My MS prog-blog

The ezine for people with progressive MS

Issue 6, February/ March 2016

Hello and welcome to the sixth 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 trial carried out in the US into stem cells for progressive MS. The results are said to be 'unprecedented' . Inside too is a feature looking at a new diet said to be of specific help for people with progressive MS. There's also some exciting news about more progress –a medicine based on biotin (Vitamin B7) for us prog-MSers. Also I talk about catheters which I have used successfully for five years.

So, please send this ezine to all other progressive MSers in your address book, and we can share our knowledge about what it's like to live with prog-MS.

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Feature

How this catheter has transformed my quality of life

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New biotin (vitamin B7) drug to be aimed at both PPMS and SPMS patients

An experimental MS drug based on a highly concentrated form of biotin (vitamin B7) is to be targeted at patients with progressive MS, rather than those with relapsing remitting forms of the illness.

This is the latest news from French pharmaceutical firm MedDay which has pioneered development of the new medication called MD1003 containing large doses of pharmaceutical grade biotin (vitamin B7).

The MedDay announcement follows release of trial results looking at the effects of MD1003 on MS patients with optic neuritis. The trial achieved statistically significant improvements in vision only in patients with progressive MS. It did not achieve statistical significance in relapsing remitting MS patients.

MedDay CEO Frédéric Sedel says that following the trial he believes the path forward for MD1003 is clear."MedDay will pursue the development and file MD1003 only in progressive forms of MS, where there is a particular need for a disease modifying therapy and no drug approved so far," he said.

The most probable explanation for the success of biotin in progressive MS is that it enables severely de-myelinated nerve cells to carry out energy metabolism at a hugely faster rate “turbo-charging” mitochondria – the energy powerhouse in nerve cells – and compensating for the cells’ lack of myelin. The amount of biotin in MD1003 is 300mg a day or 10,000 times the RDA (recommended daily allowance). A demyelinated axon may use up to 5,000 times more energy than a fully myelinated axon.

Following the release of the latest trial results it is expected that MedDay will approach regulators in Europe and the US later this year with a view to seeking regulatory approval for the new drug in progressive MS by2017.

For details of sources for all news stories go to page 13

‘Unprecedented’ results of phase 1 stem cell trial for prog-MS - phase 2 trial this Summer

“Unprecedented” results of a phase 1 stem cell trial for progressive MS will pave the way for a larger phase 2 trial to take place this Summer.

That is according to Dr. Saud A. Sadiq, Chief Research Scientist and study principal investigator at the Tisch MS Research Centre of New York where the phase 1 trial took place. "Our unprecedented Phase I results have propelled us into the next phase of research," he said. “The objective improvement experienced in bladder function, vision and walking speed in both secondary and primary progressive MS is remarkable, " he added.

It is believed the stem cell research at the Tisch centre differs from other MS stem cell trials both in terms of type of stem cells used (neural progenitor cells) and the route of administration (intrathecal – an injection in the spinal canal) it is also highly unusual in being tested on progressive MS. it is believed the new trial could start in the Summer with 40 US progressive MS patients.

Mouth stem cells could halt MS progression

Stem cells taken from mouth tissue could halt MS progression according to research carried out in a mouse model of the illness.

Researchers from the Italian University of Chieti-Pescara took gum and mouth tissue containing mesenchymal stem cells (MSCs) from mice and used these to grow a larger number of stem cells. They then induced MS in the mice and two weeks later injected the stem cells back into them.

With the new stem cells the mice had less demyelination in the spinal cord and brain after two months. There were also fewer sign of inflammation. This suggests a decrease in MS-like disease activity in the mice after treatment according to the researchers who say similar stem cell transplants might halt MS progression in humans.

For further details of all news stories go to page 13



How these clever little catheters have really improved my quality of life

Five years ago I started to self-catheterise. At first the job was fiddly and occasionally painful. Yes, I always managed to empty my bladder but I found the whole process traumatic. It was draining - emotionally as well as physically.

