

My MS prog-blog

The ezine for people with progressive MS

Issue 3, August/ September 2015



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

Inside issue 3 is lots of news including more about biotin – the vitamin that has amazing possibilities for prog-MSers, as well as two clinical trials into new medications for prog-MS that are due to report later this year.

There is also a feature looking at my experiences of five years using FES (Functional Electrical Stimulation) which I think has kept me walking. Check it out on pages 4 and 5.

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

<p><u>IN</u> <u>THIS</u> <u>ISSUE</u></p>		<p><u>Feature</u> My five wonderful walking years – all thanks to these pads <u>Pages 4-5</u></p>
<p>BIOTIN FOR PROG-MS, REPORT P8-9</p>		

New drug combats disability progression in SPMS, hopes rise for PPMS results

An experimental new MS drug significantly reduces disability progression in some people with secondary progressive MS. That is according to data released this Summer. There are hopes the drug, called ocrelizumab, will also work in patients with primary progressive MS.

Ocrelizumab targets cells which damage myelin and nerve fibres. Early results of two trials showed it significantly reduced the number of brain lesions measured by MRI scans. It also significantly reduced relapse rates and disability progression. Full results from the two trials will be released in the Autumn.

The trials looked at the drug's effects in 1,600 patients with relapsing remitting MS and secondary progressive MS where patients still had relapses. The results of a separate phase 3 trial testing ocrelizumab in primary progressive MS will also be published later this year. Makers Roche plan to submit their data to the US and EU regulatory authorities early next year, 2016.

More positive news in biotin MS trial

Further positive data has been reported in a clinical trial of MD1003, a highly-concentrated pharmaceutical grade of biotin (vitamin B7) being developed as a treatment for progressive MS.

The new trial data shows an improvement of the Clinical Global Impression of change (CGI) after 12 months treatment with MD1003. CGI is a seven point scale doctors use to assess how much a patient's illness has improved.

A second trial is now underway looking at the effect of MD1003 on MS patients with permanent visual loss following optic neuritis. An application for the drug to be licensed could be made as soon as 2016. *See Biotin feature on page 8.*

Positive early results for prog-MS drug trial – full results expected later this year

An experimental new drug treatment for secondary and primary progressive MS has reported early positive results in a continuing phase III clinical trial.

The drug called Masitinib blocks biochemical processes involved in inflammation and immune responses by targeting mast cells, a type of cell involved in allergic reactions. This leads to a reduction in immune response and inflammatory processes.

Masitinib is currently half way through a 96-week phase III trial, and a 48 week trial assessment looked for any early positive changes in the Multiple Sclerosis Functional Composite (MSFC), Multiple Sclerosis Quality of Life 54 Items (MSQOL-54), and changes in the Expanded Disability Status Scale (EDSS).

“Significant” changes were found by the trial’s Independent Data Safety Monitoring Committee (IDMC) who were also able to report no major or unexpected “adverse events” that affected the safety of patients. The Phase III trial is due to complete in December 2015 . Masitinib is taken as a tablet, twice daily.

Wheelchair campaign calls for better services

A wheelchair campaign group led by Paralympian Tanni Grey-Thompson is calling for an improvement in wheelchair provision in the UK .

The Wheelchair Leadership Alliance has presented a 10-point document to politicians, providers and manufacturers, urging them to commit to the development of an effective NHS wheelchair service.

Figures show 70% of patients wait more than three months for a wheelchair, while 30% face a delay of more than six months. About 15% of patients wait more than 12 months. *Further details of all news stories on page 12*



My five years of wonderful walking – all thanks to FES

Five years ago my MS nurse said my walking was deteriorating badly. She said: “why don’t you get an FES device from the physio department.”

At the time I didn’t know what FES meant but I did some research and a week later I was walking up and down a room being assessed by a physio.

Straight away the physio noticed my right side was weaker than my left side and said I was ‘hip hitching’ – swinging out one leg in a semi-circle rather than moving it neatly up and down.

The physio said as a result I was an “inefficient walker” and at greater risk of tripping. Sadly I knew both these things were true.

But there was good news too. The physio said I was a perfect candidate to try out the Odstock dropped foot stimulator on my right leg. This would make my walking easier with less risk of tripping. And he fitted one there and then.



Boy, was there a difference! The letters FES stand for Functional Electrical Stimulation, and FES uses small pulses of electricity to get muscles on your calf (*pictured on left*) working which aren’t being powered because of demyelinated nerves.

Ctd on page 5



Above: left – sticky pads for your legs, centre: control unit for your belt , right insoles with heel strike pad for your shoes

It works like this: A grey box the size of packet of cigarettes clips to your belt. This is the control unit (*above centre*) containing a 9 volt battery which sends electrical pulses to two sticky pads (*above left*) which you wear below your knee on your worst leg covered in a tubular bandage. These pads receive electrical pulses sent through wires from the control unit making your calf muscles contract and lifting your leg thus reducing your risk of tripping.

