



Sussex MS Treatment Centre

Southwick Recreation Ground
Croft Avenue
Southwick
West Sussex
BN42 4AB
01273 594484

www.mssussex.com

Charity Number: 801075



-Small Charity-

-Big Impact-

It is always busy here these days, but the last couple of months has been particularly so. Alan's seemingly trivial accident led to complications, and his absence since February has been noticed. It's a relief to have him back, albeit part time. Thank you to Jo, and all the volunteers, for stepping in to cover. It just proves that the work of our volunteers is absolutely essential, and you will see from this issue, we always appreciate the help you give us and one another.

The Centre has a new function as a match making agency it seems, and Alan and I are getting married in July. Nicci Mullen has kindly stepped in to organise a celebration party in July, and would be very happy to have some help. Email her on shenba@hotmail.com, if you would like to be involved.

I hope you enjoy this issue. If you would like to share anything with your fellow members in the next issue, then do let me know.

Jane

As many of you know I have recently had a rather long spell of sick leave due to what at first appeared to be a minor accident with a carving knife. The finger's on the mend and I'm back at the centre now and would like to thank everyone for their good wishes and the all the cards I received. I'll try to be more careful in future!
Thank you for all your good wishes - Alan

Being a volunteer!

I was first introduced to the MS Centre by a good friend who attends a number of the therapy sessions and who is also a volunteer covering the reception desk. She invited me to one of the many social events, on that occasion, a summer tea party.



I was immediately impressed by the many and varied facilities at the centre and by the friendliness of all the members sitting round for tea. The atmosphere was one of good humour and everyone in a very positive frame of mind. Later that year my friend was away on an extended holiday and I offered to cover her reception duties for that time. I loved the “work” from the first minute. I had never worked a cash register before but found there was always someone on hand to help and not show any impatience! I have always enjoyed dealing with phone calls and other admin jobs such as making appointments and preparing paperwork and there is plenty of that to do.

After my friend returned from holiday Alan asked me if I could come in on a Thursday, again to do reception work and whatever else is needed. A number of you may have seen me at the desk and I look forward to Thursdays as it is so busy with the Pilates and yoga drop in sessions, a number of therapies taking place, oxygen treatments as always, and a wonderful atmosphere of chat, coffee, and mutual support everywhere.

I always worked full-time in the past. I have never done voluntary work before and I would encourage anyone who feels they can offer even a few hours regularly or on the odd occasion to give it a try. I guarantee you will feel valued and that you will meet some amazing people!

Ruth
Thursday Receptionist

You're never alone at the Centre!

Dates for your diary.

As you all know we are very fond of a cup of coffee and a chat in the daytimes here at the centre and we also like a glass of wine and a bit of a party in the evening too!

Every week on Tuesday and Friday mornings we have a bit of a coffee

morning from 11 am through to around 1pm, which is an excellent chance for everyone to catch up over a coffee and a piece of cake! All are welcome so please feel free to pop in and join us.



We also have some great evening events planned for the year so here are the dates for your diary!

It's not only brilliant for the social side, but also an excellent way to share your knowledge and experiences, whether you are someone coping with a neurological condition, or someone who cares.

Some comments from people coming for a social event, or just stopping for a coffee, sum it up:-

"A problem shared is a problem lightened"

"I'd have paid a fortune to be entertained like that in Brighton, top class"

"What a wonderful place, everyone's so friendly"

Friday 11th May

60's Party, with licensed bar.

Friday 1st June

Adur Art Trail Exhibition.

Sunday 15th July

Jazz with a licenced bar and light snacks.

Friday 24th August

Wine tasting and Sensitive Foodies' food.

Friday 14th September

Comedy night with licenced bar.

Friday 5th October

Quiz night

Friday 26th October

Chilli supper night with licenced bar.



Art and Craft at the Sussex MS Treatment Centre

Preview Evening Friday 1st June

Exhibition open

Saturdays and Sundays

June 2nd/3rd, 9th/10th, 16th/17th

11am – 3pm

Following the success of last year's exhibition, our arts group will again be putting up a display of the creative work of Centre members and their friends for the first three weekends in June.

Are you arty, creative, do you paint or make crafts? If so, then there is plenty of room for you to join in and show your work. Contact Trudie at trudie.eason@hotmail.co.uk or leave a message at the Centre if you are interested, or would like more details.



If you just like looking at the work, then do please drop in and support those who are exhibiting. There will be a wide variety and some wonderful pieces to purchase for yourself or as gifts should you wish.

