

May 2009



Many Congratulations to Dave Sharp on reaching his 50th Birthday on Tuesday 26th May.

A big thank you to his wife Barbara for laying on a lovely array of food and inviting us all to enjoy in David's celebration at the Drop-In.

See if you can recognise yourselves in the photographs taken on the day which are on our Web Site.

www.mssociety.org.uk April 30 2009

Significant research announcements during MS week.

This year's MS Week is set to be one of the most memorable of awareness weeks for multiple sclerosis (MS) after a number of significant drug announcements.

Scientists specialising in MS and presenting at the annual American Academy of Neurology convention in Seattle have reported research findings that take the field of MS treatments to a "new dawn".

Head of Research at the MS Society, Dr Lee Dunster, said: "This week's announcements herald a step change in treatment options for people with the most prevalent form of MS at the time of diagnosis.

"News of the development of two oral therapies for MS marks a new dawn and this could be a huge step forward for people who currently have to inject their treatments.

"We are looking at treatments that could be available on the NHS by the end of next year that will make a real difference to people's lives."

Today (Thursday), Professor Gavin Giovannoni from Queen Mary, University of London announced trial results of the drug cladribine, which may become the first effective treatment available in tablet form for relapsing remitting MS. The Merck Serono drug, used in leukaemia for a number of years, was shown in latest studies in more than 1,300 people to bring about a 58 per cent reduction in yearly relapse rates compared to placebo.

There was also a 30 per cent reduction in progression of disability as measured by the Expanded Disability Status Scale (EDSS) and a reduction in lesion activity (as measured by MRI) in participants taking up to 30 cladribine tablets over the two years.

Meanwhile, Novartis announced news yesterday (Wednesday) of the latest results of their oral MS therapy, FTY720 (fingolimod).

The Phase III results showed that in more than 1,200 people with relapsing remitting MS the drug brought about a 52 per cent reduction in yearly relapse rates compared to beta interferon. The treatment has yet, however, to show potential to slow progression of disability.

Schoolboy petitions MSP's over vitamin D link to MS

A *Times* investigation into the links between vitamin D deficiency and multiple sclerosis led a 14-year-old boy whose mother has the disease to petition Holyrood to provide a vitamin supplement to all children and pregnant women.

Ryan McLaughlin, from Glasgow, decided he had to do something after he read an exclusive report in *The Times* showing there was a direct interaction between vitamin D and a common genetic variant, which increased the possibility of MS being inherited.

His mother, Kirsten, 34, became ill with MS three years ago and earlier this year Ryan underwent tests after he showed symptoms of the disease.

His campaign, Shine on Scotland, has started an e-petition and has already won the backing of J.K. Rowling. "I am really honoured to support Ryan in his fantastic campaign," the author said. "Ryan's mother has MS as did my own mother. I only wish I had the gumption at 14 to do what Ryan is doing and get such an important issue raised in the Parliament."

In addition to asking the Scottish government to provide vitamin D for children and pregnant women — in pills or in fortified milk or bread — Shine on Scotland is seeking clarification on the recommended daily allowance of the vitamin and a campaign to inform the public about its benefits in relation to MS.

The Times revealed in February that scientists at Oxford University had found what appears to be a genetic vulnerability to MS, apparently initiated by a lack of vitamin D. The World Health Organisation said that vitamin D supplements should be tested in Scotland "sooner rather than later".

Ryan, who like his mother is a Taekwondo champion, said: "If everyone supports us by signing the e-petition, I am confident that we can bring about real change for future generations and help to prevent thousands of new cases of MS."

Ryan's father, Alan, 34, said that the family had been planning to move to Australia when his wife fell ill. She suffered nine relapses in 13 months and at one point could barely walk.

Emigration became impossible but while on a holiday to Australia, Mrs McLaughlin's health improved in the sunshine.

The family read the report in *The Times* linking vitamin D deficiency to the high incidence of MS and contacted Professor George Ebers at the University of Oxford, who forwarded them his research findings. Mr McLaughlin said: "Ryan and I sat and studied it. At the time he was waiting for tests for MS, because he was having trouble with his eyes and with spasms.

