



My prog-MS e-zine

For people with progressive MS
and other interested people

Issue number 8, June/July 2016

Hello and welcome to the latest edition of my free e-zine about progressive MS and MS progression in general. My name is Ian Cook. I'm a 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 prog-MSers. The first feature on page 4 is about cooling aids and other ways to beat the Summer heat. In the second feature on page 8 we meet two prog-MSers who have been on MS drugs trials. Finally I now have a website for the e-zine. It is at <http://www.mymsprogblog.com>
Thanks to fellow prog-MSer Pete Joyce for helping me here.

So, please send this e-zine 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 progressive MS.

<p><u>IN</u> <u>THIS</u> <u>ISSUE</u></p>		<p><u>Feature</u> Cooling jackets and other ways to beat the heat this summer <u>Pages 4-5</u></p>
<p>- New drug could reverse progression, p2 - Food supplement could work on SPMS, p3</p>		

New drug discovery could reverse MS progression and re-generate myelin sheath

Researchers from two US universities believe they may have discovered a drug that could stimulate the regeneration of the myelin sheath and even reverse MS progression.

The drug called indazole chloride has been tested on mice infected with a mouse version of MS and was found to reduce brain and spinal cord inflammation in the mice. It also re-myelinated axons.

What is particularly interesting to prog MSers is that the drug appears to be effective long after the onset of MS. As long as the nerves haven't been totally destroyed, indazole chloride appears capable of rebuilding them.

“Our work on mice suggests that its effect is permanent,” said Associate Professor Seema K. Tiwari-Woodruff of University of California (Riverside.)- one of the two US universities involved in the research.

“But perhaps more significant, indazole chloride remyelinates - it makes new sheaths around those axons that have not been lost for good.

“This means Indazole chloride not only inhibits inflammation but is capable of reducing axon degeneration and restoring neuronal function.” Professor Tiwari-Woodruff added.

The researchers believe the drug can be tweaked to be even more effective, and eventually administered in tablet form. Clinical trials are expected to take place soon.

For details of sources for all news stories go to page 14

Supplement may be neuro-protective in SPMS

Lipoic acid, an over-the counter drug sold as a food supplement, could be neuroprotective for people with secondary progressive MS, if taken at very high doses.

This is the finding of a "highly promising" pilot study presented at the recent annual American Academy of Neurology meeting. In a two-year randomised, double-blind trial 54 patients with secondary progressive MS were given either a dummy pill or 1,200mg Lipoic Acid per day. Lipoic acid produced "a significant reduction in whole brain shrinkage, beneficial effects on walking speed, cognition, fatigue, and quality of life as well as a reduction in falls.

In a mouse model of MS—called experimental autoimmune encephalomyelitis—lipoic acid decreased inflammation as well as optic and spinal cord atrophy. Lipoic acid can be bought at health shops but generally in capsules of 100mg - far lower than the 1200mg dose use in the trial.

More positive data from biotin drug trial

New data on MD1003 -a pharmaceutical formula of high-dose biotin (vitamin B7) - suggests the drug may work for a larger group of people if taken for longer periods of time.

The new data looked at the proportion of patients who improved on the Expanded Disability Status Scale (EDSS) or a timed walk test at 9, 18 and 24 months. The number improving was 12.6 percent after nine months, with 13.2 per cent of patients demonstrating less disability at 18 months, and 15.4 percent at 24 months. Professor Ayman Tourbah, the study's principal investigator, said that almost no progression was observed in patients treated with MD1003 for 24 months, and that this had never been seen before

The information on MD 1003 was presented at the recent American Academy of Neurology Annual Meeting.

For details of sources for all news stories go to page 14



My top tips for keeping cool this summer

The days are long, the weather is glorious, but summer can be hell when you have progressive MS.

The reason is of course heat. Demyelinated nerves are poor conductors of electrical signals and their performance gets worse when your body's core temperature goes up by just half a degree centigrade.

Clearly the best solution is to avoid the heat but this isn't always possible, so I have prepared my top five cooling products

1. Cooling vests (See above) The sleeveless zip-up jacket shown above is my tried and trusted version of the Kool Max Zipper Vest (KMOVZ). It comes with water-based cooling packs which you freeze before putting into special pockets sewn into the jacket lining. Cooling packs can be re-frozen and re-used over and over again. I have been the proud owner of one of these cooling vests for around five years and yes, it really has made a difference. Some cooling vests have special cooling crystals rather than ice packs and with these you simply soak the cooling vest in cold water for a couple of minutes and the cooling crystals hold the cold temperature for a long time.

