

The Sussex Multiple Sclerosis Treatment Centre

Small Charity—Big Impact



Annual Review 2015

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. Our aims are:

- To be user led,
- To provide appropriate 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,
- To ensure that we are accessible to all who will benefit.



Chris Ash-Edwards, Nikki Manchee, Jill Brookes, Mark Randall (Company Secretary),

Martin Bennet, Gill Barnes, Virginia Keefe, Wendy Wilkinson,.

Our Board of 9 Trustees have a range of relevant knowledge and skills. 5 have MS, the others are carers or regular volunteers.

All our Board members were frequent visitors to the Centre, interacting with members and staff. This gives them a good insight into the many

They meet bi monthly.

Welcome to our Annual Review of 2015

Derek Aitken, Chair of Trustees



2015 was an extremely busy year, with our new Centre Manager and Deputy Manager (both appointed in late 2014) bringing a fresh energy to our Centre. We welcomed 144 new members: 50 with Multiple Sclerosis, 28 with other neurological conditions, 10 carers, and 58 requiring specialised Hyperbaric Oxygen Treatment (HBOT) to help them with problems such as control of cancer treatment side effects or to speed wound healing. Publicity on research into the benefits of HBOT for many conditions often leads to a sudden increase in demand which we have tried to cope with by introducing longer opening hours, but this is putting a strain on our limited resources. We continue to investigate ways we can better meet the needs of others without having a detrimental impact on our core membership of people living with MS. In the long term, our plans to replace our current aged prefabricated buildings with purpose built premises should do something to address the issue.

In addition to the HBOT demand, you will see from this report that we continue to be extremely busy providing a range of classes, therapies and social opportunities to help people of Sussex lessen the impact that MS has on their lives, but have still found the resources to improve our service as detailed on page 22.

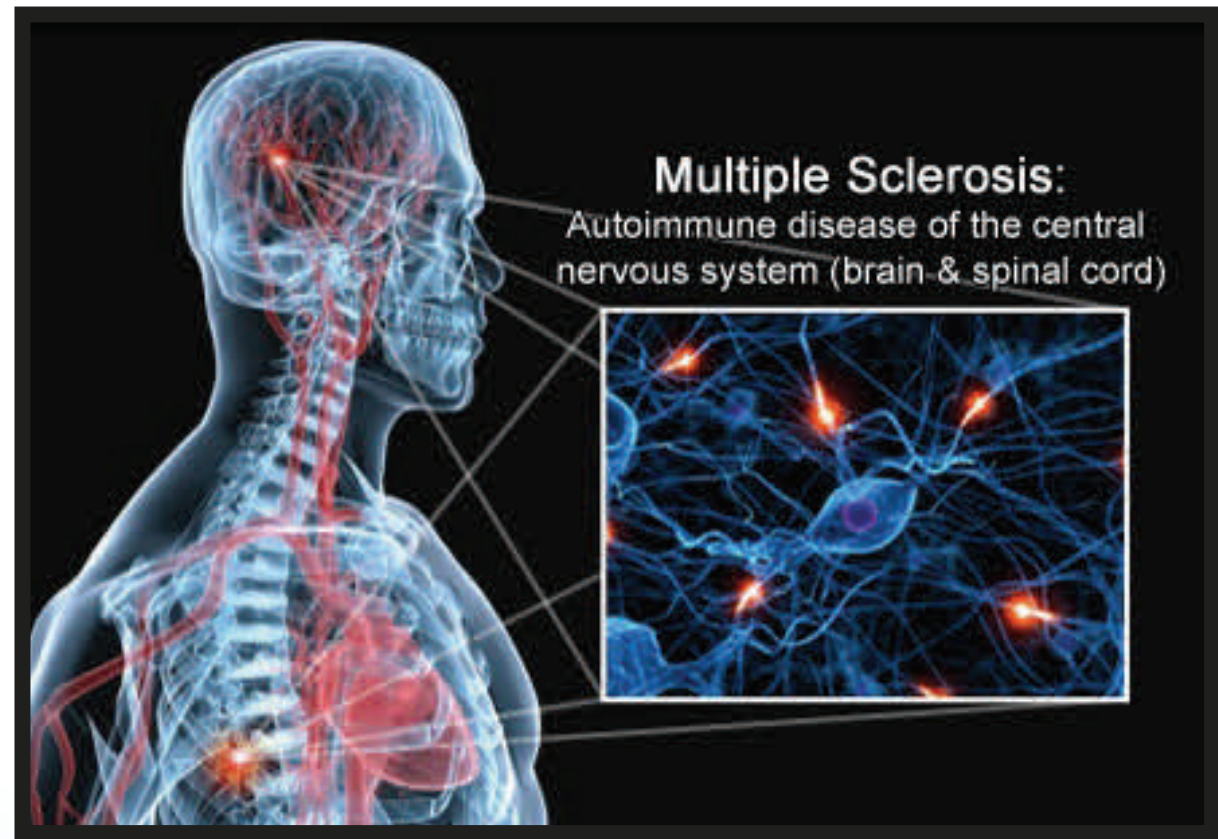
Wendy Wilkinson, a member of the Centre since 1986 and a Trustee and Chairperson for much of that time, retired from the Board when she moved away from the area in July. We would like to thank her for her commitment, dedication and generosity which saw the Centre grow so significantly to serve so many people of Sussex.

