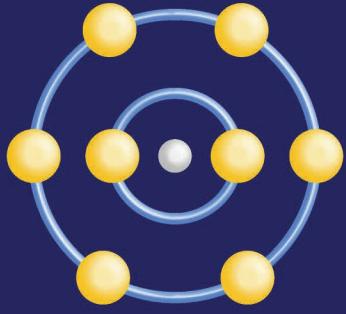
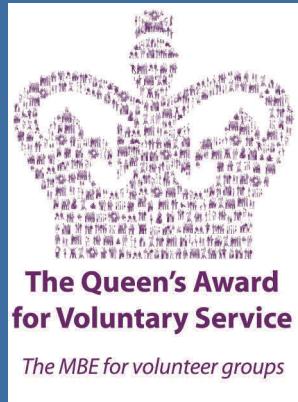


The Sussex Multiple Sclerosis Treatment Centre



The Sussex MS
Treatment Centre

Small charity, big impact



**The Queen's Award
for Voluntary Service**

The MBE for volunteer groups

Annual Review 2013

Small Charity — Big Impact

Our Centre has been running since 1984, set up by people diagnosed with Multiple Sclerosis and their families to help each other manage the condition. We still are a self help organisation, based in Southwick, serving the whole of the Sussex region and southern Surrey.

We also support people with other long term neurological conditions, such as stroke, and we offer High Dosage Oxygen Therapy to others who can benefit from a course of treatment, subject to availability.

Vision and Values

We are here to improve the health and wellbeing of all people 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.

Welcome to our Annual Review

2013 was another successful year for the MS Centre. A major highlight was being presented with the Queen's Award for Voluntary Service in July. This Centre could not possibly offer the range of services and support without our volunteers commitment and so we are extremely proud that this has been recognised.

We are pleased that we have managed to keep our services at 2012 prices, and despite this have increased our reserves. Many of our members are on a low income and it is essential that we continue to ensure that no-one is excluded on grounds of cost.

The maintenance costs of our premises are steadily rising as the prefabricated building ages, and we are currently assessing the feasibility of replacing it. Adur and Worthing Council have been extremely supportive thus far, and we hope to progress with this in 2014.

We thank you all for your support of this wonderful Centre.

"The positive and happy attitude by all at the Centre is a therapy in itself and of priceless benefit"



Building a Community

“Before I found the Centre I felt lost, lonely and frightened.”

There are many reasons why people living with MS can suffer from loneliness and isolation. People may feel self conscious and lack the confidence to go out into the wider community, anxious that their needs will not be met. Sometimes they don't want to make demands on their friends or carers, and it's simply easier to stay at home. It can lead to severe depression as well as other health risks.

Access to up to date information and support from our community are great 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.



“It is great to be able to discuss treatments/symptoms etc with like minded and knowledgeable people.”

“Lovely atmosphere, friendly and welcoming”



Quiz and Cream
Tea
on a
September
Sunday

What we did in 2013

We strive to ensure that the Centre is comfortable and welcoming, with refreshments available. In a full survey of one week in May, the Centre was visited by 192 individuals (members, carers and volunteers) . 30 of these visits were purely for social reasons.

To encourage inclusion and empowerment in 2013 we

- held seven formal “out of hours” social events, with entertainers and catering,
- increased our coffee mornings where volunteers provide refreshments and service to two a week,
- hosted the MS Society Information Library and monthly drop in clinics with an MS specialist Nurse,
- held an art exhibition over 3 weekends in June , exhibiting work by artists and craft makers,
- sent three newsletters out to all our members with information on what’s on at the Centre and articles of interest. We continue to send these to those who are not using the Centre at present to keep them informed*,
- and hosted a lively Facebook page and updated website.

*some of our members do not use the Centre for periods of ‘wellness’ and return to us in a time of need, for instance after relapse or a stressful life event.

What is Multiple Sclerosis?

The majority of our members live with Multiple Sclerosis, 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. About 15% of those diagnosed develop primary progressive MS and will become severely disabled.

Our members needs vary depending on their disease pattern, duration and aggression. Common problems seen here are a decline in mobility and flexibility, eyesight and cognitive problems, fatigue, bowel and bladder dysfunction, anxiety and depression.



