



# 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 6 OCTOBER 2008**

visit our website: [www.mssesw.org.uk](http://www.mssesw.org.uk)

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## 720 TAXIS



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Supporting Eastbourne & South Wealdon MS Society

WORKING IN PARTNERSHIP WITH



OCTOBER 2008

- MON 6<sup>TH</sup> CENTRE OPEN 10.30 - 3.30**  
**MONDAY MEN LUNCHING OUT**  
Venue to be arranged - somewhere nice - of course!
- TUES 7<sup>TH</sup> CENTRE OPEN 10.30 - 3.30**  
*TIME2TALK Drop-in & Phone-in Sessions*
- WED 8<sup>TH</sup> LUNCHEON CLUB**  
*Please ring Joyce to book*
- THURS 9<sup>TH</sup> LADIES GROUP 10.30 - 1.30**  
Centre open until 3.30
- FRIDAY 10<sup>TH</sup> CENTRE OPEN 10.30 - 3.30**  
**COFFEE MORNING 11am - 1pm**  
**MS CHRISTMAS CATALOGUE ORDERS**
- MON 13<sup>TH</sup> CENTRE OPEN 10.30 - 3.30**
- TUES 14<sup>TH</sup> CENTRE OPEN 10.30 - 3.30**
- WED 15<sup>TH</sup> LUNCHING OUT**  
Beachy Head - Vintage Inn  
*Booking essential. Please ring Joyce*
- THURS 16<sup>TH</sup> LADIES GROUP 10.30 - 1.30**  
Centre open until 3.30
- FRIDAY 17<sup>TH</sup> CENTRE OPEN 10.30 - 3.30**  
*Yoga commences 9.30*
- MON 20<sup>TH</sup> CENTRE OPEN 10.30 - 3.30**  
*First Aid Training 10.30 - 1pm*
- TUES 21<sup>ST</sup> CENTRE OPEN 10.30 - 3.30**
- WED 22<sup>ND</sup> LUNCHEON CLUB**  
*Please ring Joyce to book*
- THURS 23<sup>RD</sup> LADIES GROUP 10.30 - 1.30**  
Centre open until 3.30
- FRIDAY 24<sup>TH</sup> CENTRE OPEN 10.30 - 3.30**  
*Yoga commences 9.30*
- MON 27<sup>TH</sup> CENTRE OPEN 10.30 - 3.30**  
**MONDAY MEN LUNCH AT CENTRE**  
*Meet from 11am*
- TUES 28<sup>TH</sup> CENTRE OPEN 10.30 - 3.30**
- WED 29<sup>TH</sup> LUNCHEON CLUB**  
*Please ring Joyce to book*
- THURS 30<sup>TH</sup> LADIES GROUP 10.30 - 1.30**  
Centre open until 3.30
- FRIDAY 31<sup>ST</sup> CENTRE OPEN 10.30 - 12.30**  
*Yoga commences 9.30*

NOVEMBER 2008

- SATURDAY 1<sup>ST</sup> COMMITTEE MEETING 10.30**
- MON 3<sup>RD</sup> CENTRE OPEN 10.30 - 3.30**
- TUES 4<sup>TH</sup> CENTRE OPEN 10.30 - 3.30**  
*TIME2TALK Drop-in & Phone-in Sessions*
- WED 5<sup>TH</sup> LUNCHEON CLUB**  
*Please ring Joyce to book*  
Community Support Meeting 11am
- THURS 6<sup>TH</sup> LADIES GROUP 10.30 - 1.30**  
Centre open until 3.30
- FRIDAY 7<sup>TH</sup> CENTRE OPEN 10.30 - 3.30**  
*Yoga commences 9.30*
- MON 10<sup>TH</sup> CENTRE OPEN 10.30 - 3.30**  
**MONDAY MEN LUNCHING OUT**
- TUES 11<sup>TH</sup> CENTRE OPEN 10.30 - 3.30**
- WED 12<sup>TH</sup> LUNCHING OUT**  
Venue to be arranged  
*Booking essential. Please ring Joyce*

The Luncheon Club and Lunching Out are open to all - do come and join us for good food and good conversation

**PLEASE BOOK WITH JOYCE FOR BOTH THE 'LUNCHEON CLUB' AND 'LUNCHING OUT'**

**NEXT 'LUNCHING OUT' - WED 15<sup>TH</sup> OCT  
PRE-BOOKING ESSENTIAL**

*FOR INFORMATION ABOUT EVENTS AT OUR CENTRE OR FOR THE LUNCHEON CLUB OR 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

<b>A 'BC' ROUNDUP OF RECENT EVENTS</b>
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**National AGM**

It was excellent! I enjoyed the good company of Ian, Margaret, Joyce and Doreen. Sincere thanks to Len for a safe journey there and back. There's no denying that Simon Gillespie is determined to take the MS Society and its branches forward in the interests of all people affected by MS. Challenging times ahead and I think Simon will see that our voice is heard.

**Democracy for the disabled**

At long last disabled folk will be able to attend full council meetings at Eastbourne Town Hall. The Court Room is to be renovated and it will be fully accessible. It has been a long battle, but despite two councillors trying to thwart the plans, our Ian was there to help win the day and we now have a really good disability champion in Councillor Andrew Goodwin.

