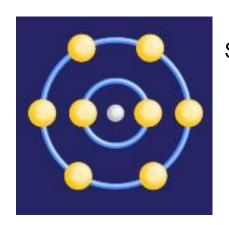
# **Sussex MS Centre**

01273 594484



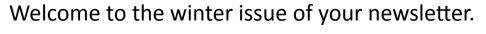
Southwick Recreation Ground
Croft Avenue
Southwick
West Sussex

BN42 4AB



#### www.mssussex.com

Small Charity - Big Impact





Charity Number: 801075

Company Registered in England 2319928

# A musical event with the amazing

# **ANGEL DELIGHTS**

Friday 24<sup>th</sup> November
Doors Open 6.30pm



£5 member: £7 member plus one: £8 guests includes a fish and chip supper

Licensed bar



and all the others who have run, walked, cycled, climbed... all in aid of the Sussex MS Centre.

## Are you eligible for discounts on your utility bills?

## **Gas/Electricity**

The schemes are different for each company, so you need to contact them. A number of suppliers offer support to people on disability benefits.

#### Watersure scheme

To qualify you need to:

Be on a water meter or have applied for one and be waiting for it to be installed, or be paying an assessed charge because it's not possible to fit a meter at your property



Be on certain benefits

Have a high essential use of water (MS continence issues aoften mean you use more than average)

Contact your suppliers for more information

## Would you like to learn some self defence moves?

One of our members recently suggested that we put on some workshops to teach our members some useful techniques for self defence.

If you are interested, please add your name to the list at reception, either in person, by phoning us or email <a href="mailto:jane.taylor@mssussex.com">jane.taylor@mssussex.com</a>.



Once we know how many of you would be interested, we'll work out how and when to make it happen!

## **Medication 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 marked in blue. If you have experiences that you are happy to share with others, particularly of those in black, 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 Madificina Ducas					
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)	Under trial				
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	Under trial				
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.

What's it for?	
Erectile dysfunction	
May lessen fatigue	
To relieve spasticity and spasm	
For severe spasm. Pump is implanted.	
To relieve spasticity and spasm and bladder symptoms	
to treat pain associated with spasticity and spasms, trigeminal neuralgia and some other pain symptoms	

Cialis (tadalafil)	Erectile dysfunction	
Clonazepam (Rivotril)	Tremor	
Dantrolene sodium	chronic, severe spasticity and spasms	
(Dantrium)		
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.	
Nortriptyline	ratigue.	
reorempty mic		
Nuedexta	pseudobulbar affect - uncontrolled laughing or crying	
Oxybutynin (Ditropan)	Bladder urgency	
Paroxetine (Seroxat)	Depression and anxiety	
Phenol	severe spasticity where other treatment options have	
	proven ineffective	
Phenytoin (Epanutin)	trigeminal neuralgia or other painful	
Fileliytoiii (Epailutiii)	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	
<b>Tolterodine (Detrusitol)</b>	Bladder problems	
Vardenafil (Levitra)	Erectile dysfunction	
Viagra (sildenafil citrate)	Erectile dysfunction	

Please – 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.



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

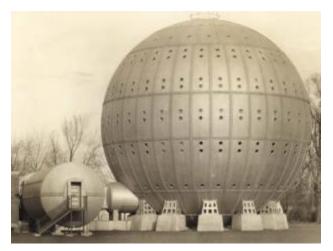


## The Extraordinary Beginnings of the HBOT Movement

An excerpt from Professor Philip James' book 'Oxygen and the Brain'

"It is common knowledge that most of us feel better during a period of high pressure, and our aches and pains often increase if barometric pressure suddenly falls. The benefits from being in compressed air were rediscovered in France in the 1830s by Junod, Tabarie, and Pravaz, beginning the extraordinary era of the compressed air baths. They flourished in Europe and America until the outbreak of WW2, and persisted in Germany until the 1970s.





The movement reached its zenith in the US with the construction of an enormous hyperbaric hotel by Dr. Orville J. Cunningham, a professor of anaesthesia at the University of Kansas. Apparently, in 1918, Cunningham had successfully treated a young doctor in his hospital suffering from severe influenza in a hyperbaric chamber that had been used for animal

experiments. He then built a large horizontal chamber and treated patients with a variety of conditions. His hyperbaric hotel was a 900-ton sphere 64 feet in diameter, with 38 rooms and 350 portholes. It was built in 1928 by the Melbourne Construction Co. at a cost of \$1 million and financed by a patient Cunningham had treated, H.H. Timken, the owner of the Timken Roller Bearing Co. of Canton, Ohio. The sphere was attached to a series of large cylindrical chambers, and the entrance was via a three-story sanatorium hotel. A history of hyperbaric medicine was the subject of a remarkable book called The Uncertain Miracle by the Pulitzer Prize winner Vance Trimble, published by Doubleday Press in 1973. The grasp of the principles he displayed is exceptional and the author is delighted to have been given a signed copy.





