

My MS prog-blog

The ezine for people with progressive MS

Issue 5, December 2015 / January 2016



Hello and welcome to the fifth 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 a **Panorama programme on BBC1 to be screened on Monday 14 December at 8.30 pm** entitled: "Can You Stop My Multiple Sclerosis?" What little I know is on page 3. Inside too is some news on the recent Tysabri trial on prog-MS on page 2 There's more

too - a feature looking at cannabis for prog MS on page 4. Finally look at my thoughts on getting more vitamin D in Winter. See page 8.

Finally, please send this ezine to all other progressive MSers in your address book, oh and do have a happy Christmas and New Year!

**IN
THIS
ISSUE**



[Feature](#)

Cannabis – new medications, legal cannabis sprays, oils and vaping devices

[Pages 4-5](#)

- Tysabri SPMS trial. Should it be re-run? – p2**
- Panorama MS special on Dec 14 – details p3**

Mixed results for two year Tysabri SPMS trial - did it last long enough?

A two year trial into Tysabri for secondary progressive MS saw several improvements in symptoms, but the drug failed to slow disability progression. A leading neurologist has questioned the trial's length.

The trial called ASCEND looked at the effects of Tysabri, (natalizumab) on disability progression in 889 people with secondary progressive MS (SPMS) who had an EDSS (Expanded Disability Status Scale) score of 6.0 to 6.5 (walking aid needed). Several improvements were seen in patients such as better upper limb function, improved relapse rates and fewer new MRI lesions. However, Tysabri did not slow the gradual increase in disability compared to a placebo. It was said to have failed to meet its primary or secondary endpoints.

Writing in his online MS research blogspot Gavin Giovannoni, professor of neurology at Barts and the London School of Medicine, said the trial was not long enough. "The limiting factor is this study was its duration; it was simply too short... I predicted this trial would be negative in relation to lower limb function, but not upper limb function. This prediction was based on the short duration of this trial (24 months).

But he said there was some good news. "The fact that this study delayed disease progression in the upper limbs is excellent news. It means it is worthwhile continuing to look for effective treatments to target this phase of the disease."

Tysabri's maker Biogen said the company was disappointed with the overall trial results but added that the research provided important insights into the benefits that the drug may provide in areas such as upper limb function which is generally affected later on in progressive MS.

Details of where to find more on Prof. Giovannoni's views on the Tysabri trial is on page 13.

New protein discovery may help fight MS progression – is this a breakthrough?

A key protein involved in the auto-immune response that drives MS progression has been identified by Australian researchers.

The protein, called CCR2, helps immune response cells called T-cells move around the body, fighting persistent infections. In MS, T-cells also attack the body's own tissues and until recently the protein believed to be involved in these auto-immune attacks was not thought to be CCR2 but a closely related protein - CCR6.

Lead researcher Professor Shaun McColl, Director of the Centre for Molecular Pathology at the University of Adelaide where the research took place, says the finding could represent a breakthrough in developing drugs to combat progressive MS. "We've now shown that the target is actually CCR2. Blocking CCR6 makes MS worse. If we can find an antagonist to block CCR2 specifically on T-cells, we should be able to control the progression of MS," he said.

BBC 1 to screen Panorama special on MS

An edition of BBC1's Panorama is to be broadcast on Monday December 14. Panorama says it has "exclusive access to patients pioneering a crossover cancer treatment that has enabled some MS sufferers with paralysis to regain their movement".

The programme is called "Can you stop my multiple sclerosis?" and there were few details as we went to press but here was online speculation that the programme might look at HSCT (Hematopoietic Stem Cell Transplantation) an existing cancer treatment in which patients effectively have their immune systems 'rebooted'. *Further details of all news stories on page 13-15*



Cannabis – Is a wind of change about to blow through the MS world?

For years prog-Msers like me have been disappointed that nothing much is happening in the world of cannabis and MS. Now all that is changing. There's new medicines, legal cannabis oils, even a legal e-cigarette (pictured above) .

Until now there has been just one cannabis based medicine licensed for treating MS. it is called Sativex - and is a cannabis based mouth spray for MS spasms and spasticity. But there's a problem. Although Sativex is highly regarded by many MSers, it is now virtually impossible to obtain on the NHS. This is because of "postcode prescribing" and official guidance from the NHS drugs watchdog NICE which in 2014 said Sativex isn't cost effective.

