

Sussex MS Centre



01273 594484

Southwick Recreation Ground

Croft Avenue

Southwick

West Sussex

BN42 4AB



- Small Charity- -Big Impact-



Charity Number: 801075

Company Registered in England 2319928

Chairman's Comment



Welcome to the Summer edition of the Belle. This edition follows on from our May AGM, and the approval, by our Corporate members, of our Directors' and Trustees' annual report, and our Financial Statements for 2015.

2015 was a very successful year for us on many fronts, so many in fact that this isn't the place to list them all. I'd urge you to read our soon to be released Annual Review, which documents all the key information, and much more.

Success, however, brings challenges, and coping with e.g. increased intake, HBOT chamber utilisation, etc. has been hard. Over the last 6 months we've gradually been forced to restrict our membership criteria, such that only those with MS (& their Carers) are currently being admitted as new members.

Existing non-MS members (ME, Stroke, Cancer, Fibromyalgia, Ataxia, etc.) are, of course, welcome to continue using our wonderful Centre. We would like to return to being as inclusive as we were previously, but that would need, not least, more volunteers.

Without the support of our many existing volunteers, we would not be able to offer the level and variety of service that we do and we are enormously grateful to them all for their commitment.

[Volunteering](#) is the life blood of a user led organisation like ours, and to paraphrase John F Kennedy: "when you value what the Centre does for you, please ask what you (and your family and friends) could do for the Centre".

Or if you prefer Marx (Karl, not Groucho): From each according to his ability, to each according to his need.

We have a lot of people in need, and, if you can help in any way, we would appreciate it. Please speak to any Trustee, or member of staff, about joining our volunteering team.

Derek Aitken

Chair

Diagnosed with MS 26 years ago

Centre member for 10 years

Manager's Comment



We were so sad to hear of the passing of our MS Nurse Lisa Black on 23 June. She was so much more than a nurse to many of our members giving so much of her time and energy to support people. She was a very special person and will be sadly missed.

We have now officially amended the name of the Centre to 'Sussex MS Centre' which we feel more reflects the changed nature and variety of services we now offer. Over the coming months we will amend all marketing material to reflect this change.

To help us to continually evaluate our service we welcome any comments on what you enjoy at the Centre and any ideas for improvement being written in the comments book at reception.

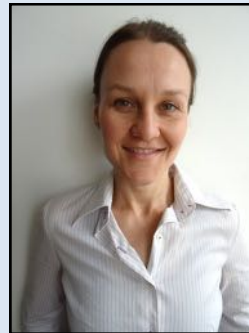
Wishing you all a good summer when it arrives!

Penny

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Introducing



EVA

MASSAGE therapist

Working on a Monday

10am—3pm

New Classes and Therapies

Drop in
KEEP FIT CLASS
with Lynne
on a
THURSDAY
afternoon

SHIATSU
With Mary
on a
MONDAY
morning

Please ring and make an appointment
01273 594484 or book at Reception



**The Sussex Multiple Sclerosis
Treatment Centre**

**Volunteers don't get paid, not
because they're worthless, but
because they're priceless.**

Sherry Anderson

Website: <http://mssussex.com>
Twitter: @MSCentreSussex

The end of a year of our fundraising partnership with



West Hove



Thank you to all who supported our fundraising events throughout the year which raised an amazing £5501.08

Wheelchair Marathon

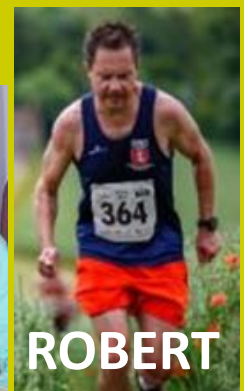
Chris White raised funds for The Centre by undertaking a wheelchair marathon on Sunday 29th May. Thank you to him for all the preparation before the race, let alone the event itself and wanting to raise funds for The Centre.



Thank you to our amazing runners in this year's Brighton Marathon raising over £2000 for The Centre and to Printech for printing our running vests

PRINTTECH

Nick Stone | Director
T +44 (0) 1273 411069 M +44 (0) 7778 896238
info@printechprocess.com www.printechprocess.com



2016



Penny's sponsored bike ride experience—Shoreham to Slinfold



Ready, steady, Go! Hilary fired the starting gun (not really!) and off the 12 riders cycled with Pete bringing up the rear as back marker, first aider and provider of encouragement and support. The young, fit and enthusiastic peddled off at great speed and were soon just a blur in the distance, leaving myself and Deborah and the self named 'old farts' team to bring up the rear.