Patients stayed in the sphere for days at increased pressure in luxurious rooms with a library and restaurant provided. They were even allowed to smoke! Cunningham treated patients with syphilis, diabetes, and cancer, arguing correctly that lack of oxygen was an important factor in these diseases. It is now known that they are all associated with lack of oxygen and with inflammation, a critical feature of the response of the body to a variety of challenges. Cunningham was making a good deal of money, and this attracted the attention of the American Medical Association. They undertook an investigation and their report claimed that there was no scientific

evidence to support the treatment, obviously discounting the increase in the level of oxygen from compressed air. The facility closed in 1937, and Cunningham died a penniless and broken man.

The sphere was dismantled in 1942, and the steel used to build Liberty ships for the war effort. It would be 60 years before the key role of oxygen in the control of inflammation would be discovered, and it explains why compressed air can be an effective treatment."

## **Dates for your diary**

**Friday November 24**<sup>th</sup>: Fish Supper with music with singers Angel Delights

Friday December 8th : Christmas Lunch

# Monday December 25th to Tuesday January 2<sup>nd</sup> CENTRE CLOSED

Sunday January 28th: Burns Lunch

Saturday March 17<sup>th</sup>: St Patrick's Day Party



#### A Breath of Fresh Air

#### A visit to Jersey Oxygen Therapy Centre

In September, Sussex MS Centre trustees Martin Bennett & Alan Taylor attended a conference at the Jersey Centre, where we met Professor Philip James, a world expert in the field of hyperbaric medicine.

Professor James qualified in medicine at Liverpool Medical School in 1966 and later specialised in diving medicine. In 1983 he published his work comparing the pathology of MS to that of decompression sickness (the bends) in divers. Five MS patients being treated by Dr James founded a community hyperbaric facility in Dundee, the first MS Therapy Centre!



with Professor Philip James

We were treated to presentations from Professor James, Dr Frank Vaughan and Deane Cook of the Isle of Man Hyperbaric Unit and the manager of the Gibraltar Hyperbaric Centre, where incidentally they carry out approximately 15,000 treatments a year.

We learnt about using hyperbaric oxygen sessions to treat not only MS, but how it is used post stroke, for people with fibromyalgia and for healing problem wounds.



The interior of a hyperbaric chamber in Beijing

In some countries hyperbaric medicine is very much part of mainstream medicine and in China there are now more than 5000 hyperbaric facilities.

The visit gave us a lot to think about as we develop our plans for a new building.

Feel free to speak to Martin or Alan if you want to know more.

Our thanks go to all the team at the Jersey Centre for inviting us.

# Smile please!



We use photos of the Centre and everyone involved in it to help us publicise what we do and how we do it. Please tell us if you do not wish your photograph to be taken or used.

The MS Centre has never, and will never, sell your personal information, addresses, email addresses etc. to third parties. We will ask your permission if we have a specific request, e.g. to be contacted by another Centre member or other specialist agency.

We continually review our fundraising policy. If you ever feel pressured by us, please put it in writing, either in the comment book or by letter to the chair of trustees. Fundraising allows us to subsidise all our services and our members who are on a low income.

New data protection legislation is being introduced next year. Your trustees are reviewing the new legislation and will develop a policy ensuring that we comply fully.



# Use your comment book

if you have any questions, concerns,

feedback (good or bad), suggestions or ideas. It is reviewed at every meeting of your Board of Trustees (once every two months – next meeting 20<sup>th</sup> November). Please pass on a serious concern to a Trustee as soon as it arises. Photos of your Trustees are on the display board in the lobby.

## **A Birthday Celebration**



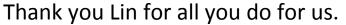
Centre member Lin MacCallum Stewart held a birthday tea in her garden to celebrate a



milestone birthday. I'll leave you to guess which one! She has been decluttering recently so didn't want presents, but instead asked for donations to the Centre. The money raised will go towards supporting all our members and help us to keep costs down. Lin was a driving



force behind setting up our benefits advice team which has helped so many of our members.





