



MainStream

The magazine of Eastbourne & South Wealden MS Society
and the Eastbourne MS Community Resource Centre

MAP House • 34-36 St Leonards Road • Eastbourne • East Sussex • BN21 3UT
Registered Charity Telephone: **01323 439447** Number: 207495

FULL BRANCH DIRECTORY ON BACK COVER

Queen's Award for Voluntary Service 2007

VOLUME 6 No 8 DECEMBER 2008

We wish you all a Happy



and Peaceful Christmas



from your committee: Bernard, Margaret, Ian, Joyce, Anita, Janet, Sue,
David, Barbara, Brian, Len, Doreen, Peter, Mary and Margaret(2)

visit our website: www.mssesw.org.uk



720 TAXIS

01323 720 720



Supporting Eastbourne & South Wealdon MS Society

WORKING IN PARTNERSHIP WITH



DECEMBER 2008

SUNDAY 7TH BRANCH XMAS LUNCH
At the Langham Hotel

MON 8TH CENTRE OPEN 10.30 - 3.30

TUES 9TH CENTRE OPEN 10.30 - 3.30

WED 10TH LUNCHEON CLUB
Please ring Joyce to book

THURS 11TH CENTRE OPEN 10.30 - 3.30
Ladies Christmas Lunch

FRIDAY 12TH CENTRE OPEN 10.30 - 3.30
No Yoga today

SATURDAY 13TH ARNDALE CAR DRAW
9am - 5pm

MON 15TH CENTRE OPEN 10.30 - 3.30
'Meet to Share' Christmas Lunch

TUES 16TH CENTRE OPEN 10.30 - 3.30

WED 17TH LUNCHING OUT...
With Carol at the Golfing Park
Forget the turkey! It's a FISH DISH DAY!
Booking Essential
Please contact Joyce

**THURS 18TH LADIES XMAS PARTY &
CENTRE XMAS RAFFLE DRAW**
10.30 - 1.30

FRIDAY 19TH
THE CENTRE WILL BE CLOSED FOR
REFURBISHMENT UNTIL
DECEMBER 28TH

If you need to contact us please use the contact numbers in the 'Mainstream' Directory (back page) and messages will also be picked up from 439447
Just call us if you need us!

MON 29TH CENTRE OPEN 10.30 - 3.30

TUES 30TH CENTRE OPEN 10.30 - 3.30

CHECK OUT OUR WEBSITE...
'MAINSTREAM' IS ONLINE EVERY MONTH
www.mssesw.org.uk

WED 31ST LUNCHEON CLUB
Ploughman's Lunch - booking essential
Please ring Joyce

JANUARY 2009

THURS 1ST NEW YEARS DAY
CENTRE CLOSED

FRIDAY 2ND CENTRE OPEN 10.30 - 3.30
No Yoga today

MON 5TH CENTRE OPEN 10.30 - 3.30

TUES 6TH CENTRE OPEN 10.30 - 3.30
TIME2TALK Drop-in & Phone-in Sessions

WED 7TH LUNCHEON CLUB
Please ring Joyce to book
Community Support meeting 11am

THURS 8TH LADIES GROUP 10.30 - 1.30
Centre open until 3.30

FRIDAY 9TH CENTRE OPEN 10.30 - 3.30
Yoga commences at 9.30
Physio recommences at the DGH

Terry Malone Memorial Tea
Please contact Margaret to book a place

SAT 10TH COMMITTEE MEETING @ 10.30

Thank you to every member who has given up their time during 2008 to make our Centre a 'second home' and a contact point for all people affected by MS in our area.
Sincere thanks to Margaret our Centre Manager

**FOR INFORMATION ABOUT EVENTS AT
OUR CENTRE OR FOR
THE LUNCHEON CLUB & LUNCHING OUT
PLEASE TELEPHONE 01323 439447**

'MAINSTREAM' is produced, published and edited by Bernard Curtis (01323 508969) for the Eastbourne & South Wealden branch of the MS Society. The views expressed, unless clearly shown to be those of the Multiple Sclerosis Society, will be deemed to be those of the author. The editor reserves the right to edit submitted material. Permission must be sought for the reproduction of original material. Printed by Custard Design 01323 733378

So... what do you think?

The results of our 'Fone the Family' event

First of all - '*thank you*' - to all the volunteers that made the calls - and '*thank you*' - to so many of you for giving of your time in responding to our telephone campaign.

With the exception of members in nursing homes or care homes, *and* the committee, basically **15** volunteers telephoned **150** members living at home.

So, what was the outcome of it all? Well, I guess you can say I am mighty proud of the team that do their best to represent and support you all. Below I have presented the results in the order the questions were asked and indicated where we need to look at improving matters.

1. Satisfaction with the branch

>99% said they believed the branch is doing an excellent job in representing all people affected by MS.

>Two members asked if we could do more to represent adult carers

>Two members requested an evening social event

2. Home visits

>Ten members who are not currently being visited have requested home visits. All of those currently being visited appreciate the contact.

3. 'Mainstream'

>99% of members contacted felt 'Mainstream' was an excellent monthly magazine.

>Six more members have requested 'Mainstream' on tape or CD

>The three types of articles that were most favourably commented on were:

1. Ian's information pages
2. The Christian content
3. Non-MS features and articles

>The requests for photos in 'Mainstream' were numerous *but* most were aware of the added cost.

