

The Belle

Issue Number 80

Spring 2018



We are delighted to introduce our new staff:
Ben Bloom, Centre Manager and Emily Dixon,
Operations and Events Co-ordinator.

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

www.mssussex.com

01273 594484



Peter Cook is just starting on the clinical trial for Biotin (MD1003), a drug that is being investigated to see if it supports myelin regeneration in people with primary or secondary progressive MS. To qualify you must have progressed on the EDSS scale by at least one point in the last two years. Peter is happy to speak about it if you would like more information.

Recruiting now: Simvastatin clinical trial for people with secondary progressive MS.

The aim of this study is to examine if repurposed Simvastatin (80mg) is a disease modifying treatment for patients with progressing Secondary Progressive Multiple Sclerosis (SPMS).

The study is designed to test the effectiveness of repurposed simvastatin in a double blind, randomised, placebo controlled trial to determine if the rate of disability progression can be slowed over a 3 year period.

Participants will be required to complete 10 study appointments over a 36 month period. This will involve nine visits to the hospital in London and at least one (1) telephone call. Participants who meet all entry requirements are randomly allocated to receive either Simvastatin or Placebo.

Participants will start off taking one (40mg) Simvastatin/Placebo tablet once daily at night for 1 month. The dose will increase after this and participants will take two (80mg) Simvastatin/Placebo tablets once daily at night for the next 35 months.

Participants must be aged between 25 and 65 and have entered the secondary progressive stage with an EDSS score of between 4.0 - 6.5. Steady progression rather than relapse must be the major cause of increasing disability in the preceding 2 years.

University College of London,
Institute of Neurology
London
WC1N 3BG

Primary Trial Contact
Dr Martha Bajwa Joseph
martha.joseph@ucl.ac.uk
+44 20 7679 6154

Information taken from UK clinical trials gateway
<https://www.ukctg.nihr.ac.uk/trials?query=%257B%2522query%2522%253A%2522multiple%2520sclerosis%2522%2>

New Year – New Logo – New Staff

We're very pleased to have finally moved into the 21st Century with a redesign of our logo – as seen on the front of this issue.

Heartfelt thanks go to Centre member Georgia Richardson and her company Ground Nation for their support in moving this forward, and to 'The Process' – the product design student group (who also worked with Barry on the wheelchair art project) for doing the ground work.



Many of you will already have met Ben Bloom, our new Centre manager who started on January 2nd. Ben has a background in retail management - at both Choccywoccydoodah and Montezumas chocolate shops (why would you want to leave says Jane!). Before coming to us he worked as Health Promotion Coordinator for Community Engagement and Outreach at the Terrence Higgins Trust.

"I have had the pleasure of meeting a lot of members already and would like to once again say how lovely it has been joining this wonderful Centre. I am always up for a chat, if you need something, have a query, want to know more about one of our treatments, have an idea or suggestion to improve the place, a complaint about something or you just need the recipe for my gluten free lemon and blueberry cake; I'm all ears. Thank you all for your support as I continue to learn everything about the

Centre, especially to our fantastic volunteer team who truly keep us all going. I'm truly filled with Hope and Joy as we heard into Spring with a lot to look forward to!"

In February, we appointed Emily as our second member of staff, snappily known as our 'Operations and Events Co-ordinator'. Emily is responsible for opening the Centre when Ben is absent and supporting us with our fundraising events programme.

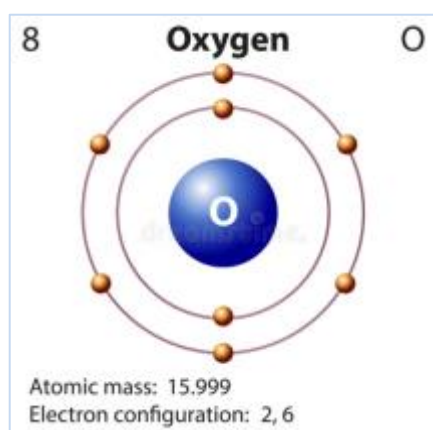
After spending a glorious three years working in hospitality management in New Zealand, Emily returned to the UK to be nearer her family and decided to move away from hospitality and is looking forward to new and exciting challenges working forward with the Sussex MS Centre.

