



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 7 NOVEMBER 2008

visit our website: www.mssesw.org.uk

'FONE THE FAMILY'

Every member of the Branch to be contacted by telephone..... page 3

FITNESS FIRST

Margaret explains a new pilot project - coming soon.....page 7

...and then we got lost!

Joyce recalls how your 'BC' was put at risk.....page 4

If I should die, think only this of me; that there's some corner of a foreign field that is for ever England.

IS THERE STILL A ROLE FOR REMEMBRANCE SUNDAY?

Read the Rev. Howard John... page 6

For Adult Social Care Ring Social Care Direct 0845 60 80 191



720 TAXIS



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Supporting Eastbourne & South Wealdon MS Society

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NOVEMBER 2008

- WED 5TH LUNCHEON CLUB
Please ring Joyce to book
Community Support Meeting 11am
- THURS 6TH LADIES GROUP 10.30 - 1.30
Centre open until 3.30
- FRIDAY 7TH CENTRE OPEN 10.30 - 3.30
Yoga commences 9.30
- MON 10TH CENTRE OPEN 10.30 - 3.30
MONDAY MEN LUNCHING OUT
- TUES 11TH CENTRE OPEN 10.30 - 3.30
- WED 12TH LUNCHING CLUB
Please ring Joyce to book
- THURS 13TH LADIES GROUP 10.30 - 1.30
Flower demonstration at 11am
Centre open until 3.30
- FRIDAY 14TH CENTRE OPEN 10.30 - 3.30
Yoga commences 9.30
- MON 17TH CENTRE OPEN 10.30 - 3.30
- TUES 18TH CENTRE OPEN 10.30 - 3.30
- WED 19TH CENTRE OPEN 10.30 - 3.30
LUNCHING OUT
Rodmill Pub 12.00 for 12.30
Food to be pre-ordered by Friday 14th
- THURS 20TH LADIES GROUP 10.30 - 1.30
General Knowledge Quiz with Steve Gates
Centre open until 3.30
- FRIDAY 21ST CENTRE OPEN 10.30 - 3.30
Yoga commences 9.30
- SUNDAY 23RD YOUNG CARERS
Christmas Crafts at MAP House
2.00pm - 5pm
- MON 24TH CENTRE OPEN 10.30 - 3.30
MONDAY MEN LUNCH AT CENTRE
Meet at 11am
- TUES 25TH CENTRE OPEN 10.30 - 3.30
- WED 26TH LUNCHEON CLUB
Please ring Joyce to book
- THURS 27TH LADIES GROUP 10.30 - 1.30
Centre open until 3.30

- FRIDAY 28TH COFFEE MORNING
& CHRISTMAS GIFT SALE 11am
Centre open until 3.30

DECEMBER 2008

- MON 1ST CENTRE CLOSED
- TUES 2ND CENTRE OPEN 10.30 - 3.30
TIME2TALK Drop-in & Phone-in Sessions
- WED 3RD LUNCHEON CLUB
Please ring Joyce to book
Community Support Meeting 11am
- THURS 4TH LADIES GROUP 10.30 - 1.30
Music Quiz with Steve Gates
Centre open until 3.30
QUIZ NIGHT AT FISHERMAN'S CLUB
- FRIDAY 5TH CENTRE OPEN 10.30 - 3.30
Yoga commences 9.30
- SUNDAY 7TH XMAS LUNCH
AT THE LANGHAM HOTEL
- MON 8TH CENTRE OPEN 10.30 - 3.30
- TUES 9TH CENTRE OPEN 10.30 - 3.30
- WED 10TH LUNCHING CLUB
Please ring Joyce to book
- THURS 11TH CENTRE OPEN 10.30 - 3.30
LADIES XMAS LUNCH OUTING
- FRIDAY 12TH CENTRE OPEN 10.30 - 3.30
- SATURDAY 13TH ARNDALE CAR DRAW

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

A 'BC' ROUNDUP OF RECENT EVENTS (1)
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I just called to say...

During the week 10th - 14th November we are embarking on:

'Fone the Family' - The MS Family

With the exception of committee members and members in residential care it is our intention to telephone every single member of the branch! It will be the biggest survey that the branch has ever carried out *and we need your support please.*

It has long been my opinion that as a committee we need to know that we are fully representing *you* and *your* concerns. It will be your opportunity to tell us what you think and what you feel we could improve on. If we are getting something wrong...please tell us. Equally, if we are getting it right...we would like to know.

