

The Belle

Issue Number 82 Autumn 2018



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

www.mssussex.com

01273 594484

Christmas Raffle, December 2018



Our grand Christmas raffle will this year be drawn on Tuesday 11th December.

As always, there are some great prizes to be won including an exciting Aerotow to 2500FT kindly donated by the East Sussex Gliding Club, M&S vouchers of varying value from £100 to £10, Platters for two on Victoria Terrace at The Grand, Afternoon tea at Stanmer House, tickets for Drusillas Park, Pantomime tickets at Eastbourne Theatre, Cinema tickets at Depot cinema and much more to be confirmed!

We have enclosed a raffle book in this edition of the Belle for you to either buy or sell the tickets. Any tickets you buy or sell to friends/family just hold on to the right hand side of the ticket and send us back the other half (with the name/address/ phone number of the person who has bought the ticket) with £1 per ticket. There is a book of 5 tickets in enclosed, just ask at reception or give us a bell if you would like us to post you more to sell!

Signed Albion T-Shirt Raffle , December 2018

Alongside our annual Christmas Raffle, we have kindly been donated a signed Brighton & Hove Albion t-shirt by player Dale Stephens who has regularly used the Oxygen Chamber to help speed up the healing of an injury. The signed Albion shirt will be up for raffle which will be drawn on **Tuesday 11th December**. Tickets are £1.00 each, which you can purchase at reception, or give us a call if you would like us to send you a book to sell tickets to friends and family yourself. Of course, all funds raised will be in aid of our wonderful Centre.



Sussex MS Centre, Autumn/Winter 2018

With the end of the year fast approaching, we have merrymaking and social events at the ready, along with a few new faces to welcome here at the Centre.

Firstly, a huge thank you to Alan Taylor, who we hauled out of retirement to fill in as temporary Centre Manager, he slipped back into the role like he had never left, I think we can all agree it has been wonderful to have him back! Alans 'holiday from retirement' will be ending by Christmas (when he will be stepping back onto the board of Trustees), as we are thrilled to announce that joining our small team made up currently of Emily and Jane, is our brand new Centre Manager Emily-Jane (yes, really-although she is better known as 'EJ' which makes it easier!).

EJ has been Centre Manager at Friends Centre, Brighton, an adult education centre, for the past ten years. She is very interested in health and complementary therapies, and is also a Bach Flower practitioner in her spare time. EJ is an enthusiast for the outdoors and a great animal lover, sharing her home with two beautiful pussy cats called Stanley and Oliver, and a husband called David. She is greatly looking forward to working closely with our volunteers, meeting all of our members and friends and helping to shape the exciting future of Sussex MS Centre. We look forward to welcoming EJ officially at the end of November.

Coming up on our events calendar is a spattering of festivities, see the back page for dates for the diary. We have two raffles to be drawn in December, we need all the support we can get from our members in selling these tickets, it's a fantastic opportunity to raise funds for the centre and be in with the chance to win some great prizes! We look forward to sharing the exciting next few months with all of our friends here at the Centre.



New classes and therapies

We are looking forward to welcoming a few new faces to the centre this Autumn, read on for more information of new therapies and classes coming up.

Belly Dancing Classes

Monday/ 11:45am-12:45pm. Drop-in class.

Fun, giggles, sparkle and shimmies is what you can expect in our Belly Dance class with Galit. You will also be learning basic Belly Dance moves with simple variations and step combinations. Special attention is given to body awareness, posture and self expression through dance. The class is gentle yet upbeat. With over 20 years teaching experience, Galit is able to work with different levels of mobility and will adjusts the lesson to the needs of the group

Acupuncture

Tuesdays & Thursdays / 10:00am-3:00pm. Book at reception

As many of you already know, we are wishing our acupuncture therapist Pippa all of the happiness in the world as she heads off on maternity leave. The lovely Evette will be stepping in to cover all of Pippas regular sessions, speak with reception to book a 40 minute acupuncture session with Evette.



Alexander Technique

1 hr Introductory session Monday 26th November 10.30am. Please sign up at reception.

Rebecca Rees, a teacher of the Alexander Technique, will run a one hour introductory workshop to show us how learning the AT can help us move around with greater freedom and ease in all our daily activity. The AT is a simple practical method of effective self-help skills that can improve our balance, patterns of movement, coordination, posture and improve our general state of well-being and energy levels.