If you'd like to get involved as a volunteer, to assist with invigilating the exhibition, or help out by baking cakes or biscuits and running the Centre Café, then we'd be more than happy.

Check on the Arts Trail website, or pick up a leaflet at the Centre to find out more.

This year's trail consists of many wonderful opportunities to enjoy and purchase locally produced art, both in artists' homes and a range of centrally located venues.

All our members and their friends are invited to attend the preview evening



Call the centre on 01273 594 484 for more details

An Event for our Carers



Carer's Event
Saturday 28th
July 10.30am – 3pm.

The day to include :

- Information on a variety of subjects and organisations which we hope you will find helpful
- “Taster sessions” of some of the therapies offered here at the Centre and which are available to all our members.
- An opportunity to speak in private to representatives from Carer's services including Crossroads and Carer's support services. Plus a chance to meet and socialise with other Carers in a relaxed and friendly atmosphere.

Tea, coffee, cakes and a sandwich lunch will be provided!

The focus of the day is on our carers. This is our first event of this kind, and we are unfortunately unable to offer cover for the person for whom you are caring. We will be welcoming your comments and suggestions on how you would like us to further support you.

To reserve a place, please return the enclosed booking form, or ring the Centre with your details.



The Big Bike Ride



Join the Big Bike Ride on May the 6th 2012,
help us raise money for the
Sussex MS Treatment Centre.

We will be cycling a 20 mile route across the beautiful West
Sussex Countryside from Shoreham Airport to Slinfold
village.

Young or old, novice or pro cyclist, everyone is welcome
to take part on this amazing day.

We provide lunch at the end of the ride plus free transport
back to Shoreham Airport.

Every year this amazing event helps the MS Treatment
Centre raise thousands of pounds. All funds raised go
towards providing vital services for hundreds of people
across the Sussex region.

So hop on your bike for the Big Bike Ride and
help a small charity make a big impact in your
community.

To register:

Call 01273 594484 or email
events@mssussex.com



Summer Is Coming!

And lots of us think of going on holiday! Don't let MS stop you!

Whatever your level of MS, there are a wide variety of opportunities to travel, and many ways to make life less stressful when you do so.

If you are flying somewhere, you can ask for **assistance** at the airport, as sometimes it can be MILES to walk. You can ask for someone else to be with you, so you don't get separated. Why arrive at your destination feeling tired out when, if the system works properly, you're treated like a VIP!

Don't forget that wheelchairs are a useful tool for *enabling* you to go places that you might otherwise not be able to get to or get tired out before you'd seen it all. A wheelchair should be viewed as an aid to minimising fatigue and increasing both your independence and ability to access where ever you want to go. I don't know about you, but I know I've snapped my friends heads off at times when I've been worn out, but now, I believe, I'm a pleasure to be with! We have one here that can be booked for borrowing, but if ours is booked, there are other places you can hire them at little cost.



If you're travelling abroad, and you are on injectable medication such as Betaferon, you will need a letter from your GP or MS nurse, or alternatively the support company (eg Betaplus) can supply you with a letter. The injectable medication **must** be carried in your hand luggage as there is a risk it may

freeze if carried in the airplane hold. If the medication needs to be stored in a fridge or you are going somewhere where the room



temperature is likely to be above 25°C, you will need to liaise with the travel company to ensure access to a fridge before you leave.

If you take regular prescription medications, these can be carried easily in your hand luggage. It is always worth taking a copy of your most recent prescription with you in case you are taken ill whilst abroad, or in case you lose any of your medications whilst away.

Having MS can add a few more challenges to travel, but we are not much more likely to need costly help whilst away than anyone else. **Insurance** companies should know this, and as long as you inform them beforehand you should be able to get adequate insurance at a reasonable price. Shop around!



If you have very restricted mobility, but would like to go somewhere different with your friends or family, we have plenty of information here on different options – tucked away in the “holidays” folder in the bookcase by reception, which you are welcome to browse through.

We’re living with MS or another condition, but we don’t all have the same taste in holidays, or levels of need or support, so we’d be delighted if you’d share your tips and information on interesting places to go, edited highlights of which we’ll publish in the next Belle.

Tysabri Campaign

Gwen Walls is coordinating a campaign to demand that Tysabri is more readily available for people with MS, after being told by her neurologist that it would be suitable for her, but was not available at present.

