three hours so you could say Shopmobility saved me money and taught me loads about scooters making me better informed. Shopmobility is so good that I did wonder whether I might be able to rent a scooter for life rather than ever buying one!

My local Shopmobility scheme is based in one of Britain's biggest shopping centres – Birmingham's bullring. The scheme is one of the UK's larger ones with five powerchairs and 40 mobility scooters on loan seven days a week. (It is shut for a few days over Christmas) The scheme carries out 5,000 equipment loans a year. The cost of the mobility scooter is a very reasonable £5 per day as a visitor. You can pay £12 as a member and then you pay £1 per scooter hire. I think it is great value! In Birmingham you also get a parking fee reduction.

Like many other British Shopmobility schemes you don't need to be a disabled blue badge holder, or claim a disability benefit to join in Birmingham. Anyone with a temporary or permanent "mobility impairment" can use a scheme's equipment and, provided they are able to register, they can be assessed and then given training to ensure they are safe. Details of Shopmobility on page 12.

Acne bacteria drug successful in treating SPMS

A drug made from bacteria which cause teenage acne is to be tested on 90 patients with secondary progressive MS (SPMS) in a new trial which follows good results in earlier studies.

The drug called MIS416 modifies the body's immune response. Researchers believe a single dose can reduce MS disease severity and regular doses will continue the improvement. It is believed that MIS416 targets other cells than T cells in the central nervous system. This is unexpected because it is believed that T cells attack the body causing MS. MIS416 is given by weekly infusion and improved symptoms in patients treated in earlier studies.

The research is taking place at Victoria University in New Zealand. The new trials are stage 2b trials and are due to report in October 2016.

Three drugs to be tested on secondary progressive MS

A landmark UK drugs trial is underway investigating whether three different drugs can slow down or halt disability in secondary progressive MS (SPMS)

The three-year £2.7m trial called MS-SMART is taking place in Britain and will test the safety and effectiveness of riluzole, amiloride and fluoxetine as MS treatments. Amiloride is licensed to treat heart disease, riluzole is licensed for motor neurone disease and fluoxetine is an anti-depressant better known as Prozac.

All three drugs have the potential to protect nerves from damage, and could potentially stop or slow disability progression in MS. Up to 15 trial sites are currently being identified in cities and towns across Scotland and England. Recruitment of 440 people with secondary progressive MS should start in April or May 2015. Study completion date is November 2017.

A trial into Prozac and progressive MS (PPMS and SPMS) is also currently taking place in Holland.



My ‘home test kit’ helps me spot a UTI urine infection, so I can treat it quickly

I think the biggest problem with MS-related urine (UTI) infection is the delay in getting it diagnosed promptly.

Until last year I would regularly wait weeks to get an infection diagnosed and this delayed treatment. Then, last year, I found out about “UTI home test kits” which really help speed things up.

A home test kit means you do the same urine test as your doctor will do in the surgery, but you do the test at home beforehand. This means you can check if you have an infection and if you do then you can book an emergency doctor’s appointment, asking to be seen that day because you **know** you have an infection. Home test kits remove all doubt.

The first thing is to go online and buy some urinalysis reagent strips (pic top left) plus sample bottles (pic top right). £20 should buy 100 strips and 10 sample bottles. Then, when you think you have an infection the reagent strips simply go into a sample bottle filled with urine. I leave the strip in for either one or two minutes depending on whether I’m testing for nitrites or leukocytes. (both of which you can get in bladder infections.)

Finally, I match my reagent strip against a comparison strip printed on the container that the strips come in, checking for signs of infection. *Continued on next page*

The two strips (mine –bottom - showing infection, comparison strip –top - showing no infection)



The graphic shows my sample strip – bottom - showing infection, with the unused comparison strip above it. See the difference between the two end boxes circled on the left hand side.

My sample (Bottom) shows high levels of leukocytes or white blood cells (PURPLE) and nitrites(PINK) Both these are signs of a UTI urine infection. Ouch!

Ctd from previous page: At the surgery my doctor will do the same test and confirm that yes I do have an infection. He then sends my sample to the lab to find the best antibiotic to treat it. One year since starting self-testing I now always know for sure whether I have an infection - there is no argument. Even better my doc has now given me a “rescue pack” of antibiotics to take if needed until the lab test results come through.

And that is not quite the end of the story because last year I read about an academic study in which MSers will do exactly what I have just described - monitor their own urine for infection with a test strip and if infected treat it themselves with a “rescue pack” of antibiotics. I sent a message to the study organisers and told them it was a great idea, and said I had been doing exactly this for the past year without problems. I think every prog-MSer and those of us who self-cath should have our own test kit and rescue antibiotics. Hope the academics doing the study agree. Bring it on!

For further info on any of this go to the information section on page 12.

