

NEWS UP-DATE

Feb 2010

JOHN DEWAR BELL

It is with great sadness that we lost our good friend John in the early hours of Thursday 21st January.

John who was diagnosed with Motor Neuron Disease in December 2008, continued to live and make the most of his life in this past year and showed great strength and determination in coming to terms with his illness.

John had been Sandy's carer for many years as well as her solid rock after the loss of her husband over 10 years ago. Their friendship blossomed and in October this year, they became husband and wife.

John supported the group along with Sandy by doing not one but two long walks to help raise funds for the group.

Doing the West Highland Way is an achievement in itself for anybody, but doing it with Sandy in the wheelchair when she needed to rest must have took great strength, determination and sheer guts to get over the wild terrain of those mountains. What pride they both must have felt when they accomplished the walk and made it to the end.

Being a glutton for punishment, if that wasn't enough for them both, the following year they went back to Scotland to accomplish the Great Glen.

Sandy has written a book and had it published about their experience and is available if anybody who would like to buy one.

John was originally from Glasgow and moved to this area to work for ICI.

He loved the island of Skye. He became very fond of the island when he was a young lad when he would visit his relatives there and stay for the full of the school summer holidays. He would visit with his mum while his dad was off at sea in the merchant navy.

I think it is safe to say, John just loved the outdoors and had many an adventure and laugh with Sandy over these last few years as they went exploring around the country and North Yorkshire Moors.

John enjoyed telling his jokes to us all, he had a real nice sense of humour. When he got the machine that helped communicate for him, he would type the jokes out for us all to listen to, so he could still get them across to us.

Even up to the night he died, he had been watching his 'Simpsons' DVD'S which he was a real avid fan of. He must have had a piece of every item of clothing from socks to jumpers as well as slippers with them on. It was therefore quite appropriate as we left the crematorium that the Simpsons theme tune was played. I'm sure John would have been smiling and laughing at us all as we went on our way.

He will be missed greatly as well as his jokes, but that lovely smile of his will be remembered always.

Susan O'Neill

New Medical Student



The group are happy to welcome Ross Holcombe as our assigned medical student for this year. As usual with our placements Ross is in his first year at Durham University studying medicine. Ross already has one degree in pharmacology from Southampton. He originates from Croydon in south east London but his grandparents came from the north Yorkshire area. He is very interested in the surgical aspects of his course, but this may change over time. He is a keen rower and part of the university rowing team and he also enjoys swimming (which is handy if the rowing goes wrong!).

You can help the group save Money!

We can save money on printing and postage of this monthly bulletin if you elect to have it sent to you by e-mail. The bulletin is always available for download from the download section of the website at :- <http://www.stocktonmsgroup.org.uk/3.html> but we are willing to send it to you every month by e-mail rather than send a printed copy.

If you are willing to have the e-mail version please send an e-mail to:- info@stocktonmsgroup.org.uk indicating you want the bulletin by e-mail or let any member of the committee know, remember to give them your e-mail address.

FOR SALE

Adult tricycle hardly used. Mirror and halogen lights, genuine reason for sale
Cost £600 new, accept £150 or nearest offer.
For further information ring Carol on 617864

FOR SALE

BT Plus 2 way baby monitor.
As new with box and carrying case. cost over £100 will accept £50 or nearest offer.
Ring Carol on 617864

*****Hot Off The Press*****

On Friday 12 February 2010 a cheque was presented to Dave Henderson (treasurer) from the Thirsty Senators Pub in Stockton for £1,400.
More on this story and how they raised the funds in next months Bulletin.

Work Focused Support for Carers

What is Work Focused Support for Carers?

Work Focused Support for Carers (WFSC) is a voluntary scheme designed to help people who wish to combine paid work with their role caring for someone.

You can choose to take part, and are free to stop taking part, at any time. Even if you don't feel ready to work now but might like to in the future, you can still take advantage of the support available.

Who is eligible?

Work Focused Support for Carers is available to carers who:

- do not work or work less than 16 hours a week
- are aged 18 or over
- are not able to get help from any of the other Jobcentre Plus employment support programmes such as New Deal or Pathways to Work.

Will my benefits be affected?

If you are in receipt of benefits they will not be affected by taking part in WFSC. If you find a job you are interested in, your personal adviser will be able to tell you how your benefits will be affected if you start work and help you apply for any in work benefits or tax credits if appropriate.



