



# new Pathways

September/October 2007

Your MS magazine of choice

Issue 45



**Ayurveda  
Made Me Feel  
Well Again**



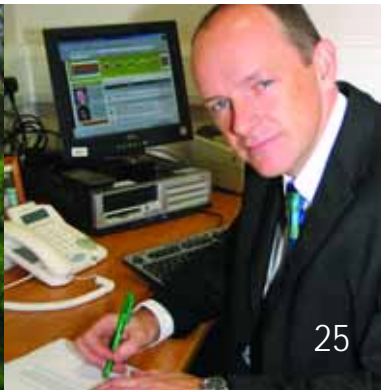
**The Power  
Of Pets**



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email: [info@msrc.co.uk](mailto:info@msrc.co.uk) Website: [www.msrc.co.uk](http://www.msrc.co.uk)

The MS 24 Hour Telephone Counselling Service: 0800 783 0518 & press 1





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## Dear New Pathways Readers

Every so often, we have a clash with a neurologist who thinks we are irresponsible to publish 'unfounded' claims for an MS treatment. This issue, that clash is over the Esperanza Homeopathic Neuropeptide treatment.

The neurologist in question, Dr Julian Furby from the Institute of Neurology, thinks it can't possibly work. Yet I hear of many MS cases where they say it does work (as well as some who say it doesn't). Who should I listen to? I think I should listen to all of them.

It's true that Esperanza has not been through double-blind placebo-controlled trials and that all the 'evidence' is anecdotal. Scientists are trained to dismiss anecdotal evidence. But I am more than happy to listen to it. Indeed, most of the articles in New Pathways are 'anecdotal evidence.'

It is interesting how often turning to alternative therapies can help MS more than orthodox drug treatment, although we are happy for those who benefit from drugs.

Cathy Macbeth didn't get much joy from her neurologist but found great success with the ancient Indian health system, Ayurveda. She writes about what it did for her on page 20.

Scottish actress and director Alison Peebles has more energy and less fatigue since changing her diet, taking many supplements, and doing exercise, hypnotherapy and hippotherapy (horse-riding). She writes about how she fights MS on page 26.

On page 25, Dr Tom Gilhooly, Alison's doctor, writes about the importance of testing the Vitamin D levels of children who have a parent with MS. We agree with Dr Gilhooly that there should be national screening for this.

Frequently, the things that most improve daily life when you have MS are practical – like computers and special software so you can dictate rather than type. For Gillian Seaney and Mary West, computers and voice-activated software like Dragon NaturallySpeaking have opened up their lives to a new and exciting world. Read what they say on page 30.

Sometimes the things that help improve quality of life come with four legs and a furry coat. I'd heard before how animals can bring joy to the life of someone with MS, but until Napo, my little Cavalier King Charles Spaniel, bounded into my life, I had no idea just how

much. You can read all about it on page 34.

Amanda Palmer started looking after her mother when she was just seven years old, and on page 44 we highlight the plight of young carers like her who, we believe, should not be taking on such a big responsibility which takes away their childhoods.

In this issue we've also got our usual interesting mix – a light-hearted short story, a travel article that will make you want to visit Amsterdam, a particularly delicious roast chicken recipe, plenty of News and Postbag, Bits n' Pieces, and also a Competition to win a pair of Hotter shoes (page 28).

Wishing you happy reading,  
Best Wishes,  
Judy Graham



Judy Graham

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**Pathways**

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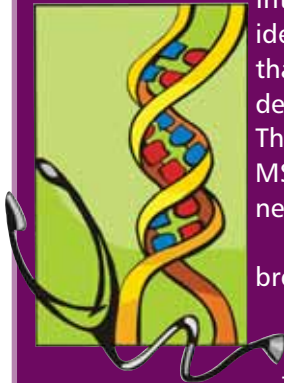
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Cover picture by Samuel Long

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## Genetic Link Breakthrough



International scientists have identified two genetic variants that each raises someone's risk of developing MS by around 30%. This sheds light on the origins of MS and could lead to developing new treatments.

It is the first major genetic breakthrough in MS since the 1970s and only became possible with the mapping of the human genome.

The major study on genes and MS, done by scientists from Cambridge University and the US, was published in the *New England Journal of Medicine*.

