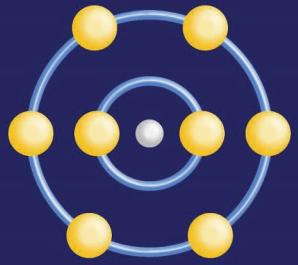


# The Sussex Multiple Sclerosis Treatment Centre



The Sussex MS  
Treatment Centre

Small charity, big impact

## Small Charity—Big Impact



## Annual Review 2014

# Small Charity — Big Impact

**Our Centre** was opened in 1984 by people diagnosed with Multiple Sclerosis (MS) and their family members. We provide peer support, therapies and group activities that help us to meet the challenges of living with this long term condition. We are based in Southwick, and serve the whole of the Sussex region and southern Surrey.

## Vision and Values

We are here to improve the health and wellbeing of all people in Sussex with MS and their families and carers.

- To be user led,
- To provide appropriate and affordable treatments, therapies and social opportunities in response to our members needs,
- To show respect to each and every individual and treat everyone with the dignity they deserve.



Our Board of Trustees is made up of Centre members, carers and volunteers.



Derek Aitken (Chairman), Chris Ash-Edwards, Gill Barnes, Martin Bennett, Jill Brookes, Virginia Keefe, Nikki Manchee, Mark Randall and Wendy Wilkinson.

# Welcome to our Annual Review

We are delighted to report that our Centre continues to provide so many life enhancing services for the benefit of the people of Sussex whose lives have been affected by Multiple Sclerosis.

2014 saw major staff changes which had an impact on our resources for the year. Alan Taylor, Centre Manager since 1996, retired in September and our Deputy Manager, Joanna Hedges, moved on in July. We are delighted to have found excellent replacements with the appointment of Penny Peters as Centre Manager in August and Hilary Green as Deputy Manager in September, and to have managed such a major transition with little disruption to our services or inconvenience to our members. The Centre continues to employ a part time Development Manager, Jane Taylor (12 hours) and a cleaner, Emma Kennard (5 hours). Our volunteers provide invaluable support with the day to day running of the Centre.

2014 also saw the retirement of three of our Trustees, Barbara Randall, Ruth Schofield and Debbie Kennard; Barbara and Ruth continue to volunteer at the Centre and Debbie has agreed to become a Patron. We would like to thank them for their service to the Centre. Chris Ash-Edwards joined the Board in September.

Another point of note is the rise in usage of our services, particularly the Hyperbaric Oxygen Chamber. There has been a lot of publicity on how this specialised treatment can assist healing of many conditions other than MS, and we strive to accommodate these others subject to availability and our limited resources.

Our heartfelt thanks go to everyone who has supported us.

# Why are we here?

## Multiple Sclerosis

The majority of our members live with Multiple Sclerosis (MS), a progressive disease of the Central Nervous System (CNS) which occurs when, for unknown reasons, the immune system attacks the myelin sheath that protects nerve fibres. This leads to scarring and slows or prevents signals travelling along the nerve. It is variable and unpredictable; in the early stages it is usually defined as relapsing/remitting, when periods of illness are followed by a nearly complete recovery, but then often moves into secondary progressive when there is a steady decline in ability. Using national statistics, we estimate there are around 1500 people living with MS in our region.

Our needs vary depending on disease pattern, duration and aggression. Common problems are a decline in mobility and flexibility, eyesight and cognitive problems, fatigue, bowel and bladder dysfunction. We are at risk of developing secondary disabilities as a result of poor muscle use.



# Supporting others

There are many reasons why people living with MS can suffer from loneliness and anxiety. People may feel self conscious and lack the confidence to go out into the wider community, or reluctant to make demands on their friends or carers, and it is simply easier to stay at home. It can lead to severe depression as well as other health risks.

## Other Long Term Conditions

As well as serving the MS community, we also welcome those with other chronic neurological conditions and have members with conditions such as Cerebral Ataxia, ME and stroke survivors. They too can feel very self conscious and vulnerable and benefit both physically and psychologically from being included in the range of accessible activities that we offer here.

Hyperbaric Oxygen is a specialised treatment which is not widely available in the UK and is now being demonstrated to aid recovery from conditions such as radiotherapy side effects, diabetic ulcers and traumatic injuries. We strive to offer it to those who will benefit, subject to availability.

## Families and carers

Family members and carers often give up working outside the home, or try to juggle their caring responsibilities with employment. They may also find it difficult coming to terms with their changed circumstances. They are at risk of their own health being affected and of isolation. They may find it difficult to access information on other support services.