2. Cooling scarves and towels. These are an alternative to a cooling vests. Many are made from material that retains water, allowing the water to evaporate slowly leaving you colder as a result. When the towel dries out you just re-wet it and within minutes it's cool again. As well as cooling scarves and towels there are also cooling ties, scarves, neck wraps and hats which can also double up as sun hats. *continued on page 5*



3. A cool pillow. If your summer heat problem is a night-time one and you find yourself suffering “hot pillow syndrome” a cool pillow could be the answer. The Chillow Plus (left) is a personal cooling pad which can be used with your existing pillow. You fill it up with tap water which is absorbed into the foam core. You can either insert the Chillow Plus into your pillow or sleep straight on it for maximum coolness. It

isn't just a fantastic way to keep cool at night, you can also use it during the daytime as a cool cushion.

4. Fans. I am a big fan of fans. Most people think of big electric fans for the office but don't underestimate the cooling effect that you can get from the hand held variety. These are portable, cheap and devastatingly effective when used with the cooling sprays. (See below)

5. Cooling sprays. These amazing aerosol sprays are sold widely at chemists, are easy to carry and unbelievably effective. You might think they are a waste of money and plant sprayers are just as good but cooling sprays really are the perfect way to chill out quickly. They have been described as air conditioning in a can, and the secret is the super-fine spray which is incredibly refreshing.



Finally, if you are planning to go to a hot country this summer then remember that some of the best ways to keep cool are actually the cheapest. Soaking your feet in cool water, putting your hands under the cold tap, taking a cool shower, wearing a hat outdoors, even putting ice cubes in your cold drinks, can help.

For details of all products go to page 14

Report says prog-MSers get ‘second class’ service

Progressive MSers get less support from specialist health care professionals than relapsing remitting MSers, despite the fact that progression inevitably brings increasing disability and more complex symptoms.

These are the findings of a report by the MS Trust which found that while almost 80 per cent of people with relapsing remitting MS had seen their neurologist and MS specialist nurse in the past year, around 40 per cent of progressive MSers hadn't seen either. A further 12 per cent of progressive MSers reported receiving no specialist support at all in the last year.

The report also says 40 per cent of people with secondary progressive MS reported seeing less of their specialists once their disease became progressive. Many reported being effectively ‘discharged’ from the care of their neurologist and their MS nurse and left to manage alone.

Re-myelination blocking cells could be drug target

Treatments which target re-myelination blocking molecules may be a promising new approach to treating progressive MS, according to research carried out at the University of Calgary, Canada.

In animal experiments researchers found that chemicals called proteoglycans block oligodendrocyte (myelin making cells) from functioning, following episodes of demyelination in MS.

In tests on 245 different drugs the Canadian scientists discovered that a chemical called fluorosamine had the greatest potential for preventing the actions of these destructive proteoglycans and promoting re-myelination and the growth of oligodendrocytes. The research is published in the journal Nature.

For details of sources for all news stories go to page 14

Plant based drug shows promise in prog–MS

An international research team has demonstrated that a new plant-derived drug can block the progression of multiple sclerosis.

University of Queensland, Australia, researcher Dr Christian Gruber said the new drug -- named T20K -- was extracted from a traditional medicinal plant, named *Oldenlandia affinis* which grows in the tropics

The drug treatment has been successful in an animal model of MS, and patent applications have been filed in several countries. Phase one clinical trials could begin as early as 2018.

Prog-MS drug link to possible raised cancer risk

A drug sometimes used to treat progressive MS may be linked to an increased risk of colorectal cancer according to a study in the medical journal *Neurology*.

The drug called Mitoxantrone suppresses the immune system and was first developed as a chemotherapy treatment for certain cancers. Its use is already limited because previous studies have shown an increased risk of leukaemia and heart damage.

However, despite an increased risk of acute myeloid leukaemia and colorectal cancer, the overall rate of cancer was low enough to justify using the drug for people severely affected by MS if no better treatment is available, said study author Mathias Buttmann, MD, of the University of Würzburg, Germany. Buttmann added that the new study was relatively small and needs to be confirmed

For further details on all new stories go to page 14



How I got on a clinical trial – and what I got out of it

Paul Steiner (pictured) from Birmingham has just been on the Canbex trial, a six week trial testing an experimental new anti-spasticity pill called VSN16R

“I first read about the Canbex/ VSN16R trial and I approached the organiser by email and received a swift response. I have been interested in clinical trials for a long time. I could claim my interest is altruistic, but in reality it is more selfish as there are very few treatments for progressive MS so it’s easy to feel abandoned by the medical profession.