4. Our Branch website

>Surprisingly (to me) only 25% of members contacted actually access the website.

>However, those that did thought it was excellent

>'Yes'.. there is a 'large print' facility on the site that you can access

5. The Wheelchair Clinic

>There were 6 specific complaints about the current service by people waiting for a wheelchair.

>There were 8 general complaints about the clinic being under-staffed and their failure to return telephone calls

Conclusion and Action

As your chairman, I think I can be generally satisfied with the 'state of play' at present and I would like to thank so many of you for your very kind comments.

<We will now attempt to take all your concerns and requests on board. We need more home visitors for our Community Team, so please bear with us and we will get the additional visiting sorted out.

<'Mainstream' is my 'baby', so 'thank you' for your lovely comments and for your suggestions. We have recently asked for costings to include photos and I will see if we can find a generous funder! Photos are very important for those who, because of their disability, are unable to visit our centre or take part in social activities.

<I will endeavour to promote the website more widely - however it is being visited by an increasing number of people and many members who have accessed it found the information very useful.

<We will attempt to solve all the Wheelchair Clinic problems that we can. Those that need specific action I will discuss with Shirley McCall who represents our Branch on the PCT.

So, do we have a relatively happy membership? Thankfully, it appears that we do! However, the times *they are a-changing*. Christmas is not the time to advise members of many changes that will affect the future of our branch. *However, January is most certainly an opportune time!*

I will ask Margaret (our Branch Secretary) and Ian and Joyce (our Vice-Chairs) to update you in the January edition of 'Mainstream' on the future of our beloved Branch *as they see it*. As for me...I will have a *few* words to say on matters, that's for sure! In the meantime, please accept my sincere thanks for taking part in our survey and for giving me so much personal support. Please be assured we will be here for you. God bless you all and a Happy Christmas. **BC**

Joyce's Jottings

Well folks it's that time of year again – Christmas is almost upon us.

I've been quietly pondering the enormity of the festive season and how our feelings for it change as we grow older. I make no secret of the fact that I become a child again when anticipating the joys of Christmas, although these feelings have gradually changed over the years.

As a child it's a whirl of nativity plays, both school and Sunday school, and anticipation of the gifts you will receive.

As a teenager it's all about the pull between family commitments and your own social life. It is now that the idea of how much it all costs begins to hit you. The presents for family and friends and the obligatory new outfits – particularly for us of the female persuasion.

But still there is the over-riding question of what *you* will receive. If you are lucky and have been raised in the Christian faith, all this is tempered by the underlying knowledge that it's not all about presents and partying; we are actually celebrating the birth of Christ.

As an adult you are faced by the reality: Christmas is expensive, children have high, often unrealistic, expectations and you have to try to instil the values which experience has taught you.

You encourage the belief in Father Christmas and groggily stumble out of bed at the crack of dawn when the noise alerts you to the fact that the little darlings have found the stockings left by Santa. You begin to realise that your children feel just as you did when you were a child.

And after a few short years you struggle to remember how it felt to be a teenager, and you force yourself to smile when they tell you they've got better things to do than accompany you to Church or sit through the Queen's speech.

Before you know it, there are grandchildren and the whole cycle begins again. You realise the power of the magic of Christmas.

It's not all about you

A large part of the magic of Christmas is when you realise there is more to it all than just you and your immediate family.

There are those of different faiths to whom our festive season means nothing. They have their own beliefs and their own festivities, but there must be mutual respect and understanding as we all celebrate in our own ways.

We must also remember those who have no family or friends to share the joys of the festive season. This may be because they are elderly, bereaved or have simply lost touch with the people who matter. There are also the children who have no-one to care and whom Father Christmas never visits.

For many years I had a reputation for filling my house with adults or children (sometimes both) who needed a place to enjoy a family Christmas. This also gave my children an insight into how others can be helped. Of course, things change and I'm no longer in a position to provide succour for others, but I still get a warm feeling when I look back at the years gone by.

Sparing a thought for others need not cost the earth. We all buy far too much food and drink and spend too much on presents; it's easy to feed another mouth or give a small gift. There are numerous ways you can contribute to bringing a little joy to someone else. There are collection points everywhere where you can drop off contributions – and the current trend for three-for-two offers means that this can be done at little or no expense.

I know there's a 'credit crunch' but most of us will still overspend this Christmas. Even those of us on fixed incomes will find the extra money somehow, but please remember those who, sometimes through no fault of their own, have no reason to be full of joyful anticipation for the coming Christmas season. Let's give thanks for what we've got and remember the *true* meaning of Christmas.

Joyce

PLEASE NOTE...

Our Centre will be closed for refurbishment on **19th Dec and reopens Monday 29th Dec**

You can still contact us on any of the numbers on the back of 'Mainstream' and messages will be picked up on 439447.

Update on PCT Wheelchair & Special Seating Meetings

from Shirley McCall

Fortunately the November meeting was held just in time for me to report for this issue of Main Stream. Many thanks Bernard for waiting for me to get it in print!

We have been having six weekly meetings at the PCT Offices in Lewes lasting one and a half hours but as from January 2009 they will be held every two months and last two hours.

Please bear in mind the next meeting is on January 16th so if you have anything you would like me to mention you are welcome to give me a ring and I will pass your enquiry on.