The analysis of DNA samples from more than 20,000 MS patients and healthy individuals pinpointed two genes on a chromosome that had not been previously connected with the disease.

The newly-identified genes are involved in

managing the activity of T-cells, the infantry of the immune system. These cells can mistakenly attack healthy tissue to cause auto-immune conditions.

Before this study, the only variant of a gene connected with a raised risk of getting MS was HLA-DRB1, which makes the body worse at recognising its own tissue. The new variants affect a different part of the immune system.

Both gene variants, IL-2RA and IL-7RA, control receptors that T-cells use to find their targets. They are likely to become the focus of MS research for new drugs to control MS.

Although MS has a significant heritable element, just because someone has these gene variants does not mean they will get MS. The vast majority of people who have them are healthy. Other environmental factors need to be at work too.

*Ref: New England Journal of Medicine, July 29th 2007.*

[www.nejm.org](http://www.nejm.org) July 29, 2007  
(10.1056/NEJMoa073493)

## Sativex Neuropathic Pain Phase III Trial Ready to Start

All patients have now been recruited for the pivotal Phase III trial for neuropathic pain in MS. The trial will be a double-blind, randomised, placebo-controlled study of Sativex in MS patients who have not achieved adequate pain relief with existing therapies.

Neuropathic pain is caused by damage to or dysfunction of the nervous system. It is usually chronic and accompanied by unpleasant burning or shooting sensations, or extreme sensitivity to touch. It is estimated that central neuropathic pain (pain

initiated or caused by damage to the central nervous system, i.e. brain or spinal cord) occurs in up to 52% of people with MS. Up to 32% of patients with MS regard pain among their most severe symptoms, describing it as frequent, disabling and inadequately managed.



The study has recruited 339 patients in the UK, Canada, France, Spain and the Czech Republic

and is GW Pharma's largest clinical trial to date. Results are expected in 2008.

GW Pharma, who make Sativex, has previously carried out a similar pivotal Phase III study with positive results. This study, which was published in the peer-reviewed journal, *Neurology*, showed that Sativex was significantly superior to placebo in reducing pain and sleep disturbance. Sativex is already approved in Canada for the symptomatic relief of neuropathic pain in MS and in cancer pain.

*Source: GW Pharmaceuticals Press Release, August 2007.*

## Early Beta-Interferon Delays Onset of MS



Beta-interferon given to patients at the very first event suggestive of MS delays the conversion to clinically definite MS, according to an international three – year study known as BENEFIT.

After 3 years, 37% patients in the early treatment group

developed clinically definite MS, compared with 51% patients in the delayed treatment group. Early treatment reduced the risk of conversion to clinically

definite MS by 41% compared with delayed treatment.

Over 3 years, 16% of patients in the early treatment group and 24% in the delayed group had confirmed progression as measured by a disability scale. Early treatment reduced the risk for progression of disability by 40% compared with delayed treatment

The authors say that the findings suggest that early treatment with interferon beta-1b prevents the development of confirmed disability.

In patients with relapsing-remitting MS, interferon beta-1b has previously been shown to have a profound effect on the development of new inflammatory lesions.

*Ref: The Lancet 2007; 370:389-397*

## Benefit of Early Treatment With Beta-Interferon “Modest.”

The benefits of early treatment with beta-interferon are ‘modest’, says Dr Sean J Pittock in *The Lancet*.

“The BENEFIT and other studies have shown that treatment with interferon beta reduced the rate of

conversion to clinically definite multiple sclerosis.

The benefits, however, were modest. Whether delaying the second attack has any long-term effect on disability remains unclear.”

*Ref: The Lancet 2007; 370.*

## MS Vaccine ‘Slows Rate of Nerve Cell Damage’

A vaccine that slows the progression of MS has been developed. Preliminary research suggests the vaccine reduces the damage done by immune cells on the myelin sheath.

Dr Amit Bar-Or and colleagues of the Montreal Neurology Institute developed a vaccine called BHT-3009 and tested it on 30 patients. Half received injections of the vaccine and the other half were given a placebo.

MRI scans were carried out to evaluate the vaccine’s safety and its effect on the immune system. The type of white blood cell known to

target myelin appeared to be reduced in the blood and spinal fluid of those who had the vaccine.