"He'd been watching J. K. Rowling being interviewed about her mother and he said to me, 'Dad, you know the line in the film *Braveheart* about how you have just one chance to make a difference — well, I want to do something about MS so that people in future don't have to suffer like Mum does every day'."

The family gathered support from various charities and four weeks ago began their campaign. Ryan, who was found to be clear of MS after an MRI scan, made a poignant YouTube video and the e-petition was started.

Ryan has received messages of support from Nicola Sturgeon, the Scottish Health Secretary, and Kathleen McDermott, the Bafta Award-winning actress.

On June 16, he will lead 500 children on a march to the Scottish Parliament to lodge his petition.

For more information visit www.shineonscotland.org.uk

Where carers can find much needed support

Britain has an estimated six million carers — the unpaid relatives and friends who look after an ill, frail or disabled person. Yet Carers UK, the charity, says that the majority of these people do not realise that they are carers and that they may be entitled to help from the State and other sources.

Here is *Times Money's* guide to the financial and other support that is available, and where to go for further information.

State help

The principal state benefit for carers is the carer's allowance of £53.10 a week. This is not a means-tested benefit, but it is available only to those aged 16 and over who care for someone who receives a qualifying disability payment (see panel, below) for at least 35 hours a week and does not earn more than £95 a week in other work. Recipients may also be entitled to the carer's premium, which boosts other benefits to which they are entitled by up to £29.50 a week. The allowance can only be claimed by one carer per person cared for, even when two parents care for a child. The same amount is paid regardless of the number of people that a carer looks after. The allowance is stopped when a carer begins to receive the state pension, which Imelda Redmond, of Carers UK, says infuriates many older carers, who feel penalised.

Ms Redmond adds that an estimated £600 million of carer's allowance is unclaimed each year, though most carers do not qualify — often because they want to stay in work on a decent wage. Research indicates that one in five people caring for 50 or more hours a week also has a full-time job.

Other help is offered by local authorities and varies across the country, with some carers moving long distances to secure the best provision. All carers are entitled to a carer's assessment from social services, regardless of entitlement to the carer's allowance. A social worker will assess their right to support, such as respite care, help with housework or grants towards specialist household equipment.

Ms Redmond says that the quality of assessments varies and that carers should contact the CarersLine on 0808 8087777 for advice on effective preparation before an assessment.

All local authorities must offer direct payments, where carers can elect to receive cash in lieu of specific caring services, so that they can make their own arrangements. Ms Redmond says that these are popular because they give carers extra flexibility.

Significantly, carers may qualify for council tax discounts of up to 50 per cent. Check the rules at the Carers UK website (Carersuk.org) or call the CarersLine for more information on this and other financial matters.

Other help

The CarersLine can advise on support from sources besides the State. Much of this is available regardless of eligibility for the carer's allowance. Some areas have carers' centres, most of which are independent charities and members of the Princess Royal Trust for Carers. These offer advice on getting financial and other help, plus free social activities. The Carers Centre for Brighton & Hove, for example, offers women's swimming groups and play days for young carers aged 8 to 12, among other events.

Another charity, Crossroads: Caring for Carers, sends trained support workers into homes to give carers time for themselves — to see friends, keep appointments or simply to sleep. Carers interested in requesting this sort of help should visit www.crossroads.org.uk for details of their local scheme.

Support is available from charities linked to conditions, too. The Parkinson's Disease Society and Multiple Sclerosis Society help carers as well as those with the diseases.

Companies may also offer help. Lloyds Pharmacy, for example, has teamed up with Carers UK to offer free health checks in Carers' Week (June 8-14). See the charity's website for further details and email charity@lloydspharmacy.co.uk to request a voucher.

Meanwhile, Saga's Carers Trust offers about 100 free respite holidays a year to carers aged over 50. People can nominate themselves or someone they know at Saga.co.uk or by requesting a form on 01303 774421. Winners receive a break of their choice from Saga Holidays for themselves and a friend, plus spending money. The trust pays for the person cared for to be looked after by professionals or relatives, as he or she prefers.