Recent research also demonstrates that learning the Technique reduces back and neck pain, muscle spasm and stiffness. It can help reduce feelings of stress and improve breathing problems. Sleep may also improve when we learn to apply the Technique at bedtime.

In the workshop we will have fun exploring our hidden neuromuscular tension habits and how these habits often limit our freedom of movement without us realising. We will learn how to "take off the handbrake" and play with the way we move around in everyday actions such as sitting, lying down and standing around.

It is changing our habits that leads to an overall reduction in muscular tension, easier patterns of movement and improved general health, breathing and feelings of well-being.

Please wear loose comfortable clothing to move around in freely

Visit <u>www.naturalspinehealth.co.uk</u> for more information about Rebecca and the Alexander Technique .



MS News

DMDs UPDATE

NICE (The National Institute for Health and Care Excellence) has published new guidance on several MS DMDs (Disease Modifying Drugs) following negotiations with the pharmaceutical companies manufacturing them.

It was feared that several DMDs including Copaxone, Avonex, Extavia, Brabio and Rebif would be withdrawn as they were not considered cost effective but NICE is now able to recommend them for routine NHS funding for the treatment of relapsing remitting MS. Betaferon will no longer be available.

NICE has also reversed it's previous decision and now recommends ocrelizumab (drug name Ocrevus) for the treatment of relapsing remitting MS. This drug will be available to people who are unable to take alemtuzumab (Lemtrada). It's taken as two intravenous infusions, given 14 days apart. It's then taken as a single infusion every six months.

Regrettably, NICE have announced that Ocrevus is still too expensive for people with primary progressive MS (PPMS). Whilst NICE acknowledges that PPMS has a substantial effect on the lives of people with the condition and that trials have shown that Ocrevus can slow the worsening of disability, they consider the benefits gained do not represent value for money. There are currently no approved treatments for PPMS



National MS Centres AGM

Summary of the National MS Centres AGM and Conference

Christopher Fox-Walker and Jane Taylor attended the National MS Therapy Centres (MSNTC) AGM and Conference at the University of Warwick on the 7th and 8th July.

The Sussex MS Centre is a member of the MSNTC which has a skilful team of Trustees and is very sensitive to delivering a good service to member centres. A large number of the sixty UK MS Therapy Centres were present. Including those from Wales and of course Scotland. Scotland has the largest number of MS sufferers per capita population.

On Saturday there was a Well Being Seminar led by Tori Ducker from the Jersey Oxygen Centre about creating a healthy workplace for centre staff and volunteers. Another discussion concerned how the MSNTC can help smaller centres.

On Sunday everyone attended the MSNTC AGM at which David Wray (Swindon) retired and Bernard Ellen (Norfolk) was elected as the new Chairperson.

The first key note speaker was MS Consultant Nurse, Bernadette Porter (from the National Hospital for Neurology and Neurosurgery, London) who discussed the large number of MS sufferers coping with urinary infections, the failure of the NHS in coping, and the setting up of special services within the NHS. In the questions period Christopher referred to the fact that all the trials conducted on the effectiveness of HBOT have demonstrated that regular use of HBOT improves bowel and bladder functions.

In the afternoon there were two Workshops. Jane attended the workshop on how to use online funding databases effectively and Christopher attended the workshop on the General Data Protection Regulations (GDPR) and how they should be applied to the centres.

The redoubtable David Downie, from the Isle of Man Centre, outlined key future issues for managing the technical provision of oxygen in the centres.

The conference was concluded with an excellent talk by Dr Bill Code (MD FRCPC from Canada) on the advances of the non-drug management of MS. Dr Code has MS and is writing a new book, entitled, 'Winning the Brain Game: A complete Layperson's Guide to Achieving Brain Health' which will be published in the UK soon (and Dr Code will be giving a free copy to every centre in the UK).

Emeritus Professor Philip James would have also given a talk but sadly could not attend due to emergency heart surgery. Dr Code and Professor James are working together on a new book and they will be suggesting to change the term Multiple Sclerosis to Microvascular Syndrome.

DO YOU SUFFER FROM FATIGUE?



