

The Belle

Issue Number 84 Summer 2019



Southwick Recreation Ground, Croft Avenue, Southwick, West Sussex, BN42 4AB

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Letter from the Centre Manager

Sussex MS Centre Summer 2019

I've now been here for six months, time that has absolutely flown by with lots of lovely members to meet and get to know, other organisations to visit and so much to learn. And there's still so much to learn... but you've all made it easier for me and welcomed me with such openness that it's like a home from home. I've been so impressed by so much about the Centre – from the day to day operation and all our dedicated reception to our doughty chamber operators and benefits team volunteers and all the rest. Thank you for being such a wonderful community of people. I'm already beginning to feel part of the furniture!



And now here I am welcoming you to the summer issue of our jam-packed Belle newsletter! So, what have we been doing all this time? We've made admin easier by taking our electronic files to the Cloud (online). This means we don't have to back up constantly, and, if need be, we can work for the Centre on our own computers from home (very useful if I've just driven to Brighton and forgotten something!). We've moved our banking online, too, which generally means not writing cheques and gives us considerably lower bank charges. And, speaking of online, we're slowly increasing our social media presence on Twitter and Facebook, a great way of spreading the word and keeping in touch with other centres.



We've also worked to improve our facilities, not least ensuring that emergency lighting and electrics are in good order. We're grateful to Willmott Dixon for installing an automatic door, to both them and Shoreham Port for helping transform our garden and to members for contributions of plants and seeds. I hope you'll take the time to step out the back



and enjoy sitting in the peace and tranquillity before or after therapy or oxygen sessions or classes amid bird song while admiring abundant veggies and flowers. And finally – but no less importantly – we've increased the number of oxygen sessions, giving more opportunities for members who can't access them in the daytime.

Sadly, by the time you read this, Emily will have left us for her new job. We would like to thank her for all her hard work and dedication to the Centre as well as for her lovely energy, and we wish her well for what promises to be a fantastic new job. Emily has put her heart and soul into her work here. Helped by Alan, she ran the Centre for four months, for which she deserves a medal! Emily has also produced the *Belle*, collating and writing material and designing the layout. This edition is her parting gift.

Finally, we have further summer events to look forward to. The Social Committee have organised a pub night on Friday 19th July, and our annual Sponsored Walk is on Saturday August 31st. We look forward to seeing you there!



Trustee Update

As you know, we've launched our new building project! Some of you attended our exciting Open Evening and saw the vibrant exhibition that staff put together for it. If you didn't see it, you may have noticed the architect's initial drawings displayed on the café area wall. This marks an important new chapter for the Centre. We love our home here, but we know that this building has not really been fit for purpose for some time.

It's a relatively long-term project, and we want everyone to feel part of the process. As things move forward we plan to have ways of consulting you all. We want to reassure you that you will have lots of chances to express your opinion. Currently we are seeking permission for the land. Once we have this, then we can seek planning permission. It all takes time as you know!

We are looking at trustee skills over the next few months and will hopefully identify some specific areas, skills wise that it be would be good to have on our trustees team, to help sustain our future but also help with the building project. We will keep you posted.

Please also keep posting any comments if you have them concerning the Centre either in the book for EJ or if its directly for us then in the trustee post box in the café area.

We wish you all a very happy Summer.



Building Project

Some of you may have already seen our architects initial plans, which we presented at our open evening and now have displayed in the café area of the Centre.

Now its just the minor matter of raising over a million pounds! All contributions and ideas welcome!!!



Social Events

Our dedicated volunteers that make up the Social Committee, aim to put on one Social Event per month, when possible. This year so far they have put on an event for Burns Night in January, a Quiz Night, Elvis entered the Centre for a fabulous night of laughter and rock n roll in April, and in June we held our annual Summer BBQ in our freshly transformed garden! Join us in July for our Pub Night Social with Fish and Chips.



Members £4.00

Member and Carer £6.00

Guest £6.00

DMD Ocrevus

Ocrevus has recently been approved for relapsing remitting and primary progressive MS.

