

My MS prog-blog

The ezine for people with progressive MS

Issue 2, June/ July 2015



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

Inside issue 2 are lots of news including two new clinical trials that are recruiting patients in the UK, plus interesting news about stem cells.

There is also a feature looking at the unexpected news that Biotin (vitamin B7) is a possible new treatment for progressive MS. And finally a report on what I think is a missed opportunity for MSers to drive with longer term licences.

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.

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BIOTIN SPECIAL REPORT – P4

Tecfidera (BG-12) trial for SPMS to include several UK sites – more details to come soon

Clinical trials are to take place soon at several UK sites to see if MS disease modifying drug, Tecfidera (BG-12) can slow down disability progression in secondary progressive MS (SPMS).

Trials are recruiting 1,170 patients with SPMS at 200 sites in Britain, Europe and the US and are due to complete in 2019. The trials will look at the effects of the disease modifying drug on disability, walking and hand movement.

Interest in Tecfidera as a treatment for progressive MS follows a study in mice which suggested that the drug may also have neuro-protective qualities.

Tecfidera, a tablet taken twice daily, is already used in relapsing remitting MS (RRMS). *More details of the clinical trials on page 11*

UK sites named for Laquinimod PPMS trial

A clinical trial is now underway in the UK examining the effects of an “immune-modulating” drug Laquinimod on Primary Progressive MS (PPMS). Trial sites include London, Bristol, Edinburgh, Liverpool, Nottingham, Oxford, Plymouth, Stoke on Trent and Swansea.

The trial will look at the effect of the drug on brain volume changes in 375 people chosen to take part. It will also record progression of disability, new lesions measured by MRI and cognition. Estimated completion date is October 2017.

Laquinimod is an experimental drug, taken once daily as a tablet. Sadly it was not licenced as a treatment for relapsing remitting MS in 2014 by the European Medicines Agency. (EMA) But the EMA noted at the time that its effect in slowing the worsening of disability appeared to be “encouraging”. *More details of the trial on p11.*

US stem cell trial shows several improvements in PPMS and SPMS patients

A group of nine progressive MSers had better balance, increased muscle strength and improved walking after stem cell treatment in the US.

Those were the key finding of a Phase I clinical trial using autologous neural stem cells in the treatment of both relapsing remitting and progressive MS. The trial was carried out at the Tisch MS Research Center in New York.

An interim analysis showed that six of nine patients treated had increased motor strength, improved bladder function and an enhanced quality of life after treatment which was said to be well tolerated. Thus far no serious adverse events have been reported. Staff at the Tisch center plan to complete the Phase I study and if the positive trends continue move on to a multi-centre Phase II efficacy trial. *More details on p 11*

‘Significant’ results in SPMS stem cell trial

Results of a trial into stem cells as an MS treatment are “significant and give new hope to patients with secondary progressive MS” (SPMS) says Dr Giovanni Mancardi, the scientist who led the study in Genoa, Italy .

In the study autologous hematopoietic stem cell transplantation (AHST) was compared to mitoxantrone as a treatment for secondary progressive or relapsing-remitting MS. A total of 21 patients with MS whose symptoms were not improving despite treatment with conventional medications took part . Most needed a cane or crutch to walk at an average age of only 36.

MRI-detected brain lesions were reduced by 79% in patients undergoing AHST compared to patients treated with mitoxantrone. Disease activity was greatly reduced by AHST. *More details are on page 11.*



Biotin tablets can be bought on the high street with claims they promote strong nail.

Biotin (vitamin B7) is good for your nails

- it may also help you with your MS.

Biotin, a vitamin that helps keep your nails strong, may also improve the symptoms of primary and secondary progressive MS. That's according to research unveiled at a major medical conference in the US.

Biotin (vitamin B7), also known as Vitamin H or Coenzyme R, has been used for years as an over-the-counter supplement to treat brittle hair and nails, and some skin conditions.

Earlier this year positive results of a phase III study into the effects of large doses of a certain type biotin on progressive MS were presented at the US Academy of Neurology (AAN). In the study 91 per cent of MS patients given very high doses of biotin saw some improvement.

A total of 154 patients with primary or secondary progressive MS were given a preparation called MD1003 which, at a dosage of 300 mg of Biotin per day, contains 10,000 times the maximum daily recommended dose and far higher than high street products which typically contain just 10 mg or 10,000mcg .