In the pipeline

The Government's new Caring with Confidence initiative is introducing free group advice sessions for carers with local providers, such as charities and local authorities. These include a session on caring and resources, outlining the financial help available.

Diane Roskell, of Caring with Confidence, says that sessions are starting over the next few weeks in areas where provision for carers is most lacking. These locations are not yet listed at caringwithconfidence.net, so call 0800 8492349 for details. The website does, however, offer online study sessions for carers and you can order a series of free self-study workbooks on 01223 400393.

Case study

Kay O'Shaugnessy, of Plymouth, gave up running her own catering business to care full-time for her disabled 11-year-old daughter, Amy, who has cerebral palsy.

The 51-year-old says: "We went from a good income to nothing. The carer's allowance works out at less than £2 an hour for a role that is physically and mentally punishing.

Mrs O'Shaugnessy had to push hard to receive three to four hours of weekly respite care from her local authority and adds: "It is hard to go to social services because you feel a huge burden of guilt, but it's the only way to get help from your local authority."

She advises carers to contact other local carers through charities such as Carers UK. "You find out much more from other carers than you ever will through professionals," she says.

Eligibility for benefits

The carer's allowance is available only to those who care for people who receive certain qualifying benefits — most often the attendance allowance or the disability living allowance (at the middle or highest rate for personal care).

The attendance allowance is a non-means-tested benefit for people aged 65 or over who need help with personal care because they are physically or mentally disabled. It is paid at higher and lower rates of £70.35 and £47.10 a week, depending on the extent of the disability. In a minority of cases, a medical examination is required before the allowance is paid.

The disability living allowance (DLA) is a non-means-tested benefit for children and adults aged under 65 who need help with personal care or have walking difficulties because they are physically or mentally disabled. It is paid in separate care and mobility components — each paid at different rates, starting at £18.65 a week, depending on the severity of disability. People can claim the DLA whether or not they work. Again, a medical check may be required.

Disabled people may also be entitled to a reduction in council tax. The rules are complicated, so it is best to contact your local authority or Citizens' Advice Bureau for help. You can locate your local bureau at www.citizensadvice.org.uk.

Those who do not live with carers and are at risk of going into residential care may be able to claim money from the Independent Living Fund. Go to www.ilf.org.uk.

Visit Direct.gov.uk, the government website, or call the Benefits Advice Line free on 0800 882200 for information on all benefits. Many disabled people and their carers are eligible for income-related benefits besides those for the condition.

Woman with MS climbing Mount Everest

A 52-year-old northern Wisconsin woman with multiple sclerosis is just days away from reaching the summit of Mount Everest, the world's tallest peak, fulfilling her dream of reaching the highest point on each of Earth's seven continents.

Lori Schneider, of Bayfield, is one of several climbers closing in on the 29,035-foot peak on the border between Nepal and Tibet, according to her online updates.

The blog lays out a schedule that has Schneider and the others reaching the summit on Saturday, four days before World MS Day.

She began her seven-peak pursuit in 1993, climbing Mount Kilimanjaro in Tanzania with her father, reaching the summit on his 61st birthday.

However, six years later at age 43, while training for Mount Aconcagua, in Argentina, her body began to go numb, and her multiple sclerosis was diagnosed.

She quit her teaching career in Colorado, ended a 22-year marriage, moved to Wisconsin (she's a Janesville, Wis., native) and "felt the panic of needing to complete my chosen task while I was still in control of my physical body," she wrote online.

Now, all that is left is Everest.

"My biggest reward through all of this has been learning about overcoming fear and limitations, and sharing this lesson with others," she wrote. "Life is too short not to go for the gusto when you are given the opportunity. I hope that all of your dreams come true as well."

To follow Schneider, visit www.alpineascents.com/Everest-cybercast.asp.

MS women aiming to do Hadrians Wall challenge on Mobility Scooters

The team - Jackie Weeden, Caroul Coulson, Marlene Fell, Maggie Dossetter, Kate Davies, Lin Holman, Sue Cook and Rosemary Hobbs, all from Kent - are travelling on Quingo Sport mobility scooters.