Writing in the *Archives of Neurology*, Dr Bar-Or said: “BHT-3009 was safe and well tolerated, provided favourable trends on brain MRI and produced beneficial immune changes.”

The vaccine – the first that appears to slow MS progression – works by inserting DNA into the body to provoke an immune system reaction.

A larger trial of the vaccine in 290 MS patients has already begun.

*Ref: Archives of Neurology online August 13, 2007.*

## Children Need Sunshine To Help Prevent MS

Children who spend more time in the sun may be less likely to develop MS when they grow up.

Scientists in California studied 70 pairs of identical twins – one of whom had MS and the other who did not.

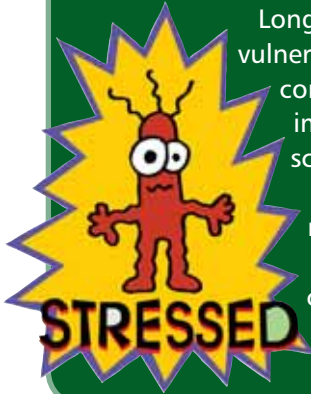
When they analysed their childhood exposure to the sun’s rays, they found that those who spent

more time outdoors were up to 40% less likely to develop MS later in life.

The findings, published in the journal *Neurology*, support earlier evidence that sunshine may help prevent MS by stimulating production of Vitamin D.

*Source: Daily Mail Tuesday July 31st, 2007.*

## Chronic Stress 'Destroys The Immune System'



Long-term stress increases vulnerability to MS and other conditions by weakening the immune system, American scientists have found.

The research, carried out on mice, also found that the physiological effects of stress could be reduced by medication, a diet rich in oily fish, and exercise.

The team increased the stress on a group of mice by introducing an older, more aggressive male mouse. When the mice were infected with a virus that attacks the nervous system, the ones who had been more exposed to social stress became sicker. The research was presented at the American Psychological Association Convention in San Francisco.

*Ref: American Psychological Association Convention August 18, 2007.*

*Source: Daily Telegraph, August 18, 2007.*

## The One-Minute Wonder Diagnostic Test

Scientists are developing a 60 second test for common brain diseases including MS and Alzheimer's.

The test involves a scanning technique called magneto-encephalography, which analyses tiny magnetic fields produced by neuron activity in the brain. The scan is non-invasive and lasts 45-60 seconds.

Scientists used the test to compare the patterns of magnetic charges in healthy brains with those with diseases such as MS.

Writing in the Institute of Physics' Journal of

Neural Engineering, the scientists say they discovered many of the patterns they predicted matched up to the disease being tested for which led to a correct diagnosis in more than 90% of subjects.

At the moment, there is no simple test to diagnose MS. But a simple imaging test such as this could mean it was diagnosed much earlier, giving an opportunity for earlier treatment.

*Source: Daily Mail, Thursday August 23, 2007.*

## Tysabri to Get NHS Funding

Patients with the rapidly-disabling form of MS will now be able to get Tysabri on the NHS. There are around 3,000 such patients in the UK.

It was approved by the National Institute for Health & Clinical Excellence in August.

Tysabri has been shown to cut relapses by 68% and reduce the risk of disability progression by 54%.

It works by stopping immune cells from attacking the nervous system.

Made by Irish drug company Elan, Tysabri costs the NHS around -£12,000 per year per patient. It is given intravenously each month.

*Source: Daily Mail Wed Aug 22, 2007*

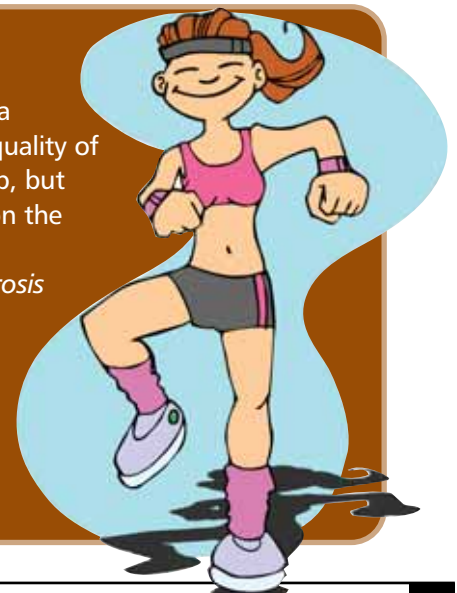
## Exercise Good For MS

Brief, moderate, aerobic and strength exercise is good for MS, says a new study.