We have a good team of volunteers assembled to make a fixed number of calls each and we would appreciate the answers to a few questions. Please give our callers ten minutes or so of your time. They will clearly identify themselves so please take the opportunity to have your say.

This is *your* branch and we are your elected representatives and in a fast-changing world we need to know that we have embraced those changes and that we are addressing the issues that are important to *you*. So, brickbat and bouquet time! Thank you in advance for your support. *(more details page 15)*

Margaret and the Happy Volunteers!

A very big 'thank you' to Margaret Davis for interviewing all of our volunteers as part of our Community Programme. Thank you also to our volunteers for taking part. The results indicate that our band of volunteers are pretty happy with their lot! There were two requests to attend a first aid course which have been immediately dealt with and vehicle escort training will be increased through Len. To maintain our Community Programme we really need more volunteers...come and join us!

It has been an absolute blessing having Margaret come on board with us. We have numerous new projects in the pipeline and she has already shown her dedication to the branch in a number of areas. Of course, her credentials are top of the range - her husband Tony is one of the founder members of our intellectual think-tank, more commonly known as the Monday Men! Good to have you with us Margaret.

Taking a risk!

Behind the scenes a huge amount of work has been undertaken by Margaret and Len with regard to our Risk Assessment on behalf of the branch. Our Risk Assessment has now been accepted as complete by the National Centre and they have been extremely complimentary about the way it has been researched and implemented. Sincere thanks to Margaret and Len for the many hours spent in completing this under Health and Safety requirements.

MS Essentials 13: Claiming DLA

This guide to claiming Disability Living Allowance (DLA) has been updated to take into account changes to the layout of the new DLA claim form. The substance of the questions on the form has not changed.

The new DLA claim form will now be in use so please ensure that if you are using 'MS Essentials 13: Claiming DLA' that it is marked 'Fifth edition' on the front cover.

Copies of the new MS Essentials 13 will be available from our Centre.

Regional Forum

Margaret, Joyce and I attended the Regional Forum at Crawley on Saturday 18 October. It's good to meet committee members of other branches in the region. Two recurring themes really dominated the day for all of us - the need to find new sources of funding and the shortage of volunteers. Certainly, the two major issues that take up so much of my time. Thank you to Margaret and Joyce for giving up their day.

**Let's lunch....together**

Oh yes...it's that time again!

Tucked away in this

'Mainstream'...your Christmas Lunch Menu and Order Form. PLEASE complete and return ASAP with your cheque. For those of you good folk requiring transport...please get your order to us now. Remember, we normally have the best part of 100 members booking up for the Christmas Lunch and many use branch transport. This is a large gathering to organise - please help us by making sure that your order is in by **Monday 24th November** at the very latest. We will organise a mega raffle as usual - so please donate a prize if you are able to. It is an excellent event for me to be able to see some of you for a natter...so get that Order Form and cheque back pretty smartish! Thank you.

Joyce's Jottings

. . . and then we got lost!

On a sunny Saturday morning, Bernard Margaret and I set off for a Branch Officers' meeting in Crawley. We were, as usual, putting the MS world to rights and enjoying the sight of many Volkswagen camper vans trundling down the motorway towards a rally at Brighton Marina. We suddenly realised we were near junction 10; we had to turn off for Crawley at junction 11 – but the next junction was 9, the signs did not go in the direction we expected!

We duly left the motorway and found our way to Crawley – but we didn't have the vaguest idea how to get to the Hawth Theatre. After some aimless driving around we stopped at a burger van and Bernard valiantly went to ask for directions. You may be able to picture him, in his suit and tie, barging through a throng of road workers patiently waiting for their burgers and fries. The girl serving came up trumps though and wrote Bernard detailed directions to our destination while her onions burned and the queue got more and more restless. Margaret and I were just beginning to think he's been abducted when he appeared – triumphant at his success and informing us that it took a man to sort out the mess made by two women getting him lost. I won't repeat what we said to him, as *he* was supposedly the navigator . . .

Anyway, the directions were perfect and we arrived on time for a really intense day of MS Branch business. I think we did a good job representing our Branch, but no-one knew of the trials and tribulations of our journey.

We need more money . . .