The volunteer marshals along the way kept us fed, watered and going in the right direction. Sue & John made sure we got safely across the A283 at Bramber and Lesley provided refreshments at the Cat and Canary Pub, Henfield.



Hilary made sure everyone took the right bridleway at Partridge Green and George provided refreshments at Southwater. He also pointed out that he had a spare bike in his van should anyone need one and as it happened Martin had a puncture on route and did need it! At Westons Hill Jane and Alan safely guided us across a sharp bend in the road. I think it was at this point that a couple of the young, fit and enthusiastic passed us on their



way back from Slinfold having already had their lunch! Jeff greeted us at Hayes Lane, Slinfold on the last stretch of the journey and it was a good job he was there to give us directions otherwise we could have ended up in Guildford!



All arrived safely at Slinfold Village Hall where a lovely spread of food had been prepared for us by Cathie, Di, Michelle and Cris. Martin from [Rossetts](#) kindly took those without transport back to the start to save them riding another 22 miles back!

I thoroughly enjoyed the bike ride taking in some stunning views along the Downslink route and can report back that it was definitely beneficial purchasing some padded undershorts to wear on the day!

Thank you to all who helped on the day and to those whose sponsorship helped me to reach a total of £435 raised for our lovely Centre.

The **ART FOR ALL** workshop – Number 3

'Three is a magic number' as 'De La Soul' sang, and it really was a magical day. Thank you to all the volunteers that made the day inspirational. Nancy and her calligraphy, Barbara with her alcohol image making, Andy for origami, Ali for wood block printing and all those that kept people fed and watered, not an easy feat when it was so busy.



Our wonderfully artistic and talented members



Collaborative Printed Banner



Pete Baker's Epic 1000 mile ride!



Pete has been doing a superb job for us pedalling away at various fundraising events to raise money and of course get himself fit for his momentous challenge.

He sets off from Land's End on 30th August, aiming to arrive in John O'Groats 12 days later.

You can support Pete by visiting his fundraising page on www.virginmoneygiving.com, click on make a donation, then in the sponsor a friend box type in Pete Baker and up he pops!



PLEASE don't forget to update us at the Centre if you change address, phone number or email address. Let us know if you no longer wish to be a member. Thank you!

ELVIS

entered the building on 17th June

Another sensational evening of entertainment with Dave Greenaway aka [Elvis](#).



Forthcoming Socials at the Centre

Tickets available a month in advance. Book your places at reception, or by phoning us. 01273 594484

If you have any specific dietary requirements, please let us know when you book.

All socials are £5 for members and carers, £7 for guests.

Friday 12th August 7pm

Supper and puds with the sensational

[Uke at the Duke](#) ~ Ukelele Band



Friday 16th September 7pm

Ladies Barbershop Choir
and High Tea



['Amor Flamenco'](#)



[Coastline Harmony](#)

Sunday 16th October 2pm Flamenco and tapas

If you have any suggestions for a social theme, don't hesitate to let Nikki know by phoning the Centre or emailing social.mssussex@gmail.com.

Wheelchair Adaptation From Concept to Final Model.



Initial Design
Concepts



2nd Prototype

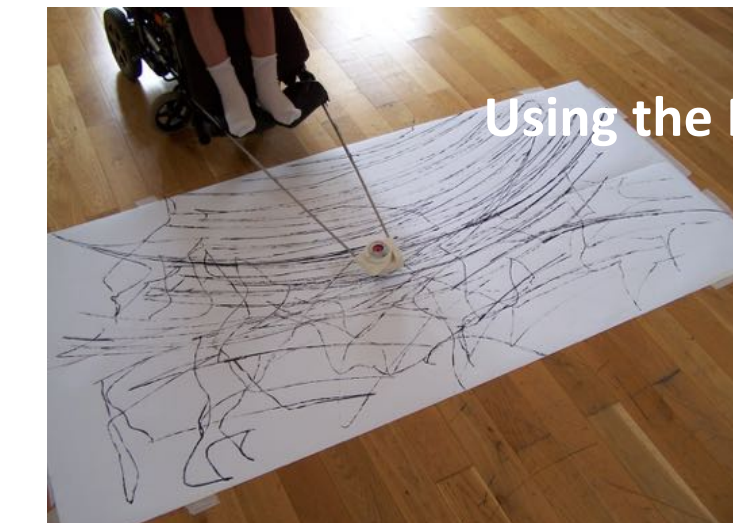


Student Exhibition
In Brighton



Using the Final Model

A lot has happened with the wheelchair adaptation since the last Spring edition of the Belle.