# Building a Community

Peer support and access to up to date information are invaluable tools for improving health and welfare. Our members are often reluctant to be “a nuisance” so gaining information during informal chats and browsing our library in their own time is very useful. NHS services are available for times of crisis, but here we learn strategies to alleviate symptoms, access useful affordable drug free therapies, keep up with current research, and find out about state entitlements; all of which are essential for improving the life chances of those with MS and their carers and families.



To encourage peer support and to ensure our members were well informed we;

- opened every weekday except for bank holidays and the Christmas period,
- ensured a member of staff or volunteer was available to welcome every visitor and that the Centre was comfortable and welcoming, with light refreshments available at all times,
- hosted 147 drop in day time socials with volunteers providing additional snacks and sandwiches,
- held seven formal “out of hours” social events, with entertainers and catering,
- hosted 11 drop in clinics with an MS specialist Nurse,
- Our volunteers provided advice and guidance to 18 disabled people and carers to identify and access statutory support,

- We displayed literature with advice on current research, drug therapies and other life enhancing services,
- sent three newsletters out to all our members with information on what's on at the Centre and articles of interest\*.
- hosted a lively Facebook page and updated website.

In a full survey of a typical week (in June), the Centre was visited by 192 individuals (members, carers and volunteers). 30 of these visits were purely for social reasons.

To support our members with managing their symptoms, we provided;

### Hyperbaric Oxygen Treatment

We have run a Hyperbaric Oxygen Chamber for over 30 years. Hyperbaric Oxygen Treatment is a simple, non invasive and painless treatment; the user sits in the chamber which is then pressurised and breathes pure oxygen through a mask. This increased pressure, combined with an increase in oxygen to 100 percent, dissolves oxygen in the blood plasma and in all body cells at up to 10 times normal concentration.



Those with MS find it provides symptom relief and we have had remarkable success from people with problem wounds, diabetic leg ulcers, sports injury, bone fractures, some dermatological conditions, radiotherapy necrosis, and peripheral neuropathy.

3,856 (7% increase from 2013) HBOT treatments were taken.

\*we continue to send our newsletter out to those with MS who are not using our services at present as experience tells us that many will return to us in a time of need, for instance after relapse or a stressful life event.

In addition to HBOT, in 2014 we provided shiatsu massage, reflexology, acupuncture, physiotherapy, osteopathy, deep tissue massage, Indian Head Massage, chiropody, beauty therapies, hairdressing and counselling. We ran weekly yoga, Pilates (x 2), physio-gym, keep fit (x 3), seated exercise, Tai Chi, and voicework classes.

- 2802 individual therapies were taken (2356 in 2013: 19% rise)
- 306 group activities were held. Each session was attended by between 5 and 17 people and a total of individuals attended one or more activity.

Individual therapists are self employed. They pay a nominal rent for the rooms, and charge our members £15 per session. Group activity participants are invited to make a donation.



*“Pilates and seated yoga are so beneficial; I find the stretching exercises...are vital for improving my limited mobility”*

*“We are so fortunate to have excellent teachers and therapists, they all understand our condition and encourage us to make the most of what we have”*

*“Wonderful— helps me to understand my body. Little problems sorted out along the way”*

*“I have seen such improvements to my MS since I joined and I believe it’s thanks to the treatments, the classes and the smiling faces”*



## Carer's Network

Our carers network continues to grow, providing a forum where carers can support one another emotionally as well as practically. They share information and advice on entitlements and respite services, help with form filling and accessing other support services. We held an information day in June with speakers from other support services which was attended by 11.



*“[My daughter] finds the treatments most beneficial...I talk with other carers and we share our experiences. I learn a lot”*

*“As a full time carer for my husband, the centre is great, not just for the treatments, but to chat to others in my position”*

## Volunteers



We estimate that we benefit from thousands of hours of volunteer time, worth over £40,000 annually if calculated on the living wage.

Volunteers operate the Oxygen Chamber, oversee reception, provide refreshments, carry out minor maintenance, organise and assist at social and fundraising events.

*“The Centre helps me with my confidence. I love to volunteer, it gives me a sense of purpose. It has become my family”*