In our autumn newsletter 2018 we wrote of how the NHS had reversed its previous decision and now recommends Ocrelizumab (drug name Ocrevus) for the treatment of relapsing remitting MS. Disappointingly however, at the same time, NICE announced that Ocrevus was still too expensive for people with Primary Progressive MS (PPMS).

The good news is that the NHS struck a deal with Roche (the pharmaceutical company) and patients with PPMS are now able to access the drug. It is estimated that 10,000-15,000 people have Primary progressive MS (PPMS) in the UK, of whom around 2,700 people could be eligible for treatment with Ocrevus.

If you have Primary Progressive MS and you have started to take Ocrevus please feedback to us. We welcome all feedback about drugs and you can contribute by going on our Drugs directory as someone that can talk with other members about a drug you have experience of.

To find out more information about Ocrevus head to:

www.mstrust.org.uk/a-z/ocrevus-ocrelizumab





Dates for the diary: CBD seminar

CBD oil seminar with John & Frankie.

Monday 15th July 10.30am-12pm

Where? In the café area at the Sussex MS Centre

Could CBD Oil give you relief? John and Frankie will cover what CBD is, how it works and how it may benefit you. We want to offer a space for our members to learn a little bit more about how CBD oil may be able to help with pain management, where we can encourage an open discussion about the potential benefits of using CBD oil.

John

John is a Personal Trainer and takes the oil himself to relieve his anxiety. CBD helps him when nothing else works and has made his life more manageable. He loves to teach others how to improve their health and gives seminars locally.

Frankie

Frankie has been in the CBD industry for a little over a year now. Frankie takes CBD for pain and anxiety and has now come off all medication and no longer feels anxious and can control her pain. Frankie loves educating people about CBD in general because of the difference it has already made in her life.

All welcome, please do pop your name on the list at reception so that we have an idea of how many people may be attending.



Dates for the diary: Shiatsu college open day

Shiatsu College Open Day

Saturday 14th September. Drop in between 11am & 4pm Where? In the gym at the Sussex MS Centre

Find out about the wonderful healing art of Shiatsu at the Shiatsu College Open Day. An opportunity to discover what Shiatsu and Acupressure Therapy could offer you and find out about our workshops and courses. Receive a Shiatsu taster session & join in our Qigong class - all free!

What's happening and when?

11am-12pm

Free Shiatsu taster sessions, information about our courses + tea & biscuits!

12pm-1pm

Qigong exercises - simple, energising and fun movements for all abilities

1pm-4pm

Free Shiatsu taster sessions, information about our courses + tea & biscuits!

For more information contact:

email: brighton@shiatsucollege.co.uk

call: 01273 782872

Facebook: @ShiatsuCollegeBrighton



Co-op Local Cause

Co-op Southwick Local Cause

We are thrilled to have been chosen as one of the Co-op Southwick's Local Causes for 2019. Robbie and his team at the Co-op have already shown our Centre so much support so far this year, from supporting us at our Open Exhibition Evening in May, to providing us dates throughout the year to hold collections at the Southwick Co-op, and even getting together a team of Co-op staff to join us on our annual sponsored bike ride in June. So far this has raised over £1000!

Yes you can help!

Become a member: Co-op gives 1% of what its members spend on Co-op branded food products in stores and selected services, as well as the money raised from carrier bags and scratch cards to local causes—like us—The Sussex MS Centre.

Choose the Sussex MS Centre as your local cause: Once you become a member, or for existing members, simply go online to coop.co.uk/membership and search for Sussex MS Centre/No. 28440

Volunteer for a collection: Our next collection dates at the Southwick Co-op are: Saturday 27th July and Saturday 14th September. Could you spare a couple of hours to come along and represent the Centre on either of these dates? To find out more email events@mssussex.com



Collection Box Appeal

Collection Boxes Appeal

"Look after the pennies and the pounds will take care of themselves!"

As you know we live more and more in a cashless society. Collection boxes are becoming relatively obsolete. Takings from collection boxes have gone down in the past few years by many thousands at the Centre and we see it on our balance sheet decreasing further!.