**Volunteer event**

The Volunteer event in the Arndale went extremely well. Let's hope we got our appeal across and that new volunteers come forward to help us. We certainly met a lot more people with, or affected by, MS. Sincere thanks to Margaret, Joyce, Sue and Tony and Margaret Davis. An excellent crew representing the branch *with our new MS banners!* (see page 13)

**'Just Diagnosed' and MS Essentials**

Just Diagnosed - an introduction to MS (Second edition) has been reviewed and updated to reflect the latest research. Still pocket-sized (A5), the new design allows more space for the notes and questions people have when just diagnosed.

MS Essentials 05: Vision and MS (Second edition) has been redesigned and has changed its colour from brown to blue. Updates include a new section on practical tips for coping with low vision. *Both publications are available from our Centre*

**PCT ANNUAL GENERAL MEETING**

Margaret and I attended the AGM of the East Sussex Downs and Weald Primary Care Trust on 25<sup>th</sup> September. Nigel Waterson MP (our Patron) asked if there would be a public apology over the fiasco to attempt to remove maternity services from Eastbourne. No such apology was forthcoming. Thank God for all those who fought so hard to keep maternity at our DGH.

**Searchlight**

Sincere thanks to Robert Stephens, General Manager of Searchlight Care Homes at Newhaven

for giving up time to conduct Margaret, Joyce, Sue and I around the homes. It was a very interesting and useful morning. Many MS folk have used the day services at Searchlight and we intend to have a closer link with them in the future.

**Disability Involvement Group (DIG)**

The DIG is now focusing on Access Eastbourne and I am delighted to be involved. The Borough Council logo is carried on the front of 'Mainstream' because I believe they are genuinely working in partnership with us. The 'big' disability issues in the town are now being identified and our voice is being heard.

**Eastbourne Access Group**

Congratulations to Ian! The Access Group has changed beyond all recognition under his chairmanship. I think we can now have confidence that access issues will be dealt with promptly and professionally. Ian's work on disabled parking issues under the soon-to-be-introduced scheme in Eastbourne is a credit to him...and he's a pretty good MS Vice-Chair as well!!

**Scooter & Wheelchair Action Group (SWAG)**

Once again I have personal reservations about the need to continue with the SWAG. Shirley very kindly took over the chairmanship for me when we felt the group had a future. However, duplicity is a waste of everybody's time. Three major issues: access under the DDA, drop kerbs and problems with the wheelchair clinic are being dealt with by the DIG, Eastbourne Access Group and the national MS Society.

Together, Ian and I are involved in all three and in addition we have the involvement of Anita Keall, Shirley McCall and Zena Gibbs. Our local MS Society has a huge representation on these groups - and they are groups with a far larger remit than SWAG. I see little point in hanging on to the SWAG for the sake of it. There are so few of us out there championing disability issues - having one less meeting to attend will be no hardship! All that matters is that we address the issues that are important to all people affected by MS. To do that effectively we must harness the support of the most influential groups.

## Joyce's Jottings

This month I can't think of a main subject, so I'll just pen a few words on a number of different topics:

### **The MS Society AGM**

In September I attended my first MS Society AGM at the Sofitel Hotel, London Heathrow Terminal Five. This brand new luxury hotel was just a shell when the Society took a leap of faith and booked it! We were among the first guests and as such we got to enjoy to five star facilities at three star prices. Each room had an enormous bed, walk-in shower, TV, computer link, towelling robe and slippers along with all the other attributes of a first class hotel. The first thing I did was turn off the air-conditioning – the room was freezing. However, we didn't have much time to enjoy the rooms – the MS Society kept us busy for the whole weekend.

There was an informal discussion on Working Locally followed by lunch and the by the AGM. Then dinner and a disco (I could mention BC's efforts to boogie on the dance floor – but I won't!)

The next morning Margaret was presenting a workshop on membership, accompanied by BC. Ian, Doreen and I went to a 'Drop in with a Director' session where we had an interesting discussion on the future of our Branch. After this there was a New Ways of Working Review followed by Sunday lunch and the journey home. It was an enjoyable and informative weekend, but incredibly tiring. We were very lucky in that Len drove us up there and then came back to bring us home. This was my first AGM and I hope it won't be my last.

### **Book Review**

A couple on months ago Judy reviewed 'A Life Interrupted' by Chris M Tatevosian. I've now read it and I'm afraid my view on this very American book is very different to Judy's. I found it really depressing that it took the author so many years to reach the realisation that he had allowed MS to destroy his marriage and effectively ruin his life. He has tried various disease-modifying drugs and is a firm believer in anti-depressants.

Had he lived Eastbourne he would have been offered support from when he was first diagnosed and we would have tried to make him realise that MS needn't be a tragedy. Yes, it's progressive and unpredictable but no-one in our area needs to battle alone.

### **What a Busy Diary I have these days**

We all know how hard Bernard and Margaret work on our behalf and I now find my diary increasingly full of MS Society commitments.

For instance, the week of the AGM I was busy for 7 days running – no wonder I was tired. I'm now on the third day of a four day 'break'. I may not be in the Centre, but I've had numerous MS Society phone calls to field, funding research to do on the computer and this article to write! This will be followed by three days of Society work – one in Crowborough, one in the MS Centre and one day trying to recruit new volunteers. All this effort certainly keeps me out of mischief and helps me to cope with MS. Volunteering has given me a new lease of life and just a couple of hours a week could change yours too!

