

January 2010

www.dailymail.co.uk 12 January 2010

## Could multiple sclerosis be caused by blocked veins?

'When I asked the neurologist why he was so sick, she said Jeff needed to stop drinking. That was flippant and made me angry because Jeff didn't touch alcohol.'

The encounter sent Joan off on a search for a better approach, and in May Jeff became one of the first in the world to have a new and controversial operation based on a radical theory about the cause of MS.

Seven months later, the improvement has been dramatic. 'Jeff had immediate and profound relief of very severe fatigue,' says Joan.

'Before the op he had trouble getting out of bed and needed naps during the day. Since then, he has had no MS attacks (when symptoms get much worse). He still has leg pain, spasms and headaches, but these are less than before.'

So, has Joan Beal discovered an effective treatment for MS?

MS affects around 100,000 people in the UK. The conventional view is that it's an auto-immune disease, like rheumatoid arthritis.

For some reason, the body turns against itself and starts destroying the myelin, the insulating fatty layer around nerve cells in the brain and spinal cord.

This affects how messages are transmitted in the brain, causing the classic symptoms of MS, including vertigo, numbness, temporary vision loss and crushing fatigue. It can also cause paralysis and incontinence.

Jeff's operation was inspired by a new theory about why the myelin gets destroyed - it's thought MS is a disease of the blood vessels, specifically the veins. The doctor at the forefront of this approach is Dr Paolo Zamboni, a professor at the University of Ferrara in Italy. He began investigating MS when his wife Elena, 51, developed the disease ten years ago.

He examined MS patients with ultrasound and found that in nearly all, the veins leading from the brain had signs of narrowing, twisting and blockage; something he didn't find in healthy patients. He saw that blockages were allowing iron from the blood to leak into the brain tissue, where it causes damage.

Dr Zamboni called the condition chronic cerebrospinal venous insufficiency (CCSVI). He calculated that by clearing the blockage in the main neck vein, he could help reverse MS symptoms.

To do this, he used a technique known as angioplasty - inserting a tiny balloon into the blocked vein and then blowing it up to open up the blood vessel. It is a standard procedure for expanding the arteries of heart patients.

By the time Joan found out about Dr Zamboni, he'd operated on 65 MS patients - including his wife, who is symptom free three years after surgery.

Of those, 50 per cent were 'relapse-free' for at least 18 months compared with only 27 per cent in a control group who didn't have the operation.

Inspired by his findings, Joan contacted one of the top cardiology experts in the U.S. who has pioneered the use of stents - another standard procedure opening blocked arteries - and sent him reports of Professor Zamboni's work. He agreed to scan the veins in Jeff's neck.

'When we saw Jeff's mangled veins on the MRI scan,' says Joan, 'our doctor was amazed. He said he'd never seen this in the jugular veins before. The left one was closed 95 per cent, the right 80 per cent.'

Just why the veins get blocked isn't clear. Dr Zamboni believes it could be a structural problem that is present from birth.

Jeff had stents put into his neck veins at Stanford University hospital in California. After describing the success of Jeff's operation on an internet MS bulletin board (thisisms.com), Joan was inundated with requests for more information.

And the cardiologist was swamped with requests for the operation. So much so that he has asked for his name to be withheld. But in the past seven months he has operated on 70 MS patients and many of them have posted reports on the website.

One wrote: 'Less spasticity in left leg; facial pain is gone; right side back pain is gone; normal sweating; high altitude headaches gone; walking gait is smoother. No progression since intervention.'

But the accounts don't gloss over the potential side-effects of the operation; these include nerve damage that stents can cause and bleeding in the stomach as a result of drugs used in the operation. So is this a breakthrough in the treatment of MS?

Dr Robert Zivadinov, leading a study for more evidence at Buffalo University in New York, says: 'If we can prove the hypothesis that CCSVI is the underlying cause of MS, then it is going to change the face of how we understand the disease.'

But the theory has attracted criticism.

Dr Alasdair Coles, an academic neurologist at Cambridge University, says: 'We know MS is an auto-immune disease because if you block the immune response with drugs, people get better.'

Dr Susan Kohlhaas, of the UK MS Society, adds: 'Our experts don't accept that blockages to draining veins from the brain are specific to people with MS or that this explains the cause of MS.'

There have been many false dawns in MS research. The cause of the damage has been linked with lack of vitamin D, lack of the hormone prolactin, mercury fillings and now CCSVI is added to the list.

Joan and many others pray that it's not another example of offering false hope.

www.mstrust.co.uk 5 January 2010

## **Research into using acupuncture to treat urinary incontinence**

Researchers in America have carried out a pilot study to identify if acupuncture is effective in reducing urinary incontinence and to test research methods for investigating this treatment. The pilot study was a double-blinded, randomised, clinical trial and included nine women with urge or mixed urge and stress UI. Subjects were randomly assigned to a true or sham (placebo control) acupuncture group. Both true and sham acupuncture treatments were performed twice a week for six weeks. All subjects were evaluated at the completion of the 6-week intervention and 4 weeks later.