A randomised control study was done in Iceland to find out the effect of aerobic and strength exercise on physical fitness and quality of life in patients with mild MS. Sixteen individuals aged 18-50 with definite MS who measured below 4 on the EDSS disability scale completed the study. After being evaluated for fitness, the patients were then randomised to an exercise group, or a control group. Those in the exercise group exercised three times a week for five weeks. The control group made no changes to their exercise

habits. Results showed a tendency to improved quality of life in the exercise group, but exercise had no effect on the degree of disability.

*Source: Multiple Sclerosis 2007; 13: 776-782 (05/09/07)*



# Postbag Your Letters

Do you have something to say or helpful information to pass on? Whether it's gripes and groans, a pat on the back, or hints and tips, we'd love to hear from you. Please write to: Judy Graham, Editor, New Pathways, MSRC, 7 Peartree Business Centre, Peartree Road, Stanway, Colchester, Essex CO3 0JN  
Tel: 0800 783 0518 or 01206 505444 Fax: 01206 505449 e-mail: info@msrc.co.uk

## Fashion – What If You're Small Like Me?

Dear New Pathways,

I thought your fashion feature in New Pathways issue 44 was good, but those of us who are small, 5ft, size 8-10, and youngish dressers, the catalogues mentioned mostly only go down to size 12.



Additions Direct: [www.additionsdirect.co.uk](http://www.additionsdirect.co.uk) have a younger fashion appeal and also deliver and take returns. Clarks do good 'stay on your feet' shoes and sandals that are low or flat. Front fastening bras PLEASE make a comeback!!

**Sue Mills,  
Southend on Sea**

## Appalling Grammar!

Dear New Pathways,

I am mortified that my article re Carnegie Hall in Issue 44 was printed with grammatical errors made during the editing.

If you read the article it reads 'Me David and Julia' where as I wrote 'David Julia and I went...'etc

I received a call from a friend about the article, a former fellow teacher who picked up on this error. I am dreadfully embarrassed about it as people will assume I made the error when it was written so I'm forced

to print off copies for people to prove that the error was made during the editing.

I would be grateful if you would write an apology for this error in the next mag so that everyone will know it was correctly written on my original article.

**Yours,  
Jenny Kewell,  
West Sussex**

*\* Ed replies: Dear Jenny, Yes – you are right! The grammar was wrong. I am the one to blame and offer you my sincere apologies. Bang goes my reputation for being a stickler for accuracy, spelling and grammar!*

## Scandalous That "Miraculous" Sativex Being Blocked

Dear New Pathways,

How much longer is this medicine going to be blocked by the review bodies when it is proven to be highly effective in most cases for neuropathic pain?

My wife managed to get trial phials last year and found it miraculous, with no side effects, unlike the current medical ineffective "poison" painkillers.

The current decision by the MHRA against GW Pharma is nothing short of scandalous and political posturing at the expense of long-suffering patients.



If Gordon Brown's wife got severe MS it would be available very quickly! The sheer hypocrisy is quite breathtaking and a lobby should be set up to have this decision rescinded!

**Yours in anger,  
Mr and Mrs D. Stuart,  
Aberdeen, Scotland**

## Suprapubic Op & Colostomy Solved Toilet Problems

Dear New Pathways,

Like Charlie Gee, I struggled for years and found that toileting ruled my life. Any time I left my home I would immediately be concerned about where the nearest toilet was.

Gradually, as my MS progressively reduced my standing ability, I gave up intermittent catheterising and had a suprapubic catheter fitted. Brilliant!

When my bladder was still able to hold about 500 ml and I was near a loo, I just used a flipflo valve to empty. But gradually I became unable to hold as much, so now wear a leg bag. With wide-legged trousers, that works fine for me.

Which only left the bowel situation! That became so distressing and disgusting, it completely domineered my every thought. I decided a year ago to have a colostomy and now my life is transformed.

I simply do not understand why more people, in my similar wheelchair-bound situation, do not elect for this simple, painless, independent 'life-giving qualities' operation.