One major item under discussion at the moment is the Approved Repairer Contract which is due for renewal in 2009. The presentation process by interested wheel chair services wishing to be considered for this contract commences in January. Service users are being involved in the tender presentations and have put forward several proposals that will be considered and have been included.

It is hoped to have a Complex seating and Mobility Needs Panel which will provide an independent forum to consider requests for mobility and seating equipment which sit outside the published eligibility criteria. Clients who require a panel decision in relation to their equipment provision will be identified by a wheelchair therapist who will then complete an application form in conjunction with the client and if appropriate, his/her family/carer.

Seating – cushions etc

I thought you may be interested to hear that there has been great progress in ensuring that a client who is permanently in a wheel chair has the correct cushion for their weight and posture.

I had to wait nearly three months for an assessment for this and was then only lucky because I accepted a cancellation at

short notice but was very impressed when I had my consultation.

I think it is called Pressure Mapping and the client has to sit on a flat square in their chair which is connected to a lap-top by a scart lead. Images then appear on the screen which denotes acute areas of pressure being endured by the client. It is then a process of elimination for the OT to find a suitable cushion to relieve that obvious pressure.

It can be quite a lengthy consultation depending on ones bony prominences! I will report back to you when I eventually receive my new cushion. **Shirley**

Relapse Support Service

Talks continue over this proposed pilot project and a further meeting was held, this time with Welbeing (Wealden & Eastbourne Lifeline). Margaret, Joyce, Sue and I attended on behalf of the branch along with representatives of the MS Society and local health professionals. The Welbeing presentation was excellent and the technology they use to ensure the safety of disabled folk living at home was quite amazing. I did think at one time that the branch would have a larger role to play in the implementation of the scheme. However, if we are able to signpost folk to the service, once it is up and running, it will be an excellent support package at the time of a relapse. I will keep you all updated on progress. **BC**

The Church in the Community

It was an honour to be asked to be the guest speaker at the Herstmonceux Free Church 'Sunday Supplement' gathering. Once a month the Church is brought into the community and such a lovely group of people attended.

I was really nervous! I have spent hours, with Margaret, over the past few years talking about MS all over our area of Eastbourne & South Wealden. This time it was just me...talking, not specifically about MS, but about my own Christian faith and the strength I personally gain from it to sustain me in my work in the MS community. I am grateful for such a very warm welcome - it was a wonderful way to spend a Sunday morning.

My thanks to Margaret and Sue for their support and to Herstmonceux Free Church for their generous donation to the branch. **BC**

WE ARE IN URGENT NEED OF VOLUNTEER DRIVERS...DO YOU KNOW ANYBODY WHO CAN HELP?

From our Minister
Rev. Dr Gerald Munro BA MA Dphil

Greetings to you all! There is a verse in the gospel of John which says... '*The light shines in the darkness, and the darkness has not overcome it.*' There is something very powerful about the image of light and is an image we associate especially with the season of Advent and Christmas.

From ancient times light has been a sign of the divine. The Bible speaks about the Eternal Light, the Inner Light and the Light of the World. Light is a central theme of many festivals celebrated at this time of the year when days are shortest and lights are longest. By affirming that we live by the Light of hope we banish the darkness that surrounds us. The eight candles of the Jewish Hanukkah proclaim our faith that freedom will not die out as long as there are steadfast and courageous people willing to uphold it.

The Lights of Christmas bear witness to the Light of the World that came to us in the form of a child. What better symbol is there for the light of hope than a child - new and fresh, open to the future and able to make choices that can change the future. At this December time we think of birth and renewal, hope, joy and peace, thanksgiving and praise. We remember Jesus, a Prince of Peace, and his message of abundant life. We light our lights this season to remind us that the darkness, however powerful it may seem at times, does not overcome us, that there remains within humanity a spark of hope that can be fanned into a light illuminating the path to a new order of freedom, peace and love in a world of tragedy and darkness. Each December the sacred hope is reborn.

Beneath our surface flaws lies a loving nature, divine in essence, and the nativity story brings out the best within us. Nations pause and wars have been known to stop on Christmas Day. Scrooges become cheerful. The wonder of Christmas is that it reveals who we really are - children of God who mask their divinity most of the year. God spends himself kindling the flame we call life. In some the flame is brilliant, in others faint, in all it derives from God. In Jesus it became so pronounced that he has been called the Light of the World. That light was in the

example he set and the truth he taught. It is now through us that the spirit of Jesus must shine through the darkness of our day. May the light proclaimed in this season be in your lives now and always.

With every good wish for a happy, peaceful and blessed Christmas and New Year.

Gerald

NEWLY DIAGNOSED WITH MS?

If you are newly-diagnosed with MS and feeling a bit low, and have no one to talk to - please just pick up the phone and give me a call.

Sue on: 01323 439447

or email: SueAustin50@aol.com

All calls are confidential

Talking really can help!

IN MEMORIAM

LESLIE JOY SINDEN

1967 - 2008

It is with sadness that we record the passing of Leslie and our love and prayers go to her family at this very sad time

Thank you Kate...

Sincere thanks to Kate Parkinson for holding a very successful Wine Tasting Evening raising £430.18. The money has been donated to the branch in memory of

Leslie Sinden

In memory of Terry...