In the study 12.3% of the Biotin treated patients saw some improvement in disability scores after treatment, as opposed to 0% of the placebo group. Only 4% of Biotin treated patients displayed disease progression after one year,

compared to 13% in the placebo group. Very few side events were reported. One possible explanation for how biotin might work centres on “virtual hypoxia.” – a lack of oxygen which affects demyelinated nerve cells. It is believed biotin may stop virtual hypoxia by boosting mitochondria - the part of the cell that fuels its oxygen delivery.

A further biotin MS trial is currently taking place at 20 sites in France and one site in the UK (University College London). The new trial (NCT02220244) looks at biotin’s effect on chronic visual loss related to optic neuritis in MS. The study completes in January 2016. This may tell us more.

So, should we all start taking biotin?

Biotin is cheap and readily available over the counter and online. As a classical guitarist I have taken biotin for years to keep my nails strong. And it works. However, the dose I take is one capsule -10mg daily. I would need to take 30 capsules a day to match the doses used in the trial - 100 mg of biotin three times a day- and I have major reservations about doing this.

I am not the only one to have doubts. US blogger Marc Stecker (wheelchair kamikaze) has primary progressive MS and has written extensively about biotin. (See link on page 11) He says that the compound used in the trial is a highly concentrated and purified pharmaceutical grade form of biotin called D-Biotin, and I do not know whether this is found in over the counter preparations. I do know that these products haven’t been formulated to treat MS

So is there another way? Yesterday I joined a facebook group called “Biotin for Progressive MS”. This is a closed group so you have to request membership. Last time I looked there were more than 1,000 members. A link to this group on page 11. Watch this space! *Details of sources for this feature on page 11.*

‘Myelin repair’ cancer drug to start clinical trials in MSers soon

A drug which has the potential to re-myelinate will soon be tested in a clinical trial. The drug - Bexarotene - is already in use as a treatment for a skin cancer - cutaneous T-cell lymphoma.

The clinical trial follows years of work by scientists from Cambridge and Edinburgh Universities who in 2010 identified a molecule in the brain called RXR-gamma, which seemed to help promote myelin repair. In animal models of MS it was found that stimulating RXR-gamma activity encouraged the brain’s own stem cells to regenerate myelin.

Bexarotene is known to target RXR-gamma. So scientists are now preparing a clinical trial to test the safety and effectiveness of this potential myelin repair therapy in MSers. More will follow when I know more. *Story sources p11.*

Asthma drug may slow MS progression

An anti-inflammatory asthma drug is to be tested on people with Primary and Secondary Progressive MS in clinical trials following suggestions that it might slow MS progression.

The drug called Ibudilast has been tested on people with relapsing remitting MS and although the research showed no benefit on slowing the rate of newly active lesions it was noted that those treated showed less progression than those in a placebo group.

Now 250 people with progressive MS will take the drug for 96 weeks. The trial takes place in the US and expects to complete in 2017. *Trial details on p11.*



A missed opportunity for longer licences

One of the problems with progressive MS is that you become increasingly dependent on your car. I can still walk short distances but I now need to drive to most places.

So, I was shocked six years ago, in 2009, when I was told I would have to apply for a UK driving licence every three years instead of waiting 'til I am 70, like non-MSers who drive. It might have made sense if I had recently been involved in an accident or suffered a new symptom affecting my driving. But neither of these things applied. So why had this new restriction been imposed?

In 2008 I had voluntarily requested an assessment from my local regional driving assessment centre after being told my MS was now progressive. No concerns were raised about my driving at the assessment, but reading the report afterwards I noticed a copy was being sent to the DVLA. (The UK Driver and Vehicle Licensing Agency) So, when the DVLA told me one month later I was now on a three year medically restricted licence it felt like a bit of an over-reaction.

Fast forward to 2014 and imagine my delight when I read the DVLA was consulting about whether to extend medically restricted three year licences to a maximum of 10 years in certain circumstances. Great idea I thought. A press release explained that in 2011-12 the DVLA had made licensing decisions on 675,000 cases at a cost of £20m. increasing the period for up to 10 years would reduce this by 61,000, saving £1.8m annually. *Continued on next page.*

Features



Driving licences



The press release also said more than three quarters of drivers who re-apply get another one, (I am now on my second three year licence) so I wrote to the consultation agreeing with the proposal. The DVLA said the overall reaction was positive, 81.4% of people agreed. So, did the ten year plan get through?