Now things may be changing and the change really could happen quite quickly. Two new medications are entering clinical trials in 2016. The first is a called MedChew RX a medical cannabis chewing gum for treating spasticity.

MedChew RX contains THC, (this is the "psychoactive" stuff that gets you high) It also contains cannabidiol, a non-psychoactive part of the plant. A Phase 1 trial of the gum is due to start in Amsterdam in the second quarter of 2016. *Continued on p5*

Continued from page 4 The second product comes from the UK . VSN16R, is a drug being developed by a company called Canbex. It doesn't actually contain cannabis but works in a related way. Someone connected with the research said the following: "Our aim is to move away from the cannabis plant and the issues associated with recreational use and abuse and develop a pharmaceutical that harnesses the benefit that the cannabinoid system has to offer but lacks the side effect/psychoactive activity associated with cannabis."

Clearly it is all very clever stuff. A trial into VSN16R is currently recruiting and is due to report in Autumn 2016. Of course any new medication would have to jump over all the various regulatory hurdles, so many MSers, are asking whether there is a quicker alternative to treating our spasms and spasticity?

The cannabis plant contains two main substances. The first - THC or tetrahydrocannabinol -gets you high. This is illegal unless it is contained in a licensed medicine like Sativex . The second is CBD or cannabidiol which is said to make you mellow but not high. CBD is not psycho-active ie: there's no "high". It is also legal in the UK. (I checked this with the Home Office)



Given its legality I recently decided to try out CBD as a way of treating my leg spasms and spasticity. Online I found a huge number of legal CBD sprays, atomisers, liquids and even CBD e-cigarettes or vaping devices available. I bought a CBD vaping device called KanaVape (*pictured above and on p 4*) It is made in the Czech Republic, has been easy to use and is actually quite relaxing, It's too early to tell whether it is in stopping my leg spasms and spasticity, I will probably know more by next year.

2016 will be as I say, a big year for cannabis and MS .

More details for this feature on page 13. VSN16R trial details on page 6.

Ocrelizumab may have rival MS treatment in existing arthritis drug rituximab

New progressive MS disease modifying drug ocrelizumab may not have the field to itself, according to a feature published in the online publication MedPage Today.

A similar drug called rituximab (Rituxan) is already available at numerous MS clinics in the U.S. and MedPage Today says Rituxan is showing results that compare favourably with recent trial data on ocrelizumab. Among 36 patients with secondary progressive MS given Rituxan at University Hospital Basel in Switzerland the risk of confirmed progression was cut by nearly 80 per cent compared to conventionally treated patients.

Rituxan currently costs about \$30,000 a year as a treatment for rheumatoid arthritis, in the US . The dosing schedules reported with off-label use for MS have been similar. It's currently not known what ocrelizumab will cost, if and when it is given regulatory approval as a prog- MS treatment.

Spasticity drug trial drug starts in London

A UK based trial is now recruiting 160 MS patients to test out a new spasticity treatment. So far two hospitals in London have been named as trial sites. More sites across the UK will be announced soon.

The phase 2 trial will test out new experimental drug called VSN16R taken daily or twice daily for 26 days by patients who have an MS diagnosis and EDSS (Expanded Disability Status Scale) score of 6.5 or less. An EDSS score of 6.5 means that patients use two walking aids - pair of canes, crutches, etc - to walk about 20m. VSN16R is said to be a drug with a unique mechanism of action, unlike any current anti-spastic drug. The trial has been organised by Canbex, a University College London Spin-Out Company. For further details of the trial go to <https://clinicaltrials.gov/ct2/show/NCT02542787>

Rheumatism / IBD drug may promote re-myelination, scientists say

A drug used to treat rheumatism and inflammatory bowel disease may also promote re-myelination in MS, according to research carried out in Korea.

Researchers from the University of Seoul gave the drug called sulfasalazine to a type of tropical fish genetically modified to demyelinate. Sulfasalazine was found to promote oligodendrocyte regeneration and re-myelination in the fish.

The researchers believe Sulfasalazine may also have reduced the number of macrophages in the central nervous system of the fish. Macrophages are immune cells believed to play a part in the MS disease process.