Andy Painton joined the Board during the year. A new Fundraising Committee was established and the Social Activities Committee was strengthened by the secondment of Lionel Warne.

Why we are here

A little bit about Multiple Sclerosis

Multiple Sclerosis (MS) is a disease of the Central Nervous System (CNS) which occurs when, for unknown reasons, the immune system attacks the myelin sheath which protects the 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.



People with MS have varying needs, depending on their disease pattern, duration and aggression. Common problems amongst our members are a decline in mobility and flexibility, eyesight and cognitive problems, fatigue, bowel and bladder dysfunction and a risk of developing secondary disabilities as a result of poor muscle use.

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 be 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.

Using national statistics, we estimate that around 1500 people live with MS in our region. In 1983, some of these people got together and founded a small 'self-help' group which has grown into this wonderfully vibrant Centre.

Who else do we support?

As well as serving the MS community and their carers, 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.

Centre Manager

Penny Peters

Penny has a background in managing day services in the care sector and joined the Centre in 2014.



Deputy Manager

Hilary Green

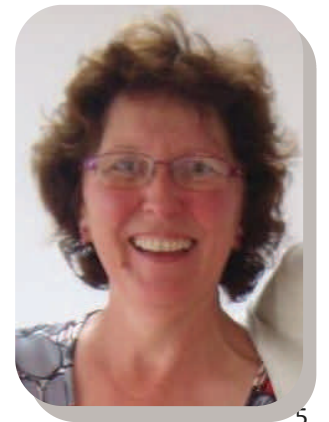
Hilary joined the Centre in 2014 after working with us in her role of Community Champion at Sainsbury's.



Development Manager

Jane Taylor

Jane retired from teaching after being diagnosed with MS in 2001. She has worked part time at the Centre since 2003.



Our Community

Peer support and access to up to date information are invaluable tools for improving the health and welfare of those who use the Centre. Our members are often reluctant to be “a nuisance” so gaining information during informal chats or at one of our drop in advice sessions 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, find out about state entitlements and new treatments and even share suggestions about good holiday destinations; all of which are essential for improving the circumstances of those with MS and their carers and families.



St George's Day party

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 153 drop in day time socials with volunteers providing additional snacks and sandwiches,
- held nine formal “out of hours” social events, with entertainers and catering,
- hosted 7 drop in clinics with an MS specialist Nurse,
- our group of trained volunteers provided advice and guidance to 25 disabled people and carers to identify and access statutory support,
- Liaised with other MS charities and support services, displaying their literature 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,
- and hosted a lively Facebook page, updated website and introduced a Twitter feed.



Hyperbaric Oxygen Treatment

We have operated a Hyperbaric Oxygen Chamber since 1984. 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.

Many of our members find the treatment really helps them manage their symptoms, reporting improvements in fatigue levels, it provides symptom relief and speeds recovery after attacks limiting the damage to the nervous system. 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.

4,351 HBOT treatments were taken (3,856 in 2014).



