

Thank you Julia

Congratulations Sue

What a wonderful send off you gave me at the AGM. I shall never forget it. Thank you for all the lovely things you said and for the amazingly generous cheque for £800. Such a surprise! As for the silver box containing so many lovely messages I shall treasure it always. I'm going to continue to be a part of our Branch AV Team so I'll hope to see you all soon at a branch meeting in the "back benches"!

Julia



New Chairman Sue's Introduction.

When Julia told us two years ago that she was planning to stand down as chairman, we all knew that it would be incredibly hard to find anyone to take her place. Who could possibly have her knowledge, experience and enthusiasm or spend as much time on the branch activities as she did? We thought about advertising the post but do feel that we need someone who has some experience of MND. As one of the many people who were asked to take on this role, I said consistently "No, no, no, no, no.....well, maybe!" and here I am!

I joined the branch 3 years ago, when my partner, Terry, was diagnosed with MND. Terry was a very fit carpenter of 58 so, like so many others, he was devastated to hear this news. I was a retired occupational therapist, who worked at St Richards Hospital in Chichester for the last 14 years of my career, but, although I had a great deal of experience of disability, community services and equipment provision, I had never come across anyone with MND. I managed to find Julia's telephone number and was very quickly drawn into the branch as a committee member. Terry enjoyed the social meetings enormously and made many friends there. In particular he appreciated being able to speak to Robert Clifford-Jones, who was able to explain the illness simply to him and he made great friends with dear Wally Smith, even learning to email so that they could keep in touch and enjoying many good outings together. They became our star collecting team in their wheelchairs together!

We were fortunate to have Julia as our visitor and the branch helped us enormously financially, buying us a stair lift, paying for hand conversions on the Motability car and lending us a riser-recliner chair, powered wheelchair, self-propelled wheelchair and many other pieces of equipment. What we would have done on our own, I cannot imagine. We both enjoyed helping with fundraising events, which gave us both a purpose and a feeling of being able to contribute a little. When Terry died in February 2009, I vowed that I would help the branch as much as I could and try to contribute to helping others with the disease, until the cure comes that we are all so anxiously awaiting.

I have been lucky enough to have been involved, together with Helen, in the creation of a new branch website. This has been developed professionally by Adrian Gorman and is looking splendid. It is, as I write, awaiting accreditation from National Office and will, I hope bring you all the branch information and news, which we will endeavour to keep as up to date as possible.



What finally convinced me that I should take on this role, however inadequately, was the tremendous support that I have received from the wonderful members of the committee and the words of encouragement from Julia, Kitty and Helen, who have all been brilliant chairmen. If they believe that I can do it, then I can and I will do my very best. I look forward to meeting those of you I don't yet know and continuing to work and have fun with those I do. Please don't hesitate to contact me if you have any ideas or problems. I won't be able to solve all the problems, but I'll know a man/woman who can!

PS: Unfortunately I shall be away for the next branch meeting and out of contact from 15th - 26th May. Not a good start, but something I planned a long time ago. Sorry!

Sue



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

RECORD NUMBER OF EMAs AWARDED

We were delighted to welcome Karen Pearce, Director of Regional Care South to present this year's Extra Mile Awards at the Thank You reception & AGM on April 26th.



1. Claire Leppard, Speech & Language Therapist. Nominated by PG



2. Jean Curry, Wheelchair Specialist Chichester Nominated by JS

3. Jenny Thomas, Occupational Therapist, Chris Satturley, Physiotherapist & Helen Brockway, OT aid All from St Wilfrid's Hospice Chichester. Nominated by PG

4. Dr Wilkinson GP Southbourne Surgery. Nominated by PG



Three other EMA winners were unable to be with us. They were Chris Kershaw Neuro Specialist Nurse at Worthing Hospital. Nominated by MF. Penny Kirton, CNS at St Barnabas and Debbie South, Community Neuro Occupational Therapist Worthing both nominated by LV.

WARMEST THANKS TO ALL THESE SUPERB PROFESSIONALS WHO HAVE GONE THE EXTRA MILE FOR PEOPLE LIVING WITH MND

TREASURER REPORTS ANOTHER GOOD YEAR FOR THE BRANCH

John Farrington reports that 2009-2010, recession notwithstanding, was another successful year for the branch with income of £49,626. Of this, £26,337.42 was spent directly on care and support to people living with MND in this area. £6,000 was invested in research, £4,000 was donated towards the national equipment service for the purchase of Lightwriters. And £11,005.68 was sent to National Office as the end of year levy with 60% going to research and 40% to care. We do have the choice of where our levy is allocated and this is what we elected to do.