In memory of our much loved and sadly missed **Terry Malone** we are holding a Memorial Tea at our Centre on: **Friday 9th January 2009**

If you would like to join us would you please contact Margaret or Bernard to book a place. If you require transport please let us know ASAP as numbers will be limited.

BC

**FUNDRAISING & DONATIONS
MONTHLY UPDATE FROM MARGARET**

The Rotherwick Foundation - **£10,000**
Grant for Community Centre core costs

Quiz Night anonymous prize money
donations:-
£100, £30, plus **£50 (£15** 3rd prize and
raffle prizes)

£100 donation Herstmonceux Free
Church

£212 - Beachy Head Marathon
sponsorship Darren Tilley

£345 Cake Break Eastbourne College

£182 - Ladies Dinner Raffle - Old
Eastbournian Lodge

£430.18 - In memoriam - Leslie Sinden

£100 - Anonymous donation towards
costs at the Centre

£100 - Anonymous donation

£120 - Val's Centre card donation tin

£40.68 - Ladies Group donation tin

£100 - Alfriston Court Xmas Fair

**THANK YOU TO EVERY INDIVIDUAL AND
ORGANISATION FOR YOUR SUPPORT**
It is more than appreciated.

**CHECK OUT OUR WEBSITE...
'MAINSTREAM' IS ONLINE EVERY MONTH**
www.mssesw.org.uk

**I.C.E from a 'Meet to Share' member
In Case of Emergency (ICE)**

The emergency services recommend that
you add contact numbers to your mobile
phone e.g..

ICE1 Mum then add the contact number,
ICE2 etc....

Responding emergency services would be
able to contact a loved-one on *your* mobile
without delay.

WE URGENTLY NEED DRIVERS...DO YOU KNOW OF ANYBODY WHO COULD DRIVE FOR US?

My Christmas Carol

I have a list of folk I know, all written in a book..
And when Christmas comes, I go and take a look.
And that is when I realise that these names are a
part..
Not of the book they are written in..
but in my heart.
For each name stands for someone
Who has crossed my path sometime...
And in that time they have become the rhythm in
each rhyme.

And while it sounds fantastic for me to make this
claim...
I really feel that I am composed of each remembered
name.
And while I may not be aware of any special link..
Just meeting you has changed my life more than you
would think.
For once I have met somebody the years cannot
erase...
The memory of a pleasant word or a friendly face.

So never think My Christmas cards are just a mere
routine of names upon a Christmas list,
Forgotten in between.
For when I send a Christmas card addressed to you..
It's because you are on the list I am indebted to.
For you are but the total of the many folk I have met..
And you happen to be one of those I prefer not to
forget.

And whether I have known you for many years or few
In some way you have made a part in shaping things
I do.
And every year when Christmas comes I realise anew
The best gift life can offer is meeting folk like you.
And may the spirit of Christmas that will forever
endure,
Leave its richest blessing in the heart of yours and
you.

And although each year as I grow older, names are
taken from my book..
Those people whom I've known and loved live in my
book of memory,
For me to take a look.

Anon
Submitted by Pat Banks

FOR SALE...WHATEVER YOU LIKE!

A member has suggested that we have a 'For
Sale' column for general items that may be of
interest to others as well as adverts for
wheelchairs and disability equipment. No
problem. If you have an item for sale, just send
me (written) details and we can have a 'general'
column in 'Mainstream' every month. **BC**

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TELEPHONE/FAX: 01323 726376

VISUAL IMPAIRMENT CONTACT NUMBERS

Eastbourne Blind Society 729511

East Sussex Association for the Blind 832252

RNIB Helpline 0845 766 9999

DISABILITY LAW SERVICE (DLS)

DLS runs a national Adviceline:
Mon to Fri - 10am - 1pm & 2pm - 5pm
Tel: 020 7791 9801 Email: advice@dls.org.uk

A. J. CROMPTON CAR BODY SERVICES

*M.O.T Repairs *Insurance Repairs *Re-sprays
54 Hammond Drive Eastbourne East Sussex
Telephone (01323) 724725

Recommended by Eastbourne & South Wealden MS Society

MS Society HELPLINES

EMAIL: helpline@mssociety.org.uk
PHONE: 0808 800 8000

Counselling

One-to-one sessions with qualified counsellor available at our Centre on Friday afternoons at 1pm or 2pm
Sliding scale of fees £5 - £10 per session
First one free of charge
Phone Jane on 07813 093117 for more information or to make an appointment.

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Please contact Margaret on:
01323 439447 or 01323 723418

Hello from Gloucestershire

Well, I have been elected to another organisations Committee so for the moment the local MS committee is on the back burner. However, I still receive their newsletter so I will share some of their ideas with you.

Did you know that **WH Smith** has, this year, chosen the MS Society as one of the charities for their in-store boxed Christmas card range? The cards are part of their signature collection and cost £4.99, of which the MS Society receives a pound. So, whilst I appreciate that members of the MS Society may well be buying their Christmas cards from the MS Christmas catalogue, what about your friends and relatives who purchase such things from the high street stores? Everyone can do their bit.

For those of you interested in world class MS information at the touch of a button, may I recommend the **MS society library**? To find this go to www.mssociety.org.uk/library where you can access the thousands of books, journals, papers and magazines contained within the MS library. This database enables anyone interested in any aspect of MS, who has access to the internet, to see, download and read what is available.

