

## **January Newsletter 2025**

Happy New Year to all of our members. As we reflect on 2024 and look towards 2025, we want to start by thanking you all for your support of our Centre. Many new members have walked through our doors this year, and all of them have mentioned the warmth, understanding, and laughter they find here. We are incredibly lucky to have such a fantastic community, and we want to take this moment to thank you again, and send our best wishes for this new year.



## **40th Festivities**

In October we finished our 40th Celebrations with a Drinks Reception for members and friends. Thank you to everyone who attended, and to the Social Commitee to volunteering their time to ensure that the event ran smoothly.

# Christmas at the Centre

Christmas was kicked off at the Centre with our Christmas Meal, supported once again by the Lloyds Bank Volunteers. We are very grateful to have had the support of these amazing people for another year, and we thank them again for bringing festive cheer to the Centre.



#### **40th Drinks Reception**



In October, we invited members and friends to come together to celebrate 40 years of Sussex MS Centre. We had live music, performed beautifully by Simon Savage (member) and his band.

We were also happy to welcome back Alistair Hignell CBE, one of our patrons. He spoke about the impact of the Centre, raising a glass to the hard work of all of the staff and volunteers.



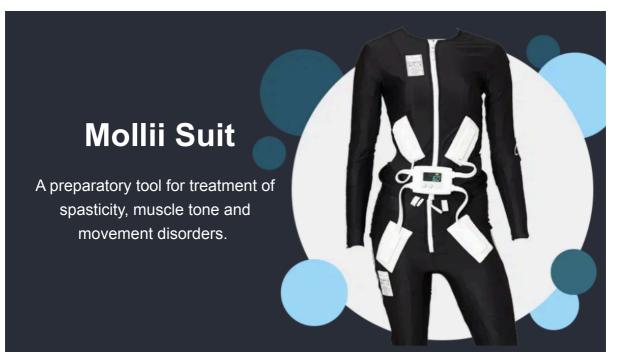
As well as Alistair, EJ Stuttard, Alan Taylor and Sam Gritt spoke of the present, our past and our future. Alan, as many of you will know, was the Centre Manager for many years and is still Secretary to our Board and our Oxygen Therapy trainer. Sam, Deputy Chairman of the Board of Trustees, looked towards the future of the Centre - continuing to provide essential therapies, classes, and support for our members as well as hopes for expansion with services being expanded.



Comedy was provided by member, Julia Harris, who had everybody laughing.

To show off the good work our charity does in the community, we invited local Councillors: Bob Lanzer, Carol O'Neal, Andrew Harvey, Jude Harvey and Robina Baine. As well as the Deputy Mayor Amanda Grimshaw and the Chair of East Sussex County Council, Councillor Roy Galley, who we were very pleased to welcome to our Centre. They were all impressed by the breadth of services we provide and our warm community.

#### **Member Recommends**



#### Member, Lucy Sleep, has had the suit since January 2024.

I was recommended to try this suit and bought one last January after having a great response in the trial. It works by stimulating the muscles via an integrated system of electrodes. Working on easing spasticity, it is very good for conditions such as cerebal palsy and MS. I don't have typical spasticity so they were unsure it would work for me, but the first time I tried it was like a miracle – I could lift my feet off the floor when sitting, raise my legs easily off the bed into the air, walk without crutches almost normally and my sit to stand time (they film and time you doing various things before and after the suit), more than halved. I had better balance and muscle control which lasted for almost two days. After this time the effects wore off and it took a few weeks for my personally purchased suit to arrive.



The suit is in 2 parts which fit like a 2piece Lycra wetsuit, then the control panel is on a belt and attaches via magnets to the front of the top and the legs. At the start I needed help to get it on and off but with practice I can now do it myself. When I am tired and my limbs are particularly heavy and my hands weak, it is much more difficult but I have found that doing it in the morning makes it easier for me. The programme runs for an hour and they advise you wear it every other day. When my own suit arrived it didn't have guite such a dramatic affect as the first one I tried and we went back to the company a few times for some tweaks and changes.

They are not made to measure and I am short legged so it took some practice to get the electrodes in the right place on my legs especially and frustratingly I have to sit whilst it is running or else they shift and it doesn't work so well. I was very disheartened that I have never seen the dramatic results of the first time again, but a couple of months ago I went for a review and they compared the videos from the very beginning to now and we realised that my baseline is overall better and the before and after videos still showed a significant improvement. I think I needed to alter my expectations – the Mollii suit is not a cure, it is a therapy and with regular use I am noticing how much it helps keep me on an even keel. We went away over Christmas and I forgot it so went almost a week without use and I was so tight in my legs and my hands were really weak and my grip very poor. Once back to wearing it again these things have improved.