"It's good for me to come with my carer. I have a treatment. My carer has a chat to all the lovely staff. The staff are very knowledgeable about MS. We both leave feeling so much better".

What we did to address this

In 2013, we offered hyperbaric oxygen treatment, shiatsu, reflexology, acupuncture, physiotherapy, osteopathy, deep tissue massage, Indian Head Massage, chiropody and counselling and responded to user requests by introducing beauty therapy. We ran weekly yoga, Pilates (x 2), physio-gym, evening keep fit (x 2), seated exercise, Tai Chi, and voicework classes.

- 387 people took 2356 individual therapies.
- 265 people used High Dosage Oxygen Treatment, taking 3576 treatments.
- 306 group activities were held. Each session was attended by between 2 and 17 people and a total of 116 individuals attended one or more activity.
- We trialled a men's exercise class in an effort to encourage more men to participate in group activities.

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.

We held 6 evening meditation sessions.



The evening keep fit class has a loyal band of followers who founded the sponsored event “Ready, Steady, Relay” as their fundraising contribution to our costs.

Supporting others

Hyperbaric Oxygen Treatment

We have run a Hyperbaric Oxygen Chamber for nearly 30 years. High Dosage Oxygen Treatment is a simple, non invasive and painless treatment; the user sits in the chamber which is then pressurised to the equivalent of a depth of up to 2 metres 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.

As well as our members who use the chamber finding it a useful tool for managing their symptoms and improving their prognosis, we have had remarkable success from people with problem wounds, diabetic leg ulcers, sports injury, bone fractures, some dermatological conditions, post radiotherapy necrosis, and peripheral neuropathy.



The regular Tuesday 10.30 'divers' playing cards in the Chamber.

"[HBO] definitely improves my condition, especially fatigue"



With more research being carried out into the benefits of using Hyperbaric Oxygen Treatment, and people using the internet to research treatment for various conditions, we have seen a considerable rise in demand for courses of treatment in our chamber, particularly some cancers.

The chamber is operated by trained volunteers and we run between 4 and 6 sessions every weekday, and a volunteer led treatment on Saturday mornings.

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 who come to use our services.

Carer's Network

Our carers network continues to grow, providing a forum where they 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.

Volunteer Value

Queens Award for Voluntary Service

We are very proud to announce that in July 2013, the Centre was presented with the Queen's Award for Voluntary Service. The Lord Lieutenant of West Sussex, Mrs Susan Pyper came to the Centre to make the presentation, and the citation was read by Mrs Lillian Edwards, Deputy Lord Lieutenant. A number of local dignitaries also attended, and over 80 of our volunteers.

It is the highest award given to local volunteer groups across the UK to recognise outstanding work done in their own communities. It was created in 2002 to celebrate the anniversary of the Queen's coronation. It is the MBE for volunteer groups.

Our volunteers cover reception, HBO chamber operation, catering, and work tirelessly to support our fundraising. Without them, we would be unable to offer the wide range of services available to our users and we are delighted that their efforts have been recognised.



"I had to wipe a tear from my eye, I felt so proud! I love this place"

"Because I only come in once a week, I hadn't realised just how many of us were involved"



We estimate that we benefit from over 3,500 hours of volunteer time, worth at least £26,775 annually if calculated on the living wage.

Working with others

We have links with

- MS Society, particularly Brighton and Hove, and Worthing branches. We hosted the Brighton branch meetings.
- Federation of Disabled People,
- MS Trust and MS Resource Centre
- Adur Voluntary Action Group
- Regional NHS MS specialist nurses

We continued our links with the CFS/ME Society. We have joined Adur Art Collective, which has allowed us to showcase the work of our creative members.

Raising Funds

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.

In 2013 trustees, staff and volunteers organised:

- a sponsored walk
- “Ready, Steady, Relay” an event for all abilities
- a sponsored bike ride
- an abseil

Members and their friends organised activities including a raffle, bridge tournament, several street and store collections, a plant sale at Windmill Nursery, 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.





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 was a star fundraiser during 2013. She organised a pamper day, a Christmas fayre and a dinner at Sussex Produce Centre, raising over £3000 for the Centre.

We are delighted that she was also awarded a Worthing Herald Community Star which recognised her exceptional achievements.