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*Joyce is a Vice-Chair of our Branch and is actively involved in the running of the Branch at every level.*



**THE SCOOTER & WHEELCHAIR ACTION GROUP OF  
EASTBOURNE & SOUTH WEALDEN MS SOCIETY**  
MS SWAG Chairman: Shirley McCall

The next PCT Strategy Meeting is on October 3<sup>rd</sup> so I will have to give you feed back in the November issue when I hope to have a few answers to questions given me at our last SWAG meeting

I was invited to attend the PCT Annual General Meeting at the Lawn Tennis Centre in Eastbourne on Thursday September 25<sup>th</sup> to assist Sue Cobby with a small wheel chair and special seating presentation.

We had a very good attendance at our September SWAG meeting when Kirsty from Southern Rail came and gave a very interesting presentation on the help available for rail travellers with varying disabilities.

This included an update on Station improvements such as installation of lifts and ramps at stations in the South that were in the past unsuitable for wheel chair users. It is also good to know that all new car parks adjacent to railway stations are to have dropped kerbs for easier access automatically sited.

It was also noted that Southern Rail are working with South East Health Limited who have expressed an interest in developing and operating a drop in health clinic off the concourse at Eastbourne Station.

Contact Details for Southern Assisted Travel are:-

Tel:0800 138 1016 (24 hours free phone)

Fax: 0800 138 1017

Textphone: 0800 138 1018

Email; [myjourney@southernrailway.com](mailto:myjourney@southernrailway.com)

Post: Southern Assisted Travel, PO Box 277, Tonbridge, Kent, TN9 2ZP

Website: [www.southernrailway.com](http://www.southernrailway.com)

[www.southernrailway.com/accessability](http://www.southernrailway.com/accessability)

**Shirley**

## Meet to Share

SOCIAL AND SUPPORT GROUP FOR LADIES

### TWO IMPORTANT NEWS ITEMS FROM SUE THIS MONTH

#### Coffee Morning

Firstly I would like to thank Jill Warrender and family for agreeing to hold a coffee morning at her home. It was a great gathering of neighbours and friends. The weather could not have been better, a lovely sunny morning. Jill, and her daughters Julie and Sally had made a fantastic selection of cakes and some lovely greetings cards. Also thanks to Jill's husband Andy for his help. Needless to say all the cakes were sold. We all had a really enjoyable morning and made an amazing **£210.81**. Many thanks to all our friends, families and neighbours for making it a great success and for supporting MS. Hopefully we will hold another coffee morning in the spring. Next time even bigger and better!

**Sue**

#### Newly-diagnosed group - Seaford

On Monday 8<sup>th</sup> September, Bernard, Margaret and Joyce joined some members and myself to have lunch at The Premium Inn, Newhaven, We all had a very enjoyable lunch and a good chat. Unfortunately some members were unable to attend due to various circumstances.

I will be arranging another meet up soon.

**But first I would like your views on trying to arrange maybe an early evening meal over in the Seaford area.** I am open to suggestions.

Please could you either phone me or email me with your thoughts. It would be really nice to get a regular arrangement going. I look forward to your response and to seeing you all soon.

**Sue**

**TELEPHONE: 01323 736359**

**EMAIL: [SueAustin50@aol.com](mailto:SueAustin50@aol.com)**

The Editor...is editing!!

Due to the number of contributions this month I have actually had to edit some articles! I have also temporarily removed the free small ads from this edition due to space, but note the numbers for the following:

**Dave Tubbs 01323 440486 or 07932 139379**

**Gary Bennett 01323 503656 or 07939 171976**

**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**

Dear Friends,

Greetings to you all. According to Jesus, the greatest of all the commandments is to love God with all your heart, soul and mind. But, for many, it is not easy to love God when we see what the world has turned out to be. It is a far cry from the Garden of Eden to the world as we know it. Some people look upon God's handiwork as a shocking place. We see the vagaries of nature, and we are puzzled. We hear of hurricanes and tornadoes ripping through cities and towns, leaving destruction and sorrow in their wake.

We hear of famines decimating entire populations. We experience bruising winters and burning summers. There are floods and landslides and much more besides. Although much of this is ascribed to man's own folly - global warming - such things are described as '*acts of God*'. And what of our own lives? What of the loss of joy and the coming of grief? What of the moral fiascos and the spiritual disasters? What of the brutal dictatorships and the ethnic cleansings? What of the misfortunes turning many people's lives into miserable tragedies? No, it is not easy to love God.

This subject - the problem of suffering - is a topic of constant conversation and challenge for the church. As you might expect, the church looks to the Bible for an answer, more precisely, to the Old Testament Book of Job. Job, who was no stranger to almost every kind of suffering, misery and pain, was much wiser than we are when he said simply, '*The Lord gave, and the Lord hath taken away, blessed be the name of the Lord.*'

Why should we complain about misfortune and disaster when we fail to acknowledge all the good things that surround us in life. Life is like an alternating current - quiet and turbulent, leaving us alone and pushing us along. Life is what it is, and we must live it as it comes - with dignity and courage and understanding over the years our love for God becomes deep and broad. It reaches far. Such love is not easy.

With every good wish to you all.

**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](mailto:SueAustin50@aol.com)

All calls are confidential

*Talking really can help!*

**CHECK OUT OUR WEBSITE...  
REGULARLY UPDATED WITH NEW PHOTOS  
[www.mssesw.org.uk](http://www.mssesw.org.uk)**

**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](mailto:advice@dls.org.uk)



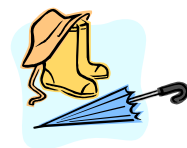
**THE RAIN POEM**

WHEN WILL THE RAIN STOP,  
PERHAPS WHEN WE PUT BACK THE CLOCKS.

