

Warrington Branch

# MiScellany

January 2009

Happy New Year  
To all

&

Apologies

For

Delays with this Newsletter.

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Charles Harvey, 9 Aldridge Drive, Burtonwood, WA5 4NP. Tel no. 223418

Good afternoon, well that is the normal polite way to start a piece of writing off, but looking at the state of the world at the moment it does not make me feel too polite. The current thing on the news is the terrorist attack in Mumbai (Non PC version Bombay) the terrorist problem is all over the world isn't it, and you don't seem to be safe anywhere.

In some respects (being completely selfish) it makes me happy to be, too poor to travel, but there again we have had a fair share of problems in this country haven't we, what with the IRA (Warrington, springs to mind) and more recently the London underground bombings (7/7). So I can not even be selfish, and stay comfortably at home, where is there that is safe in the world at the current time, if you know of a place let me know, but it needs to be not too costly to get to (and needs to speak English).

Even if you don't travel, we would all like to have a good pension, that gives us a comfortable income when we can no longer provide for ourselves, but with the way that the stock market and Banks are imploding and needing (and getting) multiple support/bailout's from the government there is not a lot of Money, left to be available and left

over for the likes of us, is there. Tied in with all of this is the recent announcement from our glorious leaders that Incapacity benefit is to be reformed, yet again, in an attempt to make the system "more responsive to peoples needs", I am not involved in the CAB at the moment but I am sure that these reforms will be causing severe worry to many legitimate claimants. I keep on hearing that these reforms are welcomed by the legitimate claimant but the funny thing is that you always see a non disabled person telling the world that people with disability actually welcome these reforms. In addition you never hear that the government are seeking to save some money. There is never an admission that there is a large amount of resentment about claimants of benefits and a wish to placate the "Daily Mail" (sorry if that is your paper of choice). The Number of times that I have seen those pictures of the Incapacity claiming Councillor, running down the touchline in a football match, always accompanying a piece about benefit fraud, must stretch in to the twenties. What you very rarely hear of is the opposite side of the coin where legitimate claimants go through month's of severe worry, attempting to obtain a decent level of benefit all the time being made to feel like a pariah within society,

What is worse is the number of people that are put off claiming at all for fear of becoming one of the so called “scrounging benefit claimants”.


How I ended up here I know not it must be a pet subject of mine and I must state that the views expressed here belong solely to the editor and are nothing to do with any other member of the society.

If you read on there will be some articles about the large world of MS so have a look through and see if any of them interest you. I have found a couple that caught my attention don't know whether that they will be included this edition but one of them was about the recent announcement that the cancer drug Alemtuzumab that apparently has a better impact on MS than Beta interferon, which if true would be a bonus but along side that I saw an article from the editor of, “Joolies joint” pleading for caution, with reference to this very drug, saying that she has seen a number of breakthroughs in the treatment of MS since she was diagnosed. What ever is included I am sure that you will have an informative read.

I hope that you all have a good Xmas meal in the Fir Grove Hotel as the hotel has recently had a facelift, since I was last there. Not that it needed one, but I am sure that it would make for a improved atmosphere for our annual gathering, anyway have a good time and do eat too much.

See you next time.  
Charles Harvey. Editor

**Support  
Your  
Branch  
Attend Functions**




**Exercise &  
Relaxation**

**Great Sankey Library  
Marina Drive**

**Tuesdays at 10.30am**

**Contact  
Mary Burke  
01925 824041  
For details**



# Christmas Cards

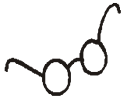
The list of people who gave donations instead of sending Christmas cards are as follows;

- John & Chris Tipping
- Liz & Roger
- Chris & Helen
- Jayne & Charles
- Pat & Peter Ordish
- Rita & Keith
- John & Mary
- Chris & Chris Askew
- Karen Daniels & her mum Viv
- Joy Carter
- Peter Travers