## **Beautiful Wheelchair Bags**



by

Marilyn Jenkins

£10



Velcro fastening

Profits donated to the MS Centre

If you would like her to make you one, please contact her via the Centre

## **Bladder Botox – A Life Changing Treatment!!**

I wrote an article for the Belle a number of years ago about bladder Botox treatment and how the effects have quite literally changed my life. A number of other members at the Centre have now received this treatment, all with positive results, so I thought it would be a good idea to share details of this procedure again.

Like many of us with M.S, I had suffered with bladder problems for a number of years and after a long process of trying various anticholinergic drugs, none of which worked for me, I was offered Botox injections. This is a new procedure for treating the symptoms of frequency and urgency caused by an over active bladder. Having tried all the various other drugs, I was sceptical about how effective the treatment would be BUT the results were amazing and the treatment completely changed my life. I can now leave the house without having to plan whatever I'm doing around my ½ hourly toilet stops! Basically, the drug completely restored my bladder function to normal.

The procedure is performed under a general anaesthetic and involves Botox being injected directly into the bladder wall via the urethra. For me, there was no recovery period and I felt fine the next day although it did take a couple of weeks for the Botox to take full effect. Prior to the procedure, there are some very intrusive diagnostic tests which are carried out to measure bladder capacity and function etc which although uncomfortable, weren't painful. Also, as a precaution, you need to be able to self catheterise, but I feel that this is a small price to pay given the dramatic results.

The effect of the Botox lasts for about 9 months and wears off gradually but I understand that this differs for each individual.

If you would like to chat about this just ask to be put in touch with me at the Centre. I am usually there on Wednesday mornings.

Yasmin



## Do you like a good party?

Help us make them happen! We're planning the social events at the centre for 2018!

We'll be rounding off this year with our ever popular Xmas Lunch but before that we have our quiz on Sunday 29th October and musical entertainment from Angel Delights on Friday 24<sup>th</sup> November. At the quiz there'll be a delicious buffet tea and Angel Delights will be accompanied by fish and chips from our local chippie. Bookings open soon so check at the Centre. We'll be kicking off next year with a Burns Supper in January and celebrating St Patrick's Day in March.

We'd like your ideas for events we could hold later in the year. You can write them in the comments book at reception, tell the staff at the Centre or e-mail Nikki at social.mssussex@gmail.com

We always need help running the socials, so if you would like to help once in a while (it doesn't have to be at every event), let us know. A bit of cooking or helping at the event will always be appreciated.

We'd love you to join in.

## **Your MS Specialist Nurses**

Brighton	Stephanie	01273 265887	stephanie.verry@nhs.net
	Verry		
	Nadia Abdo	01273 265887	n.abdo@nhs.net
Worthing,	Julie Green	07979 850632	Julie.green11@nhs.net
Littlehampton to	or		
Southwick	Nicky Davis	07979 852564	Nicola.davis4@nhs.net
Eastbourne,	Vicky Lester	01323 514809	victoria.lester@nhs.net
Seaford &			
Hailsham			
Chichester &	Katrina	07768 145978	katrina.orchard@nhs.net
Bognor	Orchard		
Horsham,	Nadine	01403 227000	nadine.morley@nhs.net
Crawley &	Morley	Ext. 7669	
Chanctonbury			
Uckfield	Gill	01825 769999	gill.ferdinands@nhs.net
	Ferdinands		
Bexhill, Hastings	Trish Dean	01424 755255	trish.dean@nhs.net
& Rother			
Mid Sussex &	Kelly Hill	01444 419532	kelly.hill4@nhs.net
Crawley			
General Team			sc-tr.msteamworthing@nhs.net





We were delighted to receive £6000 from the MCF. Thank you to everyone who voted for us and persuaded friends to do the same!

Fundraising idea!

Does anyone want to help organise an day? We could ask for donations, spend a day putting them on the site, then a week later, pack up and post everything that has sold... contact Jane if you're game!



new sailing challenges are being organised for people with MS during 2018.

A week long trip around Croatia will sail on 12<sup>th</sup> May and a trip on Lady of Avenel will take place in June.



Email <a href="mailto:challenge@sailingsclerosis.com">challenge@sailingsclerosis.com</a> for more information.

# It's that time of year again!

## **SUBSCRIPTIONS ARE DUE IN JANUARY FOR 2018**

## Please note:

If you do <u>not</u> wish to receive a paper copy of the newsletter, please ring the Centre or email <u>jane.taylor@mssussex.com</u>. Our Board of Trustees recently voted to continue sending out the paper copies, as we like to keep you and your families informed about what's going on at the Centre and with MS support... and how you and your friends and family can help us carry on!

