

April 2007

Northern Echo 28 March 2009

'More Treatment' for wonder-drug teenager'

A North-East teenager who was one of the first in the UK to be treated with a new wonder drug for multiple sclerosis has revealed she probably needs more treatment after symptoms started to return.

Patsy Peebles, 16 from Felling, Gateshead, was 15 when doctors at Newcastle General Hospital gave her an experimental new drug called alemtuzamab. It miraculously restored her to near-normal levels of energy and mobility. But nearly two years later she has developed headaches and double vision in one eye.

Now her parents, Bill and Joanna, are hoping that she will be able to have another injection of the drug.

Originally developed to treat leukaemia, there is growing evidence that alemtuzamab can help slow down and even reverse the symptoms of multiple sclerosis.

The treatment – given by injection over five days – had an almost immediate effect and Patsy was able to go out shopping with her friends again.

Previously, she had been unable to walk more than a few yards and had to rely on being pushed around in a wheelchair.

Yesterday, at an event organised by the MS Society to announce that its annual MS Life conference will be held at the Sage in Gateshead between June 12 to 14, Patsy's mother, Joanna, said "I think this drug is fantastic. "To see the change in Patsy was unbelievable. Instead of being stuck in the house all day she was able to go out shopping with her friends and start living her life again."

Chris Bray, MS Society event director, said: "Over the next three months we will be working to increase the profile of MS in the region.

"Some of the leading minds in MS research will present their current findings and answer questions."

www.mstrust.org.uk 19 March 2009

The value of FES for people with MS

Functional Electrical Stimulation (FES) can help some people with MS increase their walking speed and endurance according to newly published research.

The report, published in the journal Multiple Sclerosis, is the first of two studies into the value of FES funded by the MS Trust. FES uses external electrical stimulation through pads attached to the leg to compensate for reduced nerve activity.

Walking speed was the main measure in the study and FES was compared with an exercise regime. The MS Trust has for many years promoted the value of exercise for people with MS and in this study the exercise regime significantly increased the walking speed and endurance over the 18 week intervention period. The use of FES also showed a significant benefit resulting in increased walking speed and endurance when compared to performance without stimulation.

The second study will report in due course.

Nicola Russell, the MS Trust's Director of Services, said, "We know of a number of people with MS who find FES helpful. With the publication of this research, and the recent approval from NICE, we hope the device will become more easily available for people who might benefit."



Increased donation from Co-operative Until April 29th [Co-operative Travel](#) has increased the donation offered to [Stockton MS Group](#).

[Stockton MS Group](#) will now receive 4% of what you spend on your holiday (1% for flights). To celebrate this they have offered some fantastic money saving deals.

5% off package holidays when you book via your webshop

Book online
for a **5%** discount

If you're travelling between May and October you'll get 5% off your summer package when you book [here](#) before April 30th.

Summer holidays from just £199pp

Summer holidays
from **£199** per person

If you're looking for a money saving holiday Co-operative Travel is the place to [start](#). Deals include Majorca, Greece, Turkey and The Algarve.

Great deals from an airport near you

If you're looking for a late deal and you're not sure where to go check the Co-op's [local airport offers](#) – the prices change all of the time but you're guaranteed a great deal.

Summer holidays
from **£199** per person

Become a member
[Click here to signup](#)



Visit www.buy.at/Stocktonmsgroup for more great offers from over 150 top retailers.



JK Rowling quits Scottish Charity

Harry Potter author JK Rowling has stopped supporting a Scottish charity after a row over how it is run.

Rowling has been the patron of the MS Society Scotland for nearly 10 years, but now has decided to leave the post.

She will still donate money to scientists and try to help people with Multiple Sclerosis, but doesn't want to work with that charity any more.

It's been reported that the author fell out with the charity over problems between it and bosses in London.

The MS Society Scotland is part of the MS Society of Great Britain and Northern Ireland.

Rowling said: "I have not taken the decision to quit my position as patron of MSSS lightly."

She added that she had tried to help sort out the row between the Scottish Council and the management in London but wasn't able to do so.