What do you do with your **MS Matters** when you have finished with it? If you don't already do so, how about leaving it in your doctor's surgery? It could be of interest to patients or surgery staff and will certainly help to raise awareness of MS.

There is a **Blue Badge Map** showing parking bays, Shopmobility Centres, accessible toilets and masses more in over 100 towns and cities across the UK. Use their interactive map at www.direct.gov.uk/bluebadgemap

Also on the map are stations, including their access level. There are three access levels:

- accessible - step-free access to all platforms and staff to help
- partly accessible - step-free access to all platforms but there may not be any staff to help
- inaccessible - steps to some or all platforms

In London, Underground stations are displayed, including access information.

Where applicable, there is also information on reductions for disabled drivers on tolls for bridges and tunnels. I wish I'd known about this

facility months ago, when I was trying to get from Eastbourne to Birmingham by train!

For those of you who prefer a book format there is a **manual atlas** which contains not just maps but also route planning information such as which petrol stations are accessible, where you can park etc.. To request a free copy send a cheque for £3.99 (to cover p&p) payable to PIE Enterprises and quoting reference FREEATLAS with your name, address and telephone number to: PIE Enterprises Ltd, Caledonia House, 223 Pentonville Road, London N1 9NG.

That's it for this month.

Happy Christmas to you all. **Ruth Brinkman**

FROM OUR WEBSITE Nov/Dec

We are featuring a volunteer online each month

Introducing our Volunteer of the Month

Brian Bearne – Transport Supremo

In 1992, at the age of 58, Brian took voluntary redundancy from his job as a warehouse and transport supervisor. He then decided his future lay in voluntary work and he started to drive for the Blind Society, with which he is still involved. A member of the MS Society then asked Brian to help with our transport, which he's been doing ever since – lucky man! In those days there was only one vehicle and two drivers, and since then he has been involved with four MS vehicles and three Chairmen. Brian sits on the Committee as Transport Officer and organises drivers and escorts for our many Branch outings.

Due to insurance company policy, Brian is finally being forced to retire after 16 years of loyal Branch service and his fervent hope is that we manage to find more volunteers to carry on the good work achieved over so many years and which makes such a vast difference to our Ms members and their carers.

At our 2008 AGM Brian was presented with a well-deserved Shining Star Award in recognition of his many years of selfless service to the Eastbourne & South Wealden MS Society.

FOR ONE MONTH ONLY...THE 'BC' INFORMATION DESK

Unfortunately, at the time of going to press, Ian was poorly and not able to contribute his two very valuable pages to 'Mainstream'. I offered to do them for him...come back soon Ian...we depend on you. BC

New guide dispels myths of miracle cures

The MS Society has joined forces with charitable trust Sense About Science as part of an initiative to highlight the importance of evidence-based information on new treatments and therapies.

A guide* published today entitled 'I've got nothing to lose by trying it' explains how to tell the beneficial from the bogus in the face of miracle cure stories, new wonder-drugs and breakthrough therapies that are increasingly promoted in the media and elsewhere.

The leaflet, produced in conjunction with the Motor Neurone Disease Association, Alzheimer's Society and Parkinson's Disease Society, acts as a warning from experts to people with long-term incurable conditions about the emotional and financial costs of over-hyped treatment claims that sell false hope. Lee Dunster, Head of Research at the MS Society, said: "The significance of giving people information that is credible, accurate and based on evidence cannot be underestimated and that is why the MS Society has been involved in this important initiative."

Sense About Science is an independent organisation, which exists to promote good science and evidence for the public.

Tracey Brown, Managing Director of Sense About Science, said: "We've been contacted by so many people exhausted from the pressure they feel to try advertised treatments, dietary regimes and exercises.

"One person told us how the last years of his wife's life were spent endlessly pursuing new treatments, from goat's blood serums to unlicensed stem cell treatments abroad, all to no avail.

"This guide aims to help patients and their families to evaluate the treatment claims they are bombarded with."

Source: MS Society

**The guide can be downloaded from the MS Society website or we can download a copy for you at our centre. BC*

Statement on University of Cambridge MS drug study

The MS Society has responded to the announcement made from the University of Cambridge relating to the alemtuzumab multiple sclerosis (MS) clinical trial results.

The study, published in the New England Journal of Medicine, has found that alemtuzumab (formerly known as Campath-1H) potentially stops MS from advancing in people with early stage active relapsing-remitting multiple sclerosis (RRMS).

The trial results have also shown that the drug may also reverse disability caused by the condition in those people with early-stage MS.

Lee Dunster, head of research at the MS Society, said: "The MS Society has been following this trial closely and we are delighted that it has reported such positive results.

"This is the first drug that has shown the potential to halt and to some extent 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, which is already underway."

Although alemtuzumab has not been shown to be effective in those people living with progressive forms of the condition, the MS Society is funding research into treatments in this area. *Source: MS Society*

Multiple sclerosis - a global disorder and still poorly managed

The launch of *Atlas: Multiple Sclerosis resources in the World 2008 (MS Atlas)* during the World Congress on Treatment and Research in Multiple Sclerosis in September 2008, was met with substantial global interest. This reaction is perhaps not surprising owing to the number of countries involved and the rather sobering and thought-provoking messages the atlas contains. Together with WHO, the Multiple Sclerosis International Federation (MSIF) successfully acquired data from 112 countries, representing 88% of the world's population. Furthermore, there was good representation from all six WHO regions and a broad spread of the four World Bank income categories (low, lower middle, upper middle, and high). This survey was the largest and most representative global examination of multiple sclerosis (MS) ever undertaken.