This is another call to action for which we'd be very grateful – if you know of a shop, café or pub (or anywhere) that might possibly take a collection box and you'd be prepared to take it there and collect it when it's full please let EJ or Jane know! We can give you an official letter of authorisation to do this.



Fundraising

We have had a hugely successful few months of fundraising, from abseils to sponsored runs, a swimathon, our annual sponsored bike ride, a supermarket collection at our local Southwick Co-op and a day of fun in the community at the Lions Donkey Derby.

Brighton Marathon

We had four runners supporting our Centre in April in this years 2019 Brighton Marathon. We had Steve, Michelle, Emily and Matt take on the 26.2 miles, raising over £1500 for the MS Centre.

Sponsored Bike Ride

On Sunday 8th June we held our annual 20 mile sponsored bike ride, from Shoreham Airport to Slinfold Village hall. This year we had an amazing turn out with teams from Southwick Co-op, Rossetts Vans Worthing and many more old and new faces. We were up against a wild wind and frequent rain showers... However all of our wonderful cyclists put on a cheerful face and made it to the end for lunch at Slinfold!

The day could not have been such a success without our incredible troop of volunteers, that took on roles marshalling points along the route with refreshments, our support cyclists, and our village hall volunteers feeding our hungry teams as they arrived at Slinfold. It was a great day out for everyone; a huge thanks to all that participated and volunteered. Once all the funds are collected we hope to reach over £4000 for this event!



Fundraising

The 'iDrop'

We had a team of 23 brave participants taking on the 450ft abseil from the British Airways i360 raising funds for the Centre. Due to 50mph winds, and the tail end of 'Storm Hannah' we had to reschedule our original date for this event which was April 27th. Participants have been split into three different dates for their abseil with the last date being in July.

The June abseils went amazingly well with 18 fundraisers joining us on the 1st of June for a group abseil, and on the 15th of June we had the brave Sharon abseil solo for us. We have so far raised nearly £11,000 for the Centre, which is absolutely phenomenal! Our intrepid abseilers have done an amazing job in raising sponsorship, and they really do deserve every penny raised for this terrifying challenge!

Saturday 20th July

Our last team of abseilers are going to be taking the leap on Saturday July 20th from 8.30am. If you are able to make it down to the i360 to support our team we would love to have a crowd to cheer our group on! Contact EJ if you would like to come along to show your support.



Medication Information Exchange

DMDs and SMDs Information Exchange

Below is a list of disease modifying and symptom management drugs. We now have volunteers who are happy to talk to other members about their experiences using the drugs highlighted in blue. If you have experiences that you are happy to share with others, particularly of those not highlighted in blue, please let us know. We recommend that before you make any decisions you speak to your neurologist, MS Nurse and others who have had experience of the drug.

Disease Modifying Drugs

The aim of all of these drugs is to reduce the number and severity of relapses

| Drug Name | How taken |
|-------------------------|--|
| Aubagio (teriflumanide) | Oral daily |
| Avonex | Self inject weekly |
| Betaferon | Self inject every two days |
| Cladbribin (Mavenclad) | Intravenous injection |
| Copaxone | Self inject daily or three times a week |
| Extavia | Self inject every two days |
| Gilenya (Fingolimod) | Oral daily |
| Lemtrada | Intravenous infusion once a year for two years |
| Low Dose Naltrexone | Oral Daily |
| Plegridy | Self inject fortnightly |
| Tecfidera | Oral twice a day |
| Tysabri | Intravenous infusion once every four weeks. |
| Zynbryta | Self inject once a month |

Symptom Management Drugs

This is not an exhaustive list of all the drugs that are prescribed to provide symptom relief, but many of the below are prescribed to people with MS. Always speak to your consultant and MS Nurse about symptoms that are worrying you. There may well be a drug that will help.