Our core membership are asked for a donation towards the cost, those with other long term conditions pay £18 per treatment and people who are taking a short course to speed recovery from injury are charged £25 per session.

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

By the end of 2015 the chamber was operating at virtually full capacity when allowing for intensive courses and short notice cancellations due to illness. This led to the reluctant decision to close the offer of treatment to anyone other than those with a neurological condition.

Barry

"I joined the MS Centre in 2015 after being introduced by my MS nurse, Lisa Black. I first started with the HBOT treatment and continue to do it every week as it helps improve my energy level. I got talked into joining the Keep Fit class by the other Tuesday people when I stayed for coffee. Lynne works us really hard and it's really helped maintain mobility and stopped me being scared of trying things.

When I was first diagnosed I felt isolated as I didn't know anyone else with the condition, and couldn't explain to anyone how it felt trying to cope with the changes to my body. Since joining and meeting so many people with the same condition I have learned to deal with my MS, not just physically but more importantly mentally. It's made me realise I'm not on my own but part of a group of people who deal with the day to day tasks with great determination and a friendly, supportive attitude. I always look forward to my day as I can just enjoy the company of like-minded people."



Colin

Colin has been involved with the Centre since his wife Edna joined in 1992. Edna came in for HBOT and stayed on to operate the chamber for others after her session. After Colin retired in 1998, Edna taught him the controls and he has been a regular chamber operator ever since.

"I see the benefits that long term use of this treatment brings to people and enjoy making them feel comfortable and relaxed. I'm responsible for the chamber on Tuesdays now. We have regular training session so I keep up to date and the staff are very supportive. I really admire the people who come to the Centre and have made many friends over the years. It feels good to be able to use all my skill to help others."



Keeping fit and active together

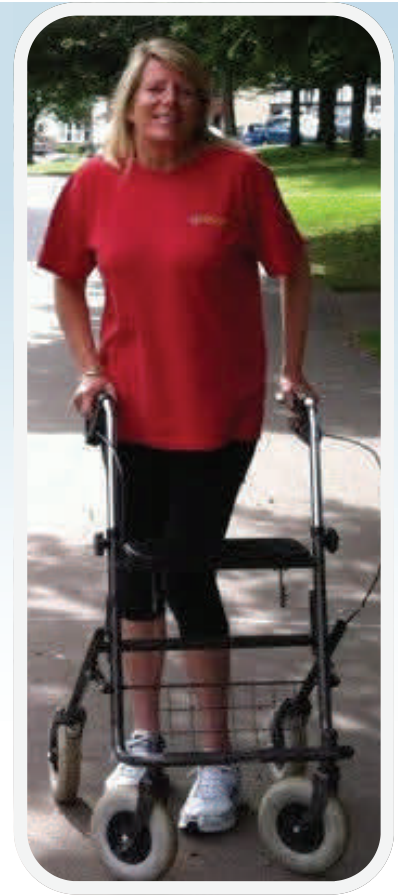
It can be hard to be consistent in your exercise regime when you live with a condition that is so variable and presents such a wide range of challenges. Participating in group activities is great for encouraging us to keep moving and feel positive. At the Centre, we offer a range of group activities to enable our members to participate in a way that suits their circumstances and target their particular disabilities. We hold at least one exercise class every weekday, eleven in total. Our members can choose from yoga, seated exercise, circuit training, evening keep fit, tai chi, Pilates, physio-gym, cardio fit and voicework.



Diana was working at Gatwick Airport when she was diagnosed in 1997 following a couple of years of odd symptoms coming and going. She joined the Centre in 1998.

"I had a bad experience at another MS group where everyone seemed to sit around depressed and it made me really frightened of what was in store for me. I was initially reluctant to visit the Centre after that experience but when I did I was blown away by the positive energy and the range of activities."

Before my diagnosis, I was obsessed with exercise classes and attended 3 or 4 per week. I struggled with explaining to everyone why I couldn't do certain things and that I wasn't being lazy so I gave up going. I started doing Pilates at the Centre, and now I get my exercise fix by attending that, yoga and even the all-round exercise class we affectionately call "sadistic PE"! They all help maintain strength and core fitness. In PE we also cover practical solutions like getting up from the floor. We all have a great time and there is loads of laughter!"