DARK CLOUDS UP IN THE SKY,  
WATCH THEM FLOATING WAY UP HIGH.

PUDDLES LEFT ON THE GROUND,  
RESERVOIRS FILLING UP ARE FULL  
AND SOUND.

RAIN, RAIN, GO AWAY,  
COME AGAIN ANOTHER DAY.



**Diane Hewitt**

**Greetings from Gloucestershire.**

I had begun to think that Mainstream would never arrive, I have been having problems with my post and I was convinced that Bernard had forgotten me, but NO it arrived.

Congratulations, first of all, to Hilary, who has my membership Secretary task and Joyce, your new Fundraising Officer. Among the first things I read – and I always read it cover to cover – was BC's column about his years drawing to a close, the next page revealed Joyce's view on this. People, it will be a TRAGEDY if this happens and God alone knows what will happen to the branch, you may lose the Centre. The older Eastbourne members will remember the branch before the Centre and before Bernard. (Perhaps, Bernard that is an idea for a few pages in a future Mainstream of people's recollections of MS life in those days, I am sure it would make interesting reading. At the very least it would remind members what they may be going back to. I can certainly remember Margaret telling me about it - the days before transport, Mainstream, the Centre etc.)

Let me tell you about Cheltenham branch and perhaps you will get a sense of the difference. I met the Chairlady of Cheltenham at the beginning of August for a cup of coffee. Cheltenham is a branch the same size as Eastbourne in terms of members; perhaps it has a few more. They have a committee of 7 or 8 people, some are able bodied, two or three are in wheelchairs. The members meet once a month at social gatherings when they go somewhere, for example, the Willow Trust Boat Trip on September 9<sup>th</sup>. I cannot tell you about it as it was fully subscribed. Weekly, there is an art class held in a Church Hall in term time only; an exercise class; hydrotherapy sessions and a Conductive Education session (whatever that is).

The only fund raising they do are collections outside large supermarkets. I can understand this attitude to fundraising however as they don't have a Centre that

needs upkeep. Over here, we do not have an MS nurse, although there is one at Gloucester. It is only when Vicky is not available to you that you realise what a big psychological advantage it is to be in the proximity of one.

Cheltenham issue a newsletter which is 10 sides of A4 and covers pretty much what you are used to although it is not produced professionally as at Eastbourne. Have members thought that if BC leaves, Mainstream may be no more? You may remember that I am a Quaker and after a visit to the Quaker meeting in Cheltenham, I discover that people can choose to receive their Quaker newsletter by email. MS members here can do the same and it saves the branch money in stationary and postage. Does Eastbourne also do this now? If so, please put my email address on the list as I am more than happy to read it on-line and save the branch money.

I have been offered a position on a subcommittee to arrange events for the Branch but more on this another time. Meanwhile, take care of yourselves and each other.

**Ruth Brinkman**

*Really good to hear from you Ruth... 'Mainstream' is now online monthly on [www.mssesw.org.uk](http://www.mssesw.org.uk). Members will know, that until recently, Ruth was our Membership Secretary and a very active committee member - we all miss her **but** she did choose Gloucestershire over Sussex!!!*

**BC**

**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.

**A FEW CLICKS... AND YOU'RE THERE:  
[www.mssesw.org.uk](http://www.mssesw.org.uk)**

**ARE YOU A GENTLEMAN AFFECTED BY MS? COME AND BE A 'MONDAY MAN'!**

## **MP PLUMBING AND HEATING**

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Recommended by Eastbourne & South Wealden MS Society

### **Free**

Manual Chair & Three-wheel Walker  
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Telephone Ron on 01323 762425

### **For Sale**

3 wheeled Electric Scooter 'Shoprider'  
Well maintained - about 5 years old £600

Plastic outdoor shelter for above £120

Please contact Margaret on  
439447 or 723418

### **For Sale**

Invacare Storm Powerchair (approx 5 yrs old)

Enigma foldable Powerchair  
£250 each

Hampden Park area - buyer collects  
For further details contact Ron on  
01323 505326

## **Membership of the MS Society Important Notice**

At the National AGM we were invited to take part in the presentation at the Membership workshop.

We were one of the first branches to join the centralised database at the National Centre in 2006. It is successful, providing different methods of payment for members, reducing administration work and therefore enabling us to increase our work in the community.

The centralised database is now being rolled out to all branches. Membership is the lifeblood of the Society; we highlighted in our presentation our recruitment of new members. The support services of the MS Nurse, newly diagnosed groups, information leaflets and encouraging people to be part of the local MS Community.

From now on, there will be no distinction between national and branch members: everyone will simply be a member of the MS Society. The initial renewal mailing for 2009 will be sent to all members in October, with a reminder being sent in either November or December.