"Sorry she is stepping down"

An MS Society spokesman said: "We are sorry she is stepping down and thank her for her good work, and for her continued support for the MS research centre in Edinburgh."

Rowling's mum died from Multiple Sclerosis at the age of 45 in 1991.

Study suggests MS association with reduced cancer risk

A new study has suggested that people with multiple sclerosis (MS) may be at a higher risk of developing certain types of cancer, such as brain tumors and bladder cancer, but a lower risk for cancer overall.

The study, published today in *Neurology*, the medical journal of the American Academy of Neurology, speculates that a potential lower risk for cancer among people with MS could be a result of lifestyle changes or treatment following diagnosis.

Researchers at the Karolinska Institute in Sweden looked at the medical records of 20,000 people with MS and 204,000 people without the diagnosis.

After 35 years, they found that the people with MS had a decreased overall risk of cancer by 10 per cent compared to people who did not have the disease.

The result was more pronounced in women. However, for people with MS the risk for certain cancers, such as brain tumors and bladder and other urinary organ cancers, increased by up to 44 percent compared to people without MS.

MS Society Head of Research, Dr Lee Dunster, said: "The theory that the risk of developing cancers may be altered by MS is interesting, however it is only theory and this study does not look into lifestyle factors that may affect detection or occurrence of cancer.

"There is no solid evidence at present to suggest MS can specifically play a role in the reduction or increase of certain types of cancer and more work is needed to find out if this theory holds true."

Gran raising money for MS sufferers with The Red Wheelies

A grandmother with a debilitating neurological illness is planning to ride the length of one of the oldest and longest landmarks in Britain on her mobility scooter.

Gill Smith (59), who suffers from multiple sclerosis (MS), will put any thoughts about her condition to one side as she travels the 73.5-mile length of Hadrian's Wall on her trusty red scooter.

Mrs Smith, of West End, March, is a member of The Red Wheelies - who describe themselves as the mobility scooter equivalent of the Red Arrows.

The Wheelies was formed by a group of people with MS, and hit the headlines in the 1990s after performing a number of formation routines on their scooters in front of the GMTV cameras.

Now they have got back together to raise money for a number of centres to help people cope with the condition.

They hope to raise £50,000 for centres in Peterborough and Kent, where the members of the group are based.

Mrs Smith said: "We are doing it to show that we can still do something, even though we have MS. There is no need for life to stop. "It is something a little different, but I'm sure it will be enjoyable, especially if the weather stays good. "I am a member of the Peterborough MS society, and it is great to be able to give something back."

The 10 members of the group will head off on their journey in May, and are hoping to complete the trip in 11 days.

The marathon trek will officially start at 11am in Canterbury Cathedral, with The Very Rev Robert Willis, Dean of Canterbury, and the Mayor of Canterbury, councillor Carolyn Parry, giving the group a civic send-off.

They will also be given the Mayor's seal of approval when they arrive at Wallsend, Newcastle, where their journey starts and at the end of the trek when they reach Bowness in Cumbria. Mrs Smith said that they had already received plenty of support.

She said: "All our families have been really supportive, and I'm sure they will keep us going. "The civic receptions will also be very exciting, and we hope a lot of people will turn out to wish us well.

"Premiere Inns have given us a reduced rate for our overnight stops, and have even offered us rooms to store our scooters.

"We have also had help with our scooters from Quingosport Scooters, and we are very grateful for all the help we have received."

Multiple sclerosis is a condition that attacks the nervous system, and the ability of nerve cells in the brain and spinal cord to communicate with each other.

COME DANCING

WHEELCHAIR users are invited to learn to dance. BBC Three are looking for people to get involved in a dance series with the winning couple taking part in an international wheelchair dance sport contest.

For details call 0207 428 5752/5755 or email wheelchair.dancers@fevermedia.co.uk

Sativex trial results announced

New research suggests that Sativex may be effective in treating spasticity in some people with MS.