The other thing that makes FES work is an insole pad which you fit inside your shoe under the heel (*pic above right*). When your heel strikes the ground it tells the control unit to send electric pulses to the sticky leg pads that contract the calf muscle and your foot lifts as if by magic.

And it really did feel like magic when I first put on the FES. My feet were literally bouncing off the ground. There was a spring in my stride and I covered a good distance pretty quickly. I was sold on FES! Five years on I am still as sold on it as I was on day one.

I now have a faster walking speed, improved ground clearance and reduced trips and falls. I also have a better walking action with fewer compensatory movements such as ‘hip hitching’. My walking is less tiring, with better stability, safety and more confidence.

If you are asking: “How can I get FES?” The answer is simple. Firstly you see your GP, hospital consultant or MS nurse who refers you for assessment by a physiotherapist. The most widely-used product is made by Odstock Medical and is called The Odstock Dropped Foot Stimulator (Pace) pictured. The other main product is The Ness L300 system from Bioness which is similar to the Odstock but without the wires. *Full contacts for FES on page 12.*

Asthma drug to be trialled in prog-MS, results expected in 2017

More than 250 MSers have been recruited for a clinical trial which will investigate the use of an existing asthma drug to treat progressive MS.

The trial of the drug MN-166 (Ibutilast) is being carried out at 28 clinical sites in the USA. An interim analysis of the drug's efficacy will be carried out as early as next year, once half the patients have completed their 96 weeks of treatment. Full results will be released in 2017. MN-166 is considered a "new molecular entity", and involves re-directing an existing drug, Ibutilast, which was first approved in Japan as a treatment for asthma more than 20 years ago.

A clinical trial in 2010 involving 297 people with relapsing remitting MS found fewer people treated with Ibutilast had signs of progression than those in a placebo group. In addition Ibutilast has been shown to reduce levels of immune cells associated with damage in MS.

Epilepsy drug could slow MS progression

A drug commonly used to prevent seizures in epilepsy could slow down the progression of disability in MS.

This is the finding of a study carried out at University College, London in which 82 MS patients with optic neuritis were given Phenytoin, an epilepsy drug which is believed to have neuro-protective qualities.

Patients who took phenytoin tablets had 30% less damage to the nerve fibres than those who received a placebo or dummy pill. Researchers are hopeful that this or similar neuro-protective approaches have the potential to slow the progression of MS. Further studies are planned.

Further details of all news stories on page 12.

New cannabis based drug to be trialled for MS related spasticity

A clinical trial is to take place in Israel later this year to test a new cannabis based treatment for MS-related spasticity.

The trial will use capsules containing two cannabis derived substances – the psycho-active THC (tetrahydrocannabinol) and the non psycho-active CBD (cannabidiol)

The poor water solubility of THC and CBD have always presented problems for developing a cannabis pill, and the trial will look at whether the new capsule can overcome this problem. The trial is due to start in the final quarter of 2015 and will last for nine weeks.

New study supports use of medicinal cannabis in MS

Medical cannabis may be useful in treating MS related spasticity according to a review in the Journal of the American Medical Association (AMA).

The review found “moderate-quality evidence” to support medical cannabis’s use in treating chronic pain and spasticity. But the authors said there was only low-quality evidence for the drug’s use in treating sleep disorders, nausea or vomiting related to chemotherapy; for producing weight gain in people with HIV; or for reducing symptoms of Tourette syndrome.

Although there was evidence to support the use of cannabis derived substances known as cannabinoids for the treatment of chronic pain and spasticity, it was said that this needs to be balanced against an increased risk of side effects such as dizziness, dry mouth, nausea, sleepiness, and euphoria.

More information on all news stories – page 12



Biotin was easy to buy and take, I am just waiting for an improvement in my MS

I was really excited when I read that a new drug was being tested for prog-MS and it had some really positive results. At last, I thought, a drug for me. I got even more excited when I realised the drug MD1003 was biotin or vitamin B7 and I could buy it online.

Generally speaking you can't buy drugs being developed. They are manufactured in laboratories behind closed doors and made to formulas which generally aren't known. But the drug in question MD 1003 is slightly different. MD1003 is a form of very high grade biotin, and biotin is actually another name for vitamin B7.

Biotin recently hit the headlines when French researchers reported their biotin drug MD1003 could help people with progressive MS. The background to the story is as follows. In April a press release was issued by a French company called MedDay saying that a biotin based drug called MD1003, which is basically large doses of pharmaceutical grade biotin supplied in pill form, had seen some impressive results in progressive MS.

As a prog-MSer with no possibility of any disease modifying drug treatment it seemed a no-brainer to try and get hold of some pharma grade biotin as soon as possible and take it.

So, earlier this year I joined a Facebook group called BiotinForProgressiveMS.

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My aim was to find where to buy pharmaceutical grade biotin in very large amounts. In no time I found myself in the company of 1,700 plus MSers who were, like me, following suggestions for online places where pharma grade biotin was on sale as a powder.