We are finding it increasingly difficult to find new sources of funds, and as we have to be totally self-funding this is now a cause of real concern to us. Margaret, Bernard and I recently went to a funding surgery in Heathfield, being held in partnership between Wealden District Council and the Eastbourne Association of Voluntary Services. We successfully managed not to get lost this time and had a very interesting meeting to discuss our funding needs and hopefully get some new ideas. We were not very heartened to be told that there is not much money available to go round everyone who deserves it – a fact of which we are only too well aware. We were

given one possible new source we had not previously heard of: The Tudor Trust.

The next morning I decided to research the Trust; they appeared to be just right for us so I rang them. They were very pleasant and helpful, and we appeared to meet all their criteria but the bottom line was that they do not fund organisations dealing with physical disabilities and no amount of spin could persuade them that we qualified – I did try very hard! This was a new one for me, I am used to Trusts not funding branches of National Charities, not funding core costs, and not funding salaries – *but physical disabilities?*

You can see from the above that things are getting fairly desperate, but we never give up and there are still others to try although we do need to be less reliant on Trusts and Foundations and find new ways to raise money. The quiz in December should easily raise £1,000, but we need something of this size at least every month of the year. I would be really grateful for any ideas you may have – the more original the better as we need to be different from all the other charities chasing money. It was comparatively easy to raise the money for the new minibus; people like a tangible outcome, but it is much more difficult to get the public interested in helping with our welfare work and Centre running expenses.

How can we make the public realise what a good job we do? How do we make ourselves stand out from the masses? These questions are giving me quite a headache so please contact me with any suggestions, however daft they may seem – the only rule if that any activity must not cost us any money – we are totally against the type of charity that loses 50% of its income to expenses.

We have some exciting ideas in the pipeline, but these can never be enough. I know we have a loyal and caring membership and we will really need your help and enthusiasm to see us through the difficult times ahead.

Joyce

-
- Q. How many women does it take to lose BC
 A. Two! (See '*...and then we got lost*' above)
 Q. How many men does it take to rescue two women
 A. Just one 'BC' (See '*...and then we got lost*' above)

I rest my case...BC!!!!

A 'BC' ROUNDUP OF RECENT EVENTS (2)
--

S.W.A.G.....job done!

I mentioned in 'Mainstream' last month that I felt that our Scooter & Wheelchair Action Group (SWAG) had done its job. It had reached a stage where it was simply duplicating the work of other groups. Added to that, other action groups already have such a strong Branch representation:

Eastbourne Access Group:
Chaired by our Ian Westgate

Seaford/Lewes Access Group:
Chaired by our Zena Gibbs

Disability Involvement Group (DIG)
I serve on this with our Ian Westgate,
Shirley McCall and Anita Keall

PCT Wheelchair Service Strategy Group
Our Shirley McCall represents us

I will recommend to the full committee on November 1st that we disband the SWAG.

Granted!

In the next few weeks I will be working with Margaret and Joyce on grant applications to the Borough, District and County Councils. I am hoping we will have some success for 2009 as part of our partnership working programme. However, we have to accept that so many are applying for a share of the same pot.

BC & Cardiopulmonary resuscitation!!

Check this out - I have been on a First Aid Course! Well, not just me - thankfully a good number of our volunteers were on the course with me. Thank you to every one of you for giving up your morning. It was an excellent course and I am really glad that I was actually required to complete it, because I am so often in attendance at our Centre. I bet our MS Nurse Vicky will be impressed on her return - I will be all white coat and stethoscope by then!!

The Eastbourne parking saga

Margaret and I attended the town centre demonstration with Lib-Dem councillors...it's not a last ditch stand that's for sure. If you have any problems regarding parking for the disabled just give Ian a call on 763226. I think we should all feel very proud of Ian and the stand he has taken, and continues to take, with East Sussex County Council on behalf of disabled folk.

Update on PCT Wheelchair & Special Seating Meetings

from Shirley McCall

I attended the September meeting which unfortunately overran due to the previous meeting having been cancelled due to annual leave. We had to vacate the board room before all the business was finished and my taxi was waiting.

I did however have the opportunity to high-light two outstanding matters:-

1. The unacceptable waiting times for assessments in the East Sussex Downs and Weald area.
2. The need for clarity regarding eligibility criteria for EPIOCS (Electric Powered In Door Outdoor Chairs)

The long wait for assessments has apparently been due to insufficient hours and the need for a new Band 6 Occupational Therapist. I was assured that a therapist with all the qualifications required has now been appointed and will commence their new post in October. I am hopeful that we shall soon all see some improvement in Assessment waiting times.