The design collective, '[The Process](#)', made up of year 2 product design students from Brighton University, have produced the final model which Barry recently tested with them. They have kindly donated this piece of kit to the Centre for members to use. If you are interested in using this, please talk to Hilary.

Physiotherapy with Diane



I'm Diane and have been working at the Centre as a physiotherapist for around 12 years. I really enjoy the vibrant atmosphere of the place and how positive people can be in the face of sometimes challenging circumstances.

I see my job as working in partnership with members, to unlock potential. I'm interested in how we move and make movement meaningful, also how we hold ourselves in our posture, which is so individual and fascinating!

In MS and other neurological conditions we want to keep movement as optimal as possible, with help from all the therapies and classes at the centre.

In a physio session I try to closely observe how you hold and move your body. I can see and feel which areas need relaxing or stretching and which parts might need strengthening. Some muscles that are stronger may help other weaker ones.

For example core muscle strength can help with walking when leg muscles weaken. The idea behind the treatment is to re-educate the nervous system as a whole at the same time as helping specific parts.

A treatment may help ease painful joints and stiff muscles, regain some mobility and balance, try out a new exercise, stand on the tilt-table or get the heart and lungs working more!



Everyone feels better when they try a bit of exercise and become more body aware, this also feeds into self-management, i.e. what you can do to support yourself.

We have a lovely, big, airy gym with lots of equipment. This includes a large plinth, parallel bars, a standing table, an active and passive bike for legs and arms, a vibro-plate, mini trampoline, pulleys, weights and gym balls etc.

'She makes sensitive observations on how you move and makes adjustments or exercise/ movements for your individual needs so that you can move/ function better. She also does Shiatsu and has "healing hands".

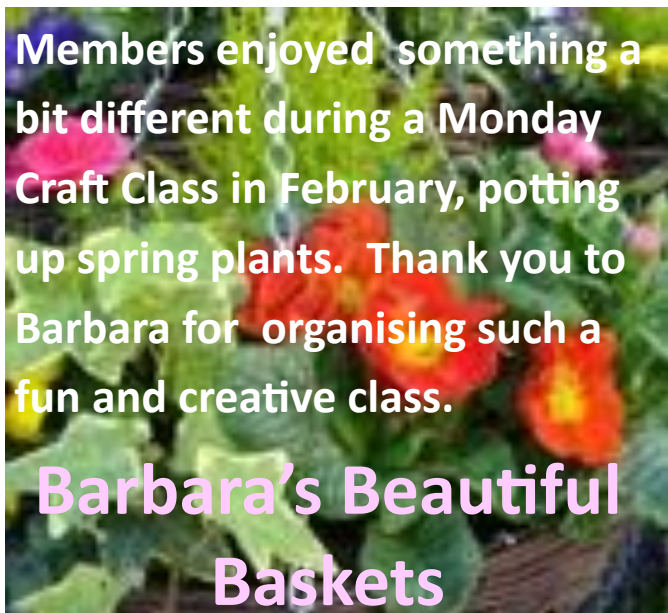
Nancy



Fantastic Farm Fund Raiser



Thank you to all who organised and volunteered to run fundraising stalls at the [Mile Oak Farm](#) Open Day. The Racing Pigs and Wellie Wanging was well received and raised £260. The event was very well attended and the organisers have said that we should receive approximately £1000 from the proceeds of the day.



Garden Patio Project

A huge **'thank you'** to HSBC for funding and providing volunteers to create our lovely new patio area in the garden and to Phil for Project Managing and Tim and Antony for providing labour.



The Patio area is all done and ready to use. Just ask if you want us to take a table and chairs out there for you so that you can enjoy this new outdoor space.

Thank you to those members who have helped us to develop our garden by donating plants and a garden bench. We hope to have a garden table soon and a shed store. There will always be work to do in the garden and we would welcome any members or their family members helping us to keep it tidy.