What help will Jobcentre Plus give me to find work?

Your adviser can help you with advice on training, finding a job, local childcare and local replacement care. Also, if you start work, your adviser can continue to provide support and advice.

What other support is available?

Jobcentre Plus may be able to help pay for things like replacement care while you attend appointments with the personal adviser, take part in a training course or attend job interviews.

Where should I go for more information?

To find out more about getting into work or training, you can:

- visit www.direct.gov.uk/carersemployment
- arrange an appointment with an adviser at your nearest Jobcentre.

MULTIPLE BENEFITS

Two new pills could make life more bearable for Multiple Sclerosis sufferers. A major drug trial found taking Cladribine a few times a year more than halves the likelihood of relapses in those with the most common form of MS. The pill also reduces the chances of the condition getting worse by nearly a third and cuts out many of the unpleasant side effects associated with the current MS treatments. A separate trial found taking the drug Fingolimod also halved the number of disabling relapses experienced by MS patients and reduced deterioration. Both pills will go on sale in the next few months. Cladribine only needs to be taken once a day for between eight and twenty days a year while Fingolimod is a once a day pill. Up to now MS sufferers have not been able to take medication in pill form. Current treatment involves regular injections or using drips. [SNIP] For Cladribine researchers from London University carried out a study involving 1,300 MS patients. The Fingolimod trial was carried out by King's College Hospital in London. Dr Eli Silber said: "Our ultimate goal is to limit the impact of this life-long condition."

news.bbc.co.uk 20 January 2010

Hope for MS pill after cladribine and fingolimod trials

Oral drugs to treat multiple sclerosis could become available in 2011 after promising results in two trials.

Drug licences have been applied for and the MS Society said it was "great news" for people with MS - current treatments involve injections or infusions.

The trials of the drugs each involved 1,000 people in over 18 countries, the *New England Journal of Medicine* says.

Cladribine and fingolimod, which come as tablets, cut relapse rates by 50-60% over two years compared with placebos.

Fingolimod was also tested against the widely used injection, beta interferon 1a. The trial showed the new drug was twice as effective in reducing the number of relapses over a year. Multiple sclerosis is the most common disabling neurological disorder affecting young adults. It affects more than 100,000 people in the UK and 2.5 million worldwide.

Symptoms include mobility problems, lack of bladder and bowel control and blurred vision.

The downside of current treatments is that they have to be injected or given by infusion.

MS sufferers have long hoped a pill would be developed. Pharmaceutical companies have been competing to get there first.

More choice

Dr Doug Brown, Biomedical Research Manager at the MS Society, said: "This is great news for people with MS and signifies a shifting tide in the treatment of the condition."

"Availability of oral therapies will give people greater choice and being able to take a tablet instead of unpleasant injections will come as welcome relief."

"The evidence is now there and we will be working with the relevant authorities to make sure those who will benefit can get access."

Doctors have also welcomed the studies.

Dr Belinda Weller, a consultant neurologist based in Edinburgh who specialises in MS, said the findings are "very significant" and indicated "a big breakthrough".

"This is the first major advance in MS therapy for a few years," she said. "I hope the drugs will soon be licensed."

But she expressed concerns both about possible side effects - which the trials suggested could include an increased risk of herpes and cancer - and that the new drugs could push up the cost of treating MS.

"More patients are likely to want to use these new drugs," she said. "Some people shun the currently available treatments because of the need to inject. This could put pressure on hospital budgets."

The MS Society called on the drug companies to price the drugs reasonably.

"The evidence is now here and we hope to see the pharmaceutical companies price these drugs responsibly so they can be made available to people with MS."

Northern Echo 12 February 2010

Region handed key role in MS drug trial

The North-East will be home to one of only three centres in the UK to trial a revolutionary drug for the treatment of primary progressive multiple sclerosis (MS).

Professor David Bates, of the Royal Victoria Infirmary, Newcastle, told The Northern Echo that once it gets under way he plans to recruit at least ten patients with this form of MS for the trial. Unlike remitting relapsing MS, where patients experience periods of relief and then sudden outbreaks, patients with primary progressive MS experience a gradual deterioration of their condition.

The patients will be given a daily pill containing fingolimod, a new drug that has already shown promise in treating MS patients with the remitting relapsing form of the disease.

Last month, the results of two international drug trials - which included a small number of patients from the RVI - were published in the *New England Journal of Medicine*.