Their journey began at Wallsend, travelling through Hexham and Brampton before passing through Rickerby Park in Carlisle and embarking on the last leg of their journey, which ends in Bowness-on-Solway.

The women hope that if successful their experience could encourage other people to follow in their tracks.

Jackie Weeden, Red Wheelie team leader, said: "We are doing all this to show that MS is not necessarily the end but can be the start of something different."

"We're sure there will be many laughs along the way and perhaps a few tears, but one of the things we will definitely have is fun - and lots of it."

To find out more and to make a donation, visit [the Red Wheelies website](#)

Disclaimer

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

MS patient: The search for 'a cure'

Linda Oatley, who has multiple sclerosis, agreed to film undercover at a treatment clinic in the Dominican Republic for Panorama's Stem Cells and Miracles. Ms Oatley - who had no intention of having the untested, unproven treatment - talks about her illness, the emotions at play and the experience of meeting a doctor who says he can fix her.

“My symptoms began in 1998 with legs that felt hot when they should be cold and cold when they should have been hot. I didn't think much about it but at some point, quite a while later, I went to a chiropractor and on to a physiotherapist. I self-diagnosed myself as having a trapped nerve of some sort.

It was the physiotherapist who first mentioned that it might be neurological. From there it was to the GP for a referral to a neurologist and then a MRI before I was told that it was MS.

I honestly, really didn't think about it. By this time my symptoms had disappeared and when you feel well you feel well. I didn't do anything about it, lifestyle or diet wise at all, nothing changed for me.

I was a motorbike rider back then and I just did more motorbike riding to prove that I could.

I was in denial, but then I had no symptoms, so it was easy enough to do.

The turning point came a couple of years later, in 2001, when I tripped at work. I looked down to see what I had tripped over and there was nothing there. I knew then what was happening, I knew it had come back.

Over the next 12 or 13 weeks I got very bad, that was when I was at the bottom. I couldn't lift my arms, my legs went weak, I couldn't write, I could barely make the stairs. I also had some optical problems, my left eye had 'fluttery' muscle spasms and it was tender to the touch. It was horrendous how quickly I became so ill.

Coming to terms

But it was the mental side that was so much more traumatic and I thought I was going to die. I was not unaware of what MS was on an intellectual level, but I was scaring myself to death on one hand as I tried, on the other hand, to come to terms intellectually with what was happening. This is why I can appreciate what people chasing stem cell cures are doing. At one point there, during those weeks and months, I would have done anything and gone anywhere for the cure. That's the key.

Back then - and it wasn't that long ago - there was less talk of stem cells, we were just waiting for the drugs that were being tested.

I was aware at the time of a DMD - disease modifying drug - that had just been licensed in the UK. I was already going into remission when I got my hands on the drug.

My condition plateaued, as it can do, with neither rhyme or reason and I started to get better. I went into remission, leaving me with a heavy limp on the right side and a weaker right side. I'm right-handed so my handwriting is horrible, particularly if I'm very tired. But from the outside I appear quite healthy, but I've got this residual damage. I've been stable for seven years.

As to how people can buy into some of the 'new therapies' being offered abroad, I would say that the brain is a very powerful instrument and it can make you believe in things.

Of the people I know through the neuro-physiotherapy clinic where I am a trustee, there is one young woman with MS who I know has spent £13,000 to travel to Europe for stem cell treatment. It was useless, there is no change at all, if anything she has probably gotten marginally worse. But she is in an electric wheelchair, she is a young woman and she can only even operate it some of the time. I don't think I could have been the one to say 'Don't do it'.

I also know a young man of 34 who has very jerky movements and his speech is quite blurry, he is wheelchair-bound and needs three physiotherapists to help him stand. Every week, he asks me, 'Linda, when are we getting these stem cells? Where are they?'

I know if he could afford it, he would travel abroad for treatment.