The Alan Bott Centre

Holidays with care support



Alan Bott 1920-2008

WHO ARE WE?

The Alan Bott Centre is a York based charity set up to help those with multiple sclerosis and similar neurological conditions. The charity is named after Alan Bott who was a member of the local MS branch for many years and did much to enhance MS facilities in York, including the building of the first MS Respite Centre in 1990 (sadly now closed).

WHAT DO WE DO?

The Alan Bott Centre (ABC) assists in the provision of holidays with care through partnership with another charity – The Royal Air Forces Association (RAFA) – using their two care hotels located in Rothbury Northumberland and Lytham St Annes on the Lancashire coast.

WHAT DOES A HOLIDAY COST?

The 2016 cost for one week's holiday, full board plus all trips, at either Rothbury or Lytham St Annes is: **£800 per week HOWEVER:**

The Alan Bott Centre charity currently provides grants of up to **£300** per person to ensure that a week's stay costs no more than **£500**.

And this applies to those with MS and similar conditions and also their carers

And furthermore, should you wish to take a holiday elsewhere that you have arranged, you can apply for the grant to assist you.

We do encourage individuals to apply for social funding or other charitable society grants to help offset the cost even further.

For more information about our charity, volunteering and much more detail about our holiday breaks please go to our website: www.thealanbottcentre.org

You can also contact us by email at enquiries@thealanbottcentre.org

And finally you can telephone us on: 01904 705340 (Alan) 01904 758577 (Jackie)

Or write to the registered office shown below.

Charity No: 1145578 – Supporting people with Multiple Sclerosis and other
Neurological conditions

Registered Office: Flat 1 Aldersyde House, Old Moor Lane, York YO24 1QR



A Sense of Freedom

Do you ever feel frustrated by your MS? Are you no longer able to take part in the hobbies you used to enjoy: walking, cycling, tennis? Do you like to be competitive? Have you ever considered **Sailing**?

I've had MS 20 years now and slowly I've lost the ability to take part in most of the sports I enjoyed, as my left side weakened. I use an orthotic to cope with drop foot, and my left arm really doesn't like to participate much in life. I am a real outdoors person and felt my frustration growing, that is until one day 4 years ago I walked into my local '[Sailability](#)' club at Frensham Pond. I haven't looked back since.

Sailing is a multi-skilled sport: sail trim, wind tactics and competitor tactics. A race can be won or lost on your start, so it's not just a physical sport, but mental too (that is if you want to take part in the racing side of sailing)

The 'Sailability' group caters for all types of disability and it's remarkable what adjustments can be made to boats to allow even the most severely disabled to sail, for fun or at more competitive levels.

Once on the water, all feeling of disability disappears and the sense of freedom is amazing. Either pottering around in my boat on a sunny day or taking part in competitions all over the country and abroad too.

I currently participate in two groups; Firstly, 'Hansa' sailing. Anticipation builds as I plan my travel with some fellow club members to the World Championships that take place in Medemblik, Holland this year during June. There are other events which form part of various series around England. Regularly on a Thursday afternoon I take part in our club training and racing. Last year I qualified as an RYA race coach level 2, so I can now give to others what has been given to me. This year I hope to gain my Power Boat level 2, so I can do more coaching on the water.

Secondly, I race a 2.4mR which is a really beautiful boat. It has been adopted by the Paralympic fleet as one of its classes, but it wasn't specifically designed for the disabled. This is a boat raced around the world by abled and disabled alike. This year one of our golden girls, who has cerebral palsy, won the World Championships in the open fleets (i.e. abled and disabled racing together). With this boat I take part in club racing and then tow her around the country to various open meetings, including, Exmoor, Norfolk, Rutland. It is also the European's in Bordeaux and another fun open event happens in Antwerp in October. Within this fleet you need to be more independent (have your own helpers, to help do the rigging bits that are a struggle). It's great fun competitively and socially too. (I even took up camping again, although I do admit getting up from my roll mat in the morning leaves a little to be desired!)

Sailing really is a great sport and open to all abilities. If you like being out and about, come along and have a go. Take it as far as you want; messing about in boats like Swallows and Amazons or on a more competitive level.