CAN YOU HELP? PARTICIPANTS NEEDED FOR FATIGUE STUDY

Current research highlights the lack of progression and understanding on the management and treatment for Multiple Sclerosis related fatigue. In this study, we will investigate a wide variety of different measuring tools to expand and develop clinical assessment and management for fatigue. We will look at your walking, coordination, muscular strength and personal experiences of fatigue through physical assessments and an interview.

The assessments are completely non-invasive and involve walking short distances indoors with sensors attached, on top of clothing, to your limbs (and running shoes, which we will provide). An informal chat about your experience of fatigue will take place after the physical assessments, which will be audio recorded.

All information is confidential

Location: University of Brighton, Eastbourne campus.

The whole process is estimated to take 2 hours.

Travel expenses will be reimbursed

If you would like more information, please contact:

Rebecca Player

University of Brighton, PhD Student, Registered Osteopath, rfp14@brighton.ac.uk

07491977740.

2019: Organised Fundraising Events

Virgin Money London Marathon 2019

We are delighted to announce that we have acquired one Virgin Money London Marathon place for April 2019. These places are fundraising gold dust, and we are absolutely thrilled that Rose (the daughter of our wonderful Jane), has accepted the challenge not only in running the epic 26.2 miles, but also raising sponsorship in aid of the Sussex MS Centre.



Brighton Marathon 2019

Brighton Marathon is also coming up in April 2019, we currently have two runners taking on the challenge to raise funds for the Centre, if you know anybody that might be interested in taking one of our remaining places for BM2019 get in touch with Emily on **events@mssussex.com** to find out more.



Dulux Revolution Cycling Event

The Dulux Revolution is a breath-taking 300km/2 day cycle event around London, visit www.london-revolution.com for more information the event.

We are currently looking into purchasing charity tickets for this event but need a minimum of 5 participants cycling to raise funds for the Sussex MS Centre to commit before we will consider buying these spaces. If you or a friend/family member has any interest in this event have a chat with Emily, or email events@mssussex.com



Fundraising for the Centre

We are always on the lookout for anybody that might like to take on an independent fundraiser to raise those all important funds for the wonderful Sussex MS Centre. Be it a fundraising afternoon tea, a sponsored sports challenge, or a day of fundraising at work, we would love for you to get involved! Chat with Emily at the Centre, or email events@mssussex.com if you would like to organise your own fundraiser for the Sussex MS Centre.



Sussex MS Centre Sponsored Events

Sponsored Walk, September 2018

We were blessed with a beautiful day for this years sponsored walk, following the River Adur from Shoreham to Upper Beeding and back. Thank you to all of the walkers that joined us for the day, and of course our volunteers that helped out marshalling the route, and making sandwiches for all back at the airport. We raised well over £2000 in sponsorship for the Centre which is a fantastic effort!



i360 Sponsored Abseil, April 2019

On 27th of April 2019 the British Airways i360 will be the hosts of a sponsored abseil for the Sussex MS Centre. The 450ft abseil from the British Airways pod is quite the challenge, and for the adrenaline junkies out there a great sponsored event to get involved with. If you would like to find out more about the 2019 'iDrop' please email Emily at events@mssussex.com

Please note; this event may not be suitable for everybody, please request an information pack to find out more.



For more information on upcoming sponsored events email events@mssussex.com

Members Recommendations

For short stays away from home...

The Willow in Notton

A Centre member enjoyed their stay at The Willow in Notton, Dorchester



so much they wanted to share it with all of you. Set in an idyllic location in farming country with sheep and ponies grazing outside, it's very peaceful and no sound of traffic. The Willow has excellent disability access accommodation in converted spacious barns. Electric riser beds and chairs are available on request.

For more info go to

https://www.cottages.com/cottages/willow-ukc2752

For mobility services, scooter servicing and repairs, a trustee recommends...

Active Days Mobility Services, Scooter servicing and repairs.