Very soon I bought three month's supply. A tub of 25 grams of biotin powder cost me \$79.99. Express courier delivery cost me \$36.50 making the whole bill \$116.49, (just under £75 or slightly under £1 a day in UK money for 83 days supply.)

I also brought some special measuring spoons and electronic scales which came to around another £20 (\$30 US) and I was soon ready to self-medicate. Biotin is water soluble and a small spoonful (100mg) dissolves easily in a little water which is what I have been taking three times a day for three weeks.

At the time of writing it is too early to say whether biotin is working yet – there is some suggestion that it might be having a very slight effect on my spasticity and spasms but my walking is no better than before.

So, you could say the jury is out and I have to remind myself that biotin didn't work for everyone on the trial, and certainly not in three weeks. I guess I will just have to be patient and hope it works for me. Of course I will let you know if and when there are any positive signs. Watch this space.

More information on page 12-13

Placenta cells could be new treatment for MS progression – US study finds

Cells taken from human placenta could stabilise and even improve MSers with progressive MS, according to a study carried out in the US.

Sixteen MS patients, including six with Secondary Progressive MS, were given an infusion of cultured mesenchymal-like cells (cells with many of the properties of stem cells) derived from healthy human placentas. These cells are believed to have immune-modulatory, anti-inflammatory, pro-regenerative and neuro-protective properties. Following infusion patients were then given monthly MRI scans to assess disease progression.

Researchers found that none of the six secondary progressive (SPMS) patients had worse MS-brain lesions one year after treatment and the majority of patients had stable or improved levels of disability. Preliminary evidence suggests that the infusion called PDA-001 could repair damaged nerve tissues in MS patients. Further trials are planned. *Contacts for news stories on page 12*

Anti-fatigue drug may help walking problems

A drug treatment for MS fatigue may also help with MS walking problems, according to a US-based pharma company.

Adamas Pharmaceuticals, Inc. is to start a phase 2 placebo controlled trial of the drug Amantadine in 60 MS patients who have problems walking. The treatment will last for one month in Spring 2016 and the company expects to have first results later in 2016.

Amantadine is an antiviral drug, used to treat influenza infections and Parkinsonism, and has also been found to be effective in relieving fatigue in MS though nobody understands why this is. *Contacts for news stories on page 12*



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

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 and they will be delivered directly to you.

IN THE NEXT ISSUE (OCT/NOV 2015)

Wii Fit is great for fun, and fitness if you have prog MS and if you hate gyms (I do!)



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Ocrelizumab story

<http://www.roche.com/media/store/releases/med-cor-2015-06-30.htm>

(Roche press release for Opera I and II trials)

<https://clinicaltrials.gov/show/NCT01194570> (Oratorio trial)

Biotin story

<http://www.medday-pharma.com/news-and-events/medday-reports-additional-positive-data-of-its-pivotal-phase-iii-study-with-md1003-in-patients-with-progressive-multiple-sclerosis/>

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masitinib story

<http://multiplesclerosisnewstoday.com/2015/07/24/masitinib-shows-promise-study-treating-progressive-ms-patients/>

<https://clinicaltrials.gov/show/NCT01433497>

Wheelchair story

<http://www.theguardian.com/society/2015/jul/20/wheelchair-users-to-launch-challenge-to-improve-nhs-service>

pages 4-5 FES Feature

<http://www.odstockmedical.com/about-fes>

http://www.bioness.com/Healthcare_Professionals/Exoskeletal_Products/L300_for_Foot_Drop.php

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Ibutilast story

<http://medicinova.com/clinical-development/core/mn-166/>

<http://www.mstrust.org.uk/atoz/ibudilast.jsp>

phenytoin story

<http://www.mstrust.org.uk/news/article.jsp?id=6728>

page 7 cannabis top story

<http://www.proactiveinvestors.com.au/companies/news/63286/phytotech-medical-to-start-multiple-sclerosis-clinical-studies-in-q4-2015-63286.html>

cannabis bottom story

<http://jama.jamanetwork.com/article.aspx?articleid=2338251>

pages 8+ 9 biotin feature

For back ground on the biotin story go to the MedDay site

<http://www.medday-pharma.com>

If you are interested in joining the MSers looking in to biotin the best place to start is <https://www.facebook.com/groups/BiotinForProgressiveMS/>

Also check out

https://www.facebook.com/groups/1422801794711545/?hc_location=ufi

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Placenta story <http://multiplesclerosisnewstoday.com/2015/05/05/promising-new-therapy-multiple-sclerosis-based-placenta-cells/>

Amantadine story

<http://multiplesclerosisnewstoday.com/2015/06/12/adamas-begins-phase-2-study-ads-5102-patients-multiple-sclerosis-walking-impairment/>

<https://clinicaltrials.gov/ct2/show/NCT02471222?term=amantadine+multiple+sclerosis&rank=1>

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