



My prog-MS ezine

For people with progressive MS
and those interested in it

Issue number 13 (free edition) , May/June 2017

Welcome to my selection of the latest news and features about progressive MS and MS progression. My name is Ian Cook. I'm a secondary progressive MSer from Birmingham, UK.

In this issue are seven pages of news including details of the drug Ocrelizumab/ Ocrevus that has just been approved for primary progressive MS in the US, plus news of the recently announced UK trial of Simvastatin in Secondary Progressive MS. There's also a feature on a new catheter for men from Coloplast that I have been trying out.

If there is any story you would like me to follow then I'm at iancookjournalist@yahoo.co.uk

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Feature

**New innovative
catheter for men
from Coloplast**

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Ocrevus (ocrelizumab) approved for PPMS in the US, European approval expected soon

The U.S. Food and Drug Administration (FDA) has approved Ocrevus (ocrelizumab) as the first disease-modifying drug for primary progressive (PPMS) patients.

European health authorities are also reviewing a request for EU approval (called a marketing application), and decisions in other countries are likely to follow.

Ocrevus, which is given every six months by infusion, is the first disease modifying drug for primary progressive patients, and uses a new non-traditional approach in fighting MS. Most traditional treatments focus on keeping immune T-cells in check, but Ocrevus works to prevent certain immune B-cells from doing harm.

New treatment reverses symptoms of progressive MS

Half of the progressive MS patients in a small experimental study saw a reversal of symptoms and one patient with secondary progressive MS saw increased walking ability from 100 yards with a walker at the start of the study to three quarters of a mile following treatment with a drug called ATA188.

The study of ATA188 was carried out on six patients with progressive MS – four with secondary progressive and two with primary progressive MS at the University of Queensland in Brisbane, Australia. It was a phase 1 clinical trial in which infusions of ATA188 were given every two weeks for six weeks. The patients were followed for the next 26 weeks.

ATA 188 works on participants' T-cells and stimulates them to boost their ability to recognize and destroy cells infected with the Epstein-Barr virus. By eliminating the EBV-infected B-cells researchers believe they may be able to reduce the destruction of myelin. The study findings were presented at the American Academy of Neurology's 69th Annual Meeting in Boston, April 22-28, 2017 in a poster presentation, titled "Symptomatic and objective clinical improvement in progressive multiple sclerosis patients treated with autologous Epstein—Barr virus-specific T cell therapy. **More details of news stories p7**

Walking drug Fampyra may work in the longer term

A study into long term use of the walking drug Fampyra (Fampridine) has shown that some people whose walking did not improve after starting treatment did show improvement when tested two years later.

In the study carried out at the University Hospital Zurich, Switzerland, researchers studied walking speed in 53 people with MS in a trial where some of the 53 were taking a dummy pill but neither they nor the researchers knew.

The researchers found that several people who had not shown improvements when they were assessed shortly after starting the therapy did show significant improvements in walking after long-term two year treatment.

The authors say the considerable proportion of patients in whom responsiveness to fampridine changed over time emphasizes the importance of regular reassessment of the drug's efficacy by doctors particularly in patients with poor initial drug responses.

Bowel problems linked to MS progression

Constipation and loose bowel movements (faecal incontinence) are common in MS and directly related to the progression of the illness, according to new research published in the journal "Open Medicine"

In the research MS patients who were constipated or suffered faecal incontinence were compared with people who didn't have MS but who suffered from these conditions.

It was found that constipated MS patients had greater sphincter hypotonia (lack of tone in the anal sphincter muscles) than constipated non-MS patients. MS patients with loose bowel movements had a lower rectal sensitivity threshold than people with loose bowels who didn't have MS .

"Lower rectal sensitivity" means that when faeces enter the rectum the threshold that triggers the defaecation reflex is lower, meaning the contents of the bowel are more likely to be released earlier. The researchers concluded that both constipation and loose bowel movements arise in MS because of impaired pelvic floor coordination caused by demyelination.

The other finding of the research is the identification of the precise mechanisms that are causing the above problems. The researchers say they believe that their research may improve therapeutic responses by helping the clinician plan a personalized rehabilitation programme for individual patients **For details of all stories go to page 7**



A new flexible male catheter from Coloplast, but is it any good?