Then, a couple of years ago, I discovered the Speedicath Compact - a "telescopic" catheter and an amazing innovation from Coloplast. A telescopic catheter has two connected sections. When you take the telescopic catheter out of its container one section slides out of the other. This gives you a full length catheter of 12" from a container just over half this size. It is very clever, super discreet to carry around, easy to use and easy to dispose of. Using it has changed my life.

The first catheter I used was non- telescopic. It was a single piece of tubing about 16" long, cumbersome to use, and difficult to carry discreetly to the loo when outside the house. Disposing of such a long length of tubing after use in a public toilet was not a simple task either. There were never any bins big enough and I couldn't exactly flush it down the loo. Using it gave me another problem. The non-telescopic catheter was very floppy. It slipped and slid through my fingers when I was trying to push it through my urethra. There were other difficulties too. *Continued on page 5*

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I have been told men and women have different problems when it comes to self-catheterisation. The male urethra is longer than the female urethra (it is 8-9" long rather than 2-3") and not straight but curved with one very tight bend. There are sensitive spots for men –where the catheter goes round the urethra's 'S' bends and also where the urethra goes through the prostate gland. A catheter with a rigid section gives you greater control while you are manoeuvring the more flexible section through these delicate and tight areas.

I remember the day my continence nurse gave me the new telescopic Speedicath Compact Male. She handed me a 7" aqua marine coloured tube with a screw cap on one end (see left) . I unscrewed the cap and was a little surprised when I started to pull out a catheter which unfolded to nearly twice the length of its container- one half sliding out of the other half.

Since I first used the Speedicath Compact Male I have never looked back. I can now use my new catheter outside the home in places like café and pub toilets and even public lavatories.

The only negative point I can make is actually quite a trivial one. It can be slow to drain the bladder. The diameter of the inner of the two inter-locking tubes appears to be slightly smaller than the catheter I used to use and consequently "flow rates" are slightly slower. A residual volume of 200 ml now takes over a minute to drain. That minor point taken into account I do think the Speedicath Compact is great to use – and even something of a design classic.

For details about the Speedicath Compact go to page 13

New PPMS drug Ocrelizumab could be on the shelf as early as next year

Ocrelizumab, a revolutionary new treatment for primary progressive MS, could be available in clinic as soon as 2017.

In a press release the pharmaceutical company Roche said that it plans to file for approval to treat primary progressive MS in the next few months , which means the drug could be available for use as soon as 2017.

The announcement follows positive results in 2015 from three large clinical trials of Ocrelizumab. The drug is an injectable monoclonal antibody medication that targets B cells.

Old drug Rituximab could be new PPMS treatment

A drug similar to Ocrelizumab, called Rituximab, could be used to treat primary progressive MS (PPMS) following new research carried out in Austria.

In the research 56 MS patients -one fifth who had PPMS - were treated with Rituximab for nine months. Almost 80% of the 56 patients benefited at least partially from treatment. Rituximab is a chimeric (ie not fully humanised) monoclonal antibody already in use off-label to treat PPMS patients but its use is expected to decline when Ocrelizumab - a very similar but fully humanised monoclonal antibody - becomes available, probably next year.

Rituximab is an older drug thsn Ocrelizumab and was due to come off patent in 2015. A story printed on the website prnewswire says that an Indian generic drugs producer Hetero Healthcare has started to produce a bio-similar drug called Maball. It is not known whether Maball will be available outside India or what its price will be , but generic drugs are usually cheaper.

For details of sources for all news stories go to page 13

New drug targets mitochondrial damage in experimental model of prog-MS

A new drug could combat progressive MS by stopping mitochondria – the cell's powerhouse – from swelling and shutting down as the disease progresses.

In a paper published in the Journal of Biological Chemistry, a group of US scientists say there is increasing evidence that mitochondrial problems occur in MS and that this may cause the slow burning neuro-degenerative damage seen in progressive forms of the disease. The scientists say a new drug currently called JW47 significantly protected axons in an experimental autoimmune encephalomyelitis disease model of neurodegeneration.