**With effect from January 2009 branches will receive from the National Centre the £5 membership fee for all members in their area.**

Any Gift Aid claimed will be distributed to the National Centres in England, Wales, Scotland and Northern Ireland. Please note, when members join or renew, they will be asked where they wish any additional donation to go – locally or nationally. When a member states no preference, it will be split between being used nationally and locally. All donations assigned to be used locally will be passed to the branch. Please contact me if you would like to discuss any issues – many thanks.  
**Margaret**

**East Sussex residents can phone one number  
to get information about  
adult social care  
Social Care Direct 0845 60 80 191**

### **MS Society HELPLINES**

**EMAIL: [helpline@mssociety.org.uk](mailto:helpline@mssociety.org.uk)  
PHONE: 0808 800 8000**

## FUNDRAISING & DONATIONS MONTHLY UPDATE FROM MARGARET

### THANK YOU TO YOU ALL FOR YOUR SUPPORT

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Monies totalling **£2,413.38** transferred from the National Centre by BACS on 7 August:-

Margaret Fuhrman - Cake Break **£92.70**

Sponsorship monies:

Peter Boddy - **£874.87** Don Lower - **£880.00**

Rebecca Corteling-Rice - **£398.71** Others - **£45**

Gift Aid - **£14.10**

Members' donations - **£108.00**

**Plus** the Bus Service Operators Grant payment transfer of **£360.29**

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Western Lawns event **£36.00**

Sponsorship monies - Don Lower **£20**

Barclays Bank community match funding in respect of Hailsham Lions event - **£410.66**

Shop Collecting Tins - **£77.00**

Four Acre Trust Young Carers Grant **£2,436.00**

Donation in respect of birthday cake **£100**

Coffee morning **£210.81**

Anonymous donation towards transport **£50**

Boot fair fundraising **£25.20**

Members coin donation **£23.00**

In Memoriam - Geoff Moxon - **£350.00**

Anonymous cheque donations of **£40 & £150**

'Those You Have Loved' Concert **£576.00**

IF YOU CAN HOLD A FUNDRAISING EVENT FOR US,  
PLEASE REMEMBER TO CONTACT  
JOYCE, MARGARET OR BERNARD FOR  
SUPPORT MATERIAL, DISPLAY STANDS ETC.

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### Fundraising...a big 'thank you'(1)

A close inspection of the fundraising events in our favour (above) reveals the amazing amount of work put in by so many individuals who care for our branch. From cake-breaks to skydiving, cycling to coffee mornings, private collections and donations, shop tins... and a concert - it is all about making that special effort to raise funds and make donations to a branch that is totally self-funding. Thank you to every single person who so kindly makes an effort to raise money for us and to those of you who donate by Standing Order. **BC**

### FROM OUR WEBSITE Sept/Oct

*We are featuring a volunteer online each month*

### Introducing our Volunteer of Month

#### Ian Westgate

"I have been a volunteer in one guise or another for as long as I can remember beginning as a youth helping people wheelchair users do their Christmas shopping so it is indeed a huge irony that I am now a wheelchair user myself, sometimes calling on the services of today's volunteers.

Being a wheelchair user does not mean my volunteering days are over. With the Eastbourne and South Wealden MS Society I have found a new and satisfying volunteering role where disability is not a barrier.

As MS maintains its unrelenting progress, every new symptom presents a new challenge. Challenges I learn to manage with the help of others experiences using procedures and methods I am happy to pass on to those who follow.

The work I do as a volunteer overshadows the importance of my career work as I investigate and unravel the complex truth behind medical research headlines. Regular sessions at Brighton University helping future generations of therapists to understand the personal side of the MS patient is a truly rewarding experience and participating in clinical and equipment trials that may ultimately benefit both the newly and yet-to-be diagnosed is something I gain a high degree of satisfaction from. Knowing that those who went before helped to develop the medication I benefit from and hoping my contribution will similarly be of benefit to others in the future is priceless."

### Fundraising...a big 'thank you'(2)

Sincere thanks to Joyce for taking on the lead role in fundraising. It is time-consuming, tiring and, in the main, a thankless task. Few trusts and foundations will support branches of a national charity, and locally, so many are after the same small amount of money available. But Joyce plods on with a smile (or is it a grimace!). Please support her dedication by doing all you can to help us raise funds. New chairs for the Centre alone will cost a fortune, so if you can hold a coffee morning or make a special donation it would be so appreciated. **BC**

<b>IAN'S INFORMATION DESK - TELEPHONE 01323 763226</b>
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## Scottish research highlights possible role of vitamin D in MS

15 Sep 2008

**A new report looking at the effect of Scotland's damp and cloudy climate on health highlights vitamin D deficiency as playing a role in a number of conditions - including MS.**

'Scotland's Health Deficit - An Explanation and a Plan', launched today by long-time vitamin D campaigner Dr Oliver Gillie, draws parallels between Scotland's weather and indicators of disease. Dr Gillie's thesis is that the high prevalence of MS in Scotland can be explained by less exposure to the sun and a move away from a fish-based diet high in vitamin D.

Dr Lee Dunster, head of research at the MS Society, said: "MS is more common further away from the equator and the lack of intense sunshine as you head north may lead to people getting less vitamin D, but the link with MS is not explicit and we need to know more.

"Current research doesn't support vitamin D as a therapy for MS, but there are reasons people with MS should look at their intake. It can reduce the risk of osteoporosis, which is important if you are less mobile, spend a lot of time indoors, or take long courses of steroids.

## Effects of glatiramer acetate on fatigue and days of absence from work in first-time treated relapsing-remitting multiple sclerosis.

[Ziemssen T](#), [Hoffman J](#), [Apfel R](#), [Kern S](#).

**MS Center, Neurological University Clinic, Technical University of Dresden, Germany.**

Treatment of multiple sclerosis patients with glatiramer acetate (Copaxone) has demonstrated a beneficial effect on disease activity. The objective of this research was to evaluate the impact of glatiramer acetate on fatigue and work absenteeism.

291 MS patients were treated with Copaxone and the levels of fatigue measured against an internationally accepted scale. (**Modified Fatigue Impact Scale**) and the results showed a marked improvement in fatigue tolerance.