Subjects randomised to the true acupuncture group had a mean 63.30% reduction in daytime accidents/day one week after treatment and 67.47% reduction at 4 weeks. In contrast, the mean reduction in daytime accidents after sham treatment was 18.88% at 1 week and 16.67% at 4 weeks.

The authors recommend further research to examine the efficacy of acupuncture in the treatment of UI in women. They also recommend further research into the use of sham acupuncture needles as part of a research study.

## **Stem cell doctor GMC hearing begins**

A doctor offering controversial stem cell treatment is before the GMC today.

Dr Trossel is accused of making false claims to patients he sent abroad for stem cell treatment and failing to warn them of potential risks.

Stem cells hold out hope for cures for degenerative diseases in future but most treatments are still unproven.

Dr Trossel was suspended by the GMC in 2007 and also has a conviction for breaching the law on stem cell treatments in Belgium.

Stem cell therapy is tightly regulated in the UK and there are guidelines for developing safe and effective treatments.

But vulnerable patients with degenerative conditions like multiple sclerosis have travelled abroad and paid thousands of pounds for unproven treatments.

Dr Trossel, who practiced in London and Rotterdam, is alleged to have injected patients with stem cells at his Rotterdam clinic.

The GMC will consider allegations that Dr Trossel acted dishonestly, abused his position as a doctor and exploited vulnerable patients with multiple sclerosis and Hodgkins' disease by offering treatments which were not in patients' interests and not justifiable on the basis of scientific evidence.

He is accused of failing to warn patients of the potential risks of stem cell therapy and exaggerating the benefits.

He is said to have sent literature to one patient in 2006 which claimed that he personally had treated "approximately 120 patients over the last year and a half of which half had MS and 10% were now walking out of a wheelchair. Another 80% have had a proven significant clinical benefit".

He is also accused of making false claims about other treatments - vitamin B therapy, aqua tilis therapy and therapeutic resonance imaging.

### **Previous conviction**

Dr Trossel is also accused of not declaring a police caution to the GMC.

The GMC will also consider a conviction in Belgium for which Dr Trossel was fined and given a suspended prison sentence breaching stem cell laws.

The GMC suspended Dr Trossel in 2007. Although he was not struck off at that stage, he was not allowed to practise as a doctor.

The hearing is planned to run until the start of March.

## **Fampridine submitted to licencing body**

Fampridine, a new oral drug to improve walking ability in some people with multiple sclerosis, has been submitted for a licence to the EMEA, the European regulator.

In two clinical trials, a greater proportion of people with relapsing remitting, secondary progressive, and primary progressive MS showed improvement in walking speed when compared to people taking a placebo (34.8% vs 8.3% and 42.9% vs 9.3%).

Pam Macfarlane, Chief Executive of the MS Trust, said "The submission of fampridine to the EMEA means that, with cladribine and fingolimod, there are there are three possible drug therapies for MS being assessed by the regulatory agencies, a really positive development for people with MS. However, it is unlikely that any of the licence applications will be granted before the end of 2010."

## Babies born in April have 'higher MS risk'

Scientists found mothers who were pregnant during the autumn and winter were most likely to give birth to those who would suffer from the debilitating neurological disease.

The researchers, based at Glasgow university and the city's Southern General Hospital, believe the spike in cases among children born in the spring may be due to a shortage of vitamin D because during a vital developmental stage their mothers are exposed to less sunshine.

Vitamin D, which is largely gained through sunlight and food, is known to regulate a gene that can predispose individuals to MS. If the gene is passed on to the unborn child, without being regulated by a sufficient amount of vitamin D, it could "hard wire" them to develop the disease in later life.

The new study, published in the European Journal of Neurology, is the biggest yet carried out in Scotland, which has the highest rate of MS in the world.

MS affects about 85,000 people in the UK and 10,500 in Scotland. While the cause is not known, experts believe a combination of genetic and environmental factors are responsible for the condition.

The Glasgow researchers examined data on about 1,300 MS patients born in the west of Scotland between 1922 and 1992. They found that about 400 people born in March, April and May went on to develop MS, 22 per cent higher than expected. Almost half of all male and a quarter of female sufferers were born in April.

By comparison, there were about 16 per cent fewer MS births in the autumn months. Those born in November had the lowest incidence of the disease.

Dr Colin O'Leary of the institute of neurological sciences at the Southern General and co-author of the study, said several theories about the condition were being explored.

"It's a very interesting observation and springtime seems to be a period of relatively high risk," he said.