| Drug Name | What's it for? | |
|-------------------------|---------------------------------|--|
| Alprostadil (Caverject) | Erectile dysfunction | |
| Amantadine (Symmetrel) | May lessen fatigue | |
| Baclofen (Lioresal) | To relieve spasticity and spasm | |

| Baclofen pump | For severe spasm. Pump is implanted. | | |
|-------------------------------|--|--|--|
| Botulinum toxin (Botox) | To relieve spasticity and spasm and bladder symptoms | | |
| Carbamazepine (Tegretol) | To treat pain associated with spasticity and spasms, trigeminal neuralgia and some other pain symptoms | | |
| Cialis (tadalafil) | Erectile dysfunction | | |
| Clonazepam (Rivotril) | Tremor | | |
| Dantrolene sodium (Dantrium) | Chronic, severe spasticity and spasms | | |
| Desmopressin (Desmotabs) | Bladder problems | | |
| Diazepam (Valium) | Spasticity and spasm. Severe anxiety. | | |
| Fampridine (Fampyra) | Can improve walking. Rarely available on the NHS. | | |
| Fluoxetine (Prozac) | Depression. Some research findings suggest it reduces the inflammation around nerves in MS. | | |
| Gabapentin | Neuropathic pain such as trigeminal neuralgia or abnormal sensations (dysaesthesia), such as burning or pins and needles | | |
| Imipramine (Tofranil) | Antidepressant which sometimes helps relieve pain and pins and needles | | |
| Modafinil (Provigil) | Fatigue. Not currently recommended for use for MS fatigue. | | |
| Nuedexta | Pseudobulbar affect - uncontrolled laughing or crying | | |
| Oxybutynin (Ditropan) | Bladder urgency | | |
| Paroxetine (Seroxat) | Depression and anxiety | | |
| Phenol | Severe spasticity where other treatment options | | |
| Phenytoin (Epanutin) | Trigeminal neuralgia or other painful sensations (dysaesthesia) if other approaches have not worked | | |
| Pregabalin (Lyrica) | Neuropathic or nerve pain | | |
| Sativex (nabiximols) | Spasticity | | |
| Steroids (methylprednisolone) | Sometimes used to aid recovery after relapse. | | |
| Tizanidine (Zanaflex) | Spasticity | | |
| Tolterodine (Detrusitol) | Bladder problems | | |
| Vardenafil (Levitra) | Erectile dysfunction | | |
| Viagra (sildenafil citrate) | Erectile dysfunction | | |

Sharing your experience is valuable to others, so please let us know if you are or have been on one of the drugs. If you are involved in a trial of or on a drug not listed here, please keep us updated.

Our transformed garden areas

Local businesses helping to transform our garden areas

You may have noticed that our front and rear gardens have had a complete makeover, courtesy of the construction company, Willmott Dixon. We thank them hugely for their brilliant efforts in organising this; liaising with other companies to help them with the project with tools and materials and then carrying out the work.

Now comes the hard work for us! A lovely blank slate to work with... At the time of writing, our raised beds are beginning to spring into new life with a cornucopia of cucumbers, courgettes, strawberries, tomatoes and radishes and flowers like lobelia, alyssum and marigolds. Please feel free to harvest the odd vegetable for your healthy lunchtime salad when they ripen!

What we would love for the rest of the summer is volunteer gardeners to help us keep the garden weed free and free from drought! Even if you have 10 minutes to spare, stepping out into the back garden and doing some watering would be very much appreciated. What we'd really like to do it set up a rota for watering if you are here regularly?! This was an issue in previous years I believe, however, we now have an outside tap complete with hose to make life easier...

Please let EJ or Jane know if you are happy to contribute a bit of time to our garden.



Thank you!

Willmott Dixon

Rob and his troop of volunteers from Willmott Dixon collaborating with other businesses to transform our front and back garden areas in May.





Shoreham Port

Donna and Terry from
Shoreham Port volunteered
their time to weed, plant and
prune our outside area in
June. The day went from wet
to wetter, but their hard work
and cheery smiles didn't fade
all day!

We would like to extend our thanks to Maybourne & Russell, Speedy, Adur & Worthing councils and Rabbit who collaborated with Willmott & Dixon in the transformation of our outside spaces.







Sussex MS Volunteer Contribution

Without our wonderful volunteers we couldn't survive and we are so grateful for the many hours a year that our volunteers generously give to the running of the Centre. Outside of the Centre, members are also helping at one off fundraising events, not to mention our fantastic Social Committee who make it possible for a variety of social events to happen annually. These events are run in such a way that no matter what a members' income, they are accessible to all.