The aim was not so much to provide detailed prevalence figures as to document and highlight the infrastructure and services available to people with MS with respect to diagnosis, treatment, and management of this chronic, disabling disorder.

Perhaps surprisingly, none of the 112 countries was free from MS, even those close to the equator, although the well documented geographical influence was evident. There was wide variation in the clinical expertise available, but no country was in a position to say that they provided an adequate, joined-up service across the spectrum of care required by people with MS.

The availability of neurologists with an interest in MS ranged from less than 0.05 to more than 1.0 per 100 000, with many countries being at the lower end. There was a similar range in the availability of MS nurses, with a far greater number of countries at the lower level, and many had no nurses with this specific expertise. As might be expected, the number of MRI scanners available for diagnosis was closely linked to the income category of the country, and a similar pattern was seen in the availability of disease modifying treatments.

By contrast, the prevalence of MS groups and organisations worldwide was encouraging, and the number of groups a country had was related directly to the availability of printed advice and information.

Several specific points were raised in the section of the atlas that deals with the biggest problems encountered by people with MS and health professionals. Both groups rated as high priorities the scant information and education about MS for the public and for health professionals, respectively, and the unavailability of disease-modifying therapies and rehabilitation services.

However, there were other factors that were not rated highly by the health professionals but about which people with MS felt strongly. Foremost among these was the importance of employment and the desire of people with MS to be supported in the workplace. This is in striking contrast with the paucity of expertise and services in vocational rehabilitation worldwide, including high income countries.

In their recent book *Neurological Disorders: Public Health Challenges*, WHO has clearly articulated the immense personal and societal burden that neurological disorders impose. During the past decade, there have been many initiatives across Europe and North America to identify the needs of people with MS and the services and expertise required to meet those needs. In the UK, this has included guidelines from the National Institute for Health and Clinical Excellence and the National Service Framework for Long-term (Neurological) Conditions.

To see how little has translated into action as a result of these initiatives, and the minor effect they seem to have had, is disappointing. In the June 2008 editorial in *The Lancet Neurology*, the findings of the European MS Platform were reported; these outlined the wide variation in access to treatment and service provision for people with MS across Europe. An audit in the UK by the Royal College of Physicians and the MS Trust has also confirmed major problems with service provision, coordination, and responsiveness.

The *MS Atlas* is a powerful tool that carries a truly global message. At a time when MS is deemed to be a treatable, manageable condition—albeit a challenging one—and where there is a clear basis for minimising the effect it has on all of those who are affected by it, it is essential that we use the *MS Atlas* to its maximum potential to redress the inadequate and inconsistent services available for people with MS worldwide.

Alan J Thompson

Institute of Neurology, University College London,
Queen Square, London WC1N 3BG, UK

Top awards for MS Trust publications

In September, MS Trust publications won British Medical Association (BMA) Patient Information Awards.

Sexuality and MS: a guide for women was awarded first prize for Patient Information - Women's Health.

Move it for MS! - an exercises DVD featuring Mr Motivator was Highly Commended.

Available from MS Trust on:

01462 476 700 or online from:
www.mstrust.org.uk/publications
Email: info@mstrust.org.uk

YOUNG CARERS

Since Halloween, when we had that tremendous party, our preschoolers had fun at the Winter Garden when they saw 'The Tiger that came to Tea.', and we have also had a Christmas crafts extravaganza. Just as we did last year, our youngsters made some delightful Christmassy crafts, which they could either keep for themselves, or use as Christmas presents. They made some lovely cards too. What a talented bunch they are! On the Saturday before Christmas, there will be 2 dozen of us going to the Panto at the Devonshire Park Theatre. I can't wait! The programme following Christmas is still being planned, so watch this space!

As ever, if anyone is aware of any Young Carers who are not on my mailing list, please do get in touch and let me know.

If you have any queries please don't hesitate to contact us.

Just call Janet or Lynne on 01323 439447

LADIES SUPPORT GROUP

The ladies group have had some jolly good Thursdays this month with flower arranging for the Christmas table, and a great quiz. Thank you to our quiz master - Steve. Doesn't Christmas come around so quickly? We shall be having a music quiz with a festive theme on 4th December, and our Christmas dinner the following week. With our Christmas party the last Thursday before Christmas - what a busy month! We shall be having a secret Santa at our party, so if you'd like to take part, just bring along a wrapped gift.

There is no limit to numbers at any of these events, but if you have any queries, just give me a call on 01323 439447.

As always, **ALL LADIES WELCOME** every Thursday 10.30 - 1.30pm.

Best Wishes, Janet



THE RAINBOW POEM

HIGH IN THE SKY RAINBOWS ARE SEEN,
THEY ALWAYS COME AFTER RAIN HAS BEEN.

PINK, GREEN, YELLOW AND BLUE,
MANY COLOURS OF DIFFERENT HUES.

A CROCK OF GOLD MAY BE FOUND,
AT THE END OF IT, ON HIGHER GROUND.