If you have been recommended for this treatment, but have also been told you will have to go on a waiting list, contact Gwen on mikeandkatie2@msn.com or ring her on 01273 385167.

**The Sussex MS Treatment Centre is excited to welcome our
new patron:
Alastair Hignell**



New Sussex MS Centre member Alastair Hignell has agreed to help us by becoming a patron of the centre.

Alastair has had a distinguished sporting career, playing cricket for Cambridge University and Gloucestershire and rugby for Bristol and Cambridge University and, from 1975 to 1979 was an England international.

Alastair was diagnosed with MS in 1999 and is a patron of MSRC. In 2008 Alastair won the BBC Sports Personality of the Year Helen Rollason Award and in 2009 was awarded the CBE. He's also well known as a sports commentator for 5 Live, Sport on 2, HTV and ITV.

His autobiography, Higgy ... Matches, Microphones and MS was published last year. Alastair has been involved with Multiple Sclerosis Charities for over 11 years, his fundraising team Higgy's Hero's came into being in 2008 and has worked to fundraise and promote the charities that Alastair has worked with.

Alastair became a member of the Sussex MS Treatment in 2011 having recently moved into the local area and we are very excited to welcome him on board as a new patron of the centre!

**Please contact the Centre if you no longer wish to receive
this Newsletter or wish to receive it in an A4 format on
01273 594484**

CAN YOU HELP???



WE HAVE COLLECTION BOXES IN THE FOLLOWING
AREAS WITH NO ONE TO COLLECT THEM

WORTHING BN11,13 & 14

PORTSLADE BN41

SOUTHWICK BN42

NEWHAVEN BN9

IF YOU CAN HELP, OR KNOW OF ANYONE WHO WOULD KEEP A
BOX FOR US, PLEASE CALL THE CENTRE AND ASK THEM TO
PUT YOUR DETAILS IN THE 'COLLECTION BOX' TRAY.

Brighton Marathon 2012

Sunday April 15th



This year we have 9 runners taking part in the Brighton Marathon. Each year this amazing event helps to raise thousands of pounds for the Centre. So we are proud to support our fantastic charity champions who are taking this immense marathon challenge for us.

You can sponsor our runners on Virgin Money giving by going to the website www.virginmoneygiving.com and searching for the individual runner's name.

This year's fantastic runners are (in no particular order!) Samuel Lott, Mandy Lawson, Angus Dunn, Ross Richardson, Bert Hudson, Etenesh Elliott, Daneil Crockford, Pete Oksines, Andrew Wesby and Julia Cole.

We need you to come along on the day of the marathon to help us cheer on our fabulous runners. So let us know if you want to be part of the MS Treatment Centre Cheer teams!

It's a great day out and a lovely chance to really support our fantastic runners and fundraisers!

Don't forget, if you are an 'ebayer' you are offered the option of donating a proportion of your earnings to charity if you so wish.

We are registered with the company, so if you would like to choose us, just search their list of charities, and up we'll come!



Every donation counts.

Street Collections

Do you live in or near, Lancing, Shoreham or Southwick?

We need your help!

On the 11th, 18th and 25th of August 2012.



Shoreham Farmers
Market
Saturday 11th August



Lancing
Saturday 18th
August



Southwick Square
Saturday 25th
August

The MS Centre has a great opportunity to run Street Collections this summer which will help to raise funds and our profile in the wider community. We'll be going out to towns in our local community and be running one day street collection events.

Can you volunteer to help out on one of these days? An hour of your time would help. Do you have any ideas about making our street collections fun, vibrant and educational to the people who we meet?

Whatever you can do, however much time you could give any help at all is appreciated, so please let us know if you would like to get involved.

Whenever we go out collecting, we always attract interest and enquiries about the Centre, so it's a great way to reach those who haven't found out about us yet, and help the public to be more informed about MS.

Please call us on 01273 594 484 or [email events@mssussex.com](mailto:events@mssussex.com)

The British London 10k Run!

Can you, or someone you know, be a charity champion and take on the challenge of the London 10k Run?



The British 10K London Run is the UK's most prestigious and sought-after 10km road race which is staged on the world's greatest route through the heart of central London.

25,000 runners fill the streets of the nation's

capital and get the unique chance to run past many of the country's greatest landmarks including Big Ben, The London Eye, St Paul's Cathedral, Trafalgar Square and Westminster Abbey. Abilities range from charity fundraisers and recreational runners right through to Olympic champions!

