

## NEWS UP-DATE

November 2009

### *STOCKTON M.S. GROUP XMAS DINNER*

*TO BE HELD ON  
MONDAY 7<sup>TH</sup> DECEMBER at 7.00 PM  
at the  
RIMSWELL HOTEL, FAIRFIELD,  
STOCKTON*

#### *STARTERS*

*Winter Vegetable Soup  
Prawn cocktail  
Vegetable Kebabs With Spicy Tomato Sauce*

#### *Main Course*

*Roast Turkey And Stuffing  
Pork Chop With Stuffing Crust  
Thai Steamed Salmon  
Vegetable Moussaka*

#### *DESSERT*

*Xmas Pudding  
Gateaux  
Cheese Cake*

*2 Courses £10      3 Courses £12*

*All money to be paid to June, by Mid November*

The Group have purchased a new minibus which is intended to replace the current White LDV.

It's a 2004 Renault Master similar to the existing blue bus.



The pictures shown are before we take out the necessary seats. We are looking for somewhere to store three removable seats and we would welcome offers from anyone who could store one or all of these in their loft for instance.

The new bus has a fully automated tail lift which will considerably help the volunteers as no lifting of the tail lift is now required (and some of us are getting older!).

The new bus will come into service as soon as the necessary documentation is completed and we can pick it up.

The Group has successfully sold the white mini bus.



Many congratulations to Sandy and John who got married on Thursday 24<sup>th</sup> September at the Swan Hotel in Billingham. We wish you both all the love and happiness that comes your way.



Congratulations are also in order to Carol Newbold who once again won prizes at the Billingham Show for Tapestry and Card Making...well done.



We would also like to send a Get Well Message to two of our good friends Bill and Betty who have been suffering from ill health recently. Our thoughts are with you both and we hope to see you back amongst us all very soon.

## **The drug that changed my life should be available to all.**

FOUR years ago, MS sufferer Linda Elsegood was wheelchair-bound, half-blind and half-deaf. She slept 20 hours a day and spent much of the time she was awake in clinics waiting for treatment, often for ailments caused by the drugs she was given to control her multiple sclerosis.

Today it's a different story. "I am transformed," says Linda, 53, a busy mother and grandmother from Norfolk, who has regained her independence after taking the drug LDN. "It has given me back my quality of life," she says.

Diagnosed in 2000, Linda was told she had an aggressive form of progressive MS and it would simply get worse, leaving her more and more incapacitated. "It was as if I were a TV that wasn't tuned in. Everything was fuzzy – sound, vision, understanding – and I couldn't retrieve from my brain the words I needed.

"Within weeks of taking LDN I was tuned in again. The burning sensation in my legs faded and I stopped needing the loo six times an hour."

LDN is Low Dose Naltrexone. Naltrexone was developed to help heroin addicts break their habit. It was while working with heroin users who also had HIV that a New York doctor noticed low doses seemed to boost their failing immune systems.

Since the drug is not available on the NHS for MS patients, Linda got hers on private prescription but her GP agreed to monitor progress.

"The effect was amazing," says Linda. "I want to make sure as many people as possible know about the drug so they might be relieved of their MS symptoms."

People suffering from a wide variety of auto-immune diseases – including MS, Crohn's disease, arthritis and psoriasis – are telling each other via the internet about the relief that LDN seems to give.

The problem is the drug isn't licensed anywhere in the world as a treatment for auto-immune diseases so GPs often don't know about it and patients who want to try it have to find a doctor willing to prescribe it privately.

LDN is cheap – a typical prescription costs £15 a month – yet that is what keeps the drug in unlicensed limbo. Trials to test its efficacy would cost around £2million. However LDN came out of patent in the Nineties so no company has a monopoly on production and anyone can make it. This means no commercial company will fund trials as they will not re-coup their costs. Yet, says Linda, there could be big savings for subsidised health services worldwide and for the NHS.