Once equipment is ordered delivery times have improved in latter months so here's hoping that with more working hours the assessment times will also show much needed improvement.

Relating to eligibility for EPIOC Chairs. If a client feels that they could benefit from an indoor outdoor wheel chair they can contact the wheel chair service and ask for a criteria pack. This will explain how the assessments are made and then if you feel you comply with the criteria it is worth completing an application form.

It was agreed at the meeting that the EPIOC Criteria be included in the work programme and service users can be involved in the development of the new criteria. **Shirley**

Poster people...

Thanks to John Simmons and Sue Austin for all their work in getting our 'Volunteers Required' posters out to so many new venues. It is a lot of work to take on. We are hoping to get an advertising campaign going on the buses. If you can give a few hours to us, please call me or Margaret. As the Branch grows - we need more of you to volunteer a little time please.

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

From our former Branch Chaplain Rev. Howard John

Is there still a role for Remembrance Day?
Many people seem have lost interest in the Day. Few observe the silence in public places; memories of the world wars are fading.

Some say it is outdated, that the time for remembering those who died in past wars is over. Some even suggest that the Day glorifies war and encourages people to think that it is acceptable.

But surely this misses the point. It confuses honouring the memory of those who've died, with honouring the things they found themselves having to do in a struggle that none of them really wanted to be a part of, but believed that they had to take part in if others were to live in freedom and peace.

It is certainly not a time to say that war is good or honourable. Rather is it a time when, as we recall those who lost their lives in conflict, we remember just why they did what they did, and rededicate ourselves to living in such a way that we don't break faith with them; that we commit ourselves again to the struggle against the things that lead to war.

Remembrance Day gives us an opportunity to renew our belief in the possibility of peace and to be actively involved in making peace. It's very clear that when the Bible writers talk about peace they're not just speaking about cease-fire agreements or a thaw in relationships.

Martin Luther King defined it well when he said that ...
"real peace is not just the absence of hostilities or tension; real peace is the removal of those underlying conditions of injustice and exploitation which fan the flames of resentment and which finally lead to war."

We need to be very clear about this, because one of the greatest pieces of nonsense is that peace will come if you do nothing. Peace has to be made; it is active. The genuine peacemaker is a fighter – he confronts prejudice, lies and injustice; he stands up to the bully.

And peace making starts right where we are, with our attitudes towards injustice around us, it concerns the rights of deprived people, it includes our relationships at home and among our neighbours.

It is right for the community to remember its collective past and gather up the lessons to be learnt for the future. It should be a vital resource for a growing generation as they seek peace and justice in the world.

Howard John

Meet to Share

SOCIAL AND SUPPORT GROUP FOR LADIES

Our next lunch is on:
24th November at 12.45pm
Coopers - Stone Cross
Hope to see you all there!

Christmas Lunch

I have arranged lunch at:
The Hydro Hotel
15th December at 12.45pm

The cost is £17.50 for a very nice choice of Christmas food plus coffee and mints. Can you please phone me if you would like to come (that's if you haven't already done so). I can't believe Christmas has come round so fast!

Don't forget the Quiz Night. It's at the Fisherman's Club on Thursday 4th December at 7.30pm. Try to get a team together. Let's try and beat The Monday Men!!

Seaford Group

Still waiting to hear from you on my idea for an early evening dinner. Can you please phone or email me...contact details below:

TELEPHONE: 01323 736359
EMAIL: SueAustin50@aol.com

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!

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

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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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(Reg. Charity No. 207495)

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FUNDRAISING & DONATIONS MONTHLY UPDATE FROM MARGARET

BACS September transfers from the National Centre: Channel Swim sponsorship **£393.19**

£190.96 Tesco store collection - Oct 6th

£197.52 Tesco store collection - Oct 14th

£35 Anonymous general donation

£25 Anonymous general donation

£51 Centre coffee morning

£63.60 Arndale (Volunteer event)

£155.20 Centre collecting tins

£50 Sovereign Radio 'Carer of the Year' event

THANK YOU TO YOU ALL FOR YOUR SUPPORT

FROM OUR WEBSITE Oct/Nov

*We are featuring a volunteer online each month
This month we have **two** special volunteers*

Introducing our Volunteers of Month

Eve Potter and Marjorie Miller

Our longest serving volunteers

Eve joined us in October 1986 after seeing an article in the local paper asking for someone to help with teas. Since then she has been invaluable in keeping us all fed and watered! She served on the Committee for 17 years with just two short breaks.