The donations received amounted to £85

MS Helpline Freephone  
0808 800 8000

## WANTED

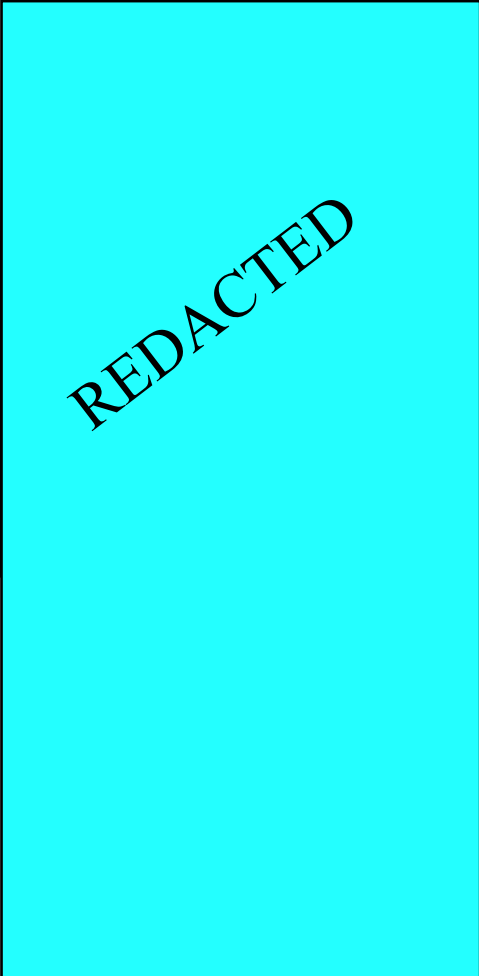


Spare Spectacles  
Contact Susan Atkinson  
Tel 727612

Used Postage Stamps  
Odd Balls of Wool  
Contact Susan Atkinson  
Tel. 727612



Our Congratulations to:-



Listening Ear - Margret Hughes - 01925 723917

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## Fundraising

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Hello again everyone, this newsletter seems to come around so quick.

I received a cheque from Stephanie Atherton for £400 this was raised from a combination of events.

Stockton Heath's Flag day was held in September, the weather managed to stay dry and although we had competition from another charity still we managed to raise £454.52. Thanks to all those who helped on the day and to Dorothy for organising the event.

In October Joan Henthorn kindly held another Quiz Night at St. Oswald's Club and raised over £700, luckily the team I was on did not come last this time. It was a lovely evening and for those of you who have never been to a Quiz evening before it is well worth attending. Thanks to Joan, her family and friends.

The Irish evening held at Alford Hall was once again well attended raised approximately £970. It was a different kind of evening. Again thanks to BT Skips for sponsoring the event. Next year we will probably revert back to the 60's & 70's theme as this is always so popular.

Our Flag Day in Birchwood Shopping Centre is on Friday/Saturday the 12 & 13<sup>th</sup> December. If anyone spare an hour on either day to help collect it would be most welcome. Please contact me on 01925 573980. The atmosphere is always lovely being especially so near to Christmas

I would also like to thank members of the Fundraising Team, Margaret Wilmot, Chris Askew, Rita Harrison and Peter Travers without their help and support my work would be so much harder. I must also thank Chris Janovitz who kindly provides all the tickets and posters for each event we hold.

I wish you all a lovely Xmas and Happy New Year and look forward to seeing many of you again next year.

Julie Richards

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[www.warringtonms.org.uk](http://www.warringtonms.org.uk)

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## Drug May Reverse MS Brain Damage

**A**lemtuzumab appears to stop progression of the disease in patients with early stage active relapsing-remitting MS - the most common form of the condition.

The University of Cambridge study, published in the *New England Journal of Medicine*, also suggests the drug may enable repair of previous damage.

However, it can produce potentially serious side-effects, they warn.

And the researchers stress their work is still at an early stage.

Alemtuzumab - a type of drug known as a monoclonal antibody - was created at Cambridge in the late 1970s, and has long been used to treat leukaemia by killing off the cancerous white cells of the immune system.

The latest three-year study, of 334 patients with relapsing-remitting MS which had yet to be treated, found that the drug cut the number of attacks of disease by 74% more than the reduction achieved by conventional interferon-beta therapy.

Alemtuzumab also reduced the risk of sustained accumulation of disability by 71% compared to beta-interferon. People on the trial who received the drug also recovered some function that had been thought

to be permanently lost, and as a result were less disabled after three years than at the beginning of the study.

In contrast, people given beta-interferon showed signs of progressively worsening disability.

This was confirmed by brain scans in which alemtuzumab patients showed signs that their brains had actually increased in size, while the beta-interferon patients' brains shrank over time.

The researchers said the findings suggested that alemtuzumab may allow damaged brain tissue to repair itself.

However, they stress that more work is needed to confirm the effects, before the drug can be considered for widespread NHS use.

Lead researcher Professor Alastair Compston said: "Alemtuzumab is the most promising experimental drug for the treatment of multiple sclerosis, and we are hopeful that the phase three trials will confirm that it can both stabilise and allow some recovery of what had previously been assumed to be irreversible disabilities."