And finally, we have a new comments book which is in reception. It now has room for feedback from Ben and the Trustees so you can see what's been done about any comments, suggestions or complaints that you may have. Please use it, it helps us to improve!



I'M LATE, I'M LATE!

To get the maximum benefit from your session in the hyperbaric chamber you should be calm and relaxed, so please try and arrive at least 15 minutes prior to your session. This will also help us run the sessions on time.



"Oxygen actually controls our most important genes. Beginning with the creation of blood cells in the embryo which continues throughout life in the healing of wounds from skin to brain. It ranks in importance with the determination of the structure of DNA."

Philip James, Emeritus Professor of Hyperbaric Medicine, Dundee University.

Your Board of Trustees

Since 1983 when the Sussex MS Centre was set up by people with Multiple Sclerosis, we have always been a user led Centre, with a philosophy of 'self-help' at the heart of what we do. To ensure this continues the majority of members of the Board of Trustees (sometimes known as the Management or Executive Committee) either have MS or it has touched their lives in some way. On occasions we second someone from outside who has skills or experience that we feel would benefit the Centre.



Chris Ash Edwards
Chairman

Chris took over as our Chairman in January this year. He was diagnosed with MS in 2001 and joined the Centre in 2014. Chris trained as a Chartered Accountant and worked for many years in financial and general management in the container shipping until taking ill health retirement in 2005. He is a Town Councillor in Haywards Heath and Vice Chairman of Mid Sussex District Council Standards Committee. He has been on our Board since 2014. Chris can usually be found at the Centre on a Monday when he takes HBO treatment.



Alan Taylor
Company Secretary

Alan was Centre Manager from February 1996 until September 2014. He oversaw the expansion and refurbishment of the Centre and was instrumental in introducing many of the services we now offer. With Martin, Alan is responsible for HBOT operator training. He is married to Jane who has MS and works part time as our Development Manager. Alan became a trustee in 2017 and is a reserve chamber operator.



Derek Aitken
Treasurer

Derek was diagnosed with MS in 1990. Prior to taking ill health retirement in 2006 he worked for a global IT company and then set up and ran his own business.

Derek has been a member of the Centre since 2007 and a Trustee since 2014 and comes to the Centre three times every fortnight to use the Hyperbaric Oxygen Chamber.



Martin Bennett
Lead HBOT operator and Health and Safety Officer

Martin worked as a Licensed Aircraft Engineer until he retired in 2006. He has volunteered at the Centre for 9 years and been a trustee for 6. He maintains our chamber, oversees our health and safety procedures and with Alan

trains all our operators. Martin's brother Ray was diagnosed with MS when he was 20 and died at the young age of 46.

Martin usually operates the chamber on Tuesday evenings, all day Wednesdays and on Thursday afternoon.



Nikki Manchee
Social Secretary

Nikki has been involved with people who have MS for over 30 years. Nikki is a nurse and for the last 18 years she has supported her partner Dom who has MS. Dom joined the Centre in 2011 and Nikki volunteered as the receptionist

on Tuesdays and Fridays, becoming a trustee in 2013. She chairs our Social Subcommittee. Dom operates the chamber every other Friday.



Alison Clough
Membership Secretary

Alison has been a member of the Centre since she was diagnosed with MS in 2005. Alison worked for Brighton and Hove Council as a Nursery Manager until retiring in 2015

and became a trustee in 2017. She is usually in the Centre on Tuesdays and Thursdays, attending keep fit and Pilates classes and occasionally for a manicure or a massage.

Christopher Fox-Walker



Christopher has MS and was involved in publicity, public relations, TV advertising and documentary film making prior to his retirement. He joined our Centre in 1989 when it was still based in Southlands Hospital. Christopher has a wealth of experience in fundraising and governance having been the Chairman of both this MS Centre and Portsmouth.

He has been using HBOT weekly for more than thirty-years.

Virginia Keefe Therapist Liaison Officer



Virginia was diagnosed with MS in 2001 and joined the Centre in 2005, becoming a trustee in 2011. She was a manager in an international engineering company for 19 years.

She is an Osteopath and offers sessions at the Centre.

Virginia attends the Centre for HBOT, Pilates, Voice work, Beauty Therapy and occasionally Acupuncture and Therapeutic massage.