More information can be found out about Sailability groups at the following web page. Local clubs are Frensham Pond in Surrey, Chipstead in Kent and Shoreham in West Sussex. So, if you fancy a bit of **freedom**, come along and have a go, a taster



Dave Durston
in his Liberty

For more information about
Sailability visit
<http://www.rya.org.uk/sailability>

For more on Dave's experiences,
Visit his blog at

<http://millieandme.net/hisblog4/>



Vitamin D levels in people with MS

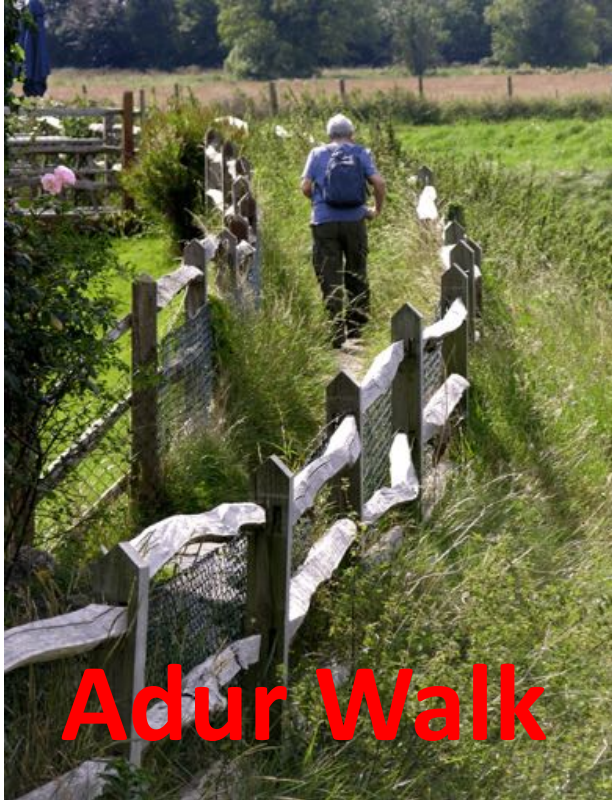
There have been a number of research trials that link low levels of Vitamin D with the development and progression of MS. The recommended daily allowance (RDA) in the UK is 400IU which is based on reducing the risk of rickets and is widely considered to be too low to benefit people with MS.

We stock a good quality one a day supplement that contain 2500% of the traditional RDA in tubs of 365 tablets – a whole year's supply! The tubs cost £11 each and are available at reception.



Fundraising Events

Raising money for the Sussex MS Centre

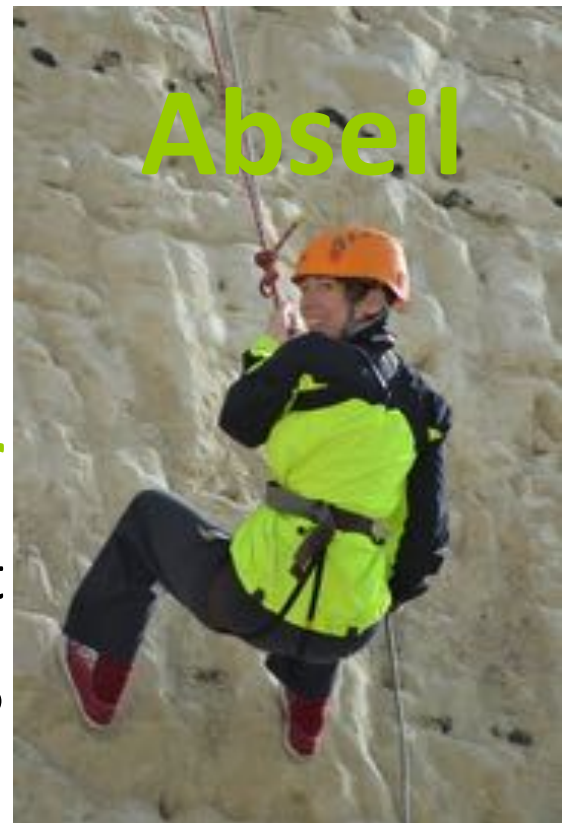


Adur Walk

Sunday 4th September

9 mile round trip from Shoreham
Airport along the banks of the Adur
River

No registration fee



Abseil

Sunday 18th September

Peacehaven Heights 115ft

Registration fee £25

We are looking for people to participate in
sponsored fundraising events to raise vital funds for our Centre.

If you would like more details please contact us on:

Email: events@mssussex.com

Tel. 01273 594484