Sativex is a cannabis based medicine that is taken as a mouth spray. Previous research has suggested that not all recipients respond to the drug, but those that do find it effective. As a result, the recent phase III trial was in two stages. In the first stage, 573 people received Sativex for four weeks. The 241 people who responded to the drug went into the second stage where they received either Sativex or a dummy placebo for 12 weeks.

The study has not been independently published, but the results announced by the manufacturer, GW Pharmaceuticals, indicate a significant improvement on spasticity scores for the treatment group. About three quarters of those receiving Sativex reported an improvement of greater than 30% in their spasticity score. 51% of people on placebo reported the same improvement.

GW Pharmaceuticals have announced their intention to submit a regulatory application in the second quarter of 2009.

Pam Macfarlane, MS Trust Chief Executive, said, "These results sound encouraging and would welcome their publication in a peer reviewed journal. The current arrangements for Sativex mean that prescription is inconsistent across the UK. We would welcome a licence as this would make access easier for those who might benefit."

Makers of Amispro

Daval has been advised by the MHRA that they have concluded their investigation into our activities and that there will be no prosecution of either the company or its employees. They have established that there is no substance to the allegations that were made and which formed the subject of the Sunday Times article of 26 November 2006. Moreover the MHRA stated that as a result of their interest in AIMSPRO and the fact that there are no issues of non-compliance of medicine legislation, that the company is now in a better position to achieve commercial success with its product.

Daval has consistently maintained that we were innocent of any and all charges and are delighted to be fully vindicated in this way.

DISCLAIMER

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

Lovers of the English language might enjoy this. It is yet another example of why people learning English have trouble with the language. Learning the nuances of English makes it a difficult language. (But then, that's probably true of many languages.)

There is a two-letter word in English that perhaps has more meanings than any other two-letter word, and that word is 'UP.' It is listed in the dictionary as being used as an [adv], [prep], [adj], [n] or [v].

It's easy to understand UP, meaning toward the sky or at the top of the list, but when we awaken in the morning, why do we wake UP?

At a meeting, why does a topic come UP ? Why do we speak UP, and why are the officers UP for election and why is it UP to the secretary to write UP a report? We call UP our friends and we use it to brighten UP a room, polish UP the silver, we warm UP the leftovers and clean UP the kitchen. We lock UP the house and some guys fix UP the old car.

At other times the little word has a real special meaning. People stir UP trouble, line UP for tickets, work UP an appetite, and think UP excuses.

To be dressed is one thing but to be dressed UP is special.

And this up is confusing:

A drain must be opened UP because it is stopped UP.

We open UP a store in the morning but we close it UP at night. We seem to be pretty mixed UP about UP !

To be knowledgeable about the proper uses of UP , look the word UP in the dictionary. In a desk-sized dictionary, it takes UP almost 1/4 of the page and can add UP to about thirty definitions

If you are UP to it, you might try building UP a list of the many ways UP is used. It will take UP a lot of your time, but if you don't give UP, you may wind UP with a hundred or more. When it threatens to rain, we say it is clouding UP . When the sun comes out we say it is clearing UP. When it rains, it wets UP the earth. When it does not rain for awhile, things dry UP.

One could go on & on, but I'll wrap it UP , for now

.....my

time is UP , so time to shut UP!

Oh...one more thing:

What is one of the first things you do in the morning & the last thing you do at night?

U P

MEMBERS COMPETITION

A £5 prize will be given 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/ County at the most southerly point of the Pennine Way
- 2/ Colour of the rainbow
- 3/ 1st U.S. president to resign
- 4/ Bones found in the lower half of your body
- 5/ February birthstone
- 6/ One of the tree ships used by Columbus in 1492
- 7/ Which fish is the source of caviar
- 8/ Zodiac sign covers part of May
- 9/ What type of bird is old Mrs Brown in the Tales of Beatrix Potter
- 10/ Which politician first said, a week is a long time in politics
- 11/ Which village 32km south of Leicester was the site of an English Civil War Conflict

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/ Superior 2/ Hall 3/ Edith 4/ Radius 5/ Aslan 5/ Tuberculosis 6/ Opal 7/ Neon