

We came, we saw, we conquered Killi...!

The Branch year got off to an inspiring start at the January meeting when Martin Rowe gave a witty and moving account of tackling Mt Kilimanjaro. This was accompanied by a series of superb slides which brought home the amazing, but sometimes unglamorous, reality of the undertaking. On the basis that if Chris Moyles could climb Kilimanjaro then so could he, Martin signed up, sought sponsors and speedily organised a number of fundraisers in advance of the trip. As he showed the training schedule to his local gym they looked him up and down and said "So you'll be coming in every day then!" Eventually, last October, Martin found himself on a sleepless overnight flight to Nairobi and a transfer to Kilimanjaro with 39 other MNDA challengers of mixed age, sex and fitness, all determined to "conquer Killi"! What they had in common was massive determination and powerful personal motivation to reach that summit. Martin's inspiration was his brother Colin who is living with MND.

Everyone had been recommended to take Diamox to help combat altitude sickness. Before the climb started they were already at 1,000m. At this stage bags had to be re-packed to meet weight requirements for the climb. Leave those sweets and snacks behind!

At the start point the group met their fantastic tour manager Henk, & the experienced guides and porters who would encourage and help them every step of the way - including Amadeus, a star chef, who cooked two birthday cakes using a frying pan as well as great meals!

Day 1: involved a scenic 4½ hour trek through the rain forest to Mandorla Huts at 2,700m. At this stage the accommodation (designed by Swedes) and loos were good. Things were to become less congenial higher up!

Day 2: the second day's climb involved a more arduous 8 hours uphill trek through an increasingly rugged and rocky landscape with great views of distant peaks Mawenzi and Kibo. The day ended at Horombo Hut, 3,700m, with "Happy Birthday" and some "incredibly tasty cake"

Day 3: a 5 hour acclimatisation trek up through the Kibo trail including a group photo call at Zebra Rock. Reaching an observation point at 4,000m they could begin to appreciate what lay ahead!

Back that evening to Horombo Hut for pan baked birthday cake and sing-along number two.



Day 4, an arduous 8 hours - getting kitted out after a quick packed lunch among the rocks - for the four hour trek through the desert zone, and a blizzard! to get to Kibo Hut at 4,700m. Living conditions - and especially loos - were pretty primitive by this time. Bed space was at a premium with 16 to a dorm! Martin's group were not alone on the mountain. Help for Heroes was one of the other charities doing the climb.

Day 5, final preparations for the summit... a 5 hour acclimatization trek at 5,000m, the highest altitude so far, followed by hot food and rest before setting off for the summit at 11 pm.

Day 5/6, a gruelling 17 hour slog! With torches on headbands they snaked their way upward in single file accompanied by the beautiful melodic singing of the porters and guides. Henk encouraged everyone to concentrate and visualise one thing to get them through. At Gilman's Point, 5,681m, they perched on the crater rim as the sun came up. Stunning views above the clouds and a realisation of just what had been achieved. A final two hour climb through snow and wind and Martin and companions stood on Uluru Peak, the very summit, 5,895m. Triumph! And a very emotional moment for each person.

Day 7, the journey down, exhausted but elated back to an overnighter at Horombo hut and down the next morning to the start where it had all begun. Champagne corks popped, speeches were made and everyone danced. "The hardest thing I have ever done but not as hard as the journey my brother is on. I'd do it again and again if only that would bring an answer now to this horrible disease."

Altogether this challenge trek raised £180,000. Thank you Martin for inspiring us. See next page for more photos. See also news of Terri Marshall who bravely climbed Kilimanjaro a month earlier and who raised money for a number of charities, including over £1,000 for the MND Association. Warmest thanks to both Terri and Martin.





Above the clouds



Brother Colin - Martin's inspiration



It's cold at the top!

SHE DID IT! Hoorah for Terri!

An ecstatic phone call to Kitty from the top of Mount Kilimanjaro in September confirmed that Terri Marshall had reached the summit... she was so elated! The ascent was not without its price: she suffered from dreadful altitude sickness. Terri saw many people stretched down the mountain and was determined not to be one of them. It was an enormous feat of endurance - huge blisters and lost toe nails... and a descent



that was as gruelling as the climb. Terri is in South Africa at the moment. We hope one day we'll be able to thank her in person. Terri climbed with companions raising funds for various charities. Over £1,000 was raised for MNDA. We wish her well and send her loving thanks for this magnificent effort.

Kitty

Coffee Morning Raises a record £940

In her first venture after joining the branch last year Myra Gibbs organised and ran a brilliantly successful coffee morning in East Wittering last November. Myra felt that there were many events held locally for other charities and it was time to do something for the MND Association and raise its profile. With various stalls including Christmas cards & jewellery, the morning raised an amazing £940. Surely a record amount for a coffee morning! Warmest thanks to Myra and all those who helped and supported her on the day. Look out for Myra's next fundraiser later in the year!