Co-enzyme Q10 fights MS fatigue and depression



Large doses of Co-enzyme Q10 – 500 mg – given to MS patients daily for 12 weeks improved MS fatigue and depression, according to researchers from Iran.

Co-enzyme Q10 is present in most cells in the body, mainly in the mitochondria of cells. This is the cell “powerhouse”

where most of the cell's supply of chemical energy is generated. Mitochondria are also involved in cell growth.

MS expert Professor Gavin Giovannoni of London’s Barts Hospital says that the new research “tantalizingly shows that Co-enzyme Q10, improves MS-related negative symptoms of fatigue and depression.” But he doesn’t go so far as to suggest MSers should supplement with it. If you do decide to supplement with 500 mg of Co-enzyme Q10 daily you may find yourself taking several pills each day as the supplements typically come in doses of 30mg, 60mg, 100mg and 200mg. It is also quite pricey.

New MS anti-spasticity drug moves one step closer

A revolutionary new MS anti-spasticity drug is to enter Phase II trials after successfully completing its Phase I (safety) trials in 2014.

The new drug, a pill provisionally called VSN16R, is said not to have the sedative side effects of existing anti-spasticity medications. Results are expected from the phase II trial in 2016.

Preclinical and Phase I clinical studies which involved 72 people demonstrated that VSN16R had “the potential to provide substantially better patient care than existing systemic anti-spastic treatments.”

Please help me develop this blog by giving me your time or your skills

The aim of this site is to provide news and information for people with progressive MS – people with Primary Progressive, Secondary Progressive and Progressive Relapsing MS.

As well as telling my story I want to feature other people with progressive MS, print other stories, air other views, and share hints and suggestions.

This requires web building skills and IT skills which sadly I don't possess. So, if there are any IT savvy or web savvy people reading this then please get in touch as you will be able to help me build a platform where our prog-MS voices can be heard and where we can lobby for a better deal. Please email me for details of all these possibilities at iancookjournalist@yahoo.co.uk

If you want to get further editions of this “blogazine” then also email me at iancookjournalist@yahoo.co.uk

IN THE NEXT ISSUE (JUNE/JULY 2015)

Renewing my fixed term driving licence was no laughing matter



Plus reports from the top US neurology conference (AAN) with details of trial results for new prog-MS drugs

Page 3 Vitamin H story – MD-1003

<http://www.biocentury.com/biotech-pharma-news/emergingcompany/2014-11-24/meddays-md-1003-could-reverse-disease-progression-in-advanced-ms-a12>

<http://www.ncbi.nlm.nih.gov/pubmed/25787192>

P3 Domperidone/Prolactin story

<http://globalnews.ca/news/1869132/calgary-multiple-sclerosis-drug-trial-now-enrolling-patients/>

See also White matter plasticity and enhanced remyelination in the maternal CNS. Gregg C et al Journal of Neuroscience 2007 Feb 21;27(8):1812-23

p4 Tcelna story

<http://www.opexatherapeutics.com/tcelna/tcelna-description/default.aspx>

p4 GNBAC1 GeNeuro/ Servier story

<http://www.geneuro.com/en/news.php?id=103&category=4#news>

p5-6 Shopmobility feature

<http://www.shopmobilityuk.org/> (for directory of all UK schemes)

Birmingham Shopmobility <http://www.birminghamshopmobility.org/>

p7 Acne drug/ MIS 416 story

<http://www.news.com.au/national/victoria/experimental-drug-containing-tiny-fragments-of-teenage-acne-bacteria-trialled-on-ms-patients/story-fnii5sms-1227212425926>

p7 MS-SMART story

<http://www.ms-smart.org/>

Details of Dutch research at

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3931920/>

p8 UTI self-test kit feature

I bought Mission urinalysis reagent strips (10 parameters) at

<http://www.amazon.com/Mission-Urinalysis-Reagent-Strips-Parameters/dp/B009WW455I> I bought “urine sample bottles” on

www.ebay.co.uk There is a guide to interpreting the urine test results on the side of the Mission Urinalysis strip containers with a helpful information leaflet inside.

See also <http://multiple-sclerosis-research.blogspot.com/2014/07/clinic-speak-intermittent-self.html> and

<http://multiple-sclerosis-research.blogspot.com/2014/07/managing-urinary-tract-infections-in.html>

P10 Co-enzyme Q10 story

<http://www.ncbi.nlm.nih.gov/pubmed/25603363>

also <http://multiple-sclerosis-research.blogspot.com/2015/02/coq10-nutriceutical-for-fatigue-and.html>

P10 VSN 16R story

<http://www.nationalmssociety.org/About-the-Society/News/Canbex-and-Ipsen-Announce-Funding-to-Start-Phase-I>

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