Mike



"I last sang seriously when I was a fourteen year old choirboy in my local church, just a few years ago!"

I had been looking at research into the beneficial effects of singing for improving physical, emotional and psychological wellbeing, for example brain function, heartbeat and breathing and suggested we started a voice workshop here. We found Rose, our extremely patient teacher in 2009 and under her guidance the group has steadily built in numbers, confidence and repertoire.

The ability to sing is not a requirement, the ability to enjoy an hour exploring the voice and leave with a smile on your face seems to be automatic."

Improving wellbeing and managing symptoms with individual treatments

We have three small treatment rooms at the Centre, for which therapists pay a nominal rent to offer treatments to our members. Our members suffer from a wide variety of symptoms so we offer a range of therapies to address each individual's needs.

Therapies are chosen to provide symptom relief, help ward off secondary disabilities and improve wellbeing.



The treatments are on offer between 10 am and 4pm. We can choose from shiatsu massage, reflexology, deep tissue massage, osteopathy, Indian Head Massage, Reiki, acupuncture, one to one physiotherapy, counselling, beauty therapy, chiropody and hairdressing. Our therapists develop an understanding of the condition and can seek advice from our staff and neuro-physiotherapists with any concerns. They are self-employed and charge between £15 and £20 per session. We assist members in particular need with these costs as necessary.

2881 individual treatments were taken in 2015.



Issy and Andy

Andy's MS was diagnosed in 2012 when aged 46. *"It was a shock for me and my wife Issy, and the unknown prognosis brought anxiety and uncertainty for us and our children. At the time, I wasn't ready to see myself as part of a 'community' with the disease, but MS slowly became more intrusive and periods of discomfort more frequent, with painful arms and legs and the 'MS hug' – a horrible feeling that your chest is being gripped by a tight band. We prepared ourselves for the worst and moved from our three storey house to a bungalow.*

My MS nurse was concerned and spoke to me about the Centre in glowing terms, so Issy and I made our first visit. From the moment we walked in, we were made to feel really welcome – it was a place where you could be yourself and use exactly how it suited you. People weren't intrusive but friendly and supportive and hugely knowledgeable. The staff were warm, funny and obviously really committed.

I started a course of HBOT which I continue to use once a week to help manage my symptoms. I have a massage to help relax my muscles and relieve pain. The therapist Viola is superb and the treatments have helped with my walking and pain relief. Issy says I am much more positive and engaged. I have joined the Board of Trustees and am now actively supporting the other members and staff in developing our services.

The Centre has improved things for me and we feel very lucky to have it here."



Carers

Those of our members whose disease pattern has been quite debilitating often come to the Centre accompanied by a carer. We offer our services to carers on the same terms as our members as they too can be vulnerable to isolation and stress related illness.

Most carers don't take treatments but enjoy a short break or relaxing here with others and sharing friendship, information and advice. Peer support and friendship are invaluable for improving the health and circumstances of the carer. Family members of those with MS can also access our services for advice and support.

We held an information day in June with speakers from other support services.

Volunteering



Without the support of our many volunteers, we would not be able to offer the level and variety of service and we are enormously grateful to them all for their commitment.

Volunteers staff reception, operate the Hyperbaric Oxygen Chamber, help with book-keeping and other administrative tasks and assist with providing refreshments and a warm welcome to everyone who visits. They also organise and run our social events and assist with fundraising.

Many of our volunteers are Centre members who enjoy putting their knowledge and skills to use in a supportive environment.

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

The MBE for volunteer groups

Val and Jaynie

"My daughter Jaynie was diagnosed in 2001 when she was 30. It progressed quite rapidly and she is confined to a wheelchair. We first came to the Centre in 2008 looking for physiotherapy and massage to help support her. We found so much more than we expected! To say it has changed our lives is not an exaggeration; we have found somewhere supportive, friendly and relaxing."

Jaynie enjoys visiting the Centre so much and that helps me too. Her condition has stabilised and I feel more relaxed. Jaynie enjoys baking cakes which we take to the Centre and I double up as a volunteer by helping out with providing refreshments, which I know they appreciate. I have made many friends. Sometimes I take a treatment but just being able to chat to people who understand really helps me to overcome stress and regain a sense of perspective. It's a life changing place!"