The Autumn Quiz

Once again, thinking caps were retrieved from dusty storage and forgotten brain cells exercised at the Autumn Quiz on the 6th November at the Aldingbourne Sports and Social Centre. About 80 people listened intently as Erica Burrows asked her difficult, and sometimes obscure questions, before they were rewarded with some delicious fish and chips in the interval. A raffle was held with many, generously donated prizes, before the second half revealed the winners, our very own Kitty, Dennis and Janet and their friends, who narrowly beat Dawn's team after a tie-breaker question. The final takings of £630 were due to the generosity of all who contributed to the evening.



Sue

THUMBS UP CLUB Winning Numbers

OCTOBER

1st 21
2nd 120
3rd 72

NOVEMBER

1st 92
2nd 169
3rd 49

DECEMBER

1st 136
2nd 73
3rd 31
4th 97

JANUARY

1st 27
2nd 78
3rd 72

12 chances to win for a £12 annual stake [The 2011 Thumbs Up Year starts in February]
Contact Graham on 01403 700286 or email him at info@little-ghyll.co.uk for further details

Daphne and Ernie Cole will be well known to any of you who have come to our branch meetings. Many newcomers have been put at their ease and warmed by a smiling welcome from Daphne and Ernie. In January Julia asked Daphne if she would like to write a brief article for this newsletter ...

Daphne writes: "I had been aware of MND and the effects of this dreadful illness, as a very good long term keep fit friend of mine, Ursula, had MND and passed away in November 2007. I had been under a Neurology Consultant for almost 18 months myself at the time and in the following January, 2008, I was told that I too had MND.

Unfortunately the Consultant failed to tell me at the time of the existence of the West Sussex South branch and the support available. We only found out about it when my husband Ernie saw an information sheet about carers at our local Doctors' surgery.

At first I was not sure I wanted to "get involved" with anything like that. I felt I might feel even more depressed seeing other people perhaps worse than I was. As time passed I plucked up the courage to make enquiries and attended my first monthly meeting at The Laurels in February 2009. I soon discovered how silly I had been to have left it for so long. It was such a lovely evening, the people were so friendly, lots of laughter and good humour.

I was assigned a Visitor, Linda, who visits us regularly for a chat and to make sure there's nothing I need in respect of help or support.

Ernie and I look forward to the annual Cobnor Boat trip.* The Cobnor Chairboat has been specially built for the disabled to enjoy. Nothing could be nicer than sailing round Bosham and Chichester harbour on a lovely sunny day, highly recommended - take a picnic lunch!

We've also taken part in collections at the supermarkets for 2 years. It's surprising the conversations you have with people who want to know more about MND. On another occasion we enjoyed helping at a car boot sale, a first for us but great fun. The Strawberry Tea at Westbourne School in July is a not to be missed event - a great chance to raise funds. Later in the year the Quiz Night with fish and chip supper is another fun evening.

The monthly meetings remain the highlight of the month. I no longer feel lonely or isolated, knowing I can pick up the phone and a group of dedicated, sincere people are there to help if needed.

The support of the branch has made such a difference to my life and I know how much they would appreciate more help. I would urge anyone out there looking for a worthwhile cause to support to know that they could not find a more deserving one than this" Daphne

(*see events diary for dates of this year's Cobnor dates)



HELP WANTED! Could you help organise the supermarket collections this year? Sue and the committee are very keen to find a person - or couple - who would be willing to take this on. Please telephone Sue on 01243 544241

RESEARCH LINKS

We have omitted our usual News from The News item this month as the latest edition is not out yet. When it is published The News is available to read as PDF on line via links on the main MND Association website www.mndassociation.org

The research development team is blogging to take you behind the scenes of MND research. The pace of research is picking up and we are all excited about being able to give you the 'inside scoop' on new discoveries, as well as giving you an insight into the work we do. I hope you will join us in keeping up-to-date with our activities and MND research advances that we will write about in this blog.

Follow us at <http://mndresearch.wordpress.com>

WEST SUSSEX SOUTH ON LINE



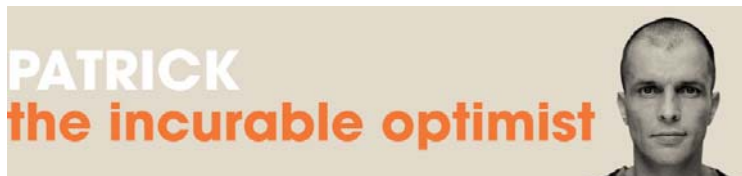
Welcome

A warm welcome to the website of the West Sussex South Branch of the MND Association

If you are on line have you visited our website yet? www.mndwestsussexsouth.co.uk There is a facility for people to make contact with the branch, to make enquiries or offer help and there are links to other organisations that could be useful plus a link to the MND Association national website.