A few weeks ago I tried out a new catheter from Coloplast – the SpeediCath Flex. (See left) I am a big fan of Coloplast catheters and have been using the SpeediCath Compact once a day for five years.

So I was surprised when I read that Coloplast were launching a new addition to their SpeediCath range. I asked myself “What could possibly be better than the SpeediCath Compact?” Well, the SpeediCath Flex, as its name suggests, is flexible rather than semi-rigid like the SpeediCath Compact, and just glides in.

The SpeediCath Flex is also sheathed in a protective wrapping (See picture above) which means you push the catheter through a wrapper on its journey through the urethra to the bladder. The catheter has less contact with the outside world so it should be even more hygienic. Intrigued I ordered a trial kit.

A couple of days later the SpeediCath Flex arrived in the morning post and at bedtime (my usual self-cathing time) I went to the bathroom where I unscrewed the looped SpeediCath Flex catheter. The first task was getting the tip of the SpeediCath Flex into the urethra. This was more of a challenge than I had anticipated as the blue surrounding ring isn't attached to the catheter tip (see picture above) and it was more difficult to get a “direct hit” or entry holding the ring. This was my first time but, over time, practice will doubtless make perfect.

The next task was getting the SpeediCath Flex through the nine inch male urethra. With the SpeediCath Compact this usually takes about three seconds from insertion until urine starts to flow, but with the SpeediCath Flex things take longer. The SpeediCath Flex's protective sheath means the catheter **Continued on page 5**

Continued from page 4 cannot be "dive bombed" through the urethra but needs to be fed through bit by bit – a technique which takes greater time and patience.

The other thing worth mentioning is the SpeediCath Flex is soft, so soft you can't feel a thing. This is good in that the catheter is less likely to rub against the sides of your urethra. However it also means it is hard to know where the catheter tip is in the urethra and how much further you have to go to reach the bladder. Once again I'm sure you will learn as you go along (literally)

When the SpeediCath Flex finally does reach the bladder the urine flows out as per usual. As long as you don't miss the toilet bowl – easily done as you're holding onto something called "Flex" which tends to move around – then you'll have no problems.

I don't want to sound at all critical because the SpeediCath Flex has many welcome innovations. It is small, easily transported, soft and therefore less likely to damage your urethra. It is also ultra-hygienic so infection should be less of a problem. And as there is no discomfort it might be a good catheter to start off with, particularly if you suffered from "catheterphobia" as I did when I first started.

However, its only disadvantages are that I found insertion more difficult, it was also more difficult to get the urine into the toilet or collecting bowl and emptying my bladder was a bit slower.

Many of these I would think are teething problems and I am certainly not dismissing the SpeediCath Flex because Coloplast make the best catheters around. However I shall probably stick with the SpeediCath Compact at home and use the SpeediCath Flex in a public toilet where its ultra-hygienic design and portability will come into their own. I may also use the SpeediCath Flex when I'm camping this Summer but for home use I think the SpeediCath Compact will remain my "go-to" Catheter.

For me the SpeediCath Compact is pretty much perfect and how do you improve on perfection?

For more information SpeediCath Flex go to page 7

UK Simvastatin trial in SPMS to start this year

Hundreds of British patients with secondary progressive multiple sclerosis (SPMS) are set to take part in a trial where they will be given simvastatin, a cheap anti-cholesterol drug that could delay symptoms.

In a trial conducted three years ago, scientists found the rate of brain shrinkage was halved among 140 MS patients who took statins.

Now University College London is launching a six-year trial, which will involve 1,180 patients at 30 hospitals across the UK.

The research will be led by Dr Jeremy Chataway, UCL Institute of Neurology London, who led the phase II trial of simvastatin. In this research not only did those taking high doses of simvastatin have a significant reduction in the rate of brain atrophy (brain shrinkage) over two years, but they also had less disability and better quality of life scores at the end of the study.