Having said all of this, we still need HELP!!

With rising inflation and it being even harder to gain funding for running costs the Centre needs to increase its income and we need to have more one-off events happening.

If you can contribute time to an event being run please contact EJ or Jane for more information! The benefits of doing this are huge; you meet new people you may never have met and you've helped create a buzz while having fun AND supported your Centre!!

By the same token if you have the energy and capacity to organise and co-ordinate a small fundraising event yourself and you know you would enjoy it, please let us know. This could be things ranging from a Jumble/Bric a Brac sale, plant sale, clothes sale, antiques sale or cake sale to a silent auction, dog show or giving a talk on your speciality or anything else you can think of!

Think outside of the box and act now to help us! It would be great to have a few events this coming Autumn!

Sussex MS Volunteer Contribution

How can you help?

Sign up for one of our supermarket collections

Our next collections at Southwick Co-op are:

- ⇒ Saturday 27th July collection
- ⇒ Saturday 14th September collection

We also need someone to take on the organising of more supermarket collections possibly at Waitrose, Tesco, Morrisons, Sainsburys etc

Volunteer to marshal at a sponsored event

Our next Centre organised fundraising event is:

Saturday 31st August Sponsored 10 Mile Walk

We need volunteers to act as marshals along the route, and also volunteers to make sandwiches at Shoreham Airport at the end of the walk

Get involved with our collection box appeal

If you know somewhere that we could put a collection box, and if you would be happy to manage the collection of this periodically, get in touch!

Volunteer at the Centre

We are always in need of volunteers here at the Centre. We have volunteer roles on reception or operating the oxygen chamber, or perhaps you would like to volunteer your time to help with our garden or to paint and decorate? If you would like to donate time on a regular basis get in touch with EJ.

Organise your own fundraiser to raise funds for the Centre

If you would like to organise an independent fundraiser we would love to hear from you!

Please email EJ or Jane on info@mssussex.com or jane.taylor@mssussex.com or ring 01273 594484



Oxygen Therapy

Good practice for divers of the belle!

To get the maximum benefit from your session in the oxygen chamber you should be calm and relaxed, have time to go to the toilet and gather reading material and maybe a glass of water etc so please arrive 15 minutes prior to your session.

It also means that sessions start on time, pleasing everyone!!

| | Monday | Tuesday | Wednesday | Thursday | Friday |
|---------------------|--------|-----------------------------|-----------|----------|--------|
| 9.00AM | 24FT | 24FT | 33FT | 16FT | 24FT |
| 10.30AM | 33FT | 33FT | 16FT | 33FT | 16FT |
| 12.00PM | 16FT | 16FT | 24FT | 24FT | 24FT |
| 1.30PM | 33FT | 33FT | 24FT | 33FT | 33FT |
| 3.00PM | | 33FT | 16FT | 16FT | |
| 5.30PM | | | 16FT | | |
| 7.00PM | | | 33FT | | |
| 7.30PM ALT WEEKS | | 33FT: ALTERNATE WEEKS | | | |

Please ring us if you are running late. We will wait 5 minutes if we need to. Knowing whether you are trying to reach us is useful.

Remember that cancelling dives, where possible, with 24 hours to spare, means we may be able to give your dive to someone else who really needs it.

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The MS Gym - feedback from a member

The MS Gym is a website designed with the aim to educate the Multiple Sclerosis Community on how to exercise safely, correctly, and effectively in order to manage your symptoms, teach your brain new ways to move around your damaged nerves.

Volunteer receptionist Lisa shares her experience with using the 'MS Gym' and how it has helped her.

My story....I've had MS for 15 years plus. I tried Tecfidera and Copaxone but didn't get on with the side effects so stopped and have chosen not to take DMT's.

For me, and probably many others the fear is of the unknown i.e progression of MS. So, one day I was on YouTube and came across a guy called Trevor Wicken. I remember him saying "if you can move one finger you can move two, if you can stand, you can walk." I thought, ok, so what's this all about?