The 2012 event is staged just 19 days before the start of the Olympic Games and the excitement and buzz within London at this time should make for a truly special occasion and the best British 10k London Run in its 12 year history. We expect to sell out in record time so avoid disappointment and sign up to run the British London 10k Run today with the Sussex MS Treatment Centre!

To register for more information email the centre at events@mssussex.com or call the centre on 01273 594 484.



Learn to use a computer from scratch or improve your skills.

UCanDoIT is a charity that teaches blind, deaf and disabled people how to use computers, with a particular focus on Internet and email skills.



Justine, Centre Member, with her UCanDoIT teacher

We teach learners in their own homes, on their own computers, as we believe that this is the best way to learn. All sessions are done on a one to one basis, by our experienced tutors, and we teach on various different specialist software for text to speech, such as Jaws, Guide and Supernova and dictation software like Dragon Dictate.

There will be a small cost per lesson depending on income, much less than you might think.

To request an application pack please call 0207 730 7766

email enquiries@ucandoit.org.uk

www.ucandoit.org.uk

Pamper Day



Centre Member Jeanette Jones is usually to be found here on a Tuesday behind her stall of cards and gifts. However, she and her friends came up with the wonderful idea of putting on a spectacular Pamper Day as a fund and profile raiser for our cause, and it was a huge success, raising over £3000!



Tim Loughton MP opened the event, and enjoyed sampling the cup cakes. Cooperative Travel from Southwick Square donated prizes and were a great support, in fact there were some fantastic raffle prizes

which the team worked hard to get. A lot of people who had never visited the Centre came to see what was on offer, as well as a number of our members who came along for a bit of pampering. Unfortunately, we double booked and members coming for oxygen treatment found they couldn't get in, for which we can only apologise. We've hopefully put a system in place that will ensure we don't make mistakes like this again. Thank you to all the volunteers and therapists for making it such a successful day.

We want your comments



Whenever people from Charitable Trusts are thinking about giving us money, they say: "So how do you measure your outcomes and the impact you have?" To which in the past, I've said words to the effect of "*well, um, people just say they like coming here, and they're often smiling when they leave*". Apparently, this isn't good enough! So, new to the Centre we have **THE COMMENT BOOK** on the desk by reception. Would you please take a moment, every now and again, to record a comment, any comment, which occurs to you? They can be positive or negative.

It doesn't have to be an essay. For instance, you could record that you found something particularly helpful (a class, a treatment), you just sat and enjoyed being sociable, you were cross that we'd run out of something, you learned from someone here about a drug or a treatment that might really help you, you were entitled to a service on the NHS or elsewhere, that a particular holiday destination was excellent, you could record that you'd had a terrible time and are never going to come here again, because unless we know, we can't change!

You may be someone who doesn't use the Centre often, but appreciate that we are here if you need us. That would be good to know too.

Thanking you in advance!

Volunteering!

Over the past few years, the Centre has really grown, and now offers over 60 individual therapies, 24 oxygen treatments, and 7 classes every week, as well as all the social stuff. but we're determined to keep the costs down. Over 200 people use the Centre every week, and we couldn't possibly keep going without your support and our team of volunteers.



There are lots of opportunities to volunteer that the centre, for instance:-

reception **café helpers** **HBO chamber operators** **event volunteers**
fundraising committee volunteers **class assistants** **collection helpers**
general centre assistants

If you want to help or know someone else who might enjoy making a difference, please get in touch and let us know. Some opportunities need a regular commitment every week, others are one off – but they are all essential.

We want to talk to you about what you would like to do to help, what skills you have that might be of use to the centre, or what new skills you would like to learn whilst working with us!

So please speak to Alan or Jo when you are in the Centre, ring 01273 594 484, or email us on events@mssussex.com!

Zippy Engineering: A unique resource for the disabled.



Zippy operates as a "**not for profit**" and specialises in bespoke building of powerchairs to solve client problems. We service and maintain these and others, in our own workshops,

Refurbishment of older models includes replacing all wearing parts, including motors, gearboxes, bearings, etc., fitting new tyres and batteries, and fully repainting in modern hard-wearing powder coating, from an attractive pallet of 30 colours. We also **repair** all accident damage, using new factory parts, or fully refurbished used parts, and some special parts we make or have made, we do not charge for inspections or estimates.

We start with an assessment to fully understand your requirements and can build almost anything you wish to order, be it for narrow doors, long range or off-road use. The choice really depends on where and how you want to use it. It makes sense to do a proper assessment of your build and weight, your mobility capability and limitations, and what you would like the chair to be able to do for you. (It can do most everything). So, if you cannot get to us, we can come to you.