MAKE A WISH, IF YOU SEE ONE TODAY,
A TRUE ONE GOES A LONG LONG WAY.

Diane Hewitt

How do *you* cope with your MS?

It was a few years back that I asked this question in 'Mainstream'. The reason for asking was that newly-diagnosed folk said they would be interested to know how people actually coped with their MS on a daily basis.

Many of you responded for me and wrote some brilliant articles - can some of you come forward and repeat the process please.

Nothing has changed my friends...in the very week I am writing this, we have had three more newly-diagnosed people contact us, and a lady who was diagnosed a year or so ago said she would appreciate reading about how others coped.

So, to give you time, we will plan for the February 'Mainstream'. If you can submit an article **would you please let me know ASAP.**

Let's say 300-350 words maximum and the deadline will be **January 20th 2009.**

Please make sure you advise me in advance that you are contributing an article so that I can plan the space.

Your contributions will be greatly appreciated...Thank you. **BC**

The Judy Parker Column

This will be my last column before we celebrate another Christmas and New Year. I wish all of the M.S. family, members and readers a very Happy Christmas.

I know that many of our members have had difficulties in many different ways this year and hope that 2009 may be better. Special love and prayers are extended to our very special June Malone.

I hope to see many of you again at our Christmas celebration meal at the Langham Hotel on December 7th.

I spoke to my friend recently who is one of the security officers in the Arndale Centre. I expressed my concern about the difficulty opening the door to the disabled lavatory if one is in a scooter or wheelchair alone. I told her that I have been tempted to pull the emergency cord to summons assistance exiting the toilet ! The member of staff with her told me that would not be a problem. A member of staff in one of the offices upstairs would be able to identify in which toilet the cord had been pulled and help would be given. All the staff have radar keys so access wouldn't be a problem for them. This was reassuring to know the procedure - don't feel uneasy if you have to summons help - it is available if required.

On that cheery but practical note I wish you all a happy holiday season and I'm sure none of us want to cope with the white and slippery stuff under our feet !

Judy

01323 486478

WIN A CAR CHARITY RAFFLE (ARNDALE CENTRE)

We have been given

SATURDAY 13TH DECEMBER

Make sure you get your tickets - every pound we raise on the day is for the Branch

Meet to Share

SOCIAL AND SUPPORT GROUP FOR LADIES

The next meeting is the Christmas Lunch at:

The Hydro Hotel

15th December at 12.45pm

Really looking forward to it. Hope to see you all there.

PS Alert. Has anybody seen **Sebastian Bear** recently? He has not been at the Centre of late. Bernard said he is at home with a cold but I have a feeling that he may have been kidnapped. If you have any information please feel free to let any of the committee know. All information will be treated with the utmost confidence!

Merry Christmas to you all

Love **Sue**

TELEPHONE: 01323 736359

EMAIL: SueAustin50@aol.com

Barack Obama...the MS connection

MS was given the highest coverage in a recent speech by Barack Obama on the 18th anniversary of the *Americans with Disabilities Act (ADA)*. The President-elect said:

"On this anniversary of the '*Americans with Disabilities Act*' (ADA), I'm reminded of my father-in-law, Fraser Robinson, who contracted multiple sclerosis at a young age. My wife Michelle watched him go from a vibrant and athletic young man to a man who used two canes to get himself to his job as a shift worker...he never wanted special treatment - he just wanted to be treated like everyone else.

As President I will build on the ADA's promise so that we make as much progress over the next eighteen years as we have over the last eighteen. That begins with reinforcing the original legislation. Recent decisions by the Supreme Court have severely restricted application of the law by creating a narrower definition of 'disability.' As a result, people with disabilities like multiple sclerosis, epilepsy, diabetes, and cancer can be fired from their jobs because they have those conditions. That's unacceptable. When I am President, I will strengthen implementation and enforcement of the ADA by signing the ADA Amendments Act into law." *Source: www.disaboom.com*

COME AND JOIN A WONDERFUL TEAM OF VOLUNTEERS - JUST GIVE US A CALL!

MAINSTREAMING WITH MARGARET

Firstly, this is a very special thank you to everyone who has supplied gifts and donated money towards our Quiz evening; we have been touched by the wonderful support we have received.

All the prize money has been donated and many raffle prizes, your generosity will enable us to run the Quiz evening raffle, plus the Xmas Lunch raffle at the Langham and the Christmas raffle in the Centre... Thank you.

The Centre itself is getting a bit of a facelift; we are going to carry out some internal refurbishment. The new chairs are looking great and so we are going to have a spring clean, plus a new coat of paint with a few extra bibs and bobs for the New Year. Therefore, please make a special note in your diary, the Centre will be closed from Friday December 19th and reopens again on Monday 29th December.

We are available on our home telephone lines if you need to call us at anytime – I will also be calling into the Centre to pick up any messages and mail.

With my 21 years as a volunteer / committee member there have been many changes. However, I would like to take this opportunity to mention two people in particular who have served on the committee for some considerable time. It can be hard work for the likes of us who are “so called able bodied”, but for those who have MS and then also helping their fellow man with MS at the same time is truly an accomplishment.