Lesley

"I used to work in a doctor's surgery as a receptionist but had a stroke in 2006 which left me paralysed down my left side. After intensive rehabilitation, I learned to walk again using a stick but my left arm has never regained full mobility. It is a hard process coming to terms with this, but I found the Centre and started to volunteer. The people here are so good at overcoming adversity. They encouraged me to drive again and adapt to my new life."

It is good to put my skills to use as a receptionist and as I live locally I can step in when they need help. It's started a whole new chapter in my life and it's great."

What else happened in 2015



Calligraphy workshop

Centre member Nancy Ouchida Howells is a renowned calligrapher and ran two classes to share her skills and experience.



Hilary, our Deputy Manager has been working with Centre member Barry and second year Product Design students from Brighton University to develop a painting tool for use with a wheelchair.



Art for All

We held two 'Art for All' Saturday workshops during the year where our members produced work using a variety of media. We were very pleased to be asked to display the work our members produced at Sainsbury's West Hove.

'Off the Wall' Exhibition



Volunteers from Lloyds Bank City Park helped Centre members Luke Adams and Matt Boysons construct a raised bed at the back of the Centre.

Our thanks go to them and to



for donating sleepers and



for donating the topsoil and compost



Brighton and Hove buses brought a double decker along to the Centre to demonstrate to our members how easy it is to use the new accessible buses.

Kick Start Your Writing workshop

February

Several members attended a very productive Saturday creative writing workshop led by Chris Sanders.



Facts and Figures

Overview

We are delighted that we were able to cut our outgoings and increase our income in 2015, resulting in a surplus of £45,587. This has begun to provide us with a safe level of reserves whilst we continue to develop our plans to replace our ageing prefabricated premises with a new build.

Expenditure

Total resources expended £123,661 (2014 £148,729).



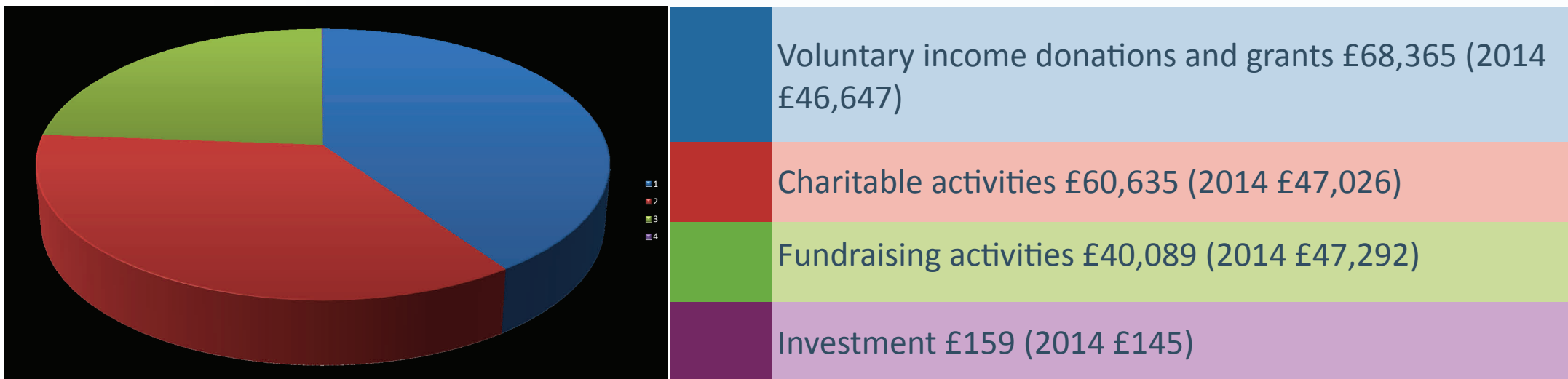
The Finance Sub Committee meets bi-monthly and our systems of financial control and oversight enable us to keep a close eye on expenditure and to ensure best value wherever possible.

During the year a small Fundraising Sub Committee has also been established to support our programme of events and activities.

Income

Incoming resources amounted to £169,248.