Christopher Fox Walker, a member for over 20 years, generously donated the funds to redo the marking out of our car park.

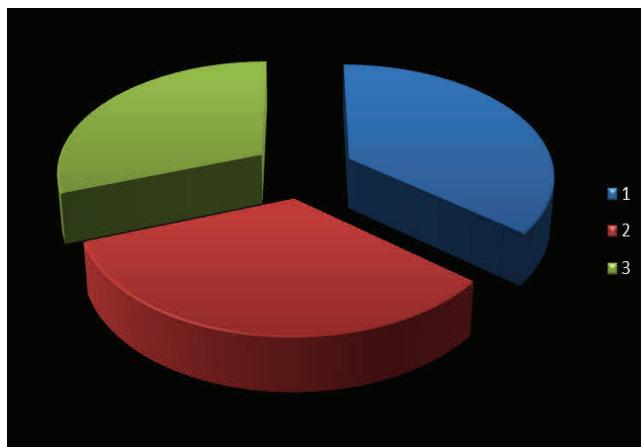
Our thanks go to P F Charitable Trust, The Dodgson Foundation, Ian Askew Charitable Trust, Sussex Community Foundation, Santander Community Fund, Co-Operative Community Fund, Brighelmstone Lodge, Adur East Lions Club, Brighton Lions Club and Adur District Council for their donations.

Rossetts of Worthing provided logistical support.
Heartfelt thanks to every contributor.

Facts and Figures

This year we achieved a surplus of £10,350 (2012 deficit £11).

Income



Voluntary income, donations and grants £53703
Fundraising activities £49772
Charitable activities, investment £45683

Total incoming resources was **£166,657** of which:

Voluntary income amounted to £53,703 (2012 £45,209). Voluntary income is the money that comes in from general donations, our collection boxes, the café, legacies and in memorium gifts and grants and donations from charitable trusts and community groups, as well as subscriptions.

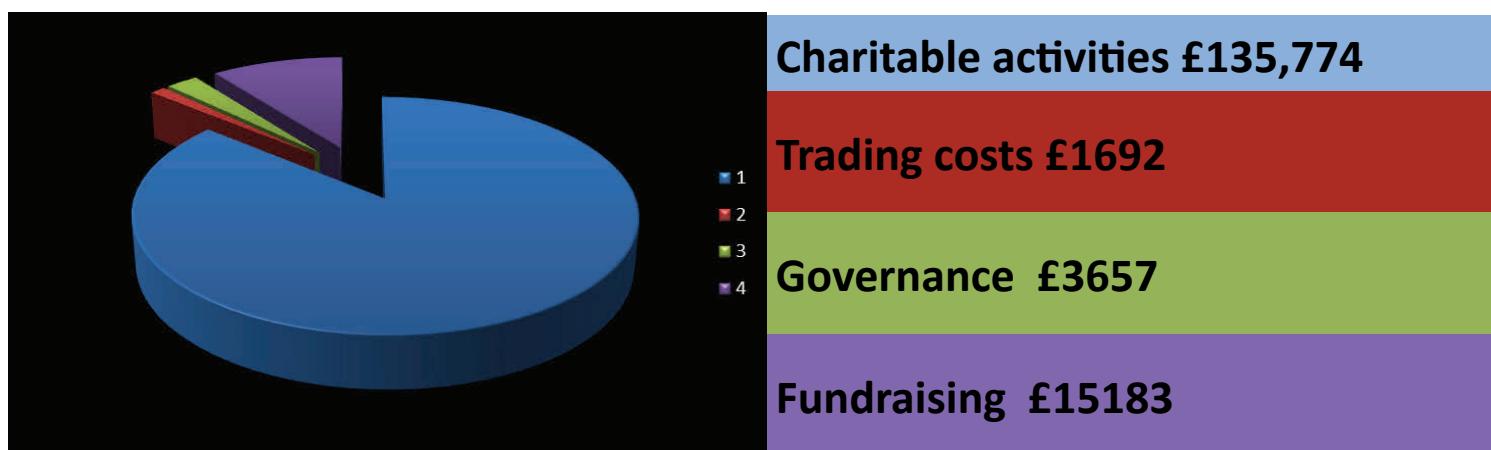
Income from activities for generating funds amounted to £49,772 (2012 £45,866) which is made up of income we work for such as the fundraising events, shop sales, room hire and store collections etc.