An additional improvement experienced by the MS patients involved with this trial was the reduction in absenteeism from work.

## TWO GOOD REASONS FOR NOT BUYING A COMPUTER.

1/ - If you enter the words Bernard Curtis into a search engine you will find two entries about our chairman.

2/ - If you do the same with the words Ian Westgate you will also find two entries about **ME!!** And please – **Don't look under IMAGES**

A Worldwide Multiple Sclerosis survey has identified the areas/countries where MS is more prevalent.

The survey dated 18<sup>th</sup> September 2008 comes as no surprise as we learn that North America (both USA and Canada) has the highest number of MS cases per 100,000 population (over 100). Britain, Holland and Germany are in this group too but China, India and the few equatorial countries where statistical information is available, show 0-5 cases per 100,000 of population having confirmed MS.

It has long been suspected that the closer one gets to the tropics, the fewer instances of MS there are but the MS map now confirms this.

Sadly this is based on where individuals are born so emigrating to the Congo to seek a cure is not an option for us Europeans.

Australia has fewer cases per 100,000 than Britain and USA but they won't have us so unfortunately we are left to 'get on with it'.

To summarise, the best advice is to keep taking the tablets and continue reading MainStream because if I learn that a cure has been discovered anywhere in the world.....

# I'LL SEND YOU A POSTCARD!

## Neuroprotective effect of transplanted human embryonic stem cell-derived neural precursors in an animal model of multiple sclerosis.

[Aharonowiz M](#), [Einstein O](#), [Fainstein N](#), [Lassmann H](#), [Reubinoff B](#), [Ben-Hur T](#).

The Hadassah Human Embryonic Stem Cells Research Center, The Goldyne Savad Institute of Gene Therapy, Hadassah-Hebrew University Medical Center, Jerusalem, Israel.

A potential new therapeutic approach for MS is cell transplantation which may promote remyelination and suppress the inflammatory process. Human embryonic stem cells -derived early multipotent (**able to develop differently**) neural precursors into the brain ventricles of mice induced with experimental autoimmune irregularity, the animal model of MS. Researchers then studied the effect of the transplanted cells on the functional and pathological appearance of the disease. Transplanted significantly reduced the clinical signs of autoimmune system attack on myelin. Histological examination showed migration of the transplanted cells to the host white matter; however, differentiation to mature oligodendrocytes (**myelin producing cells**) and remyelination were negligible. Time course analysis of the evolution and progression of Central Nervous System inflammation and tissue injury showed an attenuation of the inflammatory process in transplanted animals, which was correlated with the reduction of both axonal (**nerve fibre**) damage and demyelination. Co-culture experiments showed that the human embryonic stem cells inhibited the activation and spread of lymph node-derived T cells in response to nonspecific polyclonal stimuli. The therapeutic effect of transplantation was not related to graft or host remyelination but was mediated by an immune system irregularity remyelination mechanism. The attenuation of auto immune irregularity by multipotent neural precursors derived, demonstrated in this experiment, may serve as the first step towards further developments of human derived stem cells for cell therapy in MS.

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## Society joins medical research awards

MS Society website 22 Sep 2008

**The MS Society has been recognised as the only charity in the country to join a new awards initiative by the Fulbright Commission (a US/UK body recognising promising medical research projects) which aims to develop the talent of some of Britain's most promising medical researchers.**

On 22<sup>nd</sup> September 2008, at a service to mark the 60th anniversary of the Fulbright Treaty, the Fulbright Commission announced the first wave of new awards.

Supported by UK universities, institutes of higher education and the MS Society, the new awards will increase by 30% the scholarships it gives by 2010 to over 60. The awards aim to support the British and American higher education systems to increase the exchange of post graduate students, researchers and faculty.

The MS Society's award – the Fulbright Multiple Sclerosis Society Research Award – enables a British researcher to study in the US.

## YOUNG CARERS

**GOOD NEWS** - Four Acre Trust will support us yet again for another year. That makes our Young Carers group very lucky indeed. Consequently Lynne and I have decided to undertake a review of the way things are done, and to make a fresh start. Letters have been sent to all families with Young Carers as follows : -

Our approach to Young Carers has recently undergone a review, and we are writing to you to let you know how future Young Carers forums will differ from those in the past, as we are making changes which we hope will benefit us all.

In future, the open forums will be for school age children only, with special events laid on for pre-school children. Only school age youngsters will be invited to the forums, who can feel free to attend on their own, since transport will be provided, along with suitable supervision according to the event. Pre-school children will have their own events arranged, appropriate to their age, to which a parent or guardian will also be invited.

This new approach will take effect from October, and you will be individually notified about relevant events. Parents will not need to attend, unless specifically invited.

We have found in the past, that it is very difficult to organise events suitable for all ages. Also some youngsters will feel inhibited when mum or dad comes along, hence the changes mentioned will be given a trial run. Our next forum will be a Halloween party on Halloween, which happens to fall at the end of half term. This will be for school-age children only, mums and dads will be glad of some time to themselves by then! The pre-school children will be having their own outing to see 'A Tiger came to tea', at the Winter Garden early in November, but is it a real Tiger?

As for the Young Carers outing to London Zoo, we all had a great time at the zoo, but I for one, found that journey to get there was

rather long.

This certainly proved to be the case for our younger members, and I am sure that at the end of the day bedtime was very welcome. But hey, how often can you say you've seen a real Tiger today!

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

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

Just call Janet on 01323 487950, or Lynne on 01323 439447

## LADIES SUPPORT GROUP

The ladies programme is a bit slow getting under way.