In paying a treasurer's tribute to Julia, John said that, including the Eric Easy bequest and the Fontwell Raceday, the branch had raised over £831,540.18 during her 9 years as chairman. An amazing achievement.

He pointed out at the AGM that, of course, bank interest was down this year as was Gift Aid and alerted us to the need for as many donations as possible to be gift aided in the coming year.

With the current economic situation we all need to keep on our fundraising toes.

JULIA'S INFECTIOUS ENTHUSIASM

It was such a privilege to pay tribute to Julia last Monday. She has been a brilliant chair for the past 9 years. In your messages you described her as a treasure, a star, caring, understanding, good fun, a "great boss!" - but the word that came up again and again was "Inspiration".

Julia has inspired us all - and she does it partly by what Tony O'Hagan describes as her "infectious enthusiasm". Anyone who has met Julia will know just what he means. One of her famous expressions is "I get a bit excited....." and this can apply to anything and everything. Soon all those around her are excited too and ready to get involved, keen to roll up their sleeves, to fight for the cause or to tackle something they had never even considered doing before.

You have been a wonderful chairman Julia. You have made a difference to so many families living with MND. Thank you for everything you have done.



Helen



WHAT'S BEEN HAPPENING?

BRANCH MEETING MARCH 22ND

About 30 people attended on a drizzly evening to hear a fascinating story of furniture in the 20th century. The difference in this talk was that it was delivered with visuals of boxes designed as living rooms depicting styles from Victorian times to present day.

Hilda Burden drove from the other side of Dorking and had us spellbound. She calls herself a 'dolls house miniaturist' and she specialises in luggage in miniature.

Each of the rooms was full of every type of furniture, ornaments and décor set out for each 10 year period starting in 1900, the end of the Victorian era. The set was as for a terraced house, rented in London and she talked of the lifestyles of the decades with changes in door design, fireplaces, heating, ornaments and furnishings, and the incoming of radio and TV. On closer inspection of each room, we could see tiny, clear copies of newspapers, piano music and magazines; potted plants and wall adornments. Did you know that before the Victorian period, green wallpaper was a killer? Apparently, it contained arsenic and this was inhaled. Did you know that carpets were first made in narrow strips, sewn together to fit the room then sometime later, undone, swapped position and re-sewn to make sure the tread disappeared. Who had heard of the Accumulator radio battery? Not me. TVs appeared in the 1950s and were proudly put on

show. Later when they were no longer a status symbol, they were hidden inside a smart cupboard.

The final room showed an open plan style with a flat screen TV on the wall.

Hilda knew so much about the history of living areas throughout the 20th century. It had taken her 5 years to complete this display. It really was fascinating. A great evening.



Hilda also is involved with the charity TWAM... Tools With a Mission which collects and refurbishes tools and equipment no longer required in the UK and sends them overseas. This enables people to earn a living and help support themselves.

Each container of equipment costs about £3000 to send so TWAM are always requiring funds. Anyone with anything that may help can bring it to our branch meetings and it will be given to Hilda. From items such as sewing machines, carpentry tools, typewriters and DIY kits, to wheelchairs and bicycles are wanted. For a list of tools visit the TWAM website www.twam.co.uk

The contact number should anyone wish to check if they have suitable tools, is 01473 210220.

Also on March 22nd, Vivienne Ayres and Anne Carsova presented Julia with a cheque for £700 raised by Littlehampton Inner Wheel at their "February Fanfare" concert held that month. This was a delightful and very well attended concert held at the Woodlands Centre with performances from a wide range of talented young musicians. The evening ended with a rousing flourish from "Bayleaf Brass" a brass quintet from the Gulidhall School of Music. Huge thanks to all the young performers and to the ladies of Littlehampton Inner wheel for choosing us as one of their charities. Your generosity is so much appreciated.



SUCCESSFUL DUNK IT COFFEE MORNING

"I think Grandad would have been very proud of us all, and pleased to see his friends supporting the MNDA"

writes Natalie, (last seen in a cold wet Santa Claus outfit in our previous newsletter!)

She and her grandma, family and friends raised £265 at a dunk it coffee morning on April 8th.

Luckily this time the sun shone as you can see from the photos below.



"The cakes were all deee-licious" reports AV Linda!