Peter Cook



Peter is our newest recruit, joining the Board in January this year. Peter joined the Centre 9 yrs ago when he was diagnosed with MS. Peter spent 35 1/2yrs in the Royal Navy, he was a warfare officer and spent nearly 20yrs in special intelligence. He retired from the Royal Navy as a senior officer and then went to work for the second most senior high court judge in the county dealing with family and big money cases. Peter is now in the process of retiring having spent 12yrs with his judge.



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.



Come and join us!

We still have to cross the t's and dot the i's on a number of our social events but we're hoping to have a steel band at the summer bbq, a jazz lunch, a flamenco night and a couple of quiz nights or afternoons. Please let us know if you have any ideas or if you can help with any. These events are led entirely by volunteers (Jane got roped in as a volunteer because she's married to Alan!). If you would like to use the Centre out of hours for an event, do speak to the staff or trustees and we'll see if we can help.

If you have special dietary requirements let us know. We strive to cater for everyone.



Friday May 11th
6.00pm

£4 member
£6 member and carer
£6 guest

*Ye
Olde
Centre
Inn*

**BEDLAM
BREWERY**

Chia, Flaxseed and Tomato Crackers

From The Gut Health Diet Plan by Christine Bailey

A few of us have tried these and recommend them as a healthy snack.

Alison Clough adds a few hints!

Make 24 crackers

50g pumpkin seeds

70g chia seeds

160g flaxseed (linseed)

1 red pepper (chopped)

4 sun dried tomatoes in oil (drained

2 tomatoes (chopped)

3 tbsp lemon juice

1 tsp ground cumin

2 tbsp tamari soy sauce

½ tsp garlic salt

Preheat oven to 150°C/300°F Gas 2. Line a baking sheet with baking parchment.

Put all the ingredients into a high speed blender and add 60 mls water.

Blend to form a stiff paste.

Put the mixture onto the prepared baking sheet and spread out to about 5mm thickness using damp hands into a rectangular shape. Mark the mixture into rectangular cracker shapes using a knife. Bake for 40 – 45 minutes. Transfer to a wire rack to cool completely. Serve or store in an airtight container for up to a week.



My hints!

I halve the mixture as that lasts me just under a week.

I use ground or milled chia and linseeds such as Lidl's Alesto Super seed mix and milled chia seeds.

I wear disposable gloves when spreading the mixture.

It takes a bit of patience to get it spread out evenly!





Just Walk starts and finishes from the dramatic backdrop of Goodwood Racecourse. All of the routes are circular, and take on the rolling hills and landscape of the West Sussex Countryside including sections of the South Downs National Trail on most routes. Routes vary in length from 10 to 60 kilometres.

To find out a little more speak to Emily or email events@mssussex.com for an information pack with registration details and fundraising ideas.

Leaving a gift in your will: We were very pleased last year to receive a generous legacy from someone who really valued our Centre and wanted to leave a gift to help us in the future. Unfortunately, their solicitor made a very common mistake and recorded it as a gift to the MS Society. We are of course returning the money and are sorry that it has caused upset to the donor's family, who knew it was intended to be for us. However, the MS Society does a tremendous job funding research and supporting people with MS nationwide.

To avoid any misunderstanding, if you or someone you know wish to list the Centre as a beneficiary in their will, please check your will maker has specified Sussex MS Centre and noted our charity number 801075.

Glass class returns!

8 week course starting Monday 16th April 11am to 1pm



The Beginnings of the Sussex MS Centre

From Nothing to Southlands to Southwick

As we move into a new era, looking to expand and develop our services and hopefully provide a new building, we have been reflecting on how our Centre came into being. We all owe a debt to those that came before us and worked so hard to found our Centre. Back in 1982, when people were diagnosed with Multiple Sclerosis, they were told there was nothing to be done. People were offered very little support by statutory agencies and left to deal with their changed lives in isolation.

Don Hawkins, whose wife had MS, was not prepared to accept that. He read an article in *The Sunday Times* about **ARMS (Action Research into Multiple Sclerosis)**. ARMS was a registered charity based in London with an established nationwide counselling system. ARMS also funded medical research for MS and were promoting Hyperbaric Oxygen Treatment.