The trials confirmed that fingolimod is twice as effective as interferon, which is commonly used to treat the relapsing remitting form of MS.

They also showed that taking daily fingolimod pills was more effective than taking dummy placebo pills.

Now drug manufacturer Novartis is organising a large multi-centre international trial to see if fingolimod can be used to reduce the symptoms of patients with a different form of MS.

At the moment, people with MS have to self-inject at least weekly or travel to hospital to be infused with drugs.

Experts suspect that T-cells, a specialised form of immune cell, is responsible for much of the damage caused in MS.

Fingolimod captures these cells, which are circulating in the bloodstream, and stores them in the lymph nodes.

This means the T-cells are unable to reach the brain and damage the myelin sheaths, which protect nerve cells.

It is this scarring to the myelin sheaths that disrupts nerve signals from the brain to the body and produces the symptoms of MS.

Prof Bates said the primary progressive trial of fingolimod had been delayed because of uncertainty about the correct dosage, but once it got underway he would probably recruit ten or more patients.

MS is the most common disabling neurological condition affecting young adults in the UK, with about 100,000 people currently affected.

Apart from Newcastle, the other UK centres involved in the trial will be London and Norwich.

Dr Mark Porter: Should we all be taking vitamin D?

It could protect us against colon cancer, improve bone strength and make us happier. Dr Mark Porter asks, 'should we all take Vitamin D?'

New research showing that vitamin D may protect against cancer of the colon is the latest in a long line of studies suggesting that there is far more to this vitamin than its traditional role in helping to maintain healthy bones. And although this new study involved more than 500,000 people from ten different European countries, it is pertinent to the UK because so many of us have low levels of vitamin D - especially at this time of year.

So should more of us be considering supplements?

Vitamin D is required to help the body make proper use of calcium - the basic building block of bones - which is why interest in it has traditionally centred on rickets, a condition that results from severe deficiency. But we now understand that it does far more than maintain the skeleton, and that milder degrees of deficiency may predispose to a range of other illnesses including diabetes, lung disease, osteoporosis, multiple sclerosis (MS), rheumatoid arthritis, various cancers, and even Alzheimer's disease.

The vitamin is manufactured in the skin when we're exposed to sunlight but our northern latitude and short summers mean that for six months of the year UV levels are so low that most of us don't make enough of the vitamin to meet basic requirements.

The problem is compounded by the use of sunscreens, which further reduce natural UV exposure during the summer months when vitamin D stores are replenished, and the popularity of supplements containing vitamin A (it is thought that as many as 1 in 5 of the population take one), which antagonise some of the D's actions.

As well as manufacturing the vitamin in our skin, we also take it in from our diet. It occurs naturally in oily fish, such as tuna and herring, and liver, milk and eggs. In most industrialised countries it is added to margarine, some powdered milks, bread and breakfast cereals.

The scale of the potential problem is nicely outlined by researchers from the University of Sheffield, who looked at vitamin D levels in the cord blood of babies born at the hospital at the end of spring - the time when their mothers' vitamin D stores were likely to be at their lowest. Seven out of ten of the babies had lower than ideal levels of vitamin D, 90 per cent of whom were white, dispelling the myth that deficiency is principally a problem in ethnic minorities with darker skin (the extra pigment reduces UV penetration even further).

Meanwhile in Finland researchers tracking a group of people born in the Sixties turned up evidence suggesting a link between low levels of vitamin D and Type 1 diabetes later in life. Children brought up in the gloomy winters of Finland are more than a hundred times more likely to develop the condition than their peers in sunny Venezuela. Since then UK research has shown that children given vitamin D supplements are around a third less likely to develop diabetes.

Vitamin D is a steroid and there are receptors on almost every cell in the body. Its link with diabetes could be explained by an action on receptors in the pancreas and on the various cells in the immune system, but there are similar vitamin D specific targets in almost every other organ, including the brain, heart, muscles, kidneys and, of course, the skeleton. Little wonder then that there is growing interest in the role of the vitamin in diseases, ranging from MS to Alzheimer's.

Should we all be taking a supplement? It's too early to tell whether mass supplementation is the way forward, but it is now widely agreed that the following key groups are those most likely to benefit:-

- Women who are pregnant or breastfeeding
- Children under 5 (particularly breastfed infants)
- The over-fifties
- Vegetarians who don't eat oily fish
- Anyone who is housebound or who covers up when outside
- Those who are dark-skinned - particularly Asians.