Alemtuzumab works by destroying a type of white blood cell called a lymphocyte, which, in MS, plays a

key role in causing the damage associated with the disease.

Effectively, this shuts down the immune system, allowing it to re-boot without the original fault.

Dr Alasdair Coles, who also worked on the study, said: "The ability of an MS drug to promote brain repair is unprecedented.

"We are witnessing a drug which, if given early enough, might effectively stop the advancement of the disease and also restore lost function by promoting repair of the damaged brain tissue."

During the trial, 20% of patients treated with alemtuzumab developed either an under-active or over-active thyroid gland.

A small number developed a low platelet count, rendering them vulnerable to bleeding, and in one case this led to a fatality. However, the researchers stress this complication can be easily treated if recognised early.


Lee Dunster, head of research at the MS Society, said: "This is the first drug that has shown the potential to halt and even reverse the debilitating effects of MS and this news will rightly bring hope to people living with the condition day in, day out.

"More work is needed to prove the drug's long-term effectiveness and we are very much looking forward to the results of the next stage of this important research."

Professor Paul Matthews, of Imperial College, London, described the trial as "compelling".

However, he said: "Alemtuzumab was associated with severe adverse events in a small proportion of the patients, suggesting that it would be unsuitable for any patient except those with very aggressive forms of the disease."

Story from BBC NEWS:  
BBC News website health editor

Support  
Your  
  
Branch  
Attend Functions

Dave Hinde Travel Services  
  
**D.H.T.S.**  
Disabled Travel  
Service  
14 Seater Mini buses  
Tel. 01744 615851  
Mobile 07887 615040  
Parcel delivery service. Accounts

## 100+Club

There are 109 members if you're not one of them please consider joining contact Chris Janovitz on 723564. Remember the more people join the higher the prizes go don't delay.

5th November 2008

Members 108

Prize	Num	Name
1st	030	John Burke
2nd	105	Roger Williams
3rd	067	Jane Dolphin
4th	049	M Richardson
	044	J Wolowicz
	009	Charles Dooley
	079	Carol Little
	071	E Martin

7th December 2008

Members 108

Prize	Num	Name
1st	096	Carol Hill
2nd	057	Keith Maddocks
3rd	067	Jane Dolphin
4th	085	M Richards
	003	J Wolowicz
	076	John Paice
	056	G Atkinson
	066	W M Dooley

The amounts were £117.00, £65.00, £38.00 and 5 at £10 respectively

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Bill Hampson won Christmas bonus prize £117.00 number 054

### Forthcoming Events

4th February	Social Alford Hall 7.30pm
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4th March	AGM Alford Hall 7:30 p.m.
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1st April	Social Alford Hall 7.30pm
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Until further notice requests for transport  
For activity's telephone Mary Burke 824041  
For welfare telephone Dorothy Lewis 268820

## Activity & Social

**Pub Lunch** Friday January 9<sup>th</sup> if you are interested please contact Peter on 01925 492970

**Belle Vue Dog Racing** Tuesday January 20<sup>th</sup> if interested call Peter by 31<sup>st</sup> December on 01925 492970

**Lowry Theatre 'A game of two halves'** Thursday 12<sup>th</sup> February please contact Paul as soon as possible as the tickets are limited, ring Paul on 01606 892151

**Science Museum Manchester** Thursday 19<sup>th</sup> February 2009 if you are interested please call Margaret by 19<sup>th</sup> January on 01925 755017

**LA BOWL** 3<sup>rd</sup> March (or there about depending on the deal Rita can get) if interested please ring Rita on 01925 815873

**Pub Lunch** Thursday March 26<sup>th</sup> names please to Peter, ring him on 01925 492970

## MS Pill Shows Promising Results

Results released in December by pharmaceutical firm Novartis on the development of an oral pill for multiple sclerosis (MS) show that the drug can significantly reduce the number of relapses people experience compared to interferon beta-1a.

FTY720 (or Fingolimod) is an oral therapy that is currently being tested in a series of clinical trials as a potential treatment for relapsing-remitting MS.

The results released today were interim results from the TRANSFORMS study, a phase III or late stage clinical trial for people with relapsing remitting MS.

The pill is taken once a day and works by suppressing lymphocytes—a particular part of the immune system which is thought to be involved in causing damage to the central nervous system in people with multiple sclerosis.

MS Society Research Manager, Doug Brown, said: “An alternative to regular injections will be welcome relief for people living with MS.

“These results are very positive, and we look forward to the day when an effective and safe oral pill is available.”