The stoma support nurse I was given was superb, my surgeon was superb, and everything went so well. I never now give toileting another thought. I always leave home with a spare stoma bag but hardly ever have to change it if only out for a day.

I have had several long weekends away and visited New York recently for a week with a girlfriend. No way could I have considered any of these without my own 'extra plumbing.'

**Regards,  
Susan Olney**

## Solo Toilet Lift Worked For Me

Dear New Pathways,

I had a similar problem to Charlie Gee's. I contacted my social worker and she organised a "Solo Toilet Lift" demonstration for me and I was fortunate to have one delivered within 2 weeks. This has enabled me to remain independent and I would thoroughly recommend it; I couldn't manage without it: [www.mountway.com](http://www.mountway.com). – solo toilet lift

Hope this is of use and wish Charlie good luck.

**Best wishes,  
Lesley Levine**

## Carers: Income Is No 1 Priority

Dear New Pathways,

Your magazine is the "tops"; the best document anywhere for the latest information on MS. I was also pleased that you put in an article concerning carers. The idea of improving the National Carers Strategy is long overdue. Carers are treated abominably by the Government.

The survey mentioned in your article is important because it can influence the lives of carers via the Strategy for the next ten years. The last ten years have been a disgrace because Blair's priority was to keep benefits for carers very low, restricted tightly and to ensure that anyone who had to leave work to care full time would suffer greatly financially.

The Carers UK leaflet, 'Short Changed', highlights the poverty carers suffer, especially the insultingly low Carers Allowance of £48 per week (taxable).

So it is very odd that in the document from Carers UK 'Our Caring Future' it lists 'Recognition From Professionals' as the No 1 priority of carers. This is incredible and

unbelievable! Amazingly, income is only given third place!

This result is because the responses from carers regarding income have been divided between those under and over 65 years of age. If you look at those under 65, income IS the number one priority!

Could it be that in order to get Gordon Brown's backing that Carers UK had to make sure that Income is not the highest priority for Carers? Is it to give the Government a good excuse not to improve the financial standing of individual carers?

Carers UK is supposed to be an independent charity dedicated to further the cause of carers. It receives public money and significant tax relief. It should be representing the wishes of carers fully and accurately. Carers do not want to be part of a political propaganda campaign in order to make politicians look good.

It must be obvious to anyone, even ministers, that carers are shoddily treated and that their financial needs have been ignored disgracefully for years.

If Ministers or leading officials of Carers UK were paid £48 per week they would not be asking for more recognition of their worth, they would be demanding a decent income. That's what carers want too!

**Yours sincerely  
Roger Fownes,  
Bromsgrove, Worcs.**

## Hyperbaric Oxygen & Physiotherapy Sadly Missed During Floods

Dear New Pathways,

I am a patient of the West Yorkshire MS Therapy Centre in Horsforth, Leeds. The centre was badly hit by the recent floods and was closed for 5 weeks for repairs due to the huge water damage.

It is a very busy and successful centre giving Hyperbaric Oxygen and Physiotherapy, plus other services, not to mention support, fundraising and social contact for people who perhaps do not



have much opportunity for chatting over tea and biscuits.

The fact that we were unable to have the oxygen for 5 weeks at a stretch has made us realise just how much this treatment means to our wellbeing. Almost everyone has felt less well and noticed their MS symptoms seemed worse.

In my own case, my legs became stiff and both my legs and arms became heavy; my mind seemed to slow down and I felt depressed and lethargic. Also, bladder control was not so good and my balance was terrible.

When people ask what the oxygen does for us it's hard to explain but we are all clear about the benefits now. When I was diagnosed, the doctors I saw were really quite dismissive of the treatment, but I was very fortunate to know the lady who ran the centre at that time and she said it would do no harm to try, so I went along and have had treatment now for 20 years.

This together with yoga classes for 35 years and learning meditation, which I find restores my energy, have helped to keep my MS at bay and to cope better with everyday life.

It is good to feel that out of the flood disaster it has proved how much good the HB oxygen has done for us all and I hope that other people will give it a try.

In closing, may I say how much we appreciate the work of the staff and helpers in making these services available to us.

**Yours sincerely  
Pat Brown,  
Leeds**