Er, actually no it didn't. Earlier this month I read the draft minutes of a meeting of the panel which had considered the proposal. It said: "for drivers with Multiple Sclerosis five year licences may be appropriate in some circumstances; this would be for drivers who have previously been issued with a three year licence and who have demonstrated that their condition remains stable." The ten year period seemed to have been kicked into the proverbial long grass, certainly as far as us MSers are concerned.

So, was my only consolation the fact that I would now get a five year licence? Er, no. In the very next sentence the document said five year licences would not be issued after the first fifteen years from onset of MS. Having been diagnosed 22 years ago (and driven with no endorsements or accidents throughout) I won't get even a five year licence.

A few years ago a Disability Rights Commission spokesman described risk aversion as a new form of disability discrimination. I am not sure whether it is an exaggeration to say this is what is happening here but it does seem like a new mobility problem has just been added to people who are becoming progressively immobile anyway. *Information sources on page 11*

Drug to stop MS Blood brain barrier breach will start clinical trials this year

A drug that could halt a key event in MS – a breach of the blood brain barrier (BBB) - is to start clinical trials this Summer following pioneering research carried out by Canadian scientists.

Scientists from Montreal have successfully blocked the actions of a molecule called MCAM, (Melanoma Cell Adhesion Molecule) which allows destructive white blood cells to cross the blood-brain barrier in MS, destroying the myelin sheath that protects neurons.

New research has shown that blocking MCAM could significantly slow MS progression. Now a biotech company Prothena has developed a potentially disease-modifying antibody, called PRX003, which is designed to disrupt MCAM activity and thus prevent migration of destructive white blood cells across the blood brain barrier where they damage myelin. Clinical trials in healthy volunteers should start by the end of June 2015. *Story sources p11.*

Possible MS nerve protector to be tested soon

A naturally occurring chemical with known nerve protective qualities could soon be tested as a treatment for progressive MS, according to researchers working in the US

The chemical called lanthionine ketimine ester (LKE) reduced neurodegeneration and improved symptoms when fed to mice with induced MS. The mice had lower levels of inflammation, lower degeneration of the optic nerve and spinal cord, and only minimal damage to the myelin sheath after treatment.

Scientists at Virginia Commonwealth University and the University of Illinois at Chicago say lanthionine ketimine ester is a strong candidate for clinical trials in patients with progressive multiple sclerosis. *More details on page 12.*



Please help me 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 story 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

Also 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.

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

IN THE NEXT ISSUE (AUG/SEP 2015)

My five great years using FES – a TENS like leg device which helps walking by preventing foot drop



References contact details etc

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<https://clinicaltrials.gov/ct2/show/NCT02430532?term=NCT02430532&rank=1>

Page 2 Laquinimod story

<https://clinicaltrials.gov/ct2/show/NCT02284568?term=laquinimod+and+primary+progressive+multiple+sclerosis&rank=1>

Page 3 stem cells story 1

<http://tischms.org/news/april-23-2015-tisch-ms-research-center-new-york-reports-early-improvement-stem-cell-trial>

Page 3 stem cell story 2

<http://multiplesclerosisnewstoday.com/2015/02/16/stem-cells-used-to-treat-secondary-progressive-patients-in-clinical-trial/>

page 4 Biotin feature

<http://www.wheelchairkamikaze.com/2015/04/glimmers-of-hope-for-progressive-ms.html>

<https://www.facebook.com/groups/BiotinForProgressiveMS/>

Page 6 – Bexarotene story

Source: <http://www.mssociety.org.uk/ms-research/research-blog/2015/05/celebrating-successes-edinburgh-centre-ms-research>

Page 6 Asthma drug story

<https://clinicaltrials.gov/ct2/show/NCT01982942?term=ibudilast+multiple+sclerosis&rank=1>

page 7 - driving licence feature

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/331553/EPL_Consultation_Document_6_3_14.pdf

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page 9 blood brain barrier drug

<http://ir.prothena.com/releasedetail.cfm?ReleaseID=917188>

<http://www.nouvelles.umontreal.ca/udem-news/news/20150520-discovery-of-a-treatment-to-block-the-progression-of-multiple-sclerosis.html>

page 9 New nerve protector drug

<http://multiplesclerosisnewstoday.com/2015/05/25/new-compound-tested-lab-shows-promise-progressive-multiple-sclerosis/>

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