The study was published in the journal *Molecules and Cells*.

Weights may improve vitamin D levels in MS

Weight lifting and other forms of resistance exercise can increase the number of Vitamin D receptors in muscles and improve the uptake of Vitamin D and its metabolism. That is according to new research.

Vitamin D deficiency is a problem in people with progressive MS and is associated with muscle wasting, reduced muscle strength and an increased risk of falls and fractures.

According to the researchers, resistance training might help increase levels of vitamin D without over-reliance on vitamin supplement pills or sprays. The research has been published in the journal *Experimental Physiology*.

For further details on all new stories go to pages 13-15



How to fight brain shrinkage with Vitamin D in the month of D-cember

I recently read that high levels of vitamin D can be neuroprotective in the brains of MSers. If true this is of huge importance for prog-MSers because neuro-protection and brain shrinkage are big issues in prog-MS – more so than in relapsing remitting MS.

You probably know that the brains of MSers shrink at twice the rate of non-MSers. But you may not know that the brains of progressive MSers shrink about a third faster than the brains of relapsing remitting MSers. Given this fact and the fact that vitamin D can be neuroprotective, prog MSers need to look seriously at how we can boost our vit-D levels.

Yes, it's Winter and we all know there is no vit-D from sun at this time of year, but one way of getting "sunlight" based vit- D could be sitting on a sunbed. I have always been a bit of a snob about high street solariums - or is it solaria? - but the relentless progression of my secondary progressive MS gives me a pretty good incentive to overcome any such snobbery.

There is, however, a question mark over the use of solariums in raising vitamin D levels and it is this. I have read that you can only get decent amounts of vitamin D from exposure to UV-B light, not UV-A light, and most solariums like my local one favour UV-A tanning beds because they tan you quicker. So, perhaps you should look elsewhere for your vit-D. *ctd on page 9*



Ctd from p 8. If you want to raise levels of vit-D inside your own home then the choice is food or supplements. With food the best source is oily fish but you need to eat a lot to raise your levels substantially. I am told a 3 oz fillet of wild salmon can provide about 450 international units (IUs). But, I think you will really struggle to get more than 2,000 IU of vit-D a day from food.

In my opinion the best way to raise vit-D levels substantially is supplements. Vitamin D comes in two forms – vitamin D2 and vitamin D3. Vitamin D3 is more effective in raising your levels than D2 so be sure to buy only vitamin D3. Soft gel capsules are better than tablets as vit-D is fat soluble – it uses fat as a vehicle to take it to where it is needed in the body. In soft gel capsules vit -D comes already dissolved in oil which is of course a fat. You can also buy vit-D sprays but these are quite recent. Tablets and soft gels can be bought up to 5,000 IU of vit-D.

Finally, before you begin raising your levels have a vitamin D test. You should be able to arrange this through your family doctor although you can also do it privately. I pay for a test in May every year and it costs me around £28. I think it is well worth the money as I get a print out of all the relevant data like the D2 and D3 balance. I'm told it's best to aim for a vitamin D level of between 50 and 220 nmol/L. My last vitamin D level was 147.2 nmol/L which is about half way between the upper and lower limit. I would like to get it up to around 200 nmol/L, for more neuro-protection, but I think I will need to wait until the sun climbs higher in the sky and then sunbathe, safely of course.

More information and sources on pages 13-15.

New anti-cancer drug may have the potential to re-myelinate

A group of chemically de-myelinated mice were found to have 50 per cent more myelin when treated with a new experimental anti-cancer drug, researchers have said

The mice with chemically damaged brain myelin were treated with the drug called GANT61 for one month and as well as having more myelin they also showed an eight-fold increase in the number of neural stem cells that moved to myelin damaged areas of their brains.

These cells eventually developed into myelin producing oligodendrocytes. The researchers say their findings are the first to demonstrate that the experimental anti-cancer drug has the potential to treat MS.

Personalised T-cell SPMS drug is ‘one to watch’

A personalised T-cell drug treatment for secondary progressive MS has been named as one of the “top projects to watch” by a prestigious US drugs body.

Opexa Therapeutics is currently running a Phase 2b clinical study into a personalised MS immunotherapy drug called Tcelna. The project has been commended by Therapeutic Area Partnerships (TAP) which brings together decision-makers to assess promising new drug programmes in the US.