"There is no treatment for MS but the effects of steroids and immuno-suppressant drugs can keep someone like me in the treatment system," says Linda. "I was constantly treated for infections my body would have fought off if I hadn't been given drugs that shut down my immune system. LDN seems to regulate the immune system and get it back on track for some." Linda is spreading the word via her charity, the LDN Research Trust, supported by health professionals around the world. "I am careful not to raise false hopes," she says.

"LDN is not a cure or miracle drug and doesn't work for everyone. However people with MS should have the chance to see if it works for them."

## Blood test could predict severity of multiple sclerosis

A blood test that could predict the severity of multiple sclerosis (MS) is being developed by British scientists, promising to improve clinical management of the neurological disorder. Research has identified a biological marker in blood that seems linked to patients' prognosis after the first MS attack, paving the way for a new approach to assessing how the illness will progress. If a blood test based on the biomarker can be validated, it could be used with MRI scans and other methods to improve diagnosis.

Patients whose MS is thought likely to progress quickly could be started swiftly on therapies that can reduce the frequency and severity of attacks, while those at lower risk could be spared medication they do not need immediately. More accurate ways of assessing prognosis could also help to prepare patients for what they should expect in the future, removing the uncertainty that can be a distressing feature of the disease.

The research, led by Rachel Farrell, of the Institute of Neurology at University College London, and funded by the MS Society, also offers new insights into the biology of MS that could improve understanding of the causes of the condition.

MS is a neurological disorder that affects about 100,000 people in Britain, and the most common disabling condition of the young. It is an autoimmune disease, caused when the body's immune system attacks the myelin sheaths that insulate nerve fibres, causing transmission errors. Symptoms can include a loss of sensation and balance, fatigue, paralysis, pain, memory problems, vision problems, incontinence and sexual dysfunction.

After a first attack of MS-type symptoms, the disease can develop in several ways. A small proportion do not have more attacks, while most start with the relapsing-remitting form of MS, with attacks followed by periods of recovery. Most of these go on to develop secondary progressive MS within 10 to 15 years of diagnosis, in which symptoms worsen over time. About 10 to 15 per cent of patients have primary progressive MS, in which symptoms worsen steadily from the start, without periods of remission.

The condition is diagnosed from symptoms and MRI scans that look for characteristic lesions in the brain, as well as lumbar punctures to identify abnormalities in cerebrospinal fluid. The new research, published in the journal *Neurology*, suggests that a blood test could be added to this suite of diagnostic tools, to improve accuracy and assess an individual's likely prognosis. In the study, Dr Farrell's team investigated links between MS and Epstein Barr Virus (EBV), a virus to which about 90 per cent of people have been exposed. Almost everybody with MS has been infected with EBV, and adults who get it are at raised risk. This has led scientists to question whether a reactivation of latent EBV might be a factor in the onset of MS.

Dr Farrell said: "It's very interesting that people who are negative for EBV don't get MS. The question is: do you need EBV to develop MS, or is there something about the immune system of people without EBV that also means they don't get MS?"

In the study, the scientists looked for antibodies to EBV in 50 people who have had an attack with MS-type symptoms but who have not had MS diagnosed, 25 people with relapsing-remitting MS, and 25 people with primary progressive MS.

"We wanted to see if reactivation of the virus triggered relapses, but we found no evidence of that," Dr Farrell said. "But when we looked at the pattern of antibody response, we found people with a higher level of antibodies had more lesions. The suggestion is that a higher antibody load

is indicative of a quicker progression of MS. We have identified something that may be used as a biomarker. This may be useful in identifying those who are going to go on and develop MS." Such a test, she said, could be particularly useful in deciding whether to prescribe drugs such as beta interferon and glatiramer acetate (Copaxone) to people who have had an initial MS-type attack. They can reduce the frequency and intensity of relapses, but they are burdensome because they must be injected daily. Susan Kohlhaas, research communications officer at the MS Society, said: "People with MS find the uncertainty of what the future holds very daunting so more knowledge about what might lie in store could be a big help."

