

Super Active Supporters

This year we have enjoyed the - very active - support of some amazing young people: Julia Hammond, who not only jumped in at the deep end literally as she tackled her first sprint triathlon, raising, together with a fundraiser at The Ship in Itchenor an amazing £2733 so far. The Revd. Timothy Peskett of St Mary's Felpham ran in the Bognor Regis Round Table 10K run with undertaker Darren Miles. Lisa and Hannah our two Virgin London Marathon runners are now fully recovered! As reported in our last issue Hannah Hilbery ran her second London marathon in memory of her uncle Roly raising £1300 for research; and last week Lisa Woolgar came to the branch meeting to present a cheque for £1646. It doesn't stop there! Hayley Bromley, Rosemary's niece, will tackle the two day Mazda London Triathlon this coming weekend and in the autumn we have our two intrepid climbers, Terri Martin and Martin Rowe tackling Mt Kilimanjaro! We are full of admiration and gratitude to this amazing group of people, running, swimming, cycling and climbing on behalf of the cause.

Julia Hammond writes

I decided in February this year, after always saying I could never do anything like that, to do a triathlon. A friend had suggested it to me. I had thought I would do something this year to raise a bit of money for the MND Association but had not decided what yet. I gave it some thought for a day or so, then I entered the Eton super sprint triathlon!

The reason for me choosing the MND Association is that my father was diagnosed with a type of MND five years ago. He has always been a very physical and active man so to be given this terrible news was devastating for him and also for the whole family. He has shown such strength and endurance during the last few years it seemed fitting for me to do an endurance event.

I put my heart and soul into training and fundraising - and with help from some very special people - I managed to raise a good lot of money and also raise awareness of MND around the local area.

My race went well. It was a very emotional time, I have learnt to be a lot stronger and I can now use my endurance to get me through the tough times. I crossed the line with my dad waiting for me. It made him very proud, which was my proudest moment.

Julia has so far raised a magnificent £2733 with gift aid still to come.



Dressed for action

Darren Miles, a local funeral director and the Rector of St. Mary's Felpham, The Revd. Tim Peskett, ran the Bognor 10 K run in May in aid of the Association. Tim's mother died of MND in 2004 after living with the condition for 2 years. Darren and Tim raised £1,700 in sponsorship from the village community of Felpham. The local Rotary group, the chief sponsors of the run have said they will add up to a further 25% on top of the sum raised. With gift aid and the extra donation from the Rotary it is hoped that the final sum raised will be in the region of £2,500.



Hannah's second marathon success

As if an attack of laryngitis on the day wasn't enough Hannah Hilbery had been mugged a few days earlier but was still utterly determined to complete a second London marathon in memory of her dear uncle Roly. She raised a superb £1300 for research.

A terrific achievement.



Proud Lisa shows her medal

Lisa Woolgar presented a cheque for £1374 to Treasurer John Farrington at the July branch meeting. (Gift aid still to come.) She told how she had trained for a year by the end of which she was running 30 miles a week. The race itself was hard and she really had to push herself. Not helped by some wretched blisters which made walking tricky for the next few days. Lisa passed round her medal and spoke of her enormous sense of achievement at having actually completed her first marathon and raised so much money for such a good cause. Never again? Well maybe!



We never lose hope. We strive to find a cure for MND and to support everyone affected by this devastating disease

Cream Tea With Jazz

The sun shone on the beautiful grounds of the Westbourne House School in Chichester for our 25th Anniversary fundraising event on Sunday, 25th July. Around 200 people flocked into the grounds to the music of George's Regis Jazz Band, which played throughout the afternoon, adding to the happy atmosphere prevailing under the old trees and on the grass in front of the new Millenium Hall.

Most people were immediately attracted to the delicious cream teas, which were being served by a group of 12 helpers at beautifully decorated tables. Children headed straight for the colourful Bouncy Castle, the toy stall or the ice cream stand, while

bargain hunters perused the books and the bric a brac stall, delighted with their original purchases. Everyone had a go at the Tombola, some coming back time and time again until they had won a prize. The very clever people tried their luck at the picture quiz, which puzzled most of us for hours.