## Julie Howell on Alemtuzumab

Responding to last week's story of a new cure for multiple sclerosis, Julie Howell, who runs online MS community Jooly's Joint, has learnt not to get too excited at the headlines. Here she gives a personal analysis.

I'm 37 and was diagnosed with MS aged 19. During my time as an 'MSer', there have been many positive news stories about treatments for MS. And yet, almost 20 years since my diagnosis, there is still no cure.

I was happy to read last week that scientists at Cambridge University have found evidence that Alemtuzumab - sometimes known by its commercial name Campath-1H - appears to slow - and in some cases reverse - the progress of MS. However, when it comes to a cure I'm not holding my breath.

MS is a long game. Not a death sentence, but a life sentence, best lived positively - and patiently - until a cure is found.

It is a complex condition categorised into four degrees of severity: benign, relapsing-remitting, secondary progressive and primary progressive. Only those with 'aggressive'

relapsing-remitting MS are reported to benefit from Alemtuzumab - a fact that can be difficult to accept if your type of MS is either 'too mild' or 'too severe'.

Once trials are complete and the treatment is licensed in the UK, only those who meet the prescription criteria (which will be set according to the drug's likely effectiveness) will be eligible for Alemtuzumab, and then its availability will likely depend on eligibility criteria set by the National Institute of Clinical Excellence (NICE), the medical body that decides whether a treatment should be available on the NHS.

Jooly's Joint members are, unsurprisingly, talking about the latest news on the drug.. 24-year-old R from Manchester was diagnosed with MS at 17 and is already jaded by news of new treatments for MS: "This is worthless so long as drugs are means-tested. Most of us aren't going to get Alemtuzumab."

R's cynicism is not without foundation. Despite government directives instructing NHS Trusts to prescribe licensed MS therapies to people who fit the prescribing criteria, the MS Society has reported that many people with MS have persistently and

incorrectly been told that they cannot receive them 'due to cost'.

It's a complex situation that must be communicated clearly and sensitively to people with MS. That the NHS itself seems confused about its own rules does nothing to ease the anxiety or confusion that many people with MS feel.

Another member, lets call her S, is a 41-year-old mother from Cambridge-shire. She's been on the Alemtuzumab trial since 2003: "Alemtuzumab has given me my life back", she says. "I now walk unaided and although I still get tired if I do too much, looking at me you wouldn't think I have MS. Since going on the Alemtuzumab trial I have passed my driving test and went back to work part-time."

The scientists believe that Alemtuzumab is a great leap forward in the treatment of MS, and I hope other people with MS will feel uplifted by S's experience. But for many of us, whose lives were shattered when we received our diagnosis, the wait continues.

by Julie Howell



———— Letter to the editor (at last) ————

**D**ear Editor

I agree that there should be Winter fuel payments to those who have MS and find it necessary to have the heating on all Winter. I on the other hand are one of the few MSers who are hot all the time, so consequently our Summer bills are the same as our Winter because we have to have fans and air conditioners going nearly all the time (I've just stopped using the bedroom fan). I do say to John that I'm saving him money, but no I'm not really because the Summer bills are as bad as the Winter.

I'm looking forward to the time when my body heat sensors start behaving.

Yours sincerely  
Mary Burke

## Membership News

I'm sorry that this newsletter is considerably later than it should have been i.e. first week December. This was mainly caused my having a recurring UTI that really exacerbated my MS which made functioning at the computer practically impossible. Fortunately I'm now back firing on all cylinders (well nearly). If we had another volunteer to help with the DTP of the newsletter this could have been avoided so anyone out there who feels they could help get in touch.

Since the last newsletter we have one new member [redacted] Widnes. Unfortunately [redacted]

[redacted] was attended by Dorothy on behalf of the branch. Our condolences to family and friends.

Apologies also to Ruth Green who sent an article for inclusion but now Christmas has passed it's not really suitable, I'll hang on to it until next Christmas.

You will have all received the new style membership form anybody having problems with the new process can contact Peter Travers telephone 492970 for assistance.

Also a soon to be member of our Branch, Mandy Glover, is in the process of fundraising, by going on a sponsored slim. Any Money that she raises is to come to our branch. The web site where you can donate is [www.help.co.uk/fundraiser/Mandy](http://www.help.co.uk/fundraiser/Mandy)

Included with this newsletter is notification of our branch AGM on March 4th 2009 do please try and attend.

Until next time.

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[www.warringtonms.org.uk](http://www.warringtonms.org.uk)  
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