### **Debilitating symptoms will get progressively worse**

- Symptoms can include weakness, fatigue, loss of sensation or balance, pain, paralysis and blindness
  - Most people with MS have the relapsing-remitting form of the disease, in which attacks are interspersed with periods of remission
  - Relapsing-remitting MS generally turns into secondary progressive MS, in which symptoms worsen steadily
  - About 10 to 15 per cent of patients have primary progressive MS, in which the disease worsens steadily from the first attack
  - Treatments include beta interferon and glatiramer acetate (Copaxone), which can reduce the severity of attacks, and the slow progression of the disease
  - Almost everybody who develops MS has previously been exposed to Epstein-Barr virus
- Source: MS Society

www.dailymail.co.uk 17 September 2009

### **Men 'are more likely to leave sick partners' study shows.**

A man is seven times as likely to leave his wife when she becomes seriously ill as a woman is to abandon her husband, say researchers.

The finding comes from a study into how more than 500 married couples coped with the diagnosis of a life-threatening illness such as cancer or multiple sclerosis.

The divorce rate was no higher than average. But closer inspection revealed that the marriage was much more likely to end when the patient was a woman.

In other words, a woman is better at standing by her man than vice versa.

Of the 23 divorces in the multiple sclerosis patients, 22 occurred in couples in which the woman was ill, and just one in a marriage where the man was the patient.

Similarly, 18 of the 23 brain tumour patients whose marriage ended were women, as were 13 out of the 14 with other cancers, the U.S. study found.

Overall, 21 per cent of marriages in which the wife was ill ended, compared with just 3 per cent in which the husband was the patient.

The researchers, from Washington University in Seattle, said it appeared that women are more committed to staying with someone through thick and thin.

They added: 'Some studies have suggested men are less able to undertake a care-giving role and assume the burdens of home and family maintenance compared with women.

'A woman becomes willing sooner in the marriage to commit to the burdens of having a sick spouse.'

The analysis also showed the impact a broken relationship can have on health. Patients who separated or divorced spent more time in hospital, took more anti-depressants, and were less likely to finish courses of gruelling treatments such as radiotherapy.

## **Brain chemical could hold key to treating multiple sclerosis**

Scientists say that they have taken “a major step forward” in understanding how to reduce the severity of multiple sclerosis (MS), a university claims.

Tests on mice found that the brain chemical galanin can significantly reduce the seriousness of the disease, which attacks the central nervous system. Experiments with the molecule on human brain tissue suggest that it could have the same effect on people.

The researchers at the University of Bristol said that further study was needed but that potentially a drug could be developed within ten years. The research offers hope to some 85,000 MS sufferers in Britain.

They found that mice with high levels of galanin were resistant to the MS-like disease, experimental autoimmune encephalomyelitis (EAE).

David Wynick, who works on the function of galanin in the relief of neuropathic pain, initiated the project and worked with David Wraith and Neil Scolding on the research.

Scientists believe the key to the currently incurable condition may lie in galanin, a neuropeptide or small protein-like molecule that influences the brain’s activity. They found that mice with a large amount of galanin became “completely resistant” to the EAE, but mice that had no galanin at all developed a more severe form.

They then carried out tests on human brain tissue already affected by MS and found that galanin repaired some of the damage seen in acute sufferers of the condition. Professor Wraith, who is working on a vaccine for the prevention and treatment of MS, commented: “The results were really remarkable: rarely do you see such a dramatic effect as this.”

MS is the most common disabling neurological disease among young adults and symptoms range from pain and tiredness to spasms, paralysis and memory loss.

A spokeswoman for the university said that although the results were “very encouraging” there was still much work to be done before a drug could be developed and it could be at least ten years before one was on the market.

She said the team were now expected to seek the “substantial” funding needed to advance their findings.

### **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.

## **Chronic MS disease delayed by new drug**

A CONTROVERSIAL treatment for multiple sclerosis (MS) can significantly delay the appearance of full-blown disease in many patients with early symptoms, a research reveals today.

The drug, glatiramer acetate, cut the chance of patients getting a confirmed diagnosis of MS by almost half over a three-year period.