Full service £35 Active Days Mobility special offer. FIXED PRICES, NO NASTY SURPRISES! All mobility scooters, power-chairs, wheelchairs, rollators serviced and repaired. Batteries and Tyres supplied and fitted. Carried out at your home or workplace. A full service £35-£40: in general 50% cheaper than others. No losing your mobility aid for the day; service undertaken in just around 60 to 90 minutes. Fully trained by leading manufacturers such as Drive, Kymco and electric Mobility. Former main dealer technician. Unwanted scooters and other mobility aids purchased. Telephone: 01323 767225 or call/text mobile: 075 911 783 99 or 070 443 076 21



Members Recommendations: Oceans of Hope

Oceans of Hope runs sailing experiences over days, weekends and full weeks, to inspire and empower people with Multiple Sclerosis to live their lives to the fullest, in spite of MS.

Centre member Richard Novis writes about his experience with Oceans of Hope, on the May 2018 expedition to Croatia.

In May 2018, I spent a week sailing with 'Oceans of Hope' around the islands in Croatia, there were 60 of us altogether sailing on 10 boats. It was an amazing experience, even if you have never sailed before, or have limited mobility or fight severe fatigue, there was always a way around it.

We were a diverse group, split into 2 watches for preparing meals and sailing. Joining in with the chores was a choice, and you could do as much or as little as you wanted. We all had MS in common and regardless of limitations, when MS is the norm, we don't have to explain anything or make excuses for things that we can't do.

An unexpected bonus was that our mobility improved! The constant motion on the boat, as well as needing to get between decks meant that our muscles got stronger too.

There were just too many high points to count, great friendships, great experiences and amazing memories. I can highly recommend!

-Richard Novis-

To find out more about what Oceans of Hope have planned for 2019 visit www.oceansofhope.com or email challenge@sailingsclerosis.com



Classes and Therapies and Treatments

Therapies and Classes

We offer a variety of individual therapies and treatments, alongside regular drop-in classes in the gym. Why not try something new? Individual therapies can be booked at reception, our therapists charge between £15-£20 per session which is paid directly to the therapist. You do not need to book for any of our drop-in sessions, just turn up and enjoy! Drop in sessions are free, however a donation is much appreciated.

Hyperbaric Oxygen Therapy (HBOT)

We run our oxygen chamber Monday to Friday with at least 4 sessions per day. If you would like to talk more about HBOT or are yet to try it, have a chat with us at the Centre.

Times of Oxygen Sessions

1.5 (16ft)

Monday – 12.00pm

Tuesday – 12.00pm

Wednesday – 10.30am&3pm

Thursday – 9.00am & 3pm

Friday – 10.30am

1.75 (24ft)

Monday – 9.00am

Tuesday – 9.00 am

Wednesday - 12.00pm & 1.30 pm

Thursday - 12.00pm

Friday – 9.00am & 12.00pm

2.0 (33ft)

Monday - 10.30am & 1.30pm

Tuesday - 10.30pm, 1.30pm & 7.30pm

Wednesday - 9.00am

Thursday - 10.30am & 1.30pm

Friday – 1.30pm

Saturday – 10.30am

Individual Therapies and Therapists

Shiatsu

Shiatsu is a body-based holistic therapy using the application of pressure to acupressure points, using fingers or palms. Stretches and joint rotations are also routinely used. It can help with a wide range of symptoms, and is generally very relaxing. Sufferers say Shiatsu relieves pain and fatigue, boosts mobility and mood and makes it easier to cope with the hardships of life with an incurable illness. Treatment is given through clothing, and generally takes place on a futon on the floor, but other arrangements can be easily made.



Amanda

Mondays and Wednesdays 9.30am-1.00pm



Α

Thursdays 11am-1.00-pm

Reflexology and Indian Head

Massage

Sonia

11.00am-2.45pm Thursdays.

Indian Head Massage is a seated massage and so can be easily performed on people in wheelchairs. It can prove beneficial in many ways including relieving eye strain, headaches and promoting a sense of overall well-being. It also can increase blood flow and therefore oxygen and nutrients supplied to the head and neck, relieve mental fatigue, relax the muscles, elevate mood and promote a good quality sleep pattern

Reflexology is popular because the system works on the whole body through zones on the feet, melting away accumulated tension and stiffness.

Reflexology & Reiki

Julie

Fridays 12.15pm-1.55pm

Both complimentary therapies can be carried out in your wheelchair or on a couch, and involve no clothes being removed other than socks for reflexology.