It is very expensive (just over £6000) but you can hire them to trial at a lesser cost. If you suffer with spasticity I would definitely recommend trying one (google centres that offer this physio led service), as it may well really help. It hasn't been as miraculous for me as I'd first hoped but it definitely does help.

To find out more about the Mollii Suit, you can visit the website: <u>https://www.remotion.co.uk/.</u>

### **Physiotherapy Bursary**



# We can fund up to 5 free physiotherapy sessions at the Centre for our members.

We have a small bursary for sessions with our physiotherapists Diane and Viola, should you ordinarily struggle to pay for these. We are funding up to 5 free sessions to members.

This may be something you only need once a month or you need a short, intensive block which our physiotherapists would be able to determine after an initial session.

These appointments would be either on Tuesday afternoons, or Fridays.

If you have any questions, or would be interested in recieving these free sessions, please contact EJ via ej.stuttard@mssussex.com.

## **Upcoming Social Events**

# **Burns Night Lunch**

# Sunday 26th January

Doors open at 1pm

Haggis, Neeps and Tatties followed by Cranachan!

Members £6 Member & Carer £10 Additional Guests £10



#### Thank You Val!

Val has stepped down from her position as Social Committee Lead after 18 months.

From ambitious projects like the Summer Fair, to continuing the well-loved traditions of Burns Night and the Christmas Meal, Val has led the Social Committee to great success. A long time volunteer receptionist, Val will continue to support the Centre in many ways, but we want to take the opportunity to say a huge thank you for everything she has done in her position on the Committee.



#### Welcome Julie!

Stepping into the role of Social Committee Lead.

We also want to welcome Julie into her new role as Social Commitee Lead. She has volunteered in the Social Committee for the past year and has already taken to the new role with aplomb!

#### **Centre Updates**

#### **New Service**

We have been very lucky to welcome Emily Badakhshan, a Clinical Continence Nurse Specialist, to the Centre. She is providing free sessions which can include bladder assessments and scans.

#### **Bladder and Bowel**

Upcoming Dates: Monday 10th February Thursday 20th March

If you would like to book an appointment, call 01273 594484 or email info@mssussex.com.

#### **Fundraising for Sussex MS Centre**



# Take on a Challenge Event & raise money for Sussex MS Centre!

#### Fancy a Challenge in 2025?

This year we want to organise more exciting fundraising challenges for our members and supporters to take part in. **Take a look at the opportunities available below.** If any interest you, please contact Rebekah on 01273 594484 or via email on events@mssussex.com.







Fancy descending from the Peacehaven Cliffs? Or the Spinnaker Tower? Push yourself with the Ultra Challenge South Downs 100k which can be walked or run! From Skydiving to Bungee Jumping, there are many fundraising events for thrill seekers!

# CHOOSEUS AS YOUR LOCAL CAUSE

Co-op Members can support us through the Local Community Fund

membership.coop.co.uk/causes



This year Co-op have chosen to support us by selecting us as a 'Local Cause'.

Follow these easy steps to select us as your Local Cause, which will earn us money every time you shop with the Co-op! 1. Join the Co-op for £1 by going to <u>https://www.coop.co.uk/membership</u> (If you are already a member, you can skip this step.)

2. Go to <u>https://www.coop.co.uk/local-causes</u> and find us in the list of Local Causes. Click Sussex MS Centre, and it's done!

As this is a new year, if you've previously joined up for a Local Cause, you will have to follow these steps again. The money raised will help us to continue to support our members with many therapies and classes.

Thank you in advance.

# Could you host an Open Garden to support Sussex MS Centre?



#### **Register your interest today!**

To raise money for Sussex MS Centre, we want to put on multiple Open Garden Fundraisers over the Spring and Summer Season.

#### What is an Open Garden?

An Open Garden can be whatever you want it to be! You can show off your beautiful garden alongside a simple spread of tea and biscuits, or you can go all out and invite a group over for an Open Garden barbecue. If you are especially green-fingered, you can sell clippings of your plants plotted up! These events can be as small or as big as you'd like them to be.

Open Garden Fundraisers are a fun, community-focused way to raise money for the Centre and, if you've never put on an event before, Rebekah will be more than happy to support you.

Interested? Email Rebekah at <u>events@mssussex.com</u> or call 01273 594484.





#### **Sussex MS Centre**

Croft Avenue, Southwick Recreation Ground, Southwick, BN42 4AB, Brighton 01273 594484 <u>info@mssussex.com</u> <u>www.mssussex.com</u>

You've received this email because you've subscribed to our newsletter. To unsubscribe, click the link below.

**Unsubscrib** 

<u>e</u>