But it is still not clear how long it will take for symptom-free patients to become ill.

The drug can delay the onset of chronic symptoms, but it is still not a cure.

MS is an auto-immune disease in which the body's own defenses attacks the fatty "insulation", called myelin, that surrounds nerve fibres in the brain.

Patients can suffer a range of symptoms, ranging from a mild tingling sensation to severe paralysis.

In 85 per cent of cases, MS patients experience an initial spontaneous episode of symptoms that quickly fade away.

This event known as a "clinically isolated syndrome" (CIS), does not always develop into full blown MS. The disease is confirmed as "clinically definite" only if a second episode of symptoms occurs.

Glatiramer acetate is recommended only for "confirmed" NHS patients under guidance issued by the National Institute for Health and Clinical Excellence.

The drug was approved for NHS use only after it's manufacturer's agreed to a "risk sharing" scheme, promising to reimburse some of the cost if the medicine failed to prove effective.

Treating one patient with glatiramer acetate for a year costs about £6,650.

Trial evidence has shown the drug can reduce the frequency of symptoms in patients with intermittent or "relapsing remitting", MS by 30 per cent.

The new research looked at what happened when the injected drug was administered to patients after a CIS episode.

A total of 481 CIS patients took part in the PreCISe (patients with clinically isolated syndrome) study in 16 countries. They were randomly assigned to receive glatiramer acetate or a "dummy" drug for up to three years, unless they "converted" to full-blown MS.

The results from the University Vita-Salute in Milan, Italy, and published today in an on-line edition of the Lancet medical journal, show that glatiramer acetate reduced the risk of developing "clinically definite" MS by 45 per cent.

The time it took for patients to progress to the full blown disease was more than doubled in 25 per cent of cases, from just under a year to just under two years.

## **Trials of MS drug 'reduce relapses'**

A NEW drug which can halve the number of relapses suffered by multiple sclerosis patients has been trialled in the North-East.

The new drug – fingolimod – which has been described as potential breakthrough in MS treatment, has been shown to reduce relapse rates by 54 to 60 per cent.

Patients who would normally expect to have a disabling attack every three years, might expect to have one every six or seven years if they take fingolimod, slowing down the progression of disability.

A small group of MS patients treated at the Royal Victoria Infirmary, in Newcastle, are among a larger group of UK patients who took part in the trial of fingolimod, which is also known as FTY720.

Professor David Bates, an expert in the treatment of MS and one of the key researchers in the fingolimod trial, said the result of the latest trials reinforced the potential of the drug "as a significant breakthrough in the future treatment of relapsing remitting MS".

"Reducing the number of relapses and the progression of disability is one of the biggest concerns for patients and a key goal of treatment," said Prof Bates, who is professor of clinical neurology at Newcastle University.

Seven North-East patients were involved in the fingolimod trial and all are now taking the drug. Currently, drugs for MS have to be given by intravenous drip or by injection, but fingolimod is taken in tablet form, a major advance for patients.

"Oral therapies in MS have been awaited for many years and, provided the drug passes the hurdles of the European Medicines Agency and the National Institute for Health and Clinical Excellence we will hope to offer them to our patients in 2011," said Prof Bates.

Manufacturer Novartis intends to apply for a licence for fingolimod in both Europe and the US later this year.

The drug, which works in a different way to any other MS drug, is also being considered as a possible treatment for primary progressive MS, the more advanced form of the illness.

Nicola Russell, director of services at the MS trust, said the results of the fingolimod trial "look impressive".

[www.mstrust.org.uk](http://www.mstrust.org.uk) 15 October 2009

## **FDA panel backs Acorda's MS drug fampridine SR**

Acorda Therapeutics is celebrating the news that advisors to the US Food and Drug Administration have voted to recommend approval for fampridine as a treatment to improve walking in multiple sclerosis patients.

The agency's Peripheral and Central Nervous System Drugs Advisory Committee has voted 12 to one that clinical data presented for fampridine-SR 10mg twice-daily demonstrated "substantial evidence of effectiveness as a treatment to improve walking in people with MS. The panelists voted 10 to two (ie with one abstention) that it is "clinically meaningful and can be safe for use".