*“Operating the chamber keeps me busy! I love the people”*



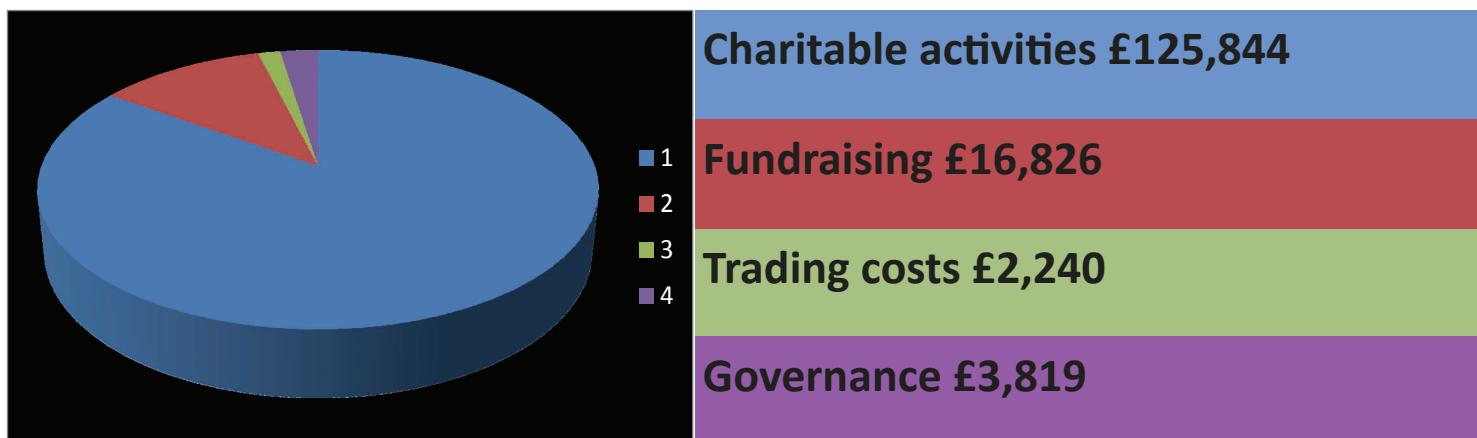
# Facts and Figures

## Overview

We incurred a deficit in 2014, which was mainly due to the additional staff costs and loss of income on fundraising events and voluntary income incurred during the staff handover period. We continue to hold a safe level of reserves. The Centre continues to be entirely self funded.

## Expenditure

Despite these circumstances, we managed to cut our outgoings with total resources expended being **£148,729** (2013 £156,306).



This breaks down as:

**Costs of providing charitable activities** (providing treatments, support costs, and purchase of capital items) was £125,844(2013 £135,770)

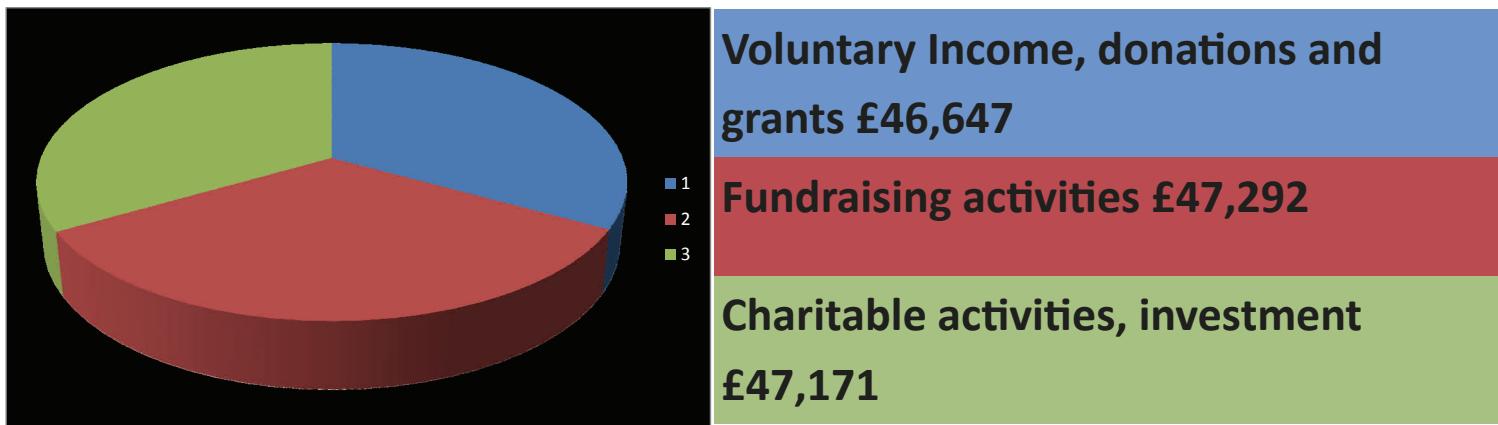
**Costs of generating voluntary income** (staff time, event expenses, marketing and publicity) £16,826 (2013 £15,183)

**Trading costs** (goods for resale) £2,240 (2013 £1,692)

**Governance costs** (auditing, travel and other financial costs) £3,819 (2013 £3,657)

# Income

Total incoming resources was £141,110 (2013 £166,657).