"Seasonal risk may be a reflection of adverse events that occurred at the time of birth, in utero in the preceding nine months, or during the months following birth, when the central nervous system continues to undergo rapid development.

"There could be an association between reduced sun exposure and vitamin D levels." O'Leary now plans to carry out a UK-wide study with scientists in Oxford.

Professor George Ebers, from Oxford University's department of clinical neurology at the John Radcliffe Hospital, said: "The difference [in developing MS in Scotland] between being born in April versus November is an astounding 50 per cent. This is real, there's no doubt of a seasonal link. There are different theories, but I think the April excess of births could be linked to a sunlight deficiency.

"The focus is on trying to prove what the environmental effect is and, pending conclusive demonstration of that effect, some people might view it as prudent to conceive at certain times of the year to lower their child's MS risk if there is a history of the disease in the family."

Ryan McLaughlin, 14, from Glasgow, whose mother has MS, launched a campaign for all pregnant women and young children in Scotland to be given Vitamin D supplements.

A spokeswoman for the Scottish government, said: "Much of the evidence of a link between vitamin D and MS is still at a very early stage. We will continue to review all well-conducted research across the world. If the recommendations on vitamin D change we'll make the appropriate arrangements."

## **Eight-month wait for a wheelchair**

A multiple sclerosis sufferer has finally been given a motorised wheelchair after an eight-month wait because the chair was too heavy for the pavement.

In November, the Evening Telegraph reported the case of two MS sufferers who were told they couldn't have a motorised wheelchair because of Government red tape.

The chair needed by Sheila Lloyd and former soldier and Gulf War veteran David Ramsey was found by Northamptonshire Primary Care Trust to be over the weight allowed on the pavement - 150kg - leading to Wellingborough MP Peter Bone taking up their cases.

Miss Lloyd, of Minerva Way in Wellingborough, was diagnosed with the disease two years ago and was using a manual wheelchair but when her condition worsened, she was assessed and told she was eligible for a motorised one in April.

After initial delays, Miss Lloyd did her own research and supplied a list of suitable makes and models to Wheelchair Services, and now has the right chair.

She said: "I have had a successful outcome because the one I was using as a temporary measure has now been given to me but I could have had it a long time ago.

"It was just daft.

"When I was initially told I couldn't have the one I needed because it was 6kg over the weight limit, I was faced with no other options.

"There are bound to be other people in the same situation as me.

"I don't even know if other primary care trusts follow the guidelines because I have seen so many other motorised wheelchairs.

"Even the police told me that there is nothing they could charge you with and that no one would take you off to a weigh bridge to check.

"Common sense has prevailed."

## **American scientists to explore stem cell repair procedure**

Researchers in the USA are recruiting for a trial that will look at the safety and tolerability of a procedure that attempts to treat MS damage in the central nervous system with an individual's own stem cells.

Previous therapies have involved using stem cells from bone marrow to repopulate an individual's immune system that has previously been largely wiped out with chemotherapy drugs.

This study will test the ability of mesenchymal stem cells isolated from the individual's bone marrow to both regulate the immune system and to help repair damaged tissue. This is a new area of research in MS.

The study is based in Cleveland, Ohio and will recruit 24 people with relapsing remitting MS. Pam Macfarlane the Chief Executive of the MS Trust commented: "Whilst this is a USA trial and thus not open to people with MS in the UK it will provide data on the potential of transplanted mesenchymal cells. The importance of stringent, controlled trials to establish efficacy and safety cannot be underestimated and it is very encouraging to see that this study is commencing in the USA where there have been reservations about stem cell research."

## **UK Stem Cell Foundation & MS Society Stem Cell Research Collaboration**

Stem cell research in multiple sclerosis (MS) has been given a much-needed shot in the arm thanks to a partnership between the UK's largest charity supporting people affected by the condition and the UK's only charity dedicated to supporting stem cell research.

The MS Society and the UK Stem Cell Foundation (UKSCF) today (Thursday) formally marked the beginning of the collaboration by announcing a call for research grant applications that can now dip into a dedicated pot of joint-funding up to £1million.

Dr Doug Brown, Biomedical Research Manager at the MS Society, said the partnership would "pump prime" and speed up stem cell research.

He added: "We're delighted to announce this partnership that is the first of its kind and look forward to receiving applications for research funding.

"Stem cells are showing real promise in MS, and the sooner we can take the science from the bench to the bedside, the sooner people with MS will get the answers they so desperately need."

The potential of stem cells as a treatment for MS has long been the subject of much interest and debate.

In 2009, the MS Society convened an International Consensus Meeting for stem cell therapies and MS and a number of international experts put forward the view that MS is a condition that could benefit greatly from targeted and increased stem cell research investment and the collaboration is in direct response to that.