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. “Top line” results for Tcelna will be announced in 2016.

For further details of all stories go to pages 13-15.

New treatment for spasms and spasticity

A new way of treating spasms and spasticity in progressive MS is being developed by US biotechnology company Flex Pharma.

The new treatment is a drug currently called FLX-787 which interferes with two receptors called TRPV1 and TRPA1 involved in neurogenic inflammation. De-activating TRPV1 stops painful, burning sensations. De-activating TRPA1 can reduce various other forms of skin irritation.

A statement issued by Flex Pharma says FLX-787 “may represent a possible future therapeutic approach to alleviate muscle spasticity in MS patients, ultimately improving their quality of life.” FLX-787 was discussed recently at the 2015 Annual Meeting of the Society for Neuroscience, in Chicago.

Pomegranate seed extract may prevent progression

A natural antioxidant found in pomegranate seeds may be able to prevent MS progression if given in incredibly small amounts, according to new research published in the International Journal of Nanomedicine.

The anti-oxidant called Nano-PSO has been shown to significantly alleviate the symptoms of prion diseases - a family of rare progressive neurodegenerative disorders. The Nano-PSO study took place using a mouse model of MS.

Although primarily considered an autoimmune disease, MS and its characteristic demyelination of nerve cells is also thought to occur as a result of a neurodegenerative process — most importantly the oxidation of MS brain proteins and lipids. Nano-PSO contains what is thought to be one of the strongest natural antioxidants, a polyunsaturated fatty acid named punicic acid (PA).

More details of news stories on pages 13-15



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 (Feb-March 2016)

For the past three years I have self-catheterised daily. There is much to tell.



Page 2

Tysabri story

Sources:

<http://multiple-sclerosis-research.blogspot.com/2015/10/newsspeak-natalizumab-spms-trial-is.html>

length dependent axonopathy hypothesis at <http://multiple-sclerosis-research.blogspot.com/2015/03/length-dependent-hypothesis-sensory-vs.html>

Page 3

New protein story

<http://multiplesclerosisnewstoday.com/2015/10/30/potential-multiple-sclerosis-therapy-based-ccr2-inhibition/>

Panorama story

<http://www.bbc.co.uk/programmes/b06ss17g>

pages 4-5 Feature on cannabis

VSN16R details

<http://multiple-sclerosis-research.blogspot.com/2015/09/trial-is-open.html>

page 6 Rituximab story

<http://www.medpagetoday.com/MeetingCoverage/ECTRIMS/54060>

VSN 16R story

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

page 7

Rheumatism IBD drug story

Source: Promotion of Remyelination by Sulfasalazine in a Transgenic Zebrafish Model of Demyelination. Suhyun Kim, Hae-Chul Park et al, molecules and cells, published online 6 November, 2015

Vitamin D weights story

Full paper title: Makanae Y et al (2015) Acute bout of resistance exercise increases vitamin D receptor protein expression in rat skeletal muscle. DOI: 10.1113/EP085207

<http://onlinelibrary.wiley.com/doi/10.1113/EP085207/abstract>

page 8+9

vitamin D

Source for info on vit D levels and neuro-protection - European Journal of Neurology 2015 Oct 31. doi: 10.1111/ene.12844. [Epub ahead of print] Vitamin D in clinically isolated syndrome: evidence for possible neuroprotection. Mowry EM

Info re: where I go for my vit D blood test <http://www.vitamindtest.org.uk/>

page 10

Anti-cancer drug and remyelination

Source: <http://www.neurology-central.com/2015/10/02/investigational-anticancer-compound-could-promote-myelin-repair-in-multiple-sclerosis/>

Personalised T cell drug story

Source: <http://www.opexatherapeutics.com/investors-relations/press-releases/press-release-details/2015/Opexa-Therapeutics-Chosen-as-One-of-the-Top-Autoimmune-Therapy-Projects-to-Watch/default.aspx>

Page 11

Flex Pharma story

Source Flex Pharma press release <http://ir.flex-pharma.com/phoenix.zhtml?c=253862&p=irol-newsArticle&ID=2098493>

Pomegranate seed story

<http://multiplesclerosisnewstoday.com/2015/11/30/pomegranate-seed-oil-may-therapy-ms-disease-progression/>

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