Information is available via Facebook and we are hoping to improve our website and twitter provision soon.



Your Centre needs an army of volunteers to make it happen. If you would like to be more active in supporting the Centre, please speak to staff or trustees about how you can help. Whether you give a couple of hours a year, or a couple of hours a day, it all ensures we're here every day and keeps our costs down, helping us open our doors to all.



## Do you suffer from foot drop?

Centre member Lisa Smith has been trying out the Swedish Ankle and Foot Drop support and reviews her experience.

"This is a foot splint that I purchased approximately one month ago. Under duress I may add as I was carrying on for as long as possible without help. However after my 3rd fall in one week I searched online and decided to give this a try. My symptom is foot drop and there are days when it feels as though I have entire leg drop!!!

The delivery was speedy and I received it the next day. I tried it on and immediately could feel the benefit. I have worn this for one month now and have not fallen even going shopping alone without my scooter or stick. It has not fixed my drop foot but it has given me back confidence and the ability to try



and correct some damage I have caused over the years by swinging my leg out in order to take a step. It provides a spring like action that helps lift the foot as well as stops you catching your toes. It makes you realise how exhausting it is to walk without a splint.

Now for the downside. Finding a shoe that accommodates the splint is tricky but not impossible. Trainers work well or a flat lace up shoe or even an Ugg boot! You also need to get used to putting it on.

This has worked so well that I have requested from my neurological hospital Queens a splint via them. My foot has been cast and I will pick it up in two week's time. They even offered me a catalogue to choose my design. Pink with butterflies of course!

Happy to answer any questions you might have. I'm at the centre all day on Fridays.

Lisa

http://www.healthandcare.co.uk/foot-drop-supports-and-afo/swedish-foot-drop-ankle-and-foot-support-standard.html



In the last issue, we wrote a piece about 'Overcoming Multiple Sclerosis' – a charity set up to promote a programme of diet and lifestyle management to improve health for people with MS. Centre Member Debbie Scrivens has been following the programme since reading about it in 2012. Debbie also comes to the Centre for HBOT and is happy to talk to anyone about 'Overcoming MS' and how well it's worked for her.

"Back in 2012, I read an article in New Pathways about a retreat in New Zealand run by Professor George Jelinek where they implemented his 'Overcoming Multiple Sclerosis (OMS) programme. It looked interesting but I wasn't sure I could persuade my husband that I should fly off halfway round the world to attend a one week retreat! I noticed that they were looking into organising a UK retreat, so I contacted OMS via their website and expressed an interest.

I got the OMS book (available free from the website) and read it cover to cover whilst on holiday in France. George has MS and so did his mother and the programme is based on research and his own experiences. It was sensible and achievable for me. I found the evidence compelling so started the diet element of the programme straight away (if I could become meat and dairy free in France I could do it anywhere!).

Fast forward to summer 2013 and I find myself on the first ever UK OMS retreat with around 30 other people with MS. Professor Jelinek presented for the week together with his wife Sandra (a doctor) and Professor Graig Hassed who is a specialist in mindfulness and meditation. They'd all flown over from Australia. There was no 'hard sell' just presentation of the evidence and guidance on how to implement the programme. By the end of the week we all knew each other really well and had opportunities to speak to the presenters on any aspect and at any time as it was residential so there was no getting away from us! In fact our group still meets for an annual weekend reunion where we talk through issues and it helps to keep us on the OMS path.

So what is this OMS programme? Well, it is a seven step evidence based programme based on diet, exercise, stress management, sunlight, vitamin D and Omega 3 supplementation and when needed medication. In my case, I found the diet element

relatively easy as I had already eliminated certain foods and in essence it is a fisheating vegan diet. This ensures that the saturated fat in your diet is kept very low. There is also an OMS cookbook available now (of which I am a contributor) which is great as you don't have to worry about what to cook. The meditation is still tricky at times but I manage 20 minutes five days a week. I have always enjoyed exercising so 20-30 minutes five times a week is definitely achievable and can be whatever you can manage (walking, swimming, cycling, yoga, Pilates, gym etc). I also take at least 5000iu Vitamin D per day and at least 20ml of flax oil (from FlaxFarm in Horsham – the best I have found). I have not had medication as yet but I am about to start on disease modifying drugs.