**Voluntary income** amounted to £46,647 (2013 £71,202). Voluntary income is the money that comes in from general donations, our collection boxes, the café, legacies and in memoriam gifts, and grants and donations from charitable trusts and community groups, as well as subscriptions.

**Income from activities for generating funds** amounted to £47,292 (2013 £49,772) which is made up of income we work for such as the fundraising events, shop sales, room hire and store collections etc.

**Incoming resources from charitable activities** was £47,171 (2013 £45,683). This is the money our members give us for using our services plus £145 that came from investments.

Figures based on the full Annual Report and Accounts 2014, audited by Hodson & Co, Chartered Accountants & Statutory Auditor, Wiston House, 1 Wiston Avenue, Worthing, West Sussex, BN14 7QL. Full copies of the accounts are available from the Centre on request.

# More detail on income and expenditure

All our funding comes from contributions from our members and their fundraising activities, and donations from community groups and charitable trusts. As always, our members give what they can towards the services they use and many made additional donations. They also encouraged their contacts, friends and family members to fundraise for us in a variety of ways. We continue to encourage ‘monthly giving’.

## Expenditure

Our policy continues to be that all people in Sussex affected by Multiple Sclerosis can access services and goods that will benefit them, subsidising services as necessary.

Our maintenance and repair budget remained high which is due to the age of our ‘temporary’ premises.

## Income

We continue to raise funds from a variety of activities. In addition to our members giving what they can (approximately one third of our annual income), trustees, staff and volunteers organised:



- a sponsored walk,
- a group skydive,
- a sponsored abseil.

Members and their friends organised activities including a raffle, bridge tournament, several store collections, many in-store



collection boxes, book sales, and printer cartridge recycling. We were also delighted to be chosen as Charity Partner by Sainsbury's West Hove holding several events there.

They also recruited participants for the Brighton Marathon, Half Marathon and Mini Mile race, the London 10k run, and the Bath Half Marathon.

Centre member Jeannette Jones organised a Christmas fair, fashion show, Pamper day, and a Cream Tea at Wiston House.

Other fundraisers of note were the Ship Hotel in Newhaven, and Tristan Manchee who cycled 400km for us.

Our grateful thanks go to Santander Community Fund, The Argus Appeal, The Henry Smith Charity and The Bridging Fund for their donations.

Rossetts of Worthing provided logistical support.

Heartfelt thanks to every contributor.



# During the year

## How we measured our achievements

We hold Management Committee meetings bi monthly at which we review feedback from our members and service take up.

The Centre is a friendly place that fosters a culture of ownership and informal contact. Consequently much of our feedback is verbal and often acted upon immediately. We have a feedback book in the community area and encourage everyone to write comments/ feedback/suggestions which they can do anonymously if they wish. This is read weekly and responded to immediately if required, and reviewed at our bi-monthly board meetings.

We held a full survey of every visitor during one week in May inviting comment and assessing the effectiveness of our services.

In response to demand, we added a meditation class.

## Looking ahead

### Our key goals for 2014

To support our staff, trustees and volunteers by mentoring and offering appropriate training to support them in their roles.

To continue to build our financial stability

To develop our plans for replacing our current accommodation with purpose built premises.

To continue to offer a warm welcome to everyone who needs us, and provide a range of activities that lift the spirits and improve the health and circumstances of people living with these chronic neurological conditions and those that care for them.

# Some feedback from our members

*"The teachers are so experienced here and I feel in very safe and competent hands, the knowledge gained inspires and supports me"*

*"The teachers are the best I have had"*

*"I am very grateful to the volunteer HBO operators who are so generous with their time and always cheery"*

*"The mindfulness meditation is extra ordinary, it really helps me on the day and as a practice that I can take home, this service [helps] anyone with pain, fatigue, anxiety... It has changed my whole approach to my condition"*

*"Understanding lovely staff. Handpicked volunteers. Superb therapists. Wonderful friendship."*

*"I feel like we are all sharing MS together and it's like being part of a big family"*

*"I have every confidence in the physiotherapist and follow her advice about exercises at home"*

*"Visits to the centre are vital to my life and keep me going. I look forward to them"*



# Our Management Committee

In 2014, our board of 11 trustees was made up of 5 service users, 2 carers, 1 therapist, and 3 volunteers.

Finally, we would all like to thank you for your support in helping us to make a significant difference to the lives of so many people living with this disabling condition and those caring for them.



## The Sussex Multiple Sclerosis Treatment Centre

Southwick Recreation Ground, Croft Avenue,  
Southwick, West Sussex, BN42 4AB  
01273 594484

[info@mssussex.com](mailto:info@mssussex.com)   [www.mssussex.com](http://www.mssussex.com)

Charity Number 801075

Company limited by guarantee No. 2319928