A Pimms Tent stood in the middle of the lawn and a stand showing photos and information about the branch and it's 25 year history was constantly manned by Frances and Julia, who were able to answer the many questions

posed. Ulla meanwhile made sure that everyone bought plenty of raffle tickets. On a hot afternoon many people just sat around on chairs under the trees, listening to the band and watching the world go by.

The generosity of visitors has raised an initial sum of over £1100, although donations are still being received.

My warm thanks go to Pam Sweet, who organised the afternoon, and to all the many helpers who worked tirelessly on Saturday and Sunday mornings, setting up the grounds and to all who helped in the afternoon, mostly clad in their bright blue or red MND T- shirts and cleared up at the end of the day. The cake bakers deserve a special mention too. We are also extremely grateful to Westbourne House School for letting us use their beautiful premises and for being so very helpful and accommodating.

This was our first event at this site, so it was, in a way, quite experimental and we were pleased with the result. We do, however, already have bigger and better plans for the future, so, maybe this could become a successful, annual event and we would welcome all your suggestions for improvements and extensions.

Sue Krueger.



THUMBS UP CLUB
Winners:

MAY

1st 99
2nd 123
3rd 52

JUNE

1st 41
2nd 84
3rd 111

JULY

1st 100
2nd 65
3rd 162

12 chances to win for a £12 annual stake

Contact Graham on 01403 700286 or email him at info@little-ghyll.co.uk for further details

THE LONG HOT SUMMER

SLINDON SIZZLES



For two afternoons at the end of June Sue Foley opened her stunning garden in Slindon under the Yellow Book Scheme. This year she chose to do teas in aid of the branch and raised an extraordinary £750. On the Sunday we visited her deliciously beautiful garden was packed with visitors. Gasps of delight at the beds awash with blue geraniums, lavenders, cistus and English roses set against flint walls. All this and picture perfect fruit and vegetables too! A garden to covet. Very many thanks to Sue and all her helpers.

PIMMS & PRAWNS HIT THE SPOT



On Friday July 9th Kitty and Dennis's Slindon garden was abuzz with conversation and laughter as about 70 people gathered for a new venture "Pimms and Prawns (and other nibbles!)" on yet another swelteringly hot evening.

A few weeks before Kitty had been wondering what to do to support Terri Martin's Kilimanjaro climb in September. Should it be a coffee morning, another Mad Hatter's Tea Party? Then we came up with the idea of a Pimms and Prawns drinks party which we'd hold early on a Friday evening. We thought a catchy title would amuse prospective guests and that everyone would enjoy a relaxing drink and nibble at the beginning of the weekend. It worked. We charged £7 a ticket in advance or on the gate and also had a super raffle. Extra lemonade was needed towards the end but it was all great fun. A lot of work on the day but well worth it to raise over £610 in an hour and a half! As always warm thanks to everyone who helped and especially Kitty and Dennis for hosting such a super evening.

Helen



Kitty and Ulla with Pimms and prawns!

ANOTHER GREAT DAY AT COBNOR

Minnie, Daphne and Ernie were among those who thoroughly enjoyed a day out on the water last month with the Cobnor Chairboat. The weather was glorious.



Linda reports that she and Mike - not forgetting little sea dog Jasper - also enjoyed a delightful couple of quiet hours and a picnic on board while the boat was at anchor in Chichester harbour. Warm thanks to John and his co - captain Roger for yet another wonderful Cobnor day.



TEAS AT MANVILLES FIELD

On Bank Holiday Monday, May 31st, a number of us drove up to Fittleworth to admire once again the beautiful garden at Manvilles Field opened by Caroline Wilson and her sister Penny Aschan under the Yellow Book Scheme and with teas in aid of the MND Association. The afternoon raised £450, a splendid result. Although Penny felt that winds had blown too hard for comfort the previous week it all looked quite gorgeous. The front of the house was covered by a stunning primrose yellow Banksian rose. There was the most spectacular tree peony that any of us had ever seen and masses of climbing roses, clematis and interesting shrubs. Very well worth a visit. Many thanks to Penny and Caroline who have supported us over many years now.

SUSSEX GRUFFS STRUT THEIR STUFF

Inside for once! June 22nd Ye John Seldon Pub in Salvington was packed to hear the Sussex Gruffs Male Voice Choir give a rousing performance. They sang songs from the musicals and others well known to those of us born way back



in the last century - so feet were tapping! The conductor kept us amused with some witty repartee. Feedback from the evening was very favourable so we hope we can tempt the Gruffs to do another performance for us soon. £260 was raised. Thank you to all Gruffs!