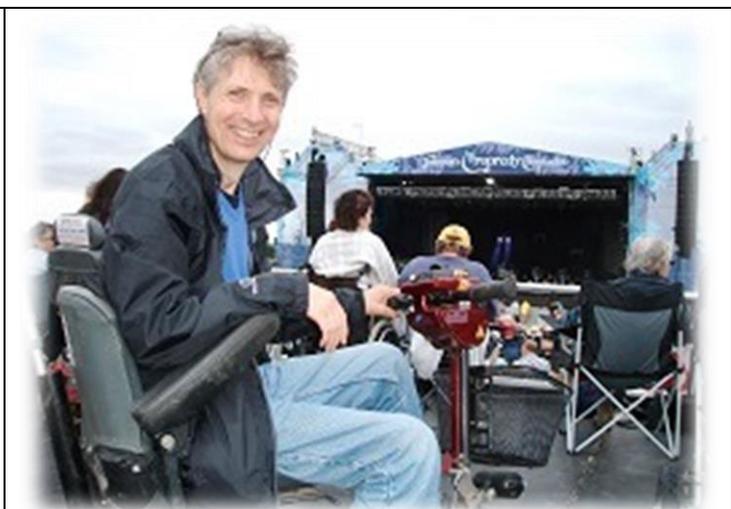
"This drug holds incredible promise for the thousands of people living with secondary progressive MS in the UK, and around the world, who currently have few options for treatments that have an effect on disability," said Chataway. "This study will establish definitively whether simvastatin is able to slow the rate of disability progression over a three year period, and we are very hopeful it will."

The trial will start in the summer of 2017. To register your interest, visit <https://www.msociety.org.uk/ms-stat2>.

For more details of stories see page 7

IN THE NEXT EDITION

My weekend at a pop festival with folk music, fun, camping and self-cathing in a tent!



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ATA 188 story

Source <https://multiplesclerosisnewstoday.com/2017/04/28/small-study-shows-unexpected-reversal-of-some-ms-symptoms/>

<http://investors.atarabio.com/releasedetail.cfm?ReleaseID=1022221>

Page 2 Ocrelizumab/ Ocrevus story

Source 1 : https://multiplesclerosisnewstoday.com/2017/03/28/fda-approves-ocrevus-as-1st-ms-treatment-for-both-relapsing-and-primary-progressive-forms/?utm_source=Multiple+Sclerosis&utm_campaign=4b49cd0bb4-EMAIL_CAMPAIGN_SPINRAZA_2016_12_23&utm_medium=email&utm_term=0_b5fb7a3dae-4b49cd0bb4-71290133

Source 2 https://www.nytimes.com/2017/03/28/health/fda-drug-approved-multiple-sclerosis-ocrevus.html?smprod=nytcore-ipad&smid=nytcore-ipad-share&_r=3

Source 3 Source: [https://www.mssociety.org.uk/ms-news/2017/03/first-treatment-licensed-primary-progressive-ms-us?utm_source=Email&utm_medium=link&utm_content=2017.04.20_Buzz_April%20\(1\)%20remainderApril%2020,%202017&utm_campaign=2017M7202_0202&spMailingID=1745933&spUserID=MjMzMTE1NTc0MzMS1&spJobID=770629970&spReportId=NzcwNjI5OTcwS0](https://www.mssociety.org.uk/ms-news/2017/03/first-treatment-licensed-primary-progressive-ms-us?utm_source=Email&utm_medium=link&utm_content=2017.04.20_Buzz_April%20(1)%20remainderApril%2020,%202017&utm_campaign=2017M7202_0202&spMailingID=1745933&spUserID=MjMzMTE1NTc0MzMS1&spJobID=770629970&spReportId=NzcwNjI5OTcwS0)

page 3 Constipation/ faecal incontinence

Source: Marola et al. Anal sphincter dysfunction in multiple sclerosis: an observation manometric study. Open Med (Wars). 2016;11(1):509-517.

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5329875/>

Fampridine/ Fampyra

Source: <https://www.msif.org/news/2017/03/09/long-term-safety-effectiveness-fampridine/>

- See more at: <https://www.msif.org/news/2017/03/09/long-term-safety-effectiveness-fampridine/#sthash.l7ZMBmpr.dpuf>

P4-5 Coloplast SpeediCath Flex for men

Source:

https://www.coloplast.co.uk/flex?gclid=CJjThLzG0dMCFYY_GwodE1wBmQ&gclid=aw.ds

Page 6 Simvastatin trial

Source: Source : <http://www.ms-uk.org/ms-patients-trial-statins-treatment-090517>

If you'd like to read a longer in depth version of the above stories, and more stories and features too, then there is a fuller version of the ezine available at only £10 a year for six issues. That's just £1.67 per issue. And payment can be done either online or by more traditional methods.

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Best wishes, Ian

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