According to the website MS research blogspot, produced by the Barts and The London Neuroimmunology Group in London, several potent neuro-protective compounds such as JW47 are currently being developed in the UK .

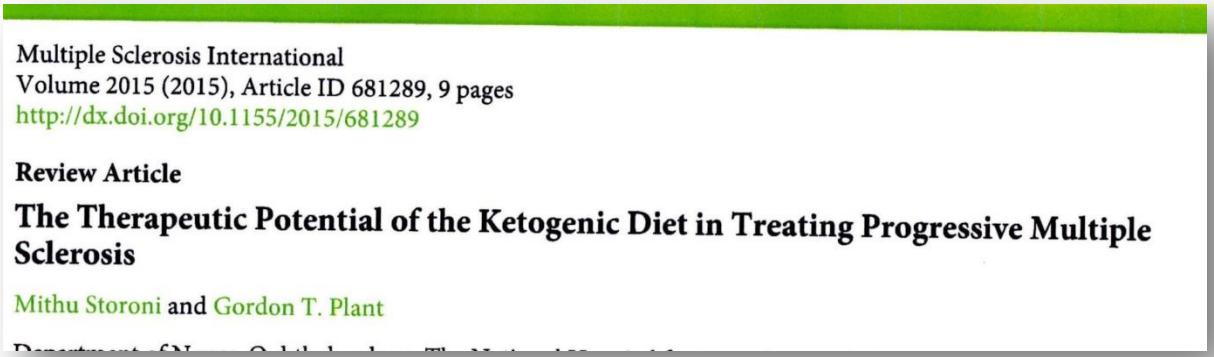
MS neuro-protective treatment works in lab tests

An experimental new MS treatment being developed by Canadian researchers has successfully reduced neurodegeneration and disease progression in human cells as well as in a mouse model of the illness.

Researchers from the University of Alberta discovered that an enzyme - granzyme B - attacks the human body in MS, destroying nerve cells. They also discovered a substance which inhibits the enzyme called serpina3n and which was found to be neuro-protective in animal tests.

The research team is now planning experiments using a human version of serpina3n to investigate its effects in MS patients. Senior study author Dr Fabrizio Giuliani said: "If we can induce neuroprotection there is a good possibility we can decrease the rate of disability associated with inflammation in the brain.." ***For further details on all new stories go to pages 13-15***

Can the 'Ketogenic' diet really help prog-MS?



Multiple Sclerosis International
Volume 2015 (2015), Article ID 681289, 9 pages
http://dx.doi.org/10.1155/2015/681289

Review Article

The Therapeutic Potential of the Ketogenic Diet in Treating Progressive Multiple Sclerosis

Mithu Storoni and Gordon T. Plant

If you think you've heard the last of diets and MS then think again. First there was the Swank diet, then the McDougall diet, then the Greer diet, and latterly the Best Bet diet. Now there's another new diet as you can see from the cutting above.

Yes, this one is called the ketogenic diet, and what makes the ketogenic diet particularly interesting is that it is said to be helpful specifically for people with progressive MS. It has "therapeutic potential" (See cutting above).

The ketogenic or "keto" diet is basically a low-carb/ high fat/ high protein diet and the difference between a keto diet and an ordinary diet is all down to the way the body converts food into energy. In an ordinary diet the body uses glucose (a form of sugar) made from carbohydrates (in foods like bread or pasta) for energy. On a keto diet your body uses not carbs but fats for energy.

The basic metabolic process for the keto diet goes as follows: the liver converts the diet's high fat content into fatty acids and ketone bodies. These ketone bodies then pass into the brain and replace glucose as an energy source. And the reason why the keto diet might be good for progressive MS is that there is emerging evidence that ketones might be neuroprotective and might improve mitochondrial function. *Continued on page 9*

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If you have read this blog before you will know there is a growing view that MS is as much a neuro-degenerative as an inflammatory disease, and that this neurodegeneration is what causes progression. One of the drivers of this process is the death of mitochondria – the energy producing part of cells.