30th Anniversary Royal Reception at St James's Palace

To commemorate 30 years of the Motor Neurone Disease (MND) Association, the charity's royal patron, HRH The Princess Royal, held a reception at St James's Palace on 6 May attended by 300 guests. The event provided an opportunity for The Princess Royal to meet volunteers from across the Association to mark this special occasion in the Association's history.

May 6th was another beautifully warm spring day and four of us, Kitty, Dennis, Julia and I, were able to attend this celebratory reception. Julia and I had travelled up together and stood chatting with old friends in the sunshine before making our way up to two very grand reception rooms where we awaited the arrival of HRH the Princess Royal.

I had been asked to introduce her to a small group of lively and interesting people. Among this group was Richard Noble, a lovely man, a world land speed record holder. Kitty had been the AV for his mother many years ago so he was very thrilled to see her again. Hugs all round! Princess Anne was charming and shared a joke with some of our group. She later gave an excellent speech which we all found very impressive. It was so good to see many old friends from branches across the country. The atmosphere was typical of MND Association events, warm and friendly with a sense of shared commitment. Staff members had worked their socks off to make sure everything ran smoothly. (And we all enjoyed the royal canapés!)

Helen



Chris Woodhead presents petition to Downing Street

Former chief inspector of schools, Chris Woodhead, travelled to 10 Downing Street to present the Motor Neurone Disease (MND) Association's petition calling for a national strategy for MND. Chris was joined by other members of the MND Association including chief executive Kirstine Knox, chair-elect Mark Todd, trustee Jean Waters and Patrick who is living with MND and his wife Kathy Joyce. Following Chris Woodhead's call in February for national action to improve the quality of life and achieve dignity in death for people with this devastating disease, over 18,000 people have signed the petition.

The campaign has had an overwhelming response since launch and with the new Government in power the charity believe now is the time to step forward and demonstrate public support for the campaign to implement this national strategy for MND. Chris said: "...we can't change the outcome, but with a coordinated approach, we can improve quality of life for those with MND and at the same time make things easier for carers and relatives.

A heartfelt thank you to everyone who supported the petition.

The Branch was again represented at The Reception at The Houses of Parliament on June 28th. Sue Krueger, our newly elected Chair, and Angela Burgess one of our Association Visitors flew the flag for West Sussex South. Sue and Angela were disappointed not to have been able to meet up with their local MP but found their visit to Westminster very interesting and found that the day provided a good opportunity to network with people from other parts of the country.



Behind the scenes of MND research

The research development team is blogging to take you behind the scenes of MND research. As some of you may already know, we blogged for the first time at last year's 20th International Symposium on ALS/ MND. Needless to say, we have now caught the 'blogging bug' and have decided to expand our focus to what's going on in the world of MND research and what we get up to in the research development team.

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

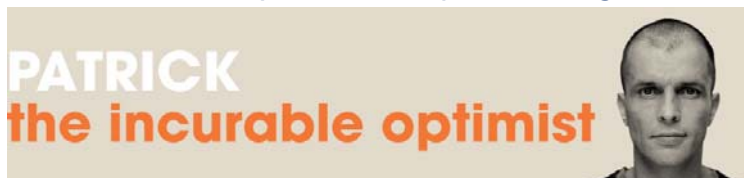


Welcome

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 is up and running and will help us keep everyone up to date with what is going on. 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 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



Patrick is the face of a wonderfully inspiring awareness campaign. He is the father of a young family, seen left with his little daughter Nancy, and an incurable optimist despite living with MND. As an artist Patrick is aiming to paint portraits of 100

other incurable optimists. And our very own Julia is portrait number 8! He has used her surname to "frank" a stamp on which Julia is "Queen"!