So what have been the results of all of this? For me, I can honestly say I feel healthier than I have ever been. I have more energy, I have lost weight and I have felt as though I am doing something proactive which can only be good. It has certainly not 'cured' my MS or stopped my walking from getting worse. However, when I see my neurologist she always says I am doing very well and not progressing at the rate she had thought I might. I was even rediagnosed recently back to relapsing/remitting MS from secondary progressive. I feel that is the right direction for me and we all have to do whatever it takes' as George would say.

Please track me down via the Centre if you want to talk to me about it"



**UK CINEMA**The CEA Card is a national card scheme developed for UK cinemas by the UK Cinema Association (UKCA).

Under the disability provisions of the Equality Act 2010, cinema operators have obligations to make reasonable adjustments in order to facilitate disabled people going to the cinema. The scheme is one of the ways for participating cinemas to ensure they make reasonable adjustments for disabled guests; in particular it ensures a complimentary ticket for someone to go with them.

To apply for the Card, you will need to meet one or both of the following criteria:

- 1. Be in receipt of the disability living allowance, attendance allowance or Personal Independence Payment;
- 2. Be a registered blind person.

### How to apply

There is an administration charge of £6.00 for the Card, which lasts for one year.

To apply online or to download an application form, please go to the CEA Card website <a href="https://www.ceacard.co.uk/applications.php">https://www.ceacard.co.uk/applications.php</a>

or call The Card Network enquiry line: 01244 526 016

## **Armed Forces MS Support**



There is a support group section of the MS Society specifically for people who are, or used to be, in the armed forces and whose lives are affected by MS.

Have a look at their website <a href="https://www.mutual-support.org.uk">www.mutual-support.org.uk</a>

# **Building project update:**

# Raise the Roof!

We are currently in discussion with Adur and Worthing Council investigating increasing the size of our plot, but remaining in the recreation ground.

We're aiming to keep the 'feel' of our current Centre but improve parking, our HBOT provision, storage and circulation space, as well as parking. And maybe add a hydrotherapy pool!

Any concerns or suggestions, jot them in the Building Project comment book. Once we get to the serious planning stage, we will be consulting with you.

THERAPIES AND TREATMENTS				
Monday	Chiropody – Pat/ Val		10.00am – 1.00pm (every 6 weeks)	
	Refle	xology/ Reiki - Julie	10.00am – 2.00pm	
		stic Massage - Eva	10.00am – 3.00pm	
	Craft	Class short courses	11.00am – 1.00pm	
	Drop in	Pilates – Lynne/James	1.15pm (1hr)	
	1	Massage - Viola	10.00am – 3.00pm	
	Acu	puncture - Pippa	10.00am – 1.00pm	
Tuesday		IHM - Teresa	12.30pm – 2.30pm	
nes_	Phy	siotherapy - Diane	11.45am – 3.30pm	
_	Drop	in Keep Fit – Lynne	10.15am – 11.15am	
	Drop	in Keep Fit – Lynne	6.00pm (1hr)	
	Refle	xology/ Reiki - Julie	10.15am – 3.45pm	
	Dr	op in Yoga – Julie	10.30am (90 mins)	
	Dro	op in Tai Chi - Mo	1.00pm (1hr)	
ay				
Wednesday	Acupuncture – Pippa		10.00am – 4.20pm	
edn	IHM (Indian Head Massage) /Reflexology		10.00am - 3.30pm	
>	– Sonia			
	Drop in Pilates – Micci		10.30am (1hr)	
	Drop in Seated Yoga – Louise or Jo		12.00pm (1hr)	
	Drop in Keep Fit - Lynne		2.30pm-3.30pm (1hr)	
	Shiatsu – Amanda		9.30am – 1.00pm	
	Osteopathy – Virginia		12.00pm – 2.00pm	
Friday	Phy	siotherapy – Viola	2.00pm – 3.30pm	
Fri	Beauty therapies - Sarah		9.30am – 2.30pm	
	Drop in Physiotherapy Gym Viola		1.00pm (1hr)	
	Drop in Voiceworks - Rose		11.00am (1hr)	
Oxygen High Dosage Oxygen Therapy – 4 sessi				
		HDOT £10 (£)	5 outside the chamber)	
	donations		C 6 4 5 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1	
All individual therapies are a suggested minimum fee of £15, to be paid direct to therapist, except physiotherapy which should be paid at reception. Please note: Less than 24 hours' notice will				
attract a minimum cancellation charge of £5 payable to the therapist.				
Hairdressing and barbering with Julie – any weekday to suit				
Со	Counselling Please ask for details		·	