We receive no funding from statutory bodies, and have a wide variety of streams of income to support our Centre. Our members give what they can for the services they use and apply their energy and enthusiasm to organising many fundraising activities and events. We are thankful that our Centre attracts donations from community groups, charitable trusts and local companies. We are also very grateful to those who remembered us in their wills or gave in memory of their loved ones. We encourage 'monthly giving' and have coin collection boxes at many sites around Sussex.



Figures based on the full Annual Report and Accounts 2015, 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 or online at www.charitycommission.gov.uk and searching for Sussex Multiple Sclerosis Treatment Centre

Thank you

Our members are our greatest ambassadors and enlisted others to support us by taking part in our Sussex cycle ride, Adur Walk and Peacehaven Heights abseil. Supporters also participated in the Brighton Half and full Marathons, Brighton Mini-Mile, Brighton 10 mile run and Sasbah Wheelchair Half Marathon. This stream of funding provided nearly a quarter of our income for the year and we are extremely grateful to every participant and volunteer who took part.



Thank you to the following companies
for supporting our events:

Rossetts
commercial

PRINTTECH

Nick Stone | Director
T +44 (0) 1273 411069 M +44 (0) 7778 896238
info@printtechprocess.com www.printtechprocess.com

SHOREHAM (Brighton City) AIRPORT
SUSSEX

We value every contribution that is made towards our income and our heartfelt thanks go to every individual, event organiser, community group and charitable trust that has helped us over the year. We are very appreciative of those who remembered us in their will or gave to us in memory of a loved one.

We would like to thank the following:

Community groups, associations and companies

Arena 80 Athletic Club, Brighthelmstone Lodge, Brighton and Hove Rotary Club, Richard John Salon, Shoreham Port, South East Chiropodists, St Michaels Church Southwick, The Croft Tea Shop, Waitrose Hove, WeBop Choir and Worthing School of Dance.

Charitable Trusts and Foundations:

ACT Foundation, Axis Foundation, PF Charitable Trust and Robert Luff Foundation.

Sainsbury's West Hove and Needlemakers Lewes chose us as their nominated charities.



How we improved during 2015

- * In response to requests from our members, we set up a medication information exchange to allow them to share their experiences of disease modifying and symptom relieving drugs,
- * Improved our ability to support those with mobility difficulties by purchasing a lifting cushion and a stand aid enabling them to be lifted in a safe and dignified manner,
- * Subsidised our social events and classes to widen participation,
- * Introduced a card payment facility,
- * Introduced a pension scheme for our staff,
- * Built two raised beds at the rear of our building.

Key goals for 2016

- * To continue to ensure our financial stability whilst developing our plans for purpose built premises,
- * Achieve RIBA Stage 3 of our new building project,
- * Increase provision of HBOT by developing links with other support agencies and recruiting volunteers,
- * Improve communications with statutory agencies that support people with MS,
- * To change our name to the Sussex MS Centre to reflect the changed nature and variety of services we now offer,
- * To continue to offer a warm welcome to everyone who needs us.

Exciting times ahead

The Sussex MS Treatment Centre was first opened in 1984 at Southlands Hospital in Shoreham.

We moved to our current site in 1994, purchasing second hand prefabricated units to house the Hyperbaric Oxygen Chamber, a couple of small therapy rooms, a communal area and an office. At the time, we offered HBOT, one weekly yoga class and a small number of limited physiotherapy, chiropody and beauty treatments.



In 2007 we added an annexe and in 2009 we refurbished and insulated the old units. We didn't bargain for how the improved premises would increase demand! Responding to members needs and requests we began offering more and more activities to improve the health and wellbeing of the people of Sussex with MS, as detailed in this review.

We are now operating at virtually full capacity, dealing with a number of restraints such as the poor circulation space and a shortage of office and storage provision. Having a multi-purpose gym involves the setting up and clearing of some heavy physiotherapy equipment. We are also seeing a steady rise in maintenance problems and associated costs. After preliminary discussions with our landlords Adur and Worthing District Council we are now investigating the feasibility of replacing these old units with purpose built premises. In 2015 we produced a design brief and appointed Martin Green from MG Architects to help us drive the project forward.

The Sussex Multiple Sclerosis Treatment Centre



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Charity Number 801075

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