Both therapies treat the whole person, not just the individual symptoms. The mind/body/spirit connection is brought back into balance and relief can be gained

for any number of physical and emotional issues, anxiety and stress.



Individual Therapies and Therapists

Beauty Therapies

Sarah

Fridays 9.30am-2.00pm Sarah joined the MS Centre in 2013 and qualified as a Beauty Therapist in 2000. Sarah has added Holistic Therapies and Sports Massage Therapy as well. The therapies offered by Sarah are Facials, Manicure, Pedicure, Lash & Brow Tint (subject to patch test), Brow Shaping, Massage, Reflexology, Hopi Ear Candling and Indian Head Massage.



Chiropody

Julia

Mondays every 6 Weeks 9.30am-2.45pm



Julias role is to provide routine foot care and maintenance for your feet. It can be anything from routine nail cutting or more specific foot concerns such as corns, calluses, fungal nails/thickened nails or bunions. These may appear as something small and insignificant but can pose great difficulties with footwear and many daily activities. The service offered is to ensure your feet are healthy and in the best possible

condition, whatever your age. As an FHP Julia is qualified to work with additional problems such as diabetes and circulatory problems.

Osteopathy

Virginia

Fridays 12.15pm-1.55pm

Osteopathy is a way of detecting and treating damaged parts of the body such as bones, joints, muscles, ligaments, nerves, connective tissue and accessing their inter-relationship. Pain and disability arise from the body's inability to compensate for the lack of harmony. In order



to function efficiently with the minimum wear, stress and energy, the osteopath uses manual techniques to assist the body in achieving a balance.

Acupuncture

Evette

Tuesdays and Thursdays 10.00am-1.50pm

Acupuncture, is a holistic form of therapy which is part of the traditional Chinese system of medicine. This system believes the body is primarily an energetic organism. Acupuncture has the potential to manage some of the symptoms of MS

and improve levels of wellbeing and quality of life. Many people find acupuncture brings benefit.



Individual Therapies and Therapists

Physiotherapy

Diane

Tuesdays 11.45am-2.45pm

In a physio session Diane will try to closely observe how you hold and move your body. Diane will try to 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. 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

Massage and Physiotherapy

Viola

Mondays, Tuesdays, Fridays, ask for Viola at reception to make a booking.

Viola is a chartered physiotherapist and massage & complementary therapist. Viola has experience with a wide range of physical and medical conditions and treat clients from the less able to the very active- for relaxation of body and mind, to promote healing and recovery. She focuses on treating the whole person and combining treatment methods to suit individual needs. Body awareness and self-help exercises are encouraged to maintain health and well-being. Viola is available for bookings on Mondays and Tuesdays at the centre, and holds 'PhsyioGym' on Friday afternoons which is a drop-in group physio session held in the Gym at the Centre.

Massage

Eva

Mondays 10.00am-2.00pm & Wednesdays 9.00am-12.00pm

Eva is an experienced, fulltime therapist and passionate about soft tissue therapy. Treatments are highly adaptive to individual needs and we also had great results with wheelchair users. Eva combines massage, structural mobilisation techniques and reflexology - which are not only deeply relaxing rejoicing, but



can also relief long-standing pains and aches, free up your joints and increase your mobility.

Group Classes

Pilates

Mondays 1.15pm-2.15pm with James or Lynn

Thursdays 10.30am-11.30am with Micci

Suitable for everyone, Pilates is ideal for someone with MS as many of the exercises are done lying down and they are all non-impact and non-weight bearing. All the exercises are gentle enough to be done by someone weakened by MS. Although it does not involve resistance against weights, this is never too high to cause strain or over-exertion. Pilates can be started at any age and any level of fitness.

Keep Fit

Lynne

Tuesdays 10.15am-11.15am & 6.00pm-7.00pm Thursdays 2.30pm-3.30pm

Join Lynne every Tuesday and Thursday for an hour of fun and fitness. There are a great variety of benefits from taking part in fitness classes, these include a strengthening of the cardiovascular and respiratory systems, improved selfesteem, an assistance with maintaining bone and muscle strength, as well as helping to manage your weight, easing depression and helping to manage stress, and helping people to sleep better.