On-site service collection & delivery available.

If you need any part, manuals, or parts-illustrations, please let me know. Information will be provided in response to e-mails, or you are welcome to make an appointment to visit me at my Hove, BN3 7GS workshop by appointment. We do have disabled toilets nearby in the complex.

An assessment and design consultation will usually take over 3 hours, for a fee of £150 - you will be able to try any chairs I have available, and the fee will be fully refunded against the purchase of a bespoke chair. Wheelchair users enjoy disabled exemption from VAT – we will take care of the paperwork!

We are a not-for-profit service. Any questions, see:
www.wheelchairs.vpweb.com.

IT'S YOUR CENTRE! So what's going on?

Your Management Committee, with the help of Jane, have put together a Strategic Plan. This is a document that looks at what we do, how we sustain what we have, and how we hope to develop over the next three years. If you would like to see a copy, it is available at the Centre, or via a link on the website.

If you would like more say in the running of the Centre, why not become a Corporate Member, or stand for election onto our Management Committee? Corporate members are entitled to vote at the Annual General Meeting, and Committee Members can use their skills to make sure the Centre runs in the interests of all our members by working on aspects of running what is effectively, a small business.

The Centre has always prided itself on being user led, and which means we try to listen and act on EVERY users suggestions and concerns, which we will continue to do. If you would like to get more involved, then speak to Alan, or one of the Trustees about what you would like to offer.

Christmas Lunch 2011

As usual, our event was a sell out, and general consensus was that it was superb value for money. The standard of catering was excellent, thank you to everyone who contributed to the wonderful spread. A particular thank you goes to Carol Brown for organising it all, and to her helpers, who worked tremendously hard to make sure everything ran smoothly and the queue didn't stretch too far!

This event is a superb demonstration of what our volunteers can do, without compromising on quality. Thank you all!



The lunch in pictures...

Alan and Ivano finished the proceedings with a well-earned toast. Ivano, an Italian student, had here been on work experience for six months, and left us the following week. He was a tremendous asset during his tenure, and we are sure he has a great future ahead of him.



A Recipe for Spring

From the Sensitive foodies Website:

<http://www.sensitivefoodies.co.uk/>

BAKED CHICKEN IN BALSAMIC VINEGAR

A simple and tasty meal, very flexible and easy.

INGREDIENTS:

3 courgettes
4 chicken thigh fillets or chicken breasts
50ml balsamic vinegar
1½ tbsp agave syrup (or 2 tbsp brown sugar if you are not avoiding it)
400g tinned tomatoes
1 tbsp olive oil
2 tbsp capers
2 tbsp chopped basil leaves
freshly ground black pepper



PREPARATION:

Heat the oven to 200C.
Cut the courgettes into slices, lengthways and lay them in an oven-proof dish.
Place the chicken pieces on top.
Mix the vinegar, agave syrup or sugar, tomatoes, olive oil and capers and pour over the chicken.
Bake for 30 minutes.
Sprinkle with the basil and black pepper.

NOTES:

This dish also works well with other vegetables such as aubergines. I sometimes add mushrooms, peppers or use fresh tomatoes depending what's in season or I have in the fridge.

Preparation and Cooking Time: 45 min

Recipe information

Dairy free: Yes

Egg free: Yes

Legume free: Yes

Best Bet: Yes

Citrus free: Yes

Gluten free: Yes

Nut free: Yes

Low GI: Yes

Burns Night with Haggis, Tatties and Neeps

Our introduction to "The Chieftain of the Pudding Race"



We tried something different for our January social and ran our first ever Burns Night.

We dined on Haggis, neeps and tatties, a meal that had been a mystery to most of us until the night, and judging by the empty plates at the end of the evening, proved to be a delicious feast



Scotsman Bob Bawtree directed the proceedings, addressed the Haggis, and leading the toast. Angela Bawtree demonstrated traditional Scottish dance, and Alan, Julia and Angela sang appropriate songs.

We'd also like to thank Alison Groom and her friends for waitressing and clearing up afterwards.

**VOLUNTEER BOOK KEEPER
DESPERATELY NEEDED!**

UP TO 3 HOURS PER WEEK

Jill Brookes, our treasurer, would really appreciate some help with keeping our records up to date. If you have some experience with book keeping, please email alan.taylor@mssussex.com and he'll pass your details on to Jill.