The UK is a recognised global leader in all aspects of stem cell research and in an ideal position to advance stem cell techniques into the clinic for the benefit of billions of people around the globe.

Progress in this area is being hindered, however, by a critical gap between currently available government and private funding and the countless promising research projects in need of financial assistance.

Without increasing commitment and funding for research and a push for clinical trials, there are fears these benefits will not be realised.

"People with MS and the world's leading researchers have made it clear that more research is needed now," Dr Brown added.

The MS Society and UKSCF will work together to raise awareness of MS and stem cell research with the aim of attracting high quality research applications.

Sir Richard Sykes, UKSCF Board of Trustees Chairman, said: "The UK Stem Cell Foundation is delighted to be joining forces with the MS Society to advance the translation of stem cell science towards innovative new therapies for multiple sclerosis."

### **DISCLAIMER**

The articles in this Bulletin are meant for the sole purpose of information only and do not necessarily reflect the views of the committee.

# YOUR JOKES

## A GOOD POSTMAN

One Monday morning the Postman is riding through the neighborhood on his usual route, delivering the mail.

As he approaches one of the homes he noticed that both cars were still in the driveway.

His wonder was cut short by Dennis, the homeowner, coming out with a load of empty beer and liquor bottles for the recycling bin.

'Wow Dennis, looks like you guys had one hell of a party last night,' the Postman comments.

Dennis, in obvious pain, replies 'Actually we had it Saturday night.

This is the first I have felt like moving since 4:00 am Sunday morning.

We had about fifteen couples from around the neighborhood over for some weekend fun and it got a bit wild.

We all got so drunk around midnight that we started playing WHO AM I.'

The Postman thinks a moment and says, 'How do you play WHO AM I?'

'Well, all the guys go in the bedroom and we come out one at a time with a sheet covering us, with only our 'family jewels' showing through a hole in the sheet.

Then the women try to guess who it is.'

The Postman laughs and says, 'Sounds like fun. I'm sorry I missed that.'

'Probably a good thing you did,' Dennis responded. 'Your name came up seven times....'

## Ear Hair

My neighbour found out that her dog could hardly hear, so she took it to the veterinarian. He found that the problem was hair in its ears. He cleaned both ears and the dog could hear fine again.

The vet then proceeded to tell the lady that if she wanted to keep this from recurring, she should go to the pharmacy and get some "Nair" hair remover and rub it in the dog's ears once a month.

So, the lady went to the pharmacy to purchase some "Nair" hair remover.

As she was paying for the goods, the chemist said to her, "If you're going to use this under your arms, don't use deodorant for a few days."

The lady replied: "I'm not using it under my arms."

The chemist then said: "Well then, If you're using it on your legs, don't shave for a couple of days."

The lady sighed: "I'm not using it on my legs either; if you must know, I'm using it on my "shihtzu"

The chemist looked her in the eye and said: "Stay off your bicycle for a week."

## Priceless

A little girl ran to her grandfather, jumped into his arms and gave him a great big hug.

Then she ran her fingers along his balding head and down the side of his wrinkled face.

"Did God make you Granddad?" she asked.

"Yes honey, he made me."

She felt her own cheek and then asked "Did God make me too?"

"Yes honey, he made you too."

"Well" she shrugged

"Don't you think he is doing a better job now than he used to?"

## MEMBERS COMPETITION

A £5 prize will be given to the member whose entry has the most correct answers. Even if you can't answer all the questions, send in those you have answered – you could still win!

**USING ONE OF THE INITIAL LETTERS FROM EACH ANSWER WILL GIVE YOU THE NAME OF A LOCAL TOWN OR VILLAGE**

- 1/ Who murdered Abel? .....
- 2/ Whose three dimensional cube became a craze? .....
- 3/ What is the name of Queen Victoria's house on the Isle of Wight? .....
- 4/ The Zodiac sign Scorpio covers part of this month .....
- 5/ Who won an Oscar for the best actor in Ghandi? .....
- 6/ What name is given to the flap of Cartilage which prevents food from entering your windpipe? .....
- 7/ August Zodiac sign .....
- 8/ Solomon Grundy became ill this day .....
- 9/ Which university has a rowing eight called Isis? .....
- 10/ How many players are there in a basketball team? .....

Name:

Address:

Send Completed Forms To:  
Mr D Henderson  
74 Windermere Road  
Stockton-on-Tees  
Cleveland TS18 4LY

All entries to be received by the next social. The winner will be drawn from entries received with the highest number of correct answers.

Answers to last quiz:

1/ Ken 2/ Italy 3/ Lawley (Sue) 4/ Dallas 5/ Athletics 6/ Lester Piggot 7/ Essex 8/ Huey  
9/ Apples 10/ Rommel 11/ Topper