Suay & Will Buckley's Cornish Coast Walk

Angie Geal writes: We were so pleased that Suay and Will Buckley came to our May Branch meeting and very interested to hear about their forthcoming challenge - 300 miles of the Cornish Coastal path in 30 days! They start at Welcome Cove on July 5th and plan to average 10 miles a day - although if they manage to do 12 or 15 they might allow themselves a day off! Will has already run 6 marathons but believes this extremely undulating trek will be a greater strain on joints. In preparation Suay and Will have invested in a camper van so that at least they will be able to sleep in their own beds each night. Suay's mother Liz sadly died from MND last year so this challenge has very special significance. We wish Suay and Will the very best of luck and fair weather. Thank you in advance! To sponsor this mammoth undertaking please go to www.virginmoneygiving.com/coastalpath



Suay with her Mum Liz

Editor's note: as I write (August 3rd) Suay and Will are completing their walk. They have done it! Many Congratulations!

CHICHESTER LADIES' PROBUS CLUB ADOPT US AS THEIR CHARITY OF THE YEAR

The Chichester Ladies' Probus Club has very kindly adopted the MND Association as their Charity of the Year for 2010, after the death of the husband of one of their members from the disease. It was, therefore, an honour to be asked to talk about the disease at one



of their monthly lunches at the Chichester Park Hotel on Monday, 28th June and to receive a cheque for £250 from their president, Joan

HELP & SPONSORS NEEDED

You will see from our diary page there is a lot happening this year!!

In August **Hayley Bromley** tackles the two day **Mazda London Triathlon**. In the autumn we have **Terri Martin** and **Martin Rowe** facing **Mt Kilimanjaro** challenges in September and October.

Meanwhile **Suay and Will Buckley** have just walked **Cornish coast**. Read their entertaining blog at <http://mndacoastalwalk.wordpress.com/>

They are hoping to come and tell us about it at one of the upcoming branch meetings. [See article bottom left]

All these very enterprising people are eagerly looking for sponsorship please!

VISIT BY CHAIRMAN ELECT



It was a real pleasure to welcome chair elect of the MND Association, **Mark Todd**, to West Sussex at the end of June. Mark was formerly an MP but stepped down at the last election, having been Chair of the All Party Committee for MND. We hoped to give him as comprehensive a picture of the branch as possible albeit crammed into one afternoon and evening. We hope he found it stimulating. Following lunch there was a chance to meet part of the team at St Barnabas Hospice and then on to two visits to people living with MND.

After a quick meeting with members of the committee and AV Team Mark enjoyed the opportunity to meet as many people as possible at the June branch meeting. In his speech he emphasised the critical role of branches and volunteers. We enjoyed having you Mark and look forward to your chairmanship from September. Special

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. They're 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.

TESCO COLLECTIONS COLLECTORS NEEDED!

TESCO LITTLEHAMPTON
Saturday August 21st

Collections are from 10.00 to 4.00 in 3 shifts.
If you can help please contact Sue on 01243 544241
or any member of the committee. Thank you!

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 SUPPORT & SPONSORSHIP IS VERY MUCH APPRECIATED

- SATURDAY August 7th & SUNDAY August 8th** MAZDA LONDON TRIATHLON
Hayley Bromley
- SATURDAY August 21st** TESCO COLLECTION 10.00 - 4.00
In 3 shifts contact Sue 01243 544241 to help
- TUESDAY September 7th** 25th Anniversary Lunch 12.30 for 1.00
BOSHAM SAILING CLUB
Tickets £6 from your AV, at Meeting or Sue on 01243 544241
- SATURDAY Sept 11th** NATIONAL CONFERENCE & AGM
Nottingham
- SEPTEMBER 17th - 27th** MT KILIMANJARO OPEN CHALLENGE
Terri Marshall
- SATURDAY October 9th** ORGAN CONCERT 7.30 pm
St Mary's Church Felpham
The Revd. Timothy Peskett
Retiring Collection for MNDA
- OCTOBER 16th – 26th** MT KILIMANJARO CHALLENGE
Martin Rowe
- SATURDAY Nov 6th** QUIZ NIGHT 7.30 pm
Aldingbourne Sports & Social Centre

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

OUR 25TH ANNIVERSARY LUNCH
We have just been offered the most wonderful venue. Do come!

Bosham Sailing Club
The Quay Bosham PO18 8LU
Tuesday September 7th
12.30 for 1.00
Tickets £6 From your AV
At Branch Meeting or from Sue



EVERYONE
VERY WELCOME!

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

Branch Officers & Committee Members 2010 - 2011

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 Julia Franklin Jan Galloway Angela Geal Liz Myles Linda Vaughan Liz Richardson