The standard dose for an adult is 10mcg day and trials looking at the safety of long-term supplementation have reported no adverse effects at intakes of more than double that. Much higher doses (50mcg a day or more) can weaken bones and increase the risk of calcium deposits (such as kidney stones) forming elsewhere.

During the summer most people will manufacture enough vitamin D by exposing their face and arms to the sun for an hour across the week. You don't have to sunbathe, just accumulate around ten minutes of exposure while going about your normal business - assuming you are not wearing a sunscreen, or a moisturiser that contains one.

www.mstrust.org.uk 11 February 2010

Research casts doubt on new MS theory

Research released yesterday has further complicated a feverish scientific debate over the treatment of multiple sclerosis, finding that as few as 56% of MS patients show signs of a blood-vessel problem that a controversial new theory cites as the cause of the disease.

Researchers also identified the blood problem in about a quarter of healthy people tested.

The University of Buffalo scientist who headed the study acknowledged the findings cast some doubt on the suggestion that a narrowing in neck veins helps trigger MS, although he says it clearly shows there is a significant link between the two.

The cause-and-effect relationship is argued by an Italian vascular surgeon, Dr Paolo Zamboni, whose ideas have thrown the MS world into an uproar, pitting hopeful patients against skeptical neurologists.

Dr Robert Zivadinov said that, based on his new findings, there is no justification for patients to undergo a vein-opening operation developed by the Italian surgeon or other, similar "endovascular" treatments until further studies indicate they are useful.

"I do not recommend any procedure at this time. I think we first need to understand the diagnostic issues," said Dr Zivadinov, who is working closely with the Italian surgeon.

"We don't know whether the endovascular treatment is helping or not."

The Buffalo neurology professor did say that his results should be encouragement for more research into the connection between MS and the vein narrowing problem that Dr Zamboni dubbed chronic cerebrospinal venous insufficiency (CCSVI).

MS specialists who have questioned the hypothesis, though, suggested the new findings call into question much of what the Italian physician has claimed.

"The whole notion of cause and effect is out the window," said Dr Mark Freedman, an Ottawa Hospital neurologist and leading MS researcher.

Dr Zamboni argues that a blockage in veins draining blood from the brains of MS patients causes blood to back up and cause inflammation that damages the myelin coating around nerve cells. That inflammation is known to trigger MS.

He published research that found the vein narrowing in 65 MS patients, but in none of the 235 healthy people who were also tested.

A later study by Dr Zamboni reported that using angioplasty -- where a tiny balloon is inflated inside a blood vessel -- to unblock patients' veins improved their condition. That study lacked a comparison group that did not get the operation, and other measures to factor out the placebo effect.

Fuelled by positive media coverage, though, the findings sparked a massive response among patients who have the chronic and frequently debilitating disease, with thousands seeking out testing and treatment.

Neurologists voicing skepticism about the research have been criticized as unwilling to accept new ideas and beholden to the pharmaceutical industry and its treatments.

Dr Zivadinov took the unusual step of issuing a news release yesterday of sketching out results of the first phase of his more rigorous study into CCSVI.

His team conducted ultrasound scans of neck veins on 280 MS patients, 161 healthy people and about 60 with other neurological conditions.

When subjects with borderline findings were included, it turned out that 56% of MS patients and 22% of healthy comparisons had the vein problem. When the borderlines were excluded, 62.5% of multiple sclerosis sufferers and 26% of healthy people tested positive for the condition.

The fact that so many more MS patients had the condition is a significant finding, said Dr Zivadinov. He also noted, however, that the vein narrowing was more common in people at more advanced stages of the disease.

"That would be against CCSVI being a primary cause of MS, although clearly this can't be determined yet," said Dr Zivadinov. "This will be very difficult to determine: what is the chicken and what is the egg."

Luanne Metz, an Edmontonbased MS specialist, said the results suggest the vein narrowing could be a risk factor for the disease, but not its cause.

"What it really does is it really warns that people need to be cautious," the neurologist said.

Dr Paul O'Connor, a neurologist at Toronto's St. Michael's Hospital, said he would advise against patients even getting tested.

"There is not a shred of real evidence anywhere that messing around with these veins does anything to help MS patients," he said. "If there is no treatment for this condition, there is no need to detect it."