“After a referral from my neurologist I visited the trial centre in London in September 2015 where I spent five days taking various medications followed by tests to assess spasticity - a growing problem. On one day I received a placebo (but neither I nor the researchers knew which day). This was followed by three weeks taking either the trial drug - VSN16R or a placebo at home.

“I wasn’t sure during the first week whether I felt any benefit. Later on I felt my spasticity was improving. However, during the final ‘washout’ period when I was taking neither the trial drug nor my prescribed anti-spasticity drug Baclofen my spasticity returned noticeably. This reduced when I re-started Baclofen, but I have not recovered to the level I felt during the trial. I will be surprised if it turns out that I was receiving the placebo. Looking back, it was good to spend time with a motivated group of researchers developing therapies for MS. They provided me with physiotherapy advice and at the end of my trial arranged for me to be referred to a local physio service and even let me join the trial organiser’s spasticity clinic in London. I would recommend anyone to get on a trial. I shall certainly be looking out for further trials,



Andy Bennett (pictured) from Norwich has SPMS and is taking part in the MS-SMART trial in London.

MS-SMART is a two year trial to test the effectiveness of three neuroprotective drugs (Fluoxetine (Prozac) , Riluzole and Amiloride) for treating Secondary Progressive MS compared to a placebo or dummy pill. This is Andy's story:

"I saw the MS-SMART trial in the press in 2013, and decided to apply. I wanted to do something for MS as a whole, plus I wanted to help myself. I believe everyone who has this "bloody thing" should do anything they can to help us all. I went down to University College London (UCL) for an initial screening and had my first MRI (one of three MRIs) in April 2015.

"The trial involves taking a tablet of a neuroprotective drug (Fluoxetine (Prozac) Riluzole or Amiloride). One in four patients is taking a placebo or dummy pill, but obviously we don't know who. The placebo aspect doesn't worry me but I would be a little annoyed if I was on it. However, as I haven't noticed any changes I suspect this may be the case. At the time of writing I have completed 36 out of the 100 weeks. I have three more trips and a final phone contact to make sure I haven't grown two heads or something.

"Visits last from 20 minutes to three hours include checks, blood tests, examinations and three MRIs! I travel from my home in Norwich by train and across London by tube or taxi. This is no problem as I still walk, albeit with Stan my trusty stick, taking a breather when I need it. There are costs involved, UCL pay a standard £24.50 per visit and I reckon I pay a similar amount. The pros and cons of taking part are tricky. I had the time and could afford to do it. I know they are still recruiting in London and I would recommend it."

For further information and details of the two clinical trials go to p 14

Anti-histamine pill may hold clue to remyelination say researchers after visual tests

An anti-histamine tablet may promote remyelination of MS damaged nerves according to research presented at the American Academy of Neurology meeting in Vancouver.

MS patients with chronic optic neuropathy showed improvements in visual tests when treated with clemastine which is also known as Tavist, said Ari Green, MD, of the University of California San Francisco.

Clemastine did have one significant adverse effect, however: it worsened fatigue, Green said. And it achieved relatively low saturation at the presumed target receptor – For this reason it may not end up as a recommended treatment for progressive MS.

However, it may point the way toward other drugs with better pharmacodynamics that leave out the antihistamine effects and focus more specifically on remyelination.

The rationale for clemastine is that, in a lab screening study of drugs that might promote the growth of oligodendrocytes – cells which make myelin -- clemastine came out on top.

Anthony Reder, MD, of the University of Chicago, who was not involved with the study, said he thought the study was important in leading toward a treatment for progressive MS.

He marvelled that a "cheap drug" such as Tavist/clemastine could have such a notable effect in a short-duration study. He agreed that clemastine has drawbacks, but called it "a clue" toward a workable remyelination approach.

For further details of all news stories go to page 14

Diet and gut flora can influence prog-MS

Diet and gut flora can affect the outcome of neuro-degenerative diseases such as progressive multiple sclerosis (MS), according to a study published in the journal Nature Medicine.

Investigators at Brigham and Women's Hospital (BWH) in the US studied MS patients to find that modifications in diet and gut flora influence a class of brain cells called astrocytes. These cells play an important role during central nervous system injury and disease, and are thought to play a part in the MS disease process.