I tell him it could be five years or maybe 10, I really don't know. I say the same stuff to him every week, but he's young, he's got to wait, it will, hopefully be there for him in a legitimate way, some day very soon.

'It was hideous'

Where I went as part of the Panorama programme, the Medra clinic in the Dominican Republic, there were no children that I saw, only adults.

I knew that I wasn't in the Dominican Republic to have this stem cell treatment, that I would not be having anything injected into me.

I do imagine that if you didn't know anything about this guy - this Dr Rader - that you'd be reassured by him.

Here he was, seeking to reassure me as I said I was a very nervous patient. I said I needed a little more time to think about it and he was saying, 'Linda, you've got to have this injection.'

This was akin to foot-in-the-door double glazing salesman tactics, it was hideous. He was saying, basically, 'Let me, the clever doctor who knows better than you, decide what's best here.'

There is this intimidation factor around doctors and people like Rader play on that. Why would you not believe him? He's standing there and saying 'I've treated 1,000 or 1,500 patients, 40 with MS and I've seen spectacular results so don't worry, just trust me.'

But I knew more about him than most would, I knew of his previous incarnation on TV and that he is qualified as a psychiatrist. I knew he was a qualified doctor, but not in any sort of discipline around neurology.

Naked greed

Filming secretly for Panorama was a bit of a worry because we didn't know how carefully they were watching us, we were a bit nervous, wondering if they had cameras on us while we waited, if they were suspicious of us. But inside all we saw was naked greed - greed and a conveyor belt of people with various neurological diseases.

I saw one man with what I think was probably cerebral palsy, a lady with MS and two other women inside this large room in the beautiful Spanish style villa in a gated setting overlooking the ocean.

Those two women were sitting at a table counting out what looked like travellers' cheques. That alone was four money-taking opportunities at \$30,000 each.

I doubt that the term I have for someone like Dr Rader can be printed.

www.mstrust.org.uk 19 May 2009

Reaction to Panorama on Stem Cell treatments

The BBC's Panorama programme on 18 May followed a person with MS and a BBC reporter as they travelled to a clinic run by an American doctor in the Dominican Republic that makes bold and unfounded claims for the treatments that it sells.

The programme also includes comment by a number of prominent researchers into stem cells, including Professor Neil Scolding, MS Trust Trustee. The doctors contrast the claims of clinics such as the one shown with the state of reliable research into stem cells as a potential treatment for MS.

Pam Macfarlane, chief executive of the MS Trust, said, "People with a long-term condition such as MS are vulnerable to cynical charlatans who can exploit their hope for a treatment to cure their condition. We would urge anyone considering paying for stem cell treatment to think very carefully - what do you know about the people providing the treatment; or the source of the stem cells; how do you know what you're being injected with; what do they know about you and your MS; what kind of follow up will you have and what are the possible side effects which you and your doctors in the UK would need to be aware of?"

"The MS Trust recognises the desperation with which some people with MS may be seeking help and hope but be aware - these are unproven treatments and some people are making a lot of money out of peddling false hopes."

If the MS Trust can help and you would like to talk to one of our Information Team about these treatments or anything else to do with MS, please call 01462 476700 9am-5pm or email infoteam@mstrust.org.uk.

www.mstrust.org.uk 06 May 2009

Improving services for people with long-term conditions in the East of England

Do you live in the East of England and have a long-term condition?

Would you be interested in helping to improve services for people with long-term conditions?

If you answered 'Yes' to both these questions NHS East of England would like your help to make a difference to the lives of others living with long-term conditions in our region.

The NHS in the East of England is committed to deliver a series of pledges to improve the health of its local population and have established a number of Programme Boards to set out plans to transform services. Pledge seven says: "We will improve the lives of those with long term conditions." To support this we are setting up The Long Term Conditions Service User Group. The main objectives of the group are to:

- inform, influence and shape the planning, delivery and evaluation of the work of the Long Term Conditions Programme Board
- advise the Programme Board on good practice
- work with the Board in communicating the work of the Board to the general population and specific communities throughout East of England

We need 20 people with personal experience of a variety of long-term conditions, either as someone living with a long-term condition or as a carer of a person with a long-term condition. We also need to ensure members of the group are drawn from all parts of our region, all age ranges and communities.