In fact all I've organised so far is our Christmas dinner, but it's a bit early to worry you with details yet, though rest assured, it **WILL** be good.

As for Thursdays at Map House, DO come along and join us, we're not just having a gossip, but some constructive conversation along with an occasional game, and if you don't come along, you'll never know what you've missed!

**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

**PLEASE SUPPORT YOUR BRANCH!  
The MS Christmas Collection  
Catalogue Event Coffee Morning  
Friday October 10<sup>th</sup>**

**at our Centre 11am - 1pm**

Please join us in the Centre and order your cards and gifts for Christmas from the MS Christmas Collection Catalogue. With all sales, 25% of monies will be transferred to the Branch account in support of our services. Please order through us.

*Transport will be available...call Margaret on 439447*

## The Judy Parker Column

I have recently been shopping in Eastbourne during my usual visit to Branch on a Thursday. I went into Boots and was a little added to see the Self Service system therein ! No problem - Boots have appointed an assistant to press all the right buttons etc. to complete the transaction ! Job done ! Primark also have a till specifically for disabled users which saves a lot of waiting time. I'd be interested to hear from any of you out there with good /bad shopping experiences.

Access to the shops, banks and chemist here in Polegate are much improved particularly HSBC , Lloyds and of course the Co-op.

Cllr. Stephen Shing, Bernard and I fought long and hard to have the access ramp constructed into the HSBC (Midland) bank - job done ! I worked very hard to have easier/safer access to the chemist. With the help of the then manager, the job was completed brilliantly , incurring no major expenditure to Lloyds.

Am pleased to report that having MainStream "on line" is spreading the word far and wide. Well done Andrew - keep up the good work.

Currently being read in Florida, Massachusetts and Alabama (U.S.A.) as well as others I'm sure. Chris Tatevosian , the author of "Life Interrupted" is today being interviewed by an old contact of mine who lived in South London. Cliff Roles is a radio reporter in Sarasota (Florida) who has a special interest in the likes of us.

I already have several more items for this column which I will report on in future issues.

If anybody out there has any contributions to add please contact me or see me at the Centre most Thursdays. Telephone 01323 486478.

**Judy.**

### OFFICIAL OPENING OF NEW TOILET FOR DISABLED IN SEAFORD

Work has recently been completed on the disabled toilet at Place Lane, Seaford as part of a programme of improvements to ensure all disabled toilets across the Lewes district comply with the requirements of the Disability Discrimination Act.

Cllr. James MacCleary, lead councillor for the community, opened the enlarged and refurbished WC. He said, *'The disabled toilet at Place Lane in Seaford is in a perfect location for people using local shops and services. It is always encouraging to see facilities like this improved for the benefit of local residents and visitors.'*

Also present were Zena Gibbs, chair of access in the Seaford and Newhaven committee, Sue Dunkley, Lewes District Council access officer and Nigel Sharpe, Lewes district Council principal architect.

Zena Gibbs said:

*'I am very pleased the official opening has taken place of the improved and enlarged Place lane accessible toilet, which is now large enough for an electric wheelchair user. This and the fact that Seaford railway station also now has a similar sized toilet means that more disabled people can be encouraged to visit Seaford town centre.'*

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***Zena Gibbs is a long-serving and active member of our Branch***

**CHECK OUT THE PHOTOS ON OUR WEBSITE**

**[www.mssesw.org.uk](http://www.mssesw.org.uk)**

### NEW PROMOTIONAL BANNERS... THANKS TO THE MS SOCIETY

For such a long time I have wanted us to have a couple of pull-up MS promotional banners for when we are out and about. I mentioned this at the AGM in London and lo and behold my wish came true. They are rather expensive *but* I am delighted to say that they will be paid for by the MS Society. Really appreciated, and they were used within a couple of days of receiving them - at the volunteer event in the Arndale Centre.

They look very posh and get our message over in a professional manner.

**BC**

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

## MAINSTREAMING WITH MARGARET

The month of September like the weather has seemed a little brighter.

We have had visitors from the National Centre down here in Eastbourne and several of us have been to the MS Society's National AGM in London.

The AGM weekend commenced with us leaving Eastbourne around 8.30 on Saturday morning and arriving back home about 5.30 on the Sunday afternoon.

It was only for the weekend but so much was packed into the Agenda, it certainly seemed much longer. I have to say it was most interesting and informative and although tiring we were all certainly glad that we went and learnt about the MS Society's vision for the future...

I have written a separate article (page 8) with regard to membership and renewals; and we were happy to assist with the membership workshop presentation, Membership to the Society is so important and it is not like "having a label", the Society is there if we are needed, social exclusion and loneliness can become such barriers. Please do not hesitate to contact us if you have any enquires or you would like to chat...it is so important.

The month itself with meetings and work schedules has been busy and even a cup of coffee these days will become involved with some discussion or another. Is that a good or bad thing you may ask yourself – perhaps making a difference is the overriding factor. People have said to me recently about "not getting involved" that statement is all very well and good but someone has to. If people do not get involved, changes or improvement, new ideas and new beginnings will never happen.

Getting involved is just what we did on Friday 26<sup>th</sup> September, with a volunteering awareness event in the Arndale Centre.

Let us hope we are successful with some new volunteers coming forward especially for driving, community support work and hopefully to help Joyce with fundraising. David our Treasurer would like to make this his last year with us, do you know of anyone who would like an exciting and rewarding

volunteering Treasurers role. Please contact Bernard direct if you can help, thank you.