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>

GRAN INSPIRES CUP DESIGN

WITHOUT even considering the clinical importance, most of us feel much better when our bodies are well-hydrated, and we value our independence above all else. But what happens when you're unable to lift a cup or drink through a straw? Here's how a few determined people got together to develop a unique product, which is now proving its worth. Chris Adams gave us this insight;

"It started literally by accident – about 13 years ago my Gran tripped on the pavement and broke both arms and lower jaw. Whilst she was in hospital she became very distressed not being able to drink without constantly asking for help.

Needless to say she quickly became dehydrated. I knew something had to be done for her. At the time I had a small business designing and making furniture, so the next day I went into the workshop and made a simple gadget so she could drink whenever she wanted. It worked a treat and the nurses seemed quite impressed.

I then researched the problem of dehydration and looked at what was on the market. It appeared there was certainly a need for a versatile yet simple product, or a system which could be used in many different situations, by people with various levels of mobility.

A seed was planted, but at the time I couldn't imagine where my idea might lead. "We've been doing our best to meet practitioners, to understand their clients' and patients' needs and to try and open the right doors along the way. It's a very steep learning curve!" said Chris Adams.

A few years passed and I wanted something else to get involved with, so I joined the Parachute Regiment as a part-time volunteer. I witnessed a few parachute accidents where colleagues sustained back and head injuries. This, together with events of the Gulf War led me to make more prototypes. The aim being to help the injured civilians and soldiers reported in the daily press, the same as today's casualties in Afghanistan. So, I was juggling my day job, part-time soldiering and what became known as the 'Drinkup' project. In the autumn of 2006 I met my mother's boss Andy and his accountant Trevor, with the idea of developing a usable product. They liked the plans and saw the potential, so we shook hands and started the ball rolling. After months of engineering design, further prototyping, making machine tools and sourcing the best components from around the world, including the iconic water jug from NHS Supplies, we were ready with our first thousand Drinkup units.

In 2008 we started vigorous awareness campaigns. I focused on elderly care in general hospitals and Paralysis in spinal cord injury centres. Trevor's mother-in-law and best pal both died from MND, so his personal interest spurred him on to deliver hundreds of emails and letters to organisations dealing with degenerative diseases. Meanwhile, Andy worked on marketing materials and developing our website.

We've been doing our best to meet practitioners, to understand their clients' and patients' needs and to try and open the right doors along the way. It's a very steep learning curve!"

Recently we invited Chris and Trevor to meet us at national office, so we could see how the Drinkup System worked and to hear more about their progress. There are about 500 Drinkups being used around the world, mostly in the UK and Europe and several in the USA, Australia and New Zealand.

It's clear that some other people with MND may find Drinkups very useful. More interestingly, Drinkup can be set-up in a 'safe-siphon' mode to deliver fluid to people who are unable to suck or use normal straws. Drinkup may also be used with thickened fluids or nutritional drinks.

The News is available to read on line via links on the main MND Association website www.mndassociation.org



THUMBS UP CLUB Winners:

FEBRUARY

1st	65
2nd	137
3rd	6

MARCH

1st	116
2nd	19
3rd	47

APRIL

1st	22
2nd	141
3rd	20

Still time to join up for 2010.

For a £12 annual stake you have 12 chances to win.

WEBSITE LAUNCH!

As you will see from Sue's article we are launching our very own West Sussex South website. You will be able to find us very soon at www.mndwestsussexsouth.co.uk

In the panel below you can get a flavour of our home page.

We are extremely grateful to Adrian Gorman who has designed what we hope you will find an exciting new venture and another way of keeping in touch with what is going on.

As time goes on we will hope to make it more interactive. We are keen to have members' stories. At one of our branch meetings we'll hope to demonstrate some of the possibilities. Do let us have your ideas and feedback.

Sue & Helen

PS. This newsletter will shortly be available on line.



Welcome

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

If you live in the southern part of West Sussex and have been affected by MND we are here to help. Whether you are living with MND, are caring for someone, or have a friend or family member with MND we are here to offer a listening ear, information and support. We hold friendly informal meetings every month at The Laurels in Rustington. There is always a welcoming positive atmosphere. Access and parking is good.

"..Time to have a chat with friends makes us realise we can all help each other. There is no need to suffer alone."

"...a lovely friendly bunch of people who make us feel warm and wanted!"

Come and enjoy a delicious cream tea...



Do you have bric-a-brac suitable for a car boot sale?

Please let us know. Martin will be manning a car boot stall this summer. Contact him rowemartin4@aol.com Or speak to him at the branch meeting.