Marj arrived in 1987 when St John's Ambulance asked for volunteers for the MS Society. She was an escort on our ambulance for many years before retiring, and now helps Eve in the kitchen.

Both these redoubtable ladies have received the MS Shining Star Award in recognition of their outstanding services to our Branch.

The perils of pavements and kerbs!

from Margaret-Clare Fuhrmann

I am thankful to have my first motorized wheelchair and have enjoyed my outings by the sea and to the shops.

I have been finding out where the dropped-kerbs are and (perhaps more importantly) where they are not. Some dropped-kerbs are in poor condition - I'm sure they started out okay, it's the motorists driving onto them or even parking on them that cause the break-ups.

My best way of getting to the Town Centre is straight up to the seafront and then over the roads at the pier with their good dropped kerbs. This is fine in good weather but I'd sooner go the shorter route when it's raining. I've tried this once (Whitley Road, Firlie Road, Ashford Road) but the terrain and dropped berbs are a nightmare.

My own road has mostly paving stones; horribly uneven, punishing on my spine and on my chair. In fact *wherever* there's pavement, it is dangerous to pedestrians and very uncomfortable for users of scooters and wheelchairs and for children in buggies - wow, talk about "rock-a-bye-baby"!

All the walkways in Eastbourne have patches of asphalt replacing broken paving. Would it not be cost-saving to completely asphalt all the walkways instead of sending workers out to deal with the most uneven bits piecemeal? It doesn't have to be black asphalt, there are attractive greens and pinks available. Yes - there will still be vehicles causing sinkage but asphalt must be easier to repair than paving, surely?

Margaret-Clare

The D.I.G in 2009...

Margaret-Clare (above) has raised a number of very important issues regarding our roads and pavements.

The Disability Involvement Group (DIG) working with Eastbourne Access will be making dropped kerbs a major campaign next year. Somehow, we also have to make motorists aware of them. We are not allowed to have a white line painted on ours outside of the Centre - with the result that if motorists aren't parked illegally in our ambulance bay they are parked across the dropped kerb.

BC

IAN'S INFORMATION DESK - TELEPHONE 01323 763226

Developments in technology may help diagnose MS in the future

01 Oct 2008

Scientists at the University of Leeds have developed a hand-held device that they claim can test for serious conditions including multiple sclerosis (MS), using a tiny sample of blood or urine.

If trials are successful the researchers hope the technology could be available in three to five years.

The device works by looking for tell-tale signs of a condition from the molecules present in the blood (called biomarkers).

Dr Laura Bell, Research Communications Officer at the MS Society said

"Currently there are no biomarkers which are known to predict MS, either in the blood or urine.

"Many people, including the MS Society, are carrying out research trying to find biomarkers for MS. A simple blood or urine test would be preferable to lumbar punctures or expensive MRI scans, the results of which can take a long time to obtain.

"Research looking for biomarkers is in the early stages, but hopefully, if they can be discovered, in the future this technology could be useful to help diagnose MS and also potentially help ascertain the benefits of experimental drugs in clinical trials."

THEY ARE AT IT AGAIN!

IF YOU RECEIVE ANYTHING AT ALL BY THE POST OR ON YOUR COMPUTER SAYING YOUR BANK, BUILDING SOCIETY OR ANY OTHER FINANCIAL SERVICE YOU ARE USING OR HAVE USED IN THE PAST AND IT SAYS IN ORDER TO CONFIRM YOUR ACCOUNT STATUS (or similar) PLEASE COMPLETE THE FOLLOWING.....

DO NOTHING – IT IS A SCAM!

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REMEMBER – YOUR BANK OR BUILDING SOCIETY KNOW YOUR DETAILS AND WOULD NEVER ASK YOU TO CONFIRM ANYTHING OF THIS NATURE.

www.mssesw.org.uk

**HAVE YOU BEEN THERE YET?
NO!!! – You don't know what you're missing!**

'Fart gas' link to blood pressure

The gas best known for being used in many stink bombs may also control blood pressure, say US researchers.