"For the first time, we've been able to identify that food has some sort of remote control over central nervous system inflammation," said Francisco Quintana, PhD, the study's senior author and an investigator in the Ann Romney Center for Neurologic Diseases at BWH.

Gut bacteria affects myelin and may cause depression

Researchers at the Center of Excellence for Myelin Repair, part of Mount Sinai Hospital in the US, say gut bacteria produce chemical compounds that affect myelin in mice.

These compounds can also cause social avoidance behaviours in the mice and study results indicate that targeting gut bacteria, might also help in treating disorders like depression often seen in MS.

Previous studies from the same research team have described a reduction of myelin and myelinated fibres in preclinical models of depression, suggesting a biological explanation for the high rate of depression in patients with MS.

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For some time I have been thinking that it would be good if there was some way that readers could send in letters about things they read in the ezine and things they want to share with other readers.

I am fortunate enough to have had my first such letter which I share with you below.

So if there is something you have to say which you want to see in the ezine then send it by email to me at iancookjournalist@yahoo.co.uk

Dear Ian

Your ezine is delivered in a pdf (portable document format) which you need to open with Adobe Acrobat Reader

My problem with acrobat files is that the original document is enlarged making the page bigger and one has to move across it with one's screen. Well since being diagnosed with SPMS in 2005, I'm discovering that to read I need to use a ruler/card to keep track of my place in the text. I can't do this when the ruler keeps falling off my screen. Also my eyesight is getting worse – MS or age? Who knows? .doc enlarges the text which is easier. Does anyone else have that sort of problem which I find difficult to explain. It's driving me mad as more and more on the web is in .pdf format. Does anyone have any ideas?

Margaret Clark

If you have any ideas to help Margaret send them on to me and I will pass them on to her– Ian Cook



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 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, and give me hints and suggestions. In

this issue we have already heard from two people taking part in clinical trials I have also started a letters page so please send me in your ideas.

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 either fill in the relevant boxes at <http://www.mymsprogblog.com> or email me at iancookjournalist@yahoo.co.uk and either way copies will be delivered directly to you.

IN THE NEXT ISSUE (Aug-Sept 2016)

Perching stools, shower seats and grab rails to make your life easier



PLUS FEATURE ON ACCESSIBLE HOLIDAYS

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Indazole chloride story

Sources www.ms-uk.org/may11

<http://www.healthline.com/health-news/new-drug-could-reverse-ms-by-mimicking-high-estrogen-in-pregnancy-121114#1>

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Lipoic acid story

<http://www.empr.com/aan-2016-multiple-sclerosis/lipoic-acid-may-provide-inexpensive-tx-option-for-secondary-progressive-ms/article/487260/>

see also

<http://www.drugs.com/npp/alpha-lipoic-acid.html>

biotin story

Source:

<http://multiplesclerosisnewstoday.com/2016/04/27/meddays-md1003-reversed-disease-progression-in-not-active-progressive-ms/>

pages 4-5 Feature on cooling products

1. The Cooling Vest KMVZ as shown :

Price = £106.95 (including delivery to most areas of the UK).

Availability - most sizes in stock but not all colours in all sizes. A fresh delivery is awaited. For details go to <http://peakpersonalcooling.uk/>

2 The Chillow Plus . Go to <http://www.personalcooling.co.uk/> for details of a range of cooling products including Chillow Plus .

page 6 MS Trust story

<https://www.mstrust.org.uk/news/news-about-ms> (April 20)

page 6 Re-myelination story

www.ibtimes.co.uk/multiple-sclerosis-drug-boosts-myelin-regeneration-mice-raising-hope-future-treatments-ms-1556869

page 7 Plant based drug story

<https://www.uq.edu.au/news/article/2016/04/breakthrough-may-stop-multiple-sclerosis-its-tracks>

P7 Pregnancy story

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

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If you want to find out more about clinical trials including the two featured then check out NHS Choices Clinical Trials homepage www.nhs.uk/conditions/clinical-trials At the bottom of the page is a link to the Clinical Trials Gateway where you can look at MS research taking place locally. The url for the Clinical Trials Gateway is: <https://www.ukctg.nihr.ac.uk/>

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Anti-histamine pill story

<http://www.medpagetoday.com/meetingcoverage/aan/57458>

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Diet and gut flora story

<http://news.harvard.edu/gazette/story/2016/05/gut-bacteria-link-and-multiple-sclerosis/>

Gut bacteria affects myelin

<http://multiplesclerosisnewstoday.com/2016/04/27/gut-bacteria-affects-myelin-content-induces-ms-like-depression-mice-study-reports/>

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