The committee also recommended by a vote of 12 to one that Acorda be required to evaluate the effects of doses lower than 10mg twice daily, but by a 10 to two vote (again with one abstention) that these studies do not have to be done prior to approval. They are concerned about allowing use for patients with renal impairment or history of seizure, but Acorda says it has proposed a risk evaluation and mitigation strategy programme relating to appropriate use of fampridine-SR.

The panel's decision is particularly welcome seeing as a couple of days ago, FDA staffers claimed that the oral sustained-release compound "has a very limited effect". However those concerns seem to have been put to one side and Acorda chief executive Ron Cohen said the company was pleased with the outcome of the PCNSD meeting, describing it as "an important milestone".

The FDA is scheduled to make its final decision by October 22 and while Acorda initially proposed the brandname Amaya, it has been reported that the company has now plumped for Ampriva. In July, Biogen Idec signed a deal to acquire the rights to the drug outside the USA.

## YOUR JOKES

A very tired nurse walks into a bank, totally exhausted after an 18-hour shift. Preparing to write a cheque, she pulls a rectal thermometer out of her purse and tries to write with it. When she realises her mistake, she looks at the flabbergasted teller and without missing a beat, she says:

'Well, that's great....that's just great....Some arsehole's got my pen!

\*\*\*\*\*

Husband and wife are shopping in Tesco's when the man picks up a crate of Stella and sticks them into the trolley

'What do you think you're doing?' asks the wife

'They're on offer, only £10 for 24 cans', he says

'Put them back. We can't afford it,' says the wife and they carry on shopping...

A few aisles later the woman picks up a £20 jar of face cream and sticks it into the trolley.

'What do you think you're doing?' asks the man,

'It's my face cream. It makes me look beautiful,' she says.

The man replies... 'so does 24 cans of Stella and it's half the price'

\*\*\*\*\*

A well dressed lady stood waiting for the bus on a warm, clear afternoon in Chicago.

When the bus stopped, and it was her turn to board, she became aware that her skirt was too tight for her to raise her leg enough to manage the height of step onto the bus.

Slightly embarrassed and with a quick smile to the bus driver, she reached behind her to unzip her skirt a little, thinking that this would give her enough slack to raise her leg.

She tried to take the step, only to discover that she couldn't.

So, a little more embarrassed, she once again reached behind her to unzip her skirt a little more, and for the second time attempted the step.

Once again, much to her chagrin, she could not raise her leg. With another little smile to the driver, she again reached behind to unzip a little more and again was unable to take the step.

About this time, a large Texan who was standing behind her picked her up easily by the waist and placed her gently on the step of the bus.

She went ballistic and turned to the would-be Samaritan and yelled, "How dare you touch my body! I don't even know who you are!"

The Texan smiled and drawled, "Well, ma'am, normally I would agree with you, but after you unzipped my fly three times, I kinda figured we was friends."

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FACT: 79,000,000 people are engaged in sex right now

FACT: 58,000,000 people are kissing

FACT: 37,000,000 people are relaxing after having sex

FACT: 1 old timer is sitting reading jokes

You hang in there. **SUNSHINE**

# 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 TWO LOCAL TOWNS OR VILLAGES**

- 1/ One of the Great Lakes .....
- 2/ One of the Planets .....
- 3/ Zodiac sign for May .....
- 4/ October birthstone .....
- 5/ Which gas was named after the Greek word for 'New' .....
- 6/ Chess Piece .....
- 7/ Linda Bellingham was famous for advertising which product .....
- 8/ Only city in Cornwall .....
- 9/ Group of workers in London familiar with the Knowledge .....
- 10/ Rainbow colour .....

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

Answers to last quiz:

- 1/ Mappa Mundi 2/ Indonesia 3/ Casablanca 4/ Harlem 5/ Icarus 6/ Grapes 7/ Albatross 8/ Neighbours State Capital...Lansing