Marathon heroines



Hannah



Lisa

Two brave young women, Lisa Woolgar and Hannah Hilbury completed the Virgin London marathon on April 25th. Lisa is a friend of Frances Ramsden one of our founder members. Hannah ran for the second time in memory of her uncle, Roly. Her personalised running vest had HANNAH on the front and FOR ROLY on the back. We hope to feature their stories in the next edition and on our website. Many congratulations to both of them.

HELP & SPONSORS NEEDED

You will see from our diary page there is a lot happening this year!! We have some wonderful young people who are running swimming, cycling and climbing mountains to raise money for the association. **Julia Hammond is taking part in her first Sprint Triathlon** at Eton on May 16th. She has also just held a hugely successful raffle and auction at The Ship in Itchenor.

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 we have just heard that **Suay and Will Buckley are planning to walk the Cornish coast in one hit!** this summer. They think this will take about a month. They are hoping to come and tell us about it at one of the upcoming branch meetings.

All these very enterprising people are eagerly looking for sponsorship.

Once our website is running we will have all the details on there. Meanwhile please come along to the branch meetings to find out more and to sign up!

Luckily there are many other things to enjoy. Do visit the beautiful gardens at **Manvilles Field Fittleworth on May 31st** where the teas are in aid of the branch. Caroline Wilson and her family have supported the branch for many years. We very much appreciate everyone's support and enthusiasm.

← **And do come along to our major summer fundraiser, a Cream Tea with Jazz at Westbourne House School, Shopwyke on Sunday July 25th.** This event follows the enormous success of A Cream Tea by the Sea two years ago. Entry is free but there will be an opportunity to make a donation – preferably using Gift Aid - so that the chancellor can also contribute to the cause! Please contact Pam if you would like to help on 01243 574239

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.

STOP PRESS! 3 TESCO COLLECTIONS COLLECTORS NEEDED!

TESCO CHICHESTER Saturday July 10th
TESCO BOGNOR Saturday August 7th
TESCO LITTLEHAMPTON Saturday August 21st

Collections are from 10.00 to 4.00 in 3 shifts. If you can help at any of these please contact Sue 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

RAFFLE PRIZES ALWAYS NEEDED

For events and branch meetings
Please contact any committee member
Or bring along & give to Frances at
A branch meeting

DATES FOR YOUR DIARY

YOUR HELP SUPPORT & SPONSORSHIP IS VERY MUCH APPRECIATED

- SUNDAY May 16th** **BOGNOR REGIS ROUND TABLE 10K RUN**
Father Timothy Peskett & Darren Miles
- SUNDAY May 16th** **ETON SUPER SPRINT TRIATHLON**
Julia Hammond tackles her 1st triathlon
- MONDAY May 24th** **BRANCH MEETING 7.30**
The Laurels Sheepfold Avenue Rustington
- SUNDAY May 31st** **TEAS AT GARDEN OPENING**
Beautiful garden Manvilles Field Fittleworth
CAKES NEEDED
- SATURDAY June 5th** **MORNING COLLECTION STORRINGTON**
Contact Sue 01243 544241
- TUESDAY June 22nd** **EVENING CONCERT BY SUSSEX GRUFFS**
Ye John Seldon Pub Salvington Worthing
- TUESDAY July 6th** **COBNOR CHAIRBOAT 11.00 am**
Trip round the harbour. Bring a picnic
- MONDAY June 28th** **BRANCH MEETING 7.30**
Meet Mark Todd chairman elect of the MND Association
- SUNDAY July 25th** **CREAM TEA WITH JAZZ 2.30pm – 5.00pm**
Westbourne House School Shopwyke
Chichester Info from Pam on 01243 574239
- TUESDAY August 3rd** **COBNOR CHAIRBOAT 2 11.0am**
- SATURDAY August 7th & SUNDAY August 8th** **MAZDA LONDON TRIATHLON**
Hayley Bromley
- SATURDAY Sept 11th** **NATIONAL CONFERENCE & AGM**
Nottingham
- SEPTEMBER 17th - 27th** **MT KILIMANJARO OPEN CHALLENGE**
Terri Marshall
- OCTOBER 16th – 26th** **MT KILIMANJARO CHALLENGE**
Martin Rowe
- SATURDAY Nov 6th** **QUIZ NIGHT**
Aldingbourne Sports & Social Centre

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: <http://www.mndassociation.org>
MND Association Reg. Charity No 294354

WEST SUSSEX SOUTH BRANCH

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