Ian and Janet have been loyal committee members for about 10 years now and they really do have to be admired. Ian with his information pages in Mainstream, which we know are truly appreciated by the membership and many other aspects of work whether it is welfare or speaking to others about the society or ms itself. He is Vice Chairman and he is also Chairman of the Eastbourne Access group. He is presently fighting many a battle regarding the parking needs for the disabled.

Janet is heavily involved with the Young Carers group and with Lynne’s support organises activities

and events. Janet has been doing this now for some considerable time plus this year she also secured the further grant from Four Acre Trust which will enable the work to be continued.

Janet also plays an active role within the ladies group on a Thursday, plus any welfare support that might also be needed.

Two very hard working committee members affected by MS, who will always be admired

Thinking about volunteers, campaign posters have been out and about on the fleet of local Eastbourne buses plus other prominent places. In the New Year we will continue to promote and campaign for more volunteers, it is absolutely vital that our work continues for many years to come.

Well Christmas is certainly coming and if we have any pennies left there are some good bargains to be found in the stores. The MS Xmas catalogue stock turned out to be rather hit and miss – most of the cards seemed to be available but the availability of the gift items left a lot to be desired.

I personally missed out on 3 items that were discontinued.

My free gift, no it was not a packet of seeds; it was a Doctor Who DVD which was originally broadcast in January 1970 with Jon Pertwee. Is there a fan out there that would like the DVD?

Please take care now - with my love and kindest wishes to you all for the festive season - Margaret

I will take this opportunity to say a very big 'thank you' to Margaret on behalf of us all for the work she has put in for another year to make our Centre such a wonderful place. Her workload on Health & Safety alone this year has been huge and our Centre is truly a credit to her dedication and care for all of us. BC

PLEASE MAKE A NOTE... YOGA & PHYSIO DATES

YOGA Last day for Yoga is: **5th December 2008**
and returns again on **9th January 2009**

PHYSIO Last day for Physio is **19th December 2008**
and returns again on **9th January 2009**

:

Tell me the old, old story...

Kindly indulge me my non-Christian friends! This will be my last Christmas as your chairman, so let's share a 2,000 year old story together. A story as wonderful today as ever it was. Forget about the credit crunch, global warming, adverts for settees and parking problems.

Let's think about a stable...a newly-born infant...and a very proud Mum. Ancient writings had foretold the birth of the child - and suddenly, one evening, a bright star heralded the event.

The baby Jesus became a child - the child became a man - and the man was crucified for our salvation.



Believe that, and life will have a purpose and death will be accompanied by the 'rod and staff' of comfort. The

full story of his life only covers a few years. Star, stable, manger...then supper of bread and wine...story ends with discovery of an empty tomb. Brilliant! Lifts the spirits immediately.

Of course, if you bring on the turkey, the tinsel and the sales that start at 8am on Boxing Day, the story is rendered almost worthless in the minds of so many. But not your 'BC'!

Truly, I love the simplicity of it all, and centuries of intellectual and theological debate have not improved it one jot as far as I am concerned. The tabloids would pay millions for the story today with headlines such as: *"Fat cats fill hotels as baby is born in underground car-park"* No doubt 'Hello' magazine would pay more millions to cover the Last Supper, and because man would immediately complicate the simple message, a thousand groups would set up claiming they knew best how to follow the teachings of Jesus.

Tell me the old, old story. The simple narrative of my childhood. Two or three of us gathered together quietly drinking it in. No hierarchy, laws, rules or regulations to govern how we listen or how we respond. The picture in my battered old Bible that my Nan gave me fifty-odd years ago is all I need as a visual aid. Stable, manger, cheery-looking couple with baby and not a credit card or a plastic Santa in sight! Now that's what I call Christmas. **BC**

Shepherd's Bush...in Sussex!

How can I produce a December edition without a 'bit' of Sussex? **BC**

December 30th

On the Downs in the brilliant morning the sheep were feeding among the gorse-brakes, and I would have stopped to look at them and listen a while to the drowsy music of the bells, only the fierce north wind would not let me halt for an instant: one had to keep steadily moving, or freeze to the marrow in its relentless icy flood.

But the bark of a dog, and then the sound of a human voice hailing me, turned my steps towards a neighbouring patch of furze.

The old shepherd was sitting apparently right in the heart of one of the biggest bushes, as safely sheltered from the wind as he would have been in his kitchen at home.

It was a 'shepherds-bush', in fact - such a haven as all South Down flock-tenders make for themselves here and there on their bleak, storm-swept rounds. The same spots are used year after year, and often generation after generation.

The dense spiny growth is partly clipped and partly pressed down into deep cup-like form, wherein, with the help of the usual home-proofed coat, it is possible to keep snug and dry, for a time, from the wildest weather.

It must have been just such another old ancestral 'shepherd's bush' from which the London suburb got its name.

from: 'A Downland Year' by Tickner Edwards
published 1939

Sebastian Bear not kidnapped...just sulking!



My friend Mrs Sue Austin is worried that I may have been kidnapped (page 13) because I have not been seen for a while...I am safe dear lady...but I have been a Sulky Sebastian. **BC** told me that after May 2009 I will not be the 'Chair's Bear' anymore because **BC** wont be the chairman. I like being 'Chair's Bear' because I get loads of cuddles. But I cant be sulky at Christmas and **BC** said we will have lots more adventures together...so 'HAPPY CHRISTMAS' and I hope you get a Teddy Bear as a present. **XX**

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