### **New chairs for our Centre**

When we moved into the Centre, the Royal Bank of Scotland donated us some really good second hand chairs. They have served us very well, but unfortunately we now have to review the situation and look into the purchase of some replacement chairs. Health and Safety has now come to fore in everything we do, it might seem a simple task, ordering new chairs – but it is not.

Firstly we must have the stackable variety because of limited space in the Centre; some chairs must have arms for support for those in need and others without arms because people should have the availability of choice...

Then comes size, we were going to order some banqueting chairs for their support design and then discovered they were too narrow – the seat width was just 16 inches, with a weight limit of 17 stone. We are now considering meeting room furniture and we must look at general use, specialty chair ordering is financially prohibitive.

We are now reviewing chairs conforming to British Standards that can be ordered with our without arms, the seating is 21.2" wide with a weight limit of 16 stone.

Details must be clarified as we are obligated to inform every one of our findings, if you would like to see the design or have any questions or queries relating to the proposed purchase of the chairs – please contact me. Thank you.

Christmas is approaching and we would like to invite you to our gift catalogue fundraising event in the Centre on Friday 10<sup>th</sup> October, coffee and cakes will be available and it starts at 11.00am.

Please join us and we will make sure we have time for a coffee and a chat. Thank you.

Kindest wishes - **Margaret**

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### **It should be said...**

Margaret gave an excellent talk on membership at the AGM in London - our beloved branch keeps its members and Margaret embraced the centralised database wholeheartedly from the beginning. I have no hesitation in saying that, in Margaret, we have the best Branch Secretary in the UK...and the best Centre Manager.

**BC**

**IF YOU CAN HELP WITH FUNDRAISING - PLEASE CALL JOYCE AT THE CENTRE - THANK YOU**

### Uncorking an adventure!

There is nothing simple about drinking red wine from Australia. I know I am prone to rambling on about their wines but that is simply because their 'reds' are fascinating in both the bottle and the contents. They are an adventure. Take my latest journey. Margaret kindly gave me a bottle of S.E Australian Shiraz Cabernet (2004 13.5%) mysteriously named 'The Breaker'.

The wine itself was all berries and earth - seriously yummy in a way that French wines used to be. Reading the label was like opening a book, perusing the first page and realising instantly that you would have to get comfy and indulge yourself in another fascinating world. There were three verses from a poem ('At the River Crossing') printed in tiny letters and the label heading read:

'The Breaker' Harry 'Breaker' Morant  
Drover, Horseman, Poet and Soldier

The computer was still on - excellent - pour another glass and 'Google' Mr Morant. Truly amazing - enough websites on him to keep me awake until the year 3000! This was one serious character who needed investigating.

Born in Bridgwater, Somerset in 1864, much of his early life is clouded in mystery, but in 1883 he arrived in Townsville, Queensland. Using the name Edwin Murrant he married Daisy O'Dwyer less than a year later. The two separated not long after and Morant moved to Winton, Queensland before finding work droving cattle. His reputation as a horseman, drinker and womaniser grew, particularly after he began contributing poetry to the *Bulletin* under the name 'the Breaker'.

At the outbreak of the Boer War in 1899 Morant was in Adelaide and he joined the 2<sup>nd</sup> Contingent, South Australian Mounted Rifles. His enlistment ended after 12 months for which he received good reports and the offer of a commission. Instead, however, he returned to England (where he is reported to have become engaged) and befriended a fellow veteran of the war in South Africa, Captain Percy Hunt.

In 1901 the two men returned to South Africa and were commissioned into a British irregular unit, the Bushveldt Carbineers. Morant served with distinction, however, the

Carbineers had already acquired a reputation for shooting prisoners, looting and insubordination. In August 1901 Percy Hunt was wounded on patrol and his body was later found stripped and mutilated. Morant, now in command, led a revenge patrol that resulted in his ordering a Boer prisoner to be shot. He later ordered a separate group of prisoners to be executed. Lieutenant Peter Handcock and others shot another group of Boer prisoners.

Morant, Handcock and other officers were arrested on 22 October and, in January, were court martialed for the killings. Morant was convicted and sentenced to be shot along with Handcock. The sentence was carried out on 27 February 1902.

Debate continues to this day as to whether or not Morant was a villain or a victim. At his trial, Morant freely admitted shooting the Boers, claiming that Kitchener himself had given instructions that no prisoners were to be taken. A claim hotly denied by Kitchener and the British Government at the time. The executions caused much disquiet in Australia particularly as the two British Officers implicated escaped with dishonourable discharges.

During a visit to Australia in 1910 General Kitchener was asked to unveil a memorial to the Boer War Dead at Bathurst. He refused unless the name of Lieutenant Peter Handcock was removed from the roll. It was removed but replaced in 1964.

Morant became something of a folk hero and his memory was revived with the film *Breaker Morant* in 1980. Two books have also been written about him: Nick Bleszynski's *'Shoot straight, you bastards!'* (2002) and Bill Woolmore's *'The Bushveldt Carbineers'* (2002).

It was reported that another (British) Officer, George Witton, was given a life sentence at the same time and returned to England where he spent time in Lewes prison. The House of Commons overturned his life sentence in 1905 and he was released after twenty eight months!

God bless Australia...the bottle is empty...and the clock insists that 3am has arrived! I thank God that red Australian wine is good for my health and leave the corkscrew handy for the next adventure...time for bed!

**BC**

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