Belly Dancing

Galit Mersand

Mondays 11.45am-12.45pm

Fun, giggles, sparkle and shimmies is what you can expect in our Belly Dance class with Galit. You will be learning basic Belly Dance moves with simple variations and step combinations. Special attention is given to body awareness, posture and self expression through dance. The class is gentle yet upbeat.



Group Classes

Yoga



Wednesdays 10.30am-12pm with Julia
Thursdays Seated Yoga 12.00pm-1.00pm with Louise

Yoga improves posture and increases flexibility and stamina. It also improves the function of the respiratory, circulatory, digestive and hormonal systems. Yoga helps to relieve and reduce stress, and promotes deep relaxation, helping us to access our inner calm and self-confidence, and to live more fully in the present.

Tai Chi

Mo

Thursdays 1.00pm-2.00pm

Tai Chi is a form of gentle exercise that combines deep breathing and relaxation techniques with slow, graceful movements. It can be done by individuals or in groups. Because Tai Chi is largely based on technique, it does not require great strength or flexibility. It is used by some people with multiple sclerosis to help with balance, stress relief and general wellbeing.

Voice Workshop

Rose

Fridays 11.00am-12.00pm

Therapeutic Voicework recognizes the body's ability to heal itself through breath work, sound, and movement, and it provides a deep sense of relaxation and well being. Join Rose each Friday for an uplifting hour in our voice workshop, we guarantee you will come out smiling!



Brighton Beach accessibility petition

Brighton resident Hannah alongside a number of other Brighton residents, have been working on a project to improve disabled access to the beach and sea.

I cannot get on the beach, and I cannot get in the sea.

I can see the sea, but I cannot reach it.

This is perhaps the most stark manifestation of my disability

The beach and sea offers so many benefits, from improving physical and mental wellbeing, to offering a free place to meet and socialise with friends. Why should those with disabilities be excluded from that?

Centre Trustee Alison recently experienced a great example of how beneficial accessible beaches can be on her holiday to Corfu, see below the map of Corfu detailing all of the Wheelchair access beaches, and a photo of the 'floating wheelchairs'. If Corfu can do it so can Brighton!

A petition is now going, with an aim to get 1300 signatures before December 13th, when it will be presented to the council. To sign the petition type the link below into your browser, it can be signed by anybody, not just Brighton & Hove residents, it will not commit the council to anything, other than giving the issue of disabled access due consideration.





23rd November at the Centre Doors 5.30pm

£4.00 Members/ £6.00 Guests/ £6.00 Member & Carer Sign up at reception

facebook

Follow us on Facebook to keep up to date with what's going on at the Centre.

Also, it's really helpful to us if you share our posts when appropriate... you never know who might see them! Search for Sussex MS Centre and follow our page, or join the group to keep in touch with other Centre members.



If you are over 50 and need some information or assistance dealing with an issue, come along to our

Information & Advice Help-desk

at

Brooke Mead Albion Street, Brighton BN2 9PY
The second Wednesday morning each month,
From 10am -12pm

10th October, 14th November, 12th December

We can offer Information & Advice on a wide range of issues affecting older people including:

- Welfare Benefits
- Community Care
- Money Matters
- Consumer Issues
- Accommodation issues
- Disability issues
- Social activities

We also have access to Free legal, Will writing and financial clinics.

Please call: Age UK Brighton & Hove on 01273 720603 for further information



Dates for the Diary

November 28th 1pm	Mulled Wine & Mince Pies, with Eastbrook School Choir	At the Centre. FREE Sign up at reception
November 23rd 5.30pm	Quiz & Fish n Chips Social 6pm	At the Centre. £4.00 Members/ £6.00 Guests. Sign up at re- ception
December 11th	Christmas raffle & Albion signed T- shirt raffle	Our Grand Christmas Raffle and the Albion Signed shirt raffle will both be drawn at the centre at lunch time
December 14th 1pm	Christmas Lunch	At the Centre £5.00 p/p sign up at reception
Christmas Closure 22nd December– 2nd January	Centre closed	Centre closed

Reminder

2019 membership subscriptions are due in January

Membership is £15.00 per year to be renewed each January, you can pay in person at reception, over the phone on 01273 594484 or by standing or-

Please note:

If you do not wish to receive a paper copy of the newsletter, please ring the Centre or email events@mssussex.com.