Incoming resources from charitable activities was £45,683 (2012 £38,010). This is the money our members give us for using our services plus £120 that came from investments.

Expenditure

We continued to maintain a tight rein on our budget, with total resources expended being **£156,306** (2012 £129,101).

£17,500 of this increase was due to a programme of updating and replacing outdated furniture and equipment. We also saw a doubling of our maintenance costs to £6,400 (2012 £3,800).



This breaks down as:

Costs of providing charitable activities (providing treatments, running, capital and support costs) was £135,774 (2012 £108,115)

Costs of generating voluntary income (staff time, event expenses, marketing and publicity) £15,183 (2012 £15,586)

Trading costs (goods for resale) £1692 (2012 £1,715)

Governance costs (auditing, travel and other financial costs) £3657 (2012 £3,685)

Figures based on the full Annual Report and Accounts 2013, 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.

Some comments from our members



"I always have someone to discuss anything I find frightening and find reassurance"

"Lots of brochures and information available"

[Hearing] "how people positively overcome MS [symptoms] makes me positive and happier"

"All suggestions I make are dealt with in a serious manner"

"It's a friendly, stress-free, accepting place to be. If one needs a hand/stumbles/drops something, it is not commented on and is not a 'big deal'... One cannot 'fail' at anything at the Centre! I find it difficult to socialise elsewhere as my concentration fluctuates and here I can go and sit quietly when I need to and there are no expectations. I always leave the Centre smiling. If it closed I'd be so depressed—I'd feel I'd lost my family"



“They keep me active and moving”

“...if I miss oxygen therapy... that my bladder incontinence is more evident”

“I have spasms and hand locking. Acupuncture is relieving this enormously”

“I love [Pilates] as it’s so much fun and different every week. It’s helping my strength and stress”

“I feel more confident because there is a trained professional who understands disability”

“The expertise of the therapist is important in making sure I am undertaking the correct exercises for my body”

“I couldn’t afford to get this level of help anywhere else”

During the year

How we measured our achievements

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

How we improved

We introduced a week long full survey of every visitor for a one week period in May, the results of which were reviewed at the following board meeting.

We introduced beauty therapy, an additional Pilates class and trialled a 'Men Only' fitness class.

We provided first aid training course for our therapists.

We made progress working towards PQASSA by reviewing and rationalising our systems.

We provided more grab rails around the building, and upgraded our communal area, Hyperbaric Oxygen Chamber and some physiotherapy equipment.

Looking ahead

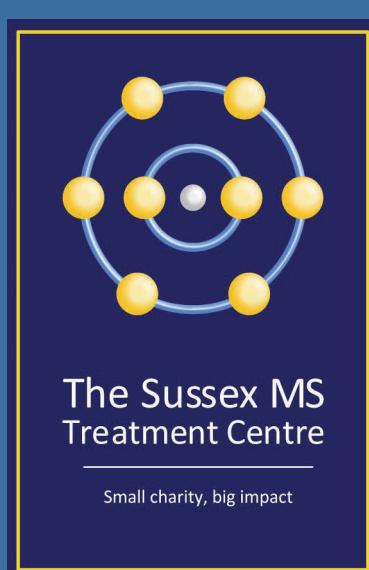
Our key goals for 2014

- 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 continue to work to improve our management systems guided by working towards the PQASSA quality mark
- To seek funding for and investigate the feasibility of replacing our current 'temporary' accommodation with purpose built premises. Our current accommodation has grown 'organically' over the years and presents a number of challenges. A new building would allow us to address many of the members concerns, such as our inaccessible kitchen and cramped circulation space.
- To ensure a smooth transition in the running of the Centre during and after the retirement of Alan Taylor, our current Centre Manager. Alan has been at the Centre for 18 years, and has overseen a period of enormous expansion and development in the services we offer.
- 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.

Our Management Committee

In 2013, 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.



Sussex Multiple Sclerosis Treatment Centre

Southwick Recreation Ground

Croft Avenue

Southwick

West Sussex

BN42 4AB

01273 594484

info@mssussex.com

www.mssussex.com

Charity Number 801075

Company limited by guarantee No. 2319928