Last year the academic paper just mentioned was published. It's titled: "The Therapeutic Potential of the Ketogenic Diet in Treating Progressive Multiple Sclerosis." In the paper Mithu Storoni and Gordon T. Plant set out their views on how the ketogenic diet could improve mitochondrial function. A lot of evidence iss produced to back up their claims that the ketogenic diet could treat the neurodegenerative component of prog-MS . *See the clickable link to the paper on page 14.*

Perhaps the best reason for thinking that there might be something in this ketogenic diet /neuroprotection theory is that the Keto diet is actually recommended as an option for treating another neurological condition – epilepsy or certain types of it. For some people with epilepsy, there is a view that a ketone-producing diet helps to prevent seizures and this is well documented in medicine. A keto diet really does seem to protect the brain.

So am I going to take up a ketogenic diet? Erm possibly. For the time being I am urgently doing research. There are lots of books out there on the ketogenic diet and recently I bought a keto cookbook and started reading the recipes. The cookbook appears to deliver the diet's high fat content through lots of meat and dairy products. It sounds tasty but I am confused because I thought fats and dairy were the sorts of things that MSers shouldn't eat too much of. So are all keto diets the same? Is there an MS-keto diet?

Yes, I am confused but I am also interested in this new theory. I just wish I had more answers but at least the keto diet is forcing me to ask some interesting questions. And so I agree very strongly with the two authors Storoni and Plant when they conclude: "the ketogenic diet deserves further investigation."
More *information and sources on pages 13-15*.

We must accept that PPMS and SPMS are the same disease, says top expert

Primary progressive and secondary progressive MS are the same disease, and dealing with the artificial separation between the two is the biggest current challenge in MS, says a top MS expert.

Professor Gavin Giovannoni, professor of neurology at Barts and the London, says there is overwhelming evidence for treating the two progressive forms of MS as the same disease. "MRI studies demonstrate that lesions on MRI in MSers with relapse-onset or PPMS are identical. The pathology and genetics of the two subtypes are the same," he said.

Prof. Giovannoni also says that once the "one disease proposition" is accepted drugs regulators will be more likely to allow drugs like ocrelizumab to be used by secondary progressive MS patients rather than just those with primary progressive MS as at present. "This is not a trivial issue and will affect how we manage MS and develop drugs for progressive MS going forward."

Protein may stop re-myelination in prog-MS

A "signalling protein" that helps cells talk to each other increases as MS progresses and this increase may stop re-myelination taking place, researchers believe.

The signalling protein called lipocalin2 (LCN2) is often found alongside another protein called neurofilament light which has been linked to neuronal injury in axons and is also present in motor neurone disease, say the researchers from the Karolinska Institute in Stockholm, Sweden led by Faiez Al Nimer MD PhD.

The Swedish researchers also found that progressive MS patients treated with Tysabri had an average 13 % reduced level of LCN2 suggesting Tysabri may after all have value as a progressive MS treatment, in spite of the recent Ascend trial.

For further details of all news stories go to page 13

New drug shows 'substantial promise' in encouraging re-myelination in MS

A biotech company based in the US has been given a grant of $680,000 by the US government's National Institutes of Health to assess the potential of a new therapeutic approach to re-myelination in MS.

Novoron Bioscience Inc is developing a new drug called NOVO-117 which aims to overcome the specific problems of re-myelination in MS. This problem is based on the apparent inability of Oligodendrocyte Precursor Cells to produce new myelin, believed to be due to the unwanted activation of a molecule called RhoA.

NOVO-117, targets RhoA by acting on a previously unknown mediator of RhoA activation — LRP1 (low density lipoprotein-related protein 1). Dr. Travis Stiles, president and CEO of Novoron Bioscience said the new approach showed substantial promise in promoting remyelination.