Small amounts of hydrogen sulphide - a toxic gas generated by bacteria living in the human gut - are responsible for the foul odour of flatulence. But it seems the gas is also produced by an enzyme in blood vessels where it relaxes them and lowers blood pressure.

The findings in mice may lead to new treatments for high blood pressure, the Science journal reported.

Researchers at Johns Hopkins University, in Maryland, found that the gas is produced in the cells lining blood vessels by an enzyme called CSE.

**"We know hydrogen sulphide is not good for us at high levels but it seems that at the lower levels in the body it is essential".
(Professor Amrita Ahluwalia)**

In mice engineered to be deficient in this enzyme, levels of hydrogen sulphide were almost depleted compared with levels in normal mice. The CSE-deficient mice also had blood pressure measurements about 20% higher than the normal mice, comparable to serious hypertension in humans.

BBC NEWS CHANNEL

25/OCT/08

Drug may reverse MS brain damage

By Richard Warry, BBC News website Health Editor
Michael Kahn LONDON (Reuters) Oct. 24th 2008

A drug developed to treat leukaemia may be a powerful new weapon against multiple sclerosis, researchers say.

Alemtuzumab* 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 (USA) 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.

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."

* **Alemtuzumab** – marketed under the name of **Campath** was first used in humans in the early 1980s to treat a form of leukaemia.

YOUNG CARERS

Halloween (all Hallows eve) seems a strange excuse for celebrating, but the party we had planned for Halloween for our youngsters was just exceptional – Thank you Clare. The next excuse for a party will be Christmas, but hey, who needs an excuse? Our Young Carers will be taking a trip to the Panto before Christmas this year, so if you've had one of my letters, be sure to send back the reply in plenty of time. The booking has been made at the theatre, provisionally, but I must confirm and pay for the seats in plenty of time, or they might sell them to someone else! We can't have that now can we? (Oh yes they will.....OH NO THEY WON'T!) All our Youngsters are kept informed and get invited to our activities, but I remain concerned that there may be youngsters out there that I don't know about. So I am relying on you – the reader, to let me know if I have missed anyone. Please refer to last months Mainstream regarding our revised approach to our Young Carers group.

Our pre-schoolers have the opportunity to see 'The Tiger that came to Tea' at the Winter Garden early in November, so I am rather disappointed that my youngest is just a bit too old for it now!

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 programme is coming together nicely, thank you Margaret and thank you Barbara. We now have a flower party with a festive theme booked for Thursday 13th November, with a pub(!)(General Knowledge) Quiz booked for the 20th. That should prove to be good fun, as well as good practise for the Fishermens quiz night which is on 4th December. And to keep those brains from going rusty, the Ladies will be having another quiz at the Centre, also on the morning of Thursday 4th December, but this time with a festive theme.

Our Christmas dinner will be the following week on 11th December at Coopers in Stone Cross, with the Ladies Christmas party the week after,

which is the last Ladies Thursday meeting before Christmas.

All these fun things coming up, and you don't have to remember to book for any of them (just turn up) APART from the Christmas dinner at Coopers. They do a three course festive menu for £7.95, (pay on the day) and I only need to know if you wish to come, so that we can ensure that we reserve enough seats. These cannot be booked in advance, but we will have an advance party going, to make sure we have enough seats saved on the day. So let me know if you wish to come as soon as you like, and I will add you to my list for reserved seats. No limit to numbers!

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

If you have any queries give me a call on 01323 439447.

Best Wishes,

Janet

THE CLOUD POEM

CLOUDS ARE FLUFFY, CLOUDS ARE WHITE,

SOME ARE DULL, SOME ARE BRIGHT.

THEY FLOAT ALONG SO VERY HIGH,

BREAKING UP IN THE BLUE, BLUE SKY.

THE SHAPES THEY FORM ARE DIFFERENT
EVERY TIME,

THEY BOB ALONG AND ARE SO FINE.

THE SUN BREAKS THROUGH THE SPACES THAT
THEY LEAVE,

AEROPLANES FLY BY WITH TRAILS AS THEY
WEAVE

Diane Hewitt

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

PLEASE REMEMBER TO RETURN YOUR ORDER
FORMS FOR THE BRANCH CHRISTMAS LUNCH
AT THE LANGHAM HOTEL ASAP
NOVEMBER 24TH IS THE LATEST DATE

The Judy Parker Column

Following my last report about the availability of radar keys for access to disabled toilets I learnt from one of the security staff in the Arndale Centre that we can buy one from the Shopmobility venue. Or ask one of the security staff, all of whom have a key to let you through the door!