Both he and Dr Freedman also suggested that Dr Ziadinov may be in a conflict of interest, given that his Buffalo Neuroimaging Analysis Center is now offering neck scans to MS patients for fees of \$4,500 to \$6,000.

Dr Ziadinov said he and his colleagues debated the ethics of providing the service for a fee, but decided they had an ethical obligation to do so, partly because 15,000 MS patients had approached them to be part of clinical trials that have spots for just 500. The proceeds will fund the research, he added.

Source: National Post

DISCLAIMER

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

Truth or Fiction

To all: I can't vouch for the truth in all of these (only some of them) but here they are for what it's worth.

There is an old Hotel/Pub in Marble Arch, London, which used to have a gallows adjacent to it. Prisoners were taken to the gallows, (after a fair trial of course) to be hung. The horse drawn dray, carting the prisoner, was accompanied by an armed guard, who would stop the dray outside the pub and ask the prisoner if he would like "ONE LAST DRINK".

If he said YES, it was referred to as ONE FOR THE ROAD.

If he declined, that prisoner was ON THE WAGON.

They used to use urine to tan animal skins, so families used to all pee in a pot & then once a day it was taken & sold to the tannery. If you had to do this to survive you were, "Piss Poor", but worse than that, were the really poor folk, who couldn't even afford to buy a pot, they "Didn't have a pot to Piss in" & were the lowest of the low.

Here are some facts about the 1500's:

Most people got married in June, because they took their yearly bath in May and they still smelled pretty good by June. However, since they were starting to smell, brides carried a bouquet of flowers, to hide the body odor. Hence the custom today, of carrying a bouquet when getting married.

Baths consisted of a big tub filled with hot water. The man of the house had the privilege of the nice clean water, then all the other sons and men, then the women and finally the children. Last of all the babies.

By then the water was so dirty you could actually lose someone in it.

Hence the saying, "Don't throw the baby out with the Bath water!"

Houses had thatched roofs, thick straw piled high, with no wood underneath. It was the only place for animals to get warm, so all the cats and other small animals (mice, bugs) lived in the roof. When it rained it became slippery and sometimes the animals would slip and fall off the roof.

Hence the saying "It's raining cats and dogs."

There was nothing to stop things from falling into the house. This posed a real problem in the bedroom, where bugs and other droppings could mess up your nice clean bed. Hence, a bed with big posts and a sheet hung over the top, afforded some protection. That's how canopy beds came into existence.

The floor was dirt. Only the wealthy had something other than dirt.

Hence the saying, "Dirt Poor."

The wealthy had slate floors, that would get slippery in the winter when wet, so they spread thresh (straw) on floor to help keep their footing. As the winter wore on, they added more thresh, until, when you opened the door, it would all start slipping outside. A piece of wood was placed in the entrance way.

Hence: a thresh hold. (Getting quite an education, aren't you?)

England is old and small and the local folks started running out of places to bury people. So, they would dig up coffins and would take the bones to a bone-house and reuse the grave. When reopening these coffins, 1 out of 25 coffins were found to have scratch marks on the inside and they realized they had been burying people alive. So they would tie a string on the wrist of the corpse, thread it through the coffin and up through the ground and tie it to a bell.

Someone would have to sit out in the graveyard all night, (the graveyard shift) to listen for the bell; thus, someone could be, "Saved by the Bell" or was considered a "Dead Ringer"

And that's the truth.

Now, whoever said History was boring !!! So . . . get out there and educate someone!

MEMBERS COMPETITION

A £5 prize will be given to the member whose entry has the most correct answers. Even if you do not know 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/ Chess piece
- 2/ Rainbow Colour
- 3/ July Birthstone
- 4/ What is Barries boyfriend called
- 5/ Assassinated by James Earl Ray
- 6/ One of the nine planets of our solar system
- 7/ Musical term for Quick or Lively
- 8/ Name of the two wheeled cart used to transport condemned prisoners during The French Revolution
- 9 One of the Great Lakes
- 10/ American state where you would find the Grand Canyon
- 11/ A street on the Monopoly Board

Name:

Address:

Send Completed Forms To:
Mr D Henderson
74 Windermere Road
Stockton-on-Tees
Cleveland TS8 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/ Cain 2/ Rubick's 3/ Osborne 4/ October 5/ Kingsley (Ben) 6/ Epiglottis 7/ Leo 8/ Thursday 9/ Oxford 10/ Nine