As a member of the group you will need to be willing to attend a meeting every two months. You will need to be comfortable speaking to others with long-term conditions to find out their views and convey these to the Programme Board. In addition to this you may be required to contribute by phone or email and you may be invited to attend workshop sessions. Travel expenses will be reimbursed.

If you are interested in joining the group please contact [Jane Ross](#) or ring 01223 597589 for an application pack. If you would like to find out more please contact [Heather Ballard](#) / 01223 597668 or [Douglas Smallwood](#) / 02074241100.

We look forward to hearing from you

Closing date for applications is **Friday 29 May 2009**.

YOUR JOKES

KIDS IN CHURCH

3 YEAR OLD Reese

'Our Father who does art in heaven
Harold is his name....Amen

After the christening of his baby brother in church, Jason sobbed all the way home in the back seat of the car. His father asked him three times what was wrong...Finally, the boy replied, "That preacher said he wanted us brought up in a Christian home, and I wanted to stay with you guys."

One particular four-year-old prayed:
"And forgive us our trash baskets
as we forgive those who put trash in
our baskets."

A Sunday school teacher asked her children as they were on the way to church service, "And why is it necessary to be quiet in church?"

One bright little girl replied:
"Because people are sleeping."

A mother was preparing pancakes for her sons, Kevin 5, and Ryan 3. The boys began to argue over who would get the first pancake.

Their mother saw the opportunity for a moral lesson. "If Jesus were sitting here, He would say, "Let my brother have the first pancake, I can wait.'"

Kevin turned to his younger brother and said, "Ryan, you be Jesus!"

A father was at the beach with his children when the four-year-old son ran up to him, grabbed his hand, and led him to the shore where a seagull lay dead in the sand. 'Daddy, what happened to him?' the son asked. 'He died and went to Heaven,' the Dad replied. The boy thought a moment and then said, 'Did God throw him back down?'

A little boy was overheard praying:
"Lord, if you can't make me a better boy,
don't worry about it. I'm having a real
good time like I am.."

A woman invited some people to dinner. At the table, she turned to her six year-old daughter and said, 'Would you like to say the blessing?' 'I wouldn't know what to say,' the girl replied. 'Just say what you hear Mommy say,' the wife answered. The daughter bowed her head and said, 'Lord, why on earth did I invite all these people to dinner?'

Out of the mouths of Babes

TEACHER: Maria, go to the map and find North America.

MARIA: Here it is.

TEACHER: Correct. Now class, who discovered America?

CLASS: Maria.

TEACHER: John, why are you doing your math multiplication on the floor?

JOHN: You told me to do it without using tables.

TEACHER: Glenn, how do you spell 'crocodile?'

GLENN: K-R-O-K-O-D-I-A-L'

TEACHER: No, that's wrong

GLENN: Maybe it is wrong, but you asked me how I spell it.

TEACHER: Donald, what is the chemical formula for water?

DONALD: H I J K L M N O.

TEACHER: What are you talking about?

DONALD: Yesterday you said it's H to O.

TEACHER: Winnie, name one important thing we have today that we didn't ten years ago.

WINNIE: Me!

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!

- 1/ Ewan McGregor played who in the film Rogue Trader?
- 2/ What is the term for the water induction process in plants?
- 3/ Who married Gaynor Regan in 1998?
- 4/ If you had the strand and Fleet Street in Monopoly, what would you need to complete the set?
- 5/ Who provided the voice for Woody in the film Toy Story?
- 6/ On which island would you find 838 stone monoliths?
- 7/ Which alternative form, of treatment involves massaging the soles of the feet?
- 8/ The flag of which country is not rectangular?

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/ Derbyshire 2/ Orange 3/ Richard Nixon 4/ Metatarsals 5/ Amethyst 6/ Nina 7/ Sturgeon
8/ Taurus 9/ Owl 10/ Wilson (Harold) 11/ Naseby