I would also urge all of you that have a Lifeline pendant to **WEAR IT AT ALL TIMES** - either around your neck or pinned to clothing. I have got into the habit of placing mine around my neck as soon as I get out of bed! No point having one if it's stored somewhere around your home and not instantly accessible when needed.

I have a dentist giving me a home visit towards the end of the month - thanks to one of our members who informed me that 'home dentists' are available - you'll need to get a referral from your GP. If treatment is necessary this particular practice will provide transport to the surgery which is in Milfoil Drive.

Your GP may also be able to recommend chiropodists who are able to treat you at home if you have mobility problems.

As I wrote about Boots 'helpfulness' in my last report I have taken a copy of the October 'Mainstream' in for the Manager's benefit!

So Christmas will soon be with us again and I would strongly recommend you support our Branch by ordering as much as possible from the new MS Catalogue - a copy of which is in the Centre.

Don't forget to contact me if you have any additions you'd like included in this column. You may see me at the Centre on a Thursday (Ladies Group) or give me a ring at home.

Judy

01323 486478

THE LATE MR TERRY THOW

Very sadly, my Carol has lost her very good friend Terry Thow to cancer. I first met Terry when we were at the Golfing Park with the Luncheon Club on a 'dining-out' day. He asked me about MS and some of the people with us. When Carol visited him he would always ask about the branch and he subsequently became a very generous supporter of our work, making substantial donations to the branch.

Despite his cancer, he was touched by people with long-term conditions and we are grateful for his generosity.

Our love and prayers go to his family and to Carol at this time.

Bernard

Hands off!!

A petition to demand the Government diverts no more National Lottery money to pay for the 2012 Olympics has been started by a network of funding advisers. The Government took £638m from lottery funds last year to pay for the rising cost of the games.

The petition from the Funding Advisers Forum reads: "*Lottery funds should benefit the voluntary and community sector, not the Government. Lottery funds are diminishing and the voluntary sector is suffering from a lack of investment opportunities.*"

A statement added: "*Despite promises from the Government to the contrary, the recent cut in this year's lottery funding shows that the Government's raids on the lottery to fund the 2012 Olympics are having a detrimental impact on community projects.*"

Source: www.thirdsector.co.uk

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

On the Buses!

We will shortly have posters on all the buses appealing for volunteers. Combined with the efforts of Sue and John (see page 5) we are making every effort to get badly needed help. If **you** can give us some help it would be more than appreciated. The 'few' are becoming increasingly overloaded with work.

BC

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

MAINSTREAMING WITH MARGARET

I hope my article finds you all keeping as well as possible, here is a little bit of news and views to keep you all updated.

Following on from my article in last months Mainstream regarding the centralization of Membership, it was even a surprise to me when I received an e-mail with my own details for renewal. When I spoke to the National Centre, the first batch of 5,000 renewals has already been sent electronically nationwide, and nearly 1,000 have already renewed. It will be interesting to see the percentage that has opted for electronic / telephone renewal. Not everyone will use this method but it certainly seems the way forward.

On a personal note the new proposed Fitness First project is a really exciting step forward. With this new service it will be a wonderful opportunity for people affected by MS to have a more flexible approach to their own personal needs. I am delighted that carers will also have the opportunity to be involved with the project. Back support and strengthening is so important when you are caring, and I would like to see as many carers as possible join the new scheme. Please do not hesitate to contact me if you would like to have a personal chat as I would be pleased to hear from you.

The coffee morning combined with the Christmas catalogue orders went very well. It was lovely to see some new and some returned faces in the Centre – special thank you to everyone for coming. It was a very pleasant morning and quite a cheery gathering, everyone deciding on what they wanted to order and we were very keen if our order came to over £25 as we were eligible for a free gift. We all like the free gifts, it was claimed the free gifts covered a price range; however at this stage everyone seems to have

received several packets of flower seeds. It will be interesting to see my free gift when it arrives – I will let you all know...

A First Aid course was arranged in October and the people who attended in the Centre really enjoyed themselves and thought it all very worthwhile. Bernard was on the course and was really pleased with the training, we may never need these things but in life you never know.