Don contacted ARMS for information on setting up a Centre. With their support, he placed ads in the local press for a public meeting in a church hall in Hove. Apparently it was extraordinary – so many people in wheelchairs and walking with sticks heading towards the hall, full of hope; the first offered to them since their diagnosis and for many of them, the first time they had met others in similar circumstances. Following the meeting a fundraising campaign began and an anonymous donor offered to double the first £10,000. Many of the local Lions groups were very generous. Premises were found in an



annex at Southlands Hospital and the first centre was opened in 1984 with the hospital authority offering the centre a lease on generous terms. The next step was the purchase of a pressure chamber and Don Hawkins found and purchased the chamber we still use today at a cost of £30,000. The name of the centre was ***The South Weald Friends of ARMS (HBO)***.

The principal objects of the centre were to bring together people with MS and to offer HBOT and to provide advice, counselling and guidance. There was a small waiting area and one therapy room in which limited physiotherapy, chiropody and beauty treatments were offered. The importance of getting together, sharing information and working together for the common good soon became apparent and lunches were held in the hospital gym.



A UK network of over 50 HBOT centres developed, each linked to the central *ARMS* office but around 1993 *ARMS* ran into financial difficulties and went into liquidation. To protect our Centre from any repercussions, our Board of Trustees transformed the centre into a private limited company, changing its name to the ***Sussex MS Treatment Centre Ltd.*** At

about the same time, the lease at the hospital expired and our committee were offered a lease at a peppercorn rent on our current site by Adur District Council. Another fundraising campaign followed and raised the money to purchase and install six second hand prefabricated units and move us to Southwick Recreation Ground.

A year after we moved to Southwick, Don finally retired from being Chairman, to be replaced by Christopher Fox Walker. Our history since we arrived here will be told in the next issue.





BAKED POTATO AND...

We now have a stock of potatoes and various store cupboard fillings – tuna, mayonnaise, baked beans etc etc for you to help yourself and cook in the microwave.

Let us know if you want us to stock any other fillings, or bring your own. If you need advice on microwaving potatoes just ask. Put your donation in the bucket.



SUSSEX MS CENTRE

VEGAN DAY

Join us for a day of delicious vegan dishes. Bring along your own vegan dish, share recipes, or just pop along to try some delicious vegan creations.

WEDNESDAY 16TH MAY

Please note:

If you do not wish to receive a paper copy of the newsletter, please ring the Centre or email

jane.taylor@mssussex.com.

“WE THE PEOPLE”

“We the people”, the famous first three words of the Constitution of the United States of America. But what is a constitution?

A constitution is defined in the dictionary as:

- the system of fundamental principles according to which a nation, state, corporation, or the like, is governed.
- the document embodying these principles.

Of course, not only countries have constitutions, but so do all properly run organisations and the Sussex MS Centre is no exception.

You will have read in this newsletter about the beginnings of the Sussex MS Centre and how, in 1988, the Centre became a Limited Company in it's own right. This protected us from any repercussions from the collapse of ARMS.

Limited Companies that trade to make a profit are formed by people who invest money to start the business. In return they are granted shares in the company and have a say in how the company is run, receiving a share of any profits made. Their shares can also increase or decrease in value according to the success of the company. However, because Sussex MS Centre is a registered charity and a “not for profit” company, we don't have shareholders, we have guarantors. We are not here to make a profit for people, but to offer service to the MS community.

Our guarantors agree to support the organisation by giving their personal guarantee that if we have to go into liquidation they will contribute £1 towards the Centre's liabilities. Those who act as guarantors get a say in how the charity is run to ensure that

we are not driven into liquidation by poor governance and remain loyal to our charitable remit to serve the MS community.

Sussex MS Centre is a Limited Company and must abide by our "constitution" as set out in a document called our "Memorandum and Articles of Association", often abbreviated to "M & AA". If you would like to see our "M & AA", Ben has this in the office and will happily let you have a copy.

In our case, our guarantors, who are also called corporate or company members, can vote at the Centre's Annual General Meeting (AGM).

At every AGM, all your trustees stand down and offer themselves for re-election. The accounts for the previous year are also reviewed and (hopefully!) approved. Company members have the opportunity to ask questions and our auditor is in attendance. For the last 20 years we have been audited by Matthew Hodson who has impressed us with his methodical analysis of our accounts and by his helpful financial advice. We vote to appoint auditors at the meeting.

If a Company Member has a particular concern that they feel is not being addressed they can vote to call an Extraordinary General Meeting. The rules for such procedures are set out in our governing document, our M & AA.