Mixed results for AIDS drug trial in MS -

The trial of an AIDS drug to treat MS has failed to meet its primary outcome measure in a small clinical trial, organisers have said.

However, trial organisers also said there was some "interesting biomarker data" to come out of the trial of the drug Raltegravir. This data will be presented at an academic meeting later in 2016.

Trial organisers have said they are not giving up exploring the idea that a virus is involved in MS. In a statement they said "We plan to focus our attention this year on EBV (Epstein Barr Virus) as the trigger and driver of MS disease activity." To pursue this goal a small crowdfunding campaign has been launched. This will raise money to test whether an old generic antiviral drug – famcyclovir - is capable of suppressing EBV infection in MS. Famcylovir has been shown to reduce the activity of the Epstein-Barr virus.

For further details of all news stories go to page 13

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 (April-May 2016)

UTI infections, antibiotics, and an operation - my neurogenic bladder

References contact details etc

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Biotin story

Source: http://www.medday-pharma.com/news-and-events/medday-provides-update-on-ms-on-study-of-md-1003/

Page 3

Tisch Clinic story

http://tischms.org/

Mouth stem cells story

Source; http://multiplesclerosisnewstoday.com/2016/01/13/ms-progression-halted-using-stem-cells-derived-gum-tissue/

pages 4-5 Feature on self catheterisation

for details about Speedicath Compact for men and women including how to get free samples go to http://www.coloplast.co.uk/Global/Continence/Catheter-samples/?gclid=Cj0KEQiAoby1BRDA-fPXtITt3f0BEiQAPCkqQZJOzHT8Ya-4RElT_a8H-pyubSHXiT47tAN9Oi-p_QYaAnou8P8HAQ&gclsrc=aw.ds

page 6 Ocrelizumab story

http://www.roche.com/media/store/releases/med-cor-2015-09-28b.htm

page 6 Rituximab story

http://www.medpagetoday.com/clinical-context/MultipleSclerosis/54926?xid=nl_mpt_DHE_2015-12-01&eun=g507668d0r

http://www.prnewswire.com/news-releases/hetero-announces-the-launch-of-biosimilar-rituximab-maball-in-india-520727741.html

page 7 Mitochondria story

Warne J, Pryce G, Hill J, Shi X, Lennerås F, Puentes F, Kip M, Hilditch L, Walker P, Simone MI, Chan AW, Towers GJ, Coker A, Duchen MR, Szabadkai G, Baker D, Selwood DL.Selective inhibition of the mitochondrial permeability transition pore protects against neuro-degeneration in experimental multiple sclerosis.J Biol Chem. 2015. pii: jbc.M115.700385. [Epub ahead of print]

P7 neuro-protective treatment story

Source: http://multiplesclerosisnewstoday.com/2015/12/08/ms-therapy-aims-slow-brain-inflammation-fewer-side-effects/?utm_source=Multiple+Sclerosis&utm_campaign=ae9380f83e-RSS_WEEKLY_EMAIL_CAMPAIGN&utm_medium=email&utm_term=0_b5fb7a3dae-ae9380f83e-71290133

page 8+9 Feature on ketogenic diets

Multiple Sclerosis International Volume 2015 (2015), Article ID 681289, 9 pageshttp://dx.doi.org/10.1155/2015/681289 The Therapeutic Potential of the Ketogenic Diet in Treating Progressive Multiple SclerosisMithu Storoni and Gordon T. Plant

http://www.hindawi.com/journals/msi/2015/681289/

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SPMS and PPMS – same disease

http://multiple-sclerosis-research.blogspot.com/2016/01/researchspeak-new-year-prediction.html

Protein story

http://www.ms-uk.org/jan31

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Novoron Bioscience story

http://www.novoron.com/company-news/

Raltegravir story

http://multiple-sclerosis-research.blogspot.com/2016/01/crowdfunding-charcot-project-2.html

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