We are also able to upload members' stories so if you have a personal story or information that you think would help or interest or amuse other people please send it to Sue or Helen.

And while you're on line do visit one of the most amazing sites you'll ever see
www.patricktheoptimist.org



JAN RETIRES AS AV

At the January Branch Meeting Jan Galloway retired as an Association Visitor. Julia spoke warmly of Jan and her early days with the branch. She praised Jan's tremendous support for her people living with MND and also spoke of her valuable contribution to the AV team, keeping them on their toes. She remembered too a wonderful garden party held in Jan's beautiful garden in the summer of 2004. We've all appreciated Jan's contribution to the branch in many ways. Julia complimented Jan for always looking so beautiful and glamorous recalling how she had even managed to look stunning in an AV team spoof catwalk show one Christmas where she had been persuaded into an outrageous outfit by Linda! Julia wished her happy times with her family and grandchildren.



Jan thanked everyone and said how very much she had enjoyed working as a Visitor. She is going to keep in touch and has promised to come back to the Christmas meeting in November.

BRANCH MEETINGS NOVEMBER



Our Christmas Branch meeting on 22nd November was, once again, extremely well attended, so that every chair in the Laurels Day Centre had to be retrieved from remote corners to accommodate us. The delicious and plentiful buffet was too hard to resist so, this year, we started the meeting with the refreshments, before we were admirably entertained by the Melodians, a local choir in which our very own Linda sings. They sang to an enthusiastic audience - including patron Lady Sarah Clutton, families and friends. The medley featured many old favourites about Paris, Capri, Amsterdam - and Dover! so we could all join in.

Sue then gave thanks to the many people who have helped us in so many different ways this year and gave a brief summary of the fundraising activities. John followed up with more details of the money which had been raised before a splendid raffle of many generously donated gifts. To judge by the laughter and friendly chat I believe everyone had a good time and we all agreed that 2010 had been a successful year for our branch.

JANUARY



Martin presenting Sue a cheque for £330

TAKING A BREAK



There are now a number of organisations which offer well adapted holiday accommodation. Livability provides serviced accommodation and self catering properties. Some of the self catering houses and bungalows are in our area, including a stunning bungalow with amazing views over the channel at Selsey and a large house at Felpham with breathtaking panoramic views over the coast.

There are also two hotels, one in Minehead, Somerset and one in Llandudno, which provide fully accessible bedrooms plus restaurant etc. Have a look at their website and click on Holidays at www.livability.org.uk or email info@livability.org.uk or write for brochure to Livability, 50 Scrutton Street, London EC2 4XQ.

There are a number of links on the Livability site to providers of foreign breaks too, including Enable Holidays www.enableholidays.com.

They say : “Enable Holidays is the specialist tour operators for wheelchair users - their families and friends, slow walkers, older travellers and a broad range of travellers looking for an easier way to enjoy their holiday. Holidays are offered across the Mediterranean, the Aegean, the Canary Isles, Egypt and Florida - plus city breaks throughout Europe. Above all else the team at Enable takes great pride in helping you find the right holiday to meet your precise needs.

All the properties we feature have been personally audited by an experienced Enable Holiday’s auditor. Our 150 point auditing process covers access and wheelchair manoeuvrability throughout the accommodation and around the resort itself. To make your choice easier still we have developed the Enable E-grading system to provide at-a-glance information about our findings”

Has anyone used either Livability or Enable Holidays? Or are there any other people or places you would like to recommend? Do send in your personal recommendations.



HELP AVAILABLE FOR DRIVERS

The Queen Elizabeth Foundation is an organisation which can be helpful in all sorts of ways for people living with MND. Their mobility service can expertly assess your driving ability, advise on adaptations, suggest gadgets or suggest alternative vehicles which may be more appropriate. If that is what you want they will do their best to ‘keep you on the road’.

QEF isn’t there to sell you a car but to help you have all the relevant information you need to choose what is right for you.

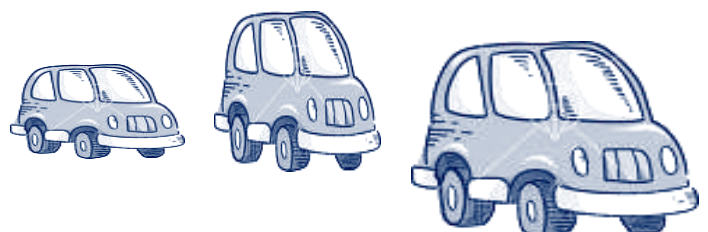
You can see and practise with all sorts of clever gadgets which make life easier, eg. lifts for getting wheelchairs in and out of the boots of cars, etc., etc. You can also practice drive on their ‘roads’ with instructors advising and encouraging you.