Becoming a Company Member

Applications for Company Membership are considered by the Committee at every Committee Meeting.

Your current committee have been discussing for some time the membership structure of the Sussex MS Centre as many different people use the Centre, some only coming for a short course of treatment and some more long term.

We remain fundamentally a centre for people with MS, but we are proud to have been able to offer the facilities of the MS centre to the wider community.

Just to complicate matters, the Charity Commission has introduced a new way of registering a charity and that is to be a CIO, a Charitable Incorporated Organisation. This would mean that we no longer have to report to Companies House. However we would have to adopt a standard governance format that could differ from our current "M & AA". This would simplify our reporting procedures and is an option your committee are currently considering.

We'll keep you posted, but, if you have any concerns or would like to discuss this or other matters just ask to speak to a committee member; there's usually one at the centre on most days. You can also e-mail the committee on info@mssussex.com, marking your e-mail "committee" or write to:

The Committee
Sussex MS Centre
Southwick Recreation Ground
Croft Avenue
Southwick
West Sussex
BN42 4AB

SOUP AND A ROLL!



We will be offering soup and bread for £1 at the Centre every Thursday.

Please let Ben, Emily or Jane know if you are interested in coming along so we make enough and order bread (gluten free option available.)

OPEN MEETING

MONDAY 21st MAY

There will be an Open Meeting at the Sussex MS centre on Monday 21st May starting at 2.30 pm.

The theme of the meeting will be:

“Communications at the MS Centre”

The meeting will be facilitated by Lin McCallum-Stewart and will be run in workshop format, enabling all members attending to participate.

Lin is very experienced in running these types of meetings and we are sure that, with her guidance, the meeting will be a positive experience and help us all to improve our MS Centre.

Spaces will be limited, so book yours ASAP.

To book your place at the meeting or if you have any topics that you particularly want to raise regarding communications you can let Lin know by writing to her via the MS Centre or e-mail

info@mssussex.com

Please mark your letter or e-mail OPEN MEETING

Have you paid your £15 subscription for 2018?
Please check at reception.

Your subscription helps us to keep in touch with you, to administer all the services at the Centre and it entitles you to access all the wonderful, subsidised treatments and classes available here.

Dates for your diary

Come and join us at any of the following. If you can help with fundraising, cooking or staffing a stall etc, please let Emily know, otherwise just come along and enjoy!

	Thursdays	Soup and a roll available at the Centre
May	Friday 11 th evening	Pub night at the MS Centre
	Saturday 12 th evening	Cheque for us presentation by Bedlam Brewery at the Duke of Wellington pub, Shoreham
	Wednesday 16 th	Vegan Day at the Centre
June	Saturday 3 rd	Adur East Lions Donkey Derby Buckingham Park, Shoreham We will have a stall there – if you can help, please speak to Emily or Jane
	Saturday 9 th	Shoreham to Slinfold Bike Ride Please help us by recruiting participants or offering to marshall or cater at the end. Speak to Emily.
	Sunday 17 th	BBQ with (hopefully) with live music
	Saturday 30 th	Open day at Mile Oak Farm. If you can help us run a stall, please let Emily know
July	Sunday 22 nd	Centre Social theme TBA

Treatments available at the Centre

**massage – shiatsu – reflexology – reiki - osteopathy
– acupuncture – beauty therapies - chiropody**

We have a number of appointments available with our therapists. All our treatments are chosen to help you to manage any MS symptoms and to improve your wellbeing. Come along and talk to any of our therapists or staff about which treatments might benefit you the most. If cost is an issue, speak in confidence to Ben.



Our Christmas lunch was a complete sell out and a great success as always. Pete Baker did a great job calling the raffle, and Eastbrooke Academy choir came and gave a rousing performance. Their enthusiasm is heartwarming. Well done to all the volunteers for providing such a great spread and the Lloyds Bank volunteers for helping prepare, serve and clean it all away again.



Well nearly anyway. We'll be holding ours on June 17th this year.

If you would like to become a member of the social team and help us put together our events, please speak to Jane, Alan or Nikki.



SUSSEX MS
MS CENTRE
small charity big impact

FUNDRAISING BIKE RIDE

SATURDAY 9TH JUNE

20 MILES FROM SHOREHAM AIRPORT TO
SLINFOLD VILLAGE

To Register email
events@mssussex.com

Or call 01273 594484