I did some research and found the MS gym. The creator is Trevor Wicken. I joined the gym and spent some time looking at the vast amounts of information on the web site. The MS Gym has exercises designed specifically for a certain symptom you may be experiencing for instance, foot drop, hyperextension, neck pain, dexterity weakness or edema. The list is so vast that I could not possibly list it all. It explains the bio mechanics of our bodies and how you can gain better movement.

I do not want to preach to anybody about what they would get out of looking into the MS Gym but I would encourage people to at least take a look.

I can honestly say that I have learnt far more about MS from The MS Gym than any neurologist has been able to offer me. It has REMOVED my fear of MS and if I gained nothing else (which actually would already be incorrect – as I have seen gains in my dexterity and MS hug alleviated already) then it has been worthwhile me joining.

To find out more head to the MS Gym webpage:

www.themsgym.com



Weekly classes and therapies schedule

| Monday | Chiropody– Julia | 9.30am-4.15pm (every 6 Weeks) |
|-----------|--|--------------------------------|
| | Alexander Technique - Rebecca | 10.00am-3.00pm |
| | Massage- Eva | 10.00am-4.00pm |
| | Drop in Belly Dancing– Galit | 11.45am-12.45pm |
| | Drop in Pilates— Lynne/James | 1.15pm-2.15pm |
| Tuesday | Shiatsu- Al | 10.00am-3.00pm |
| | Massage- Viola | 10.00am-3.00pm |
| | Acupuncture- Evette | 10.00am-1.20pm |
| | Drop in Keep Fit- Lynne | 10.15am-11.15am |
| | Physiotherapy– Diane | 11.45am-3.30pm |
| | Drop in Keep Fit- Lynne | 6.15pm-7.15pm |
| Wednesday | Massage- Eva | 9.00am-2.30pm |
| | Reflexology/Reiki- Julie | 10.50am-3.45pm |
| | Drop in Yoga- Julia | 10.30am-12.00pm |
| | Drop in Tai-Chi- Mo | 1.00pm-2.00pm |
| Thursday | Acupuncture- Evette | 10.00am-4.20pm |
| | Indian Head Massage/ Reflexology– Sonia | 10.00am-3.45pm |
| | Drop in Pilates– Micci | 10.30am-11.30am |
| | Drop in Seated Yoga– Louise | 12.00pm-1.00pm |
| | Drop in Keep Fit- Lynne | 2.30pm-3.30pm |
| Friday | Shiatsu– Amanda | 9.30am-1.00pm |
| | Massage– Viola | 9.30am-11.30am |
| | Beauty/ Holistic Therapies– Sarah | 9.30am-2.30pm |
| | Drop in Voice Works- Rose | 11.00am-12.00pm |
| | Osteopathy– Virginia | 12.00pm-2.00pm |
| | Drop in Physiotherapy Gym– Viola | 1.00pm-2.00pm |
| | Physiotherapy 1:1— Viola | 2.15pm-4.15pm |

Please call reception on 01273 594484 for individual therapist bookings and enquiries.

Other ways to support the Centre

You can easily support the Sussex MS Centre in a variety of different ways. We are now linked up to a range of causes that reward charities when you shop! All we ask is that you select the Sussex MS Centre as your chosen charity for AmazonSmile and Give As You Live. If you normally shop at Co-op, why not become a member and select us as your chosen local cause?

AmazonSmile

Every time you shop at smile.amazon.co.uk Amazon will donate to the

Sussex MS Centre, just remember to choose us as a charity when you login to AmazonSmile!

smile.amazon.co.uk/ch/801075-0



Give As You Live

Give as you Live is the free and easy way to raise free funds for Sussex MS Centre, simply by shopping online.

From holidays and travel, to clothing and gifts, you can raise hundreds of

pounds from all your online purchases.

Spread the word to friends and family to support the Centre.

giveasyoulive.com/join/sussexmscentre



Co-op Local Cause

Become a co-op member and you can choose to support us via Co-op, selecting the Sussex MS Centre.

Local cause number, 28440