Our Branch can help with the assessment fee, if necessary, and people who have had assessments with QEF are usually very satisfied with the outcome, and feel ‘enabled’ rather than ‘disabled’ after a few hours with them.

There is a also fleet of donated cars which can be loaned for families to use. Your Mobility Allowance can be used to rent the car for as long as required, helping all the family to enjoy time out together.

QEF helped one of our people recently who had been told she might not drive any more; she passed her Driving Ability test at QEF with flying colours! Julia

Queen Elizabeth Foundation Damson Way
Foundation Drive, Carshalton, Surrey SM5 4NR
Tel. 02087701151 Email: mobility@qef.org.uk
Website www.qef.org.uk



NOTICE BOARD

A WARM WELCOME TO OUR BRANCH MEETINGS

We really look forward to welcoming you and your family and friends to our monthly branch meetings, normally held on the fourth Monday of each month [unless there's a Bank Holiday!] at The Laurels, Sheepfold Avenue Rustington. Meetings are very friendly and informal. Parking and access is good. Please speak to your Visitor if you have transport needs or if you need a lift.

A BIG THANK YOU!

I would like to thank all the kind people who sent me cards, flowers and good wishes for my recent knee operation.... I am glad to say it has all gone well. I am still doing my exercises, and have been very fortunate to have made a full recovery! Julia



YOUR NEWSLETTER

If you would like to help produce this newsletter or would like to become The Editor please contact Helen at RHCJ@aol.com Your articles are very welcome.

RAFFLE PRIZES ALWAYS NEEDED

For events and branch meetings please contact any committee member or bring along & give to Frances at any branch meeting

DATES FOR YOUR DIARY

YOUR HELP AND SUPPORT IS VERY MUCH APPRECIATED

- MONDAY FEBRUARY 28th** **BRANCH MEETING 7.30 pm**
The Laurels Sheepfold Avenue
Rustington Social evening
- MONDAY MARCH 28th** **BRANCH AGM 7.30pm**
NB a month earlier this year!
The Laurels Sheepfold Avenue
Rustington (Wine & nibbles)
- MONDAY APRIL 18th** **BRANCH MEETING 7.30 pm**
The Laurels Sheepfold Avenue
Rustington
- FRIDAY JUNE 3rd** **SUMMER SOIRÉE with songs and verse**
Slindon College, Slindon
Donations at this event in aid of West Sussex South MND Association.
Organised by Dennis Mounstephen.
Times and further details to be confirmed.
- TUESDAY JUNE 14th** **COBNOR CHAIRBOAT TRIP 1 from 11.00**
TUESDAY JULY 12th **COBNOR CHAIRBOAT TRIP 2 from 11.00**
These very popular trips start from Cobnor Activities Centre at
Cobnor Point Chidham PO18 8TE. Bring a picnic. Talk to John
Farrington or your Visitor for further information.
Do ask if you need help to get there.
- SUNDAY JULY 17th** **SUMMER FAIR**
Westbourne House School
Ideas & Helpers needed now and
on the day. Contact Sue 01243 544241

There are more events to come which we are still organising. We will let you know times and dates as soon as they are confirmed.

If you would like to put a fundraiser together do let us know. We will put it in the online diary as well as in the newsletter.

Please contact your Visitor or any committee member for details of any of the events or meetings

MND
connect
08457 626262

MND Connect offers advice, practical and emotional support and directing to other services and agencies. The service is for people living with MND, carers and family members, Health and Social Care Professionals and Association staff and volunteers who directly support people with MND. Our opening hours are Monday to Friday 9.00am to 5pm.

In addition, people affected by MND can also contact us by telephone outside of normal office hours: Monday to Friday 7pm until 10.30pm.

Email: mndconnect@mndassociation.org [Emails can be answered in office hours]

Motor Neurone Disease Association
PO Box 246
Northampton
NN1 2PR

TEL: 01604 250505
FAX: 01604 624726

Email: enquiries@mndassociation.org
Website: www.mndassociation.org
MND Association Reg. Charity No 294354

WEST SUSSEX SOUTH BRANCH

www.mndwestsussexsouth.co.uk

President: Dr Robert Clifford-Jones **Vice Presidents:** Professor Anthony O'Hagan Kate Pottinger
Branch Patrons Lady Sarah Clutton The Viscountess Cowdray Josh Gifford MBE Kay Glendinning MBE

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Chairman Sue Krueger 01243 544241 **Secretary** Gill Pitt 01243 514155

Treasurer John Farrington Tel: 01243 868364

Helen Clifford-Jones Janet Denny Frances Ramsden Martin Rowe Rosemary Smith

Association Visitor Team

Evelyne Arnold Angela Burgess Ann Colman Julia Franklin Angela Geal Liz Myles Linda Vaughan Liz Richardson