Likewise risk assessments have been completed regarding our transport operation – we are required to maintain high standards of Health and Safety. The replacement chairs are being ordered today, it will be good to have some new furniture in the Centre. The present chairs which were second hand and donated by the Royal Bank of Scotland when we opened the Centre; have done us proud as they say.

The next couple of months ahead are going to be really busy, with meetings planned and new projects in the pipeline plus fundraising events it will certainly keep us all on our toes. The raffle prizes for the quiz night on the 4th December are going fairly well – so thank you to all of those who have donated so far. We are keen to find a sponsor for the 1st prize money for the actual quiz itself i.e. £100, if you are able to help us with this, please give Bernard or myself a ring – thank you.

The annual Xmas Lunch details are enclosed with the magazine; it is always lovely to see as many of you as possible... please return the details as soon as you can thank you.

That is all for the moment, take care and I will catch up again next time

Margaret

Telephone: 01323 439447
Email: Margaret.Barrett@btinternet.com
Website: www.mssesw.org.uk



AN ASSOCIATION OF GENTLEMEN REPRESENTING
THE EASTBOURNE & SOUTH WEALDEN MS SOCIETY

MONDAY 10TH NOVEMBER

Dining Out - Venue to be arranged

MONDAY 24TH NOVEMBER

Lunch at the Centre

MONDAY 1ST DECEMBER

XMAS LUNCH AT THE GOLDEN GALLEON

**ALL GENTLEMEN WELCOME...
COME AND JOIN US.**

Contact BC on 439447 or 508969

Help in everyday living...

The following are all updated information and advice telephone numbers and websites for older people, those with disabilities and those who care for them.

Direct.gov.uk

A public information website from the government. www.direct.gov.uk

Benefits Enquiry Line

Freephone 0800 882 200

Counsel and Care

Advice and information for elderly people, their families and carers.

Phone 0845 300 7585

www.counselandcare.org.uk

Carers UK

Advice and information for carers

Phone 0808 808 7777

www.carersuk.org

Older People's Advocacy Alliance

Provides information on independent advocacy for elderly people

Phone 01543 490861

www.opaal.org.uk

**'Fone the family'...The MS Family
What we need to know**

On page three I have announced our plan to telephone all members of the Branch during the week 10th - 14th November. So, what do we need to know? It's very simple really. *Are we truly representing your interests?*

I believe there comes a time when we need to stop - and listen! We have developed a number of new services over the past few years and established new groups - but are **you** being represented?

As a committee it is our responsibility to see that you have a voice and that your particular concerns are given the same importance as the more general issues that face people affected by MS.

Information and signposting are key to the success of the Branch and part of **BRANCHOUT**, the MS Society's campaign to transform local services. Thanks to Margaret and Ian we have a huge amount of evidence-based information available to all members. We also act as a 'signpost' to other services. It is not always the Branch that is best equipped to deal with a particular issue. We work with many other people and organisations; so if you have a problem with a local taxi firm, the Wheelchair Clinic or any service provider - we can help by advising you who is best suited to deal with your concerns. It is not always the Branch.

I sincerely hope that during 'Fone the Family' week you will have had the opportunity to tell us what you think of us as a local representative body for all people affected by MS in our area.

And 'YES'...I do know that 'Fone' is very American!! But come on...it does read pretty good! (*I have been told off about it - and did I listen? No!*) Anyway, all I can ask you to do is to enter into the spirit of the exercise and give us a few minutes of your time.

The feedback will be discussed by the committee and published in the next 'Mainstream'. Please be assured that any personal feedback will be treated as confidential.

So, I look forward to 'Foning' some of you!
Thank you again for your support.

Bernard

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YOUNG CARERS Janet Forshaw	
ADULT CARERS OUTREACH & SUPPORT	Contact through Community Support Officer
MS INFORMATION Ian Westgate	ian@mssesw.org.uk
MENS GROUP 'The Monday Men' Bernard Curtis	bernard@mssesw.org.uk
TRANSPORT	Contact the MS Centre Manager or Chairman
PUBLIC RELATIONS Bernard Curtis	bernard@mssesw.org.uk
PHYSIOTHERAPY Ian Westgate	ian@mssesw.org.uk
YOGA Anita Keall	
MS NATIONAL HELPLINE	0808 800 8000
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MS NURSE SPECIALIST Vicky Lester	

Our MS Centre is independently funded and was established in February 2004 and officially opened